Evidence-Based Practice

A GUIDE TO EVIDENCE-BASED PRACTICES

for INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

SAGINAW COUNTY
COMMUNITY MENTAL
HEALTH AUTHORITY

Table of Contents

FORWARD

This report on evidence-based practices is one of a series that cover the various populations served by the Saginaw County Community Mental Health Authority (SCCMHA). It is devoted to practices that have been shown to be of benefit to persons with developmental disabilities whose needs, like those of other populations served by the public mental health system, can potentially outstrip scarce funding and lead to difficult allocation choices. It is hoped that this report, like those that preceded it, will serve to inform policy and practice and encourage the use of scarce resources for services, supports, and practices that have been scientifically demonstrated to be effective.

It is also hoped that this report will underscore SCCMHA's commitment to assuring that individuals with developmental disabilities have ample opportunities to exercise as much control as feasible over the supports required to design and achieve lives of quality and meaning characterized by opportunity, inclusion, and participation, and provided in a manner that recognizes inherent competencies, reflects personal preferences, and conveys the inherent value and respect for such persons as full members of our community.

The research consulted for the contents of this paper is broad-based and encompasses the fields of medicine, mental health, biotechnology, child welfare, education, psychosocial rehabilitation, sociology, and the justice system. The electronic version has active hyperlinks to various sections within the document as well as external web sites which are marked in [blue underlined text](#).

It should be noted that this document represents a snapshot in time; as knowledge accumulates and technologies evolve, updates and revisions may be needed. Moreover, readers may not find information on all areas of interest. Additional resources are provided in the first two appendices for those who wish more depth and information on additional topics.

The term intellectual disability (ID) is used throughout this paper rather than the diagnostic label mental retardation (MR) which many advocates, families and people with intellectual disabilities find offensive and which has fallen into disfavor, except in sections that refer to specific diagnoses.

This report is intended for SCCMHA's use and, as such, may not be reproduced or distributed without the express permission of SCCMHA. The writer gratefully acknowledges the support and sponsorship of SCCMHA and commends the organization for its continued efforts to provide the highest quality services and supports to members of the community.

Barbara Glassheim[1]
December, 2008

---

[1] Barbara Glassheim, LMSW, ACSW, BCD, a consultant to the Saginaw County Community Mental Health Authority, has extensive public and private sector behavioral health care clinical and administrative experience.

EXECUTIVE SUMMARY

The provision of services and supports for people with developmental disabilities has historically been shaped by prevailing stereotypes regarding capacity limitations and has focused on deficiencies and impairments. This resulted in segregation, isolation, and medicalized approaches applied in congregate settings such as institutions, group homes, day habilitation, and sheltered workshops.

Relationships, community inclusion, and individualized service planning emerged during the late 1970s in the language of many court orders and consent decrees that called for major reforms of state operated institutions. In the mid 1980's, funding for services began to shift from the predominant Intermediate Care Facilities/Mental Retardation (ICF/MR) funding stream to the more flexible Home and Community Based Services Waiver (HCBS) that stimulated the development of community-based residential and day program alternatives. These were subsequently expanded into a number of variations including family care homes, apartment living, home ownership, supported employment, as well as in-home and school-based supports for children with developmental disabilities.

Today, more people with developmental disabilities are living and working in their communities with supports tailored to their individual needs. Negative social stereotypes are gradually eroding, and people with developmental disabilities are increasingly viewed as full-fledged members of their communities in roles as neighbors, coworkers, and friends. After many years of having little voice in laws and services of importance to them, individuals with developmental disabilities are creating change and engaging in full participation in the design of and access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, integration, and inclusion in all facets of community life. Adults with developmental disabilities are more independent and self-sufficient as a result of employment, transportation, housing, and health services. Children with developmental disabilities are more integrated into their communities through participation in inclusive educational and child care settings. Innovative approaches have been developed including adoptions for children with special needs, flexible and consumer/family-driven supports, and employment for people who formerly worked only in sheltered workshops.

However, despite decades of progress, individuals with developmental disabilities still experience discrimination in critical areas such as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services. Individuals with developmental disabilities are frequently offered lesser services, programs, activities, benefits, jobs, or other opportunities.

This report details ways in which people with developmental disabilities can be supported to lead independent lives as productive and valuable members of the community. It is divided into various sections, the first of which is comprised of introductory remarks and traces the evolution of services and supports for persons with developmental disabilities. The next section offers an overview of key evidence-based practice concepts and a discussion of their relevance to persons with developmental disabilities. Cultural considerations are reviewed in the following section which includes information on stigma, abuse and vulnerability, and issues affecting older adults, various ethnic groups, deaf culture, and women with developmental disabilities. The next section offers information related to self-determination, person-centered planning, and empowerment. It contains material on various self-directed services and supports. This followed by a review of services, supports, and issues related to working with families. The next section covers prevention and early intervention.

A section on systems collaboration is included next. It contains information regarding housing, education, employment, transportation, recreation and leisure, collaborating with the child welfare system, roles that faith-based communities can play, working with the justice system, mental health and medical care for co-occurring disorders, and models related to service coordination. This is followed by a section on transition supports to promote successful adult role acquisition and functioning. A section containing various interventions is offered next and includes programs and treatments that have been shown to be of benefit to persons with developmental disabilities. The next section contains information for measuring outcomes related to quality of life. The final section contains conclusions and recommendations.

A number of appendices are appended to the report. These include selected references and resources, a glossary (which has hyperlinks to define terminology used throughout the document), a quick reference guide, information on assessing system principles and values regarding person-centered planning, self-determination, and quality of life determinants. The last appendix contains a copy of the Community Imperative, a declaration supporting the right of all people with disabilities to community living, from the Center on Human Policy at Syracuse University.

INTRODUCTION

Throughout history people with disabilities have been viewed as deviant, deficient, and lacking skills, talents, developmental potential, decision-making capacity, and as having little value to society. Behaviors exhibited by persons with developmental disabilities have engendered, scorn, ridicule and rejection. They have been subjected to segregation in demeaning environments with inappropriately controlling practices, and, consigned to performing menial or inconsequential tasks.

Societies have long held dichotomous views of people with visible differences and treated them with a mix of charity and exclusion. In ancient Greece, being born with a physical difference was viewed as a sign of anger of the gods, and infants with perceptible disabilities were left to die to appease the gods. At the same time, however, pensions for soldiers who became disabled from wounds during battle were provided. In ancient Rome, people with disabilities were mistreated in circuses and other forms of entertainment while medical procedures to prevent or cure certain disabilities were developed. The Old Testament held that people with disabilities were blemished and therefore unable to offer the bread of God, but the ancient Hebrews also believed that persons in need should be cared for by the community. Christianity projected this dualism by associating disability with sin while promoting healing and forgiveness of those who sinned.

In Europe during the Middle Ages people who were physically or intellectually different often resided within the community, but were impoverished and forced to beg for food and other necessities. Interestingly, beggars with disabilities were advantaged by the ease of receiving alms from people of wealth. They organized guilds and other associations, often combining collections and providing mutual assistance, thereby beginning the tradition of self-help for persons with disabilities. For example, in Spain during the fourteenth century an association of persons who were blind was formed. Its bylaws, written in 1329, provided for the mutual loan of guides, visits to each other during illnesses, and a fair division of alms received.

State welfare was developed in Europe during the 1500s and locked institutions for "undesirables" were developed along with the establishment of medical involvement in disability determination and thus entitlement to the receipt of welfare. During the Age of Enlightenment new scientific ideas regarding diagnosis, classification, and treatment of people deemed as unwanted members of society arose. Enlightenment ideas of progress, human perfectibility, individual freedom, the efficacy of empiricism, and the importance of direct experience and concrete activities to knowledge acquisition later became the foundation for new methods of education and treatment of children with disabilities.

Scientific concern for the care of persons with mental retardation in the United States resulted from the work of French Encyclopedists during the eighteenth century which focused on concern for the welfare of various oppressed peoples. The first work with "mental deficients" began at the end of the eighteenth century in institutions such as the Bicetre and the National Institute for the Deaf and Dumb in Paris. There Jean-Marc Itard met Victoire of Aveyron, known as the "Wild Boy of Aveyron", and began what is regarded as the first documented case of special education. Edouard Seguin opened a school for "mental deficients" in France in 1848, but left after the revolution that same year and came to the United States where his philosophy of moral treatment influenced the care of "mental defectives" here. Samuel Gridley Howe, an early experimenter in the care of children with intellectual disabilities, began training blind children with mental retardation and helped establish a special experimental school at that time.

During the eighteenth century opportunities afforded by the Industrial Revolution lead to housing and care using the asylum model. People were placed by or removed from their families (usually

during infancy) and housed in large institutions, many of which were self-sufficient due to the labor of the residents. Some of these institutions provided a very basic level of education (e.g., differentiation between colors, basic word recognition, and numeracy), but most continued to focus solely on the provision of basic needs. Conditions in such institutions varied widely, but the support provided was not usually individualized and services focused on easing the burdens of providers rather than residents' needs as aberrant behavior and low levels of economic productivity were regarded as a burden to society.

During the late 1800s a shift from the perception of people with mental retardation as "innocents" and "unfortunates" to that of social parasites, criminals, prostitutes, and paupers occurred. In 1891, Congress amended the Immigration Act to exclude "all idiots, insane persons, paupers or persons likely to become a public charge, persons suffering from a loathsome or a dangerous contagious disease, persons who have been convicted of a felony or other infamous crime or misdemeanor involving moral turpitude, polygamists..."

The philosophy of eugenics rose to prominence during the latter part of the nineteenth century. This philosophy combined the religious tradition of degenerationism (i.e., that people with disabilities were marks of evil and sin) with the sciences of genetics and evolution into a type of social Darwinism that viewed the evils of society as genetically based. Thus, mental deficiency, criminality, delinquency, prostitution, and alcoholism were seen as the result of defective genes. This led to a movement of sterilizing persons deemed mentally defective (particularly women) that was strongly advocated by the medical field and government (e.g., Oliver Wendell Holmes was a strong advocate of sterilization). Sterilization was presented to the public as a humane way to address social problems (rather than the other component of the eugenics program which was a euthanasia movement that advocated killing babies and children deemed mentally defective). In Germany, euthanasia became official medical policy around 1920 and was openly taught and practiced in medical establishments. While euthanasia never became official medical policy in the United States, it was openly advocated and practiced. During World War II, the American Psychiatric Association published a lead editorial in their journal endorsing legal euthanasia of children with mental retardation and the provision of psychotherapy to their parents to assuage their guilt.

Considerable efforts were spent classifying and labeling people with developmental disabilities. These measures, which included early versions of the Stanford-Binet Intelligence Test, were used to create standards for immigration, sterilization, and restrictive marriage, social segregation, and euthanasia. By 1917, thirty one of the forty eight states had institutions for people with mental retardation. However, at the same time awareness that education and community support could benefit such individuals and their families arose along with the view that mental retardation was not predominantly a medical problem but rather one of education and economics.

Initially institutions and schools (or colonies, as they were originally called) attempted to provide relatively normal living conditions and operated under a philosophy of treatment and training devoted to educating residents and providing opportunities for them to work on the grounds. However, over time, the character of these institutions changed. The economic depression of the 1930's and World War II in the 1940's led to diminished fiscal resources and fewer and less trained staff in state institutions. The depression also led to the financial destitution of many families and an increase in the number of individuals admitted to residential facilities. The institutions became very crowded and by 1941, the percentage of persons living in institutions had increased dramatically.

During the 1960s the living-in-community model developed by Jean Vanier in the L'Arche communities in France and elsewhere was promulgated along with the anti-psychiatry movement. The civil rights movement in the United States led to the development of various self-help

movements for persons with disabilities, such as the Independent Living movement and People First. Concerns regarding the segregation of people with developmental disabilities in institutions were brought to the forefront with the 1969 publication of Wolf Wolfensberger's *The Origin and Nature of Our Institutional Models* which posited that society characterizes people with disabilities as deviant, sub-human, and burdens of charity, resulting in the adoption of the deviant role. Wolfensberger argued that this dehumanization, and the segregated institutions that result from it, ignored the potential productive contributions that all people can make to society. He pressed for a shift in policy and practice to recognize human needs and the provision of the same basic human rights for persons with developmental disabilities granted to the rest of the population. The publication of this book is regarded as the primary impetus for increasing awareness of human rights and self-advocacy, desegregation, and de-institutionalization that began in the 1970s in accordance with the principles of [normalization](#).

Attitudes regarding people with developmental disabilities have continued to evolve substantively as the. philosophies of integration and inclusion began to predominate as well as the view that all people benefit when individuals with developmental disabilities are integrated into society and living as independently and productively as possible. Yet, despite this, uncertainties linger regarding some personal rights and freedoms, such as whether people with developmental disabilities should be allowed to have children, drink alcohol, live on their own, or drive a car. Moreover, while individuals with developmental disabilities are increasingly participating in society and adding to its enrichment, they are still all too often segregated and relegated to lesser services, programs, activities, benefits, jobs, and opportunities, and face an overwhelming range of challenges that affect all aspects of their lives, including where they live, attend school, opportunities for gainful employment and careers, type and quality of health care they receive, and, most prominently, the ability to participate in a meaningful way in their communities and society at large. While they comprise less than two percent of the population, individuals with developmental disabilities are among the most vulnerable members of our society.

AN OVERVIEW OF EVIDENCE-BASED PRACTICE CONCEPTS

Evidence-based practices consist of interventions that have been scientifically researched, studied, replicated successfully by independent investigators, and have been shown to produce measurable and sustained beneficial outcomes. In addition, practices that are deemed to be evidence-based have sound theoretical underpinnings that explain why they work, procedures to evaluate outcomes, standards for conducting and evaluating staff training, procedures for maintaining quality and fidelity to the model of treatment delivery, and a written manual containing protocols for practitioners and clinical research replications. Evidence-based practices incorporate the clinical expertise of the practitioner, the best available evidence from scientifically sound research, and the concerns, expectations, values, and goals of the consumer.

Numerous sets of guidelines for different aspects of evidence-based practices have been developed, most of which have a medical basis. It has been argued that the provision of services to individuals with developmental disabilities does not readily fit into a treatment framework or conform to conventional notions of treatment (in contrast to the medical and mental health arenas) because services involve much more than the provision of treatment, cure, or the amelioration of the symptoms of an illness or disorder. In the field of developmental disabilities treatments or interventions are often used to decrease or eliminate the intensity of specific symptoms (rather than the disability in general), teach skills and provide habilitation, implement supports to enhance quality of life and community participation, and provide support to family members and others (e.g., direct support staff).

The study of developmental disabilities is multidisciplinary and incorporates information from healthcare and rehabilitation, as well as psychosocial habilitation, education, and biotechnology. A variety of biological, social, and behavioral effects of interventions are involved which leads to a lack of consistency in what is studied, how outcomes are measured, and where results are reported. Disparate data need to be connected in manner that allows for analysis and comparison. Therefore, it has been suggested that evidence-based practice needs to be conceptualized more generally and include a broader frame of reference and range of actions, rather than focus on the use of evidence-based treatments alone.

Randomized clinical trials represent the standard for determining the efficacy of a given intervention. However, because such trials are often difficult to conduct, many studies employ less well-controlled research designs. Methods are therefore needed to evaluate different research designs found in the literature and confer significance to their findings. This has led to use of grading systems to determine the level of evidence. One system, known as Sackett's rules of evidence, is based on five levels of evidence:

Level I: Large randomized trials, producing results with high probability of certainty. These include studies with positive effects that show statistical significance and studies demonstrating no effect that are large enough to avoid missing a clinically significant effect.

Level II: Small randomized trials, producing uncertain results. These are studies which have a positive trend that is not statistically significant to demonstrate efficacy or studies showing a negative effect that are not sufficiently large to rule out the possibility of a clinically significant effect.

Level III: Non-randomized prospective studies of concurrent treatment and control groups, i.e., cohort comparisons between contemporaneous subjects who did and did not receive the intervention.

Level IV: Non-randomized historical cohort comparisons between subjects who did receive the intervention and earlier subjects who did not.

Level V: Case series without controls. The clinical course of a group of consumers is described, but no control of confounding variables is undertaken. This is a descriptive study which can generate hypotheses for future research but does not demonstrate efficacy.

Recommendations in support of an intervention can be generated based on these five levels of evidence. Outcomes supported by at least one, and preferably more, Level I studies yield grade A recommendations, and outcomes supported by at least one Level II study receive a B grade. Grade C recommendations are assigned to outcomes supported by Level III, IV, or Level V studies. The grade indicates the degree of certainty of a conclusion, generated by the strength of the supporting research evidence. Grade A conclusions are generated from the strongest research evidence and are thus the most definitive. Grade B conclusions are based on weaker evidence and are only tentative. Grade C conclusions are based on the weakest, suggestive evidence are the least reliable.

While Sackett's system is effective for summarizing the quality of evidence, it has been criticized for its limitations particularly with regard to developmental disabilities, including its dependence on large group studies (because it evolved from clinical work in epidemiology and internal medicine where large group studies and randomized controlled trials are readily conducted). Small group studies and single subject designs prevail in developmental disabilities research whereas Sackett's model excludes less rigorous studies and relies upon those with stronger designs. In addition, this system can be misleading because it focuses on the type of design rather than on the actual design (i.e., the extent to which threats to validity have actually been controlled). Finally, there is the potential for confusion as, for example, when two randomized controlled trials demonstrate opposite results. In this classification, these Level I studies produce Grade A evidence for an intervention, but dissimilar findings change the strength of the evidence in support of an intervention.

The American Academy for Cerebral Palsy and Developmental Medicine's (AACPDM) Levels of Evidence Classification System describes categories of treatment evaluation as: group methods (i.e., between-subjects designs), single-subject methods (i.e., within-subjects designs), outcomes research methods, and qualitative methods. It includes five levels of evidence based on Sackett's model:

Level I: Well-controlled experiments with random allocation and manipulation of intervention.

Level II: Studies that do not include randomization but are otherwise well controlled experiments or comparison studies.

Level III: Comparison studies with one (or both) of the comparisons being retrospective.

Level IV: Designs that have no comparison groups/conditions.

Level V: Non-empirical research (which can only provide an indication of possible relationships between interventions and outcomes).

The developmental disabilities literature indicates that the application of evidence-based practices should make the needs of consumers' a primary focus. It is recommended that practitioners adopt a process of ongoing knowledge acquisition that entails continuously posing specific questions of direct practical importance to consumers, searching objectively and efficiently for the best current evidence relative to each question, and taking appropriate action guided by that evidence. Thus, understanding and evaluating evidence requires basic queries such as:

   ▶   What constitutes evidence?
   ▶   What is the quantity and quality of the evidence?

> ▶   Does the theory behind the approach make sense?
> ▶   Is the intervention individualized and based on assessment?
> ▶   What training is required?
> ▶   Does it include some form of data collection and ongoing supervision?
> ▶   What are the costs/risks and possible side effects for the consumer, family, staff, or agency (including money, time, energy, and expectations)?
> ▶   What are the potential benefits?
> ▶   Will it make a difference to the consumer's quality of life?

In sum, working within an evidence-based practice framework entails making decisions based on the best data available (taking into account its possible limits) with the goal of improving the lives of individuals with developmental disabilities and those they touch. In addition, examinations of evidence related to specific interventions needs to be guided by values (e.g., helping people with developmental disabilities), specific contexts and issues relevant to each individual, common sense, and a critical analysis of the strengths and limitations of different types of evidence to answer different questions.

It should be noted standards of care are determined on the basis of all clinical data available for an individual situation and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Moreover, adherence to evidence-based practice models and guideline recommendations does not ensure a successful outcome for everyone. Evidence, in of itself, does not constitute sufficient grounds for clinical decision-making, but rather provides a foundation for it. A comprehensive list of evidence-based interventions for individuals with developmental disabilities is lacking although guidelines based on reviews of evidence-based practices[2] for autism spectrum disorders are available. Finally, a number of popular approaches used for individuals with development disabilities have little if any sound scientific evidence to support them.

---

[2] Additional information on evidence-based practice concepts can be found in other reports in this series at http://sccmha.org/quality.html.

Cultural Considerations

Increasing attention is being paid to the role of culture and its impact on disability. This impact is influenced by societal views of disabilities, various ethnic group norms and levels of acculturation, gender, age, type of disability, and other factors. Five elements of cultural competence have been identified to help ensure consumers and their families receive effective services and supports provided in a culturally congruent manner that is compatible with their beliefs and practices: (1) valuing diversity, (2) cultural self-assessment, (3) understanding the dynamics of cultural interactions, (4) incorporating cultural knowledge, and (5) adapting practices to the diversity of the setting in which they are delivered.

Maltreatment

Persons with developmental disabilities have been the target of discrimination across cultures for thousands of years, the manifestations of which include isolation, exclusion, and even extermination. Their risk for abuse is estimated to be two to five times higher than that of the general population and four to ten times greater for being victimized by crime. In addition, it is estimated that ninety percent of people with developmental disabilities will be sexually assaulted over the course of their lives. Lack of education, self-esteem, self-advocacy skills, understanding of social norms, appropriate behavior, and communication difficulties are factors attributed to this high incidence of abuse. People with developmental disabilities are vulnerable to other types of abuse including:

- Psychological or emotional abuse (i.e., verbal abuse, shaming, and belittling)
- Constraint and restrictive practices (e.g., turning off an electric wheelchair to prohibit movement)
- Financial abuse (e.g., charging unnecessary fees, withholding pensions, wages, etc.)
- Legal or civil abuse (e.g., restricted access to services)
- Systemic abuse (e.g., denial of access to an appropriate service due to perceived support needs)
- Neglect (e.g., withholding help when required such as assistance with personal hygiene, failure to provide adequate nourishment and shelter)
- Sexual exploitation

The presence of a disability increases both the risk of maltreatment and its impact. Children with disabilities experience abuse at approximately three and one half times the rate of that of their peers without disabilities and are almost twice as likely to experience sexual abuse (although only three percent of such assaults are ever reported). Children with developmental disabilities experience greater levels and longer periods of dependence upon caregivers for personal needs. Physical and cognitive disabilities can impair the ability to understand, resist, or inform someone about abuse. In addition, symptoms of abuse or neglect can be ignored due to confusion with manifestations of the disability itself. Finally, increased isolation and fewer opportunities to socialize can contribute to low self-esteem and less opportunity to learn how to prevent or stop abuse.

Adults (both men and women) with developmental disabilities are more than four times as likely to be assaulted. Many women with developmental disabilities experience violence perpetrated by spouses, dates, or sexual partners. While some sexual assaults and homicides are attributable to harm from caregivers, intimidation, excessive control, neglect, and general disrespect have been found to be much more common forms of violence. Many individuals with developmental

disabilities are powerless to escape from this form of maltreatment due to lack of choice regarding residence, care providers, or participation in programs. Some individuals are not even aware of their right to humane treatment. In addition to abuse from people in positions of power, abuse from peers has also been cited as a significant problem.

WOMEN

Women with developmental disabilities face double discrimination in the forms of sexism and ableism, which set standards for woman and normality and lead to exclusion, devaluation, and marginalization. These women receive lesser amounts of education, training, rehabilitation services, earnings, and social welfare benefits and experience higher rates of unemployment. They are less likely to marry, more likely to have difficulty maintaining custody of their children if they divorce, have higher rates of divorce than their male counterparts, and experience high levels of intimate personal violence. In addition, many women with developmental disabilities have experienced isolation from their communities in institutions, undergone forced sterilization, and prevented from having intimate relationships with men due to societal fears regarding the creation of genetically inferior children. Even though many women with developmental disabilities living in the community today experience new freedoms, rights, and responsibilities, they still confront cultural stereotypes and discriminatory practices.

Double discrimination serves to perpetuate violence against these women on the basis of their devalued status in society. They are also perceived as easy targets. As a result, women with developmental disabilities have among the highest rates of physical, sexual, and emotional violence by spouses, ex-spouses, boyfriends, and family members. Women with developmental disabilities are also subjected to significant amounts of violence from other people with disabilities. Studies suggest that women with developmental disabilities are four to ten times as likely to be sexually assaulted and more than half (54.1%) result in physical injuries. In addition, three percent become pregnant, and four percent contract sexually transmitted diseases. Most (ninety five percent) have been found to suffer social, emotional, and behavioral harm as a result yet only twenty percent receive appropriate counseling or treatment services. Moreover, many of these assaults are not reported to authorities and, of those reported, less than thirty three percent (32.8%) result in formal charges, and only half of the individuals who are charged receive a conviction. In recognition of the vulnerability of women with disabilities, the Violence Against Women Act of 1994 was reauthorized in 2000. The Violence Against Women Act 2000: Strengthening Supports to Women with Disabilities includes language that addresses the needs of women with disabilities, and provides funding for expanded protection, services, and education.

OLDER ADULTS

A number of significant issues are faced by older adults with developmental disabilities and their caregivers. Two-generation, elderly families with caregivers and recipients of care that are aged sixty and older can experience changes in parental roles due to retirement, illness, or death. Caregiver roles may reverse so that adults with developmental disabilities assume caregiver roles for their parents as a result of parents' declining health. These families are confronted with a number of challenges including coping with and planning for the inevitable termination of care-giving roles, potential changes in household composition, and succession planning. Parents may not be able to retire along with their peers, have limited social lives due to continued care giving roles, and experience declines in health that can interfere with care giving abilities. Succession planning has been identified as crucial; determinations regarding whether a sibling or another person will assume caregiver responsibilities for both the person with a developmental disability as well as their aging parents (or other family members who provide care) are critical to ensuring ongoing needs are met.

Older adults with developmental disabilities have distinct needs for residential alternatives, long-term financial and legal planning, and medical care (e.g., advanced health care directives). Many older adults with developmental disabilities benefit from special services such as nutritional sites for older adults, senior day activities, respite, in-home assistance, individual counseling, support groups, caregiver training, and others. Studies have shown that premature aging and earlier decline in functional skills occurs in populations with developmental disabilities. Research indicates that people with Down syndrome have a significantly higher incidence of Alzheimer's disease[3] at an early age. Alzheimer's Associations across the country have been working to provide services and supports for this population. A number are replicating a program started in Rochester, New York in 2006 which provides workshops on various topics (e.g., changing the lighting and layout of a room to make it more comfortable for people with Alzheimer's disease), grief counseling for relatives, and training for caregivers in the use of calm and predictable bathing and feeding techniques.

A network of supports for senior citizens with developmental disabilities that allows them to receive typical aging services as well as developmental disabilities services (e.g., senior day care, caregiver supports, and specialized residential supports) is recommended:

> ➢ Services that meet immediate needs (e.g., respite, housekeeping assistance, transportation, and emotional supports)
> ➢ Assistance with obtaining determinations of eligibility for financial supports
> ➢ Help with obtaining financial planning information (e.g., entitlements, alternatives to guardianships, and trusts)
> ➢ Assistance with negotiating various service systems and advocacy for obtaining eligible services, including services for older adults as well as entitlements and resolving problems with social services agencies
> ➢ Assistance in decision-making regarding future planning
> ➢ Environmental modifications to improve accessibility
> ➢ Counseling and support groups

ETHNIC GROUPS

Every culture deems certain goals to be normative and desirable. Various cultural views regarding level of functioning and skills expected of children at specific ages indicate a need for caution in diagnosing children with developmental delays. Moreover, sociocultural background and native language need to be considered in assessments of intelligence and level of impairment. For example, a common focus in working with families is to help children become autonomous and self-reliant, a goal that reflects the premium that Western cultures place on independence. In contrast, many Asian cultures (e.g., Japanese) place a premium on interdependence (i.e., belongingness, dependency, and reciprocity) and an emphasis on autonomy and self-reliance per se is viewed as a sign of selfishness and immaturity. In Western cultures seeking assistance for social and emotional problems is seen as rational and constructive, but in traditional Chinese

---

[3] Alzheimer's disease has been found to co-occur during the third decade of life along with a significant incidence of early gait and speech deterioration, epileptic seizures, and myoclonus. Some studies suggest that sixty to seventy five percent of people with Down syndrome over the age of sixty will have the disease. Moreover, the disease is responsible for the sharp decline in life span in persons with Down syndrome over the age of forty five.

culture is viewed as shameful and help is sought only when problems are somaticized (e.g., strange behavior reflecting an underlying liver problem).

According to the National Council on Disability, persons from minority groups with disabilities are more likely to be underserved, receive fewer comprehensive services, drop out of services, and achieve less favorable outcomes than their Caucasian counterparts. In addition, there is a paucity of trained bicultural and bilingual professionals available to provide accessible, culturally competent services and outreach to underserved populations.

African-American and Hispanic/Latino families have been shown to underutilize family support programs. Many rely on their own family support systems and have a lack of trust in government services. The migrant status of some Hispanic/Latino families and language barriers they often face deter individuals and families from seeking available supports. Native American families often lack services. Many lack trust in government programs and are frequently given referrals to reservation agencies or the Bureau of Indian Affairs rather than being offered services from state and community programs. Asian families may be discouraged from seeking help due to racism, cultural barriers, and lack of knowledge of available services. In Asian cultures, there may be considerable resistance to talking about disabilities. Cultural barriers, such as the reluctance to bring shame to the family, because of the perceived stigma related to a family member with a disability, hinder utilization of services.

Deaf Culture

Individuals with deafness vary considerably. In general, people who have been deaf since birth or infancy[4] are less likely to view deafness as a disability, but rather as a culture replete with its own language, values, customs, and communities, and are more likely to be fluent in American Sign Language[5]. Individuals who become deaf during late adolescence or adulthood, on the other hand, are more apt to view deafness as a disability, be fluent in English, and confront communication barriers in hearing as well as Deaf settings. A subset of the deaf population has minimal or a lack of fluency in any language.

Individuals with early-onset deafness who are fluent in American Sign Language may not communicate well in written English while those who are late-deafened may be able to communicate through a signed adaptation of English, but may be unable to communicate effectively in American Sign Language. There is disagreement among educators as well as people who are deaf regarding whether children who are deaf should be taught American Sign Language or English[6] as their primary language.

A number of tenets of Deaf Culture are at variance with current concepts and practices within the mental health and developmental disabilities field regarding inclusion and integration into the broader community. Deaf Culture views it members as having more opportunities for success when they live and learn within environments designed specifically for their support. Thus, mainstreaming to ensure the delivery of services and supports in the least restrictive setting for people who are deaf may be mostly effective in a Deaf community or specialized program that

---

[4] More than ninety percent of children who are deaf have parents who are hearing.

[5] American Sign Language is not a signed version of English, but is a distinct language with its own meanings, colloquialisms, and etiquette. It is third most commonly used language in the United States.

[6] Even the most accomplished lip readers absorb less than half of the words spoken to them.

recognizes their unique needs and offers communication that is most accessible, whereas mainstreaming into the general hearing population can result in miscommunication and social isolation.

The literature indicates that people who are deaf experience significant levels of physical and sexual abuse, particularly those who have developmental disabilities. In addition, many are misdiagnosed with developmental delays due to communication problems which can lead to inaccurate assumptions regarding cognitive abilities. Moreover, most of the diagnostic tools in use have not been normed for Deaf Culture and many cannot be administered in American Sign Language. This problem is compounded by the paucity of professionals fluent in American Sign Language and knowledgeable about Deaf Culture.

It is recommended that people who are deaf or hard of hearing select modes of communication, intervention modalities (e.g., peer support and self-help services), treatment settings, assistive devices, and living arrangements in order to best meet their cultural, linguistic, and social needs. Certified Deaf Interpreters (CDIs), who are native signers of American Sign Language, can function as intermediaries between individuals who are deaf and have limited proficiency in any language and professionals. However, specialized treatment programs for this population are strongly recommended, whether established as free-standing or developed within those already established.

EMPOWERMENT AND SELF-DETERMINATION

Historically, people with developmental disabilities and their families were offered few, if any, choices for their lives. Families of children with severe disabilities could institutionalize their children or keep them at home with no publicly funded assistance or education. Adults with severe disabilities could be placed in public institutions or reside in the community without services or supports. People with developmental disabilities were often on the receiving end of sociopolitical change and had very little voice in laws and regulation, types of services made available, or accommodations for housing, education, and employment. Recognition of the importance of normalized and typical environments, providing individualized supports, and focusing on strengths and capabilities have engendered enhanced role status, greater social equity, and increases in adaptive behaviors. The establishment of a federally guaranteed right to education and the expansion of community services have led to expanded options. Driven by the principles of rights, independence, choice, and inclusion, and self-advocacy environments of self-sufficiency, inclusion, and acceptance have been created. However, despite this progress many people with developmental disabilities continue to be denied opportunities to make choices about some of the most basic aspects of their lives.

The concepts of Normalization and Social Role Valorization (SRV) engendered the widespread emergence of community residential options during the late 1960s and 1970s and provided the foundation for educational integration, supported employment, and community participation for persons with developmental disabilities. The inclusion movement for people with disabilities is ongoing and extends to all arenas. In education it is represented by the placement of students with disabilities in general education classrooms and changing systems so that specialized school support becomes fully integrated and coordinated with general education programs in neighborhood schools. In the vocational sphere it involves replacing sheltered workshops with supported employment. In housing it involves replacing group homes and other congregate facilities with supported living arrangements in which people select their housemates and the neighborhood they wish to reside in. Community inclusion entails replacing artificial social and recreational opportunities (e.g., social groups for people with disabilities) with those that emphasize participation with people who may not have disabilities (e.g., membership in religious groups, community gyms, and social and ethnic clubs).

The self-advocacy movement began in Sweden in the 1960's when parents asked their children what types of supports and services they wanted and in the United States through the People First movement that began in Oregon during the early 1970's. "Nothing about us without us" is the slogan adopted by the disability community as a theme of self-advocacy. It calls for incorporation of the perspectives of individuals with disabilities in all phases of service delivery including policy,

procedure, and protocol development as well as governing board membership and training activities[7]. It also includes choice (i.e., preferences, opportunities, and control).

Supporting choice requires recognition that everyone has preferences and desires irrespective of the severity of their disability. At the same time, the fact that someone wants something, even if they see it as very important, does not mean that it has to be delivered. Preferences reflect what people want; opportunities reflect what is available. Moreover, what people do not want is as important as what they do want. People with disabilities have not historically had control over who they spend time with and activities they engage in and thus were not permitted to avoid people and activities that are undesirable.

Promoting choice is based on the following principles:

- The presumption that all people are competent to make choices about their lives
- Individuals who have difficulty expressing their preferences need to be surrounded by a core group of people who know them well in order to provide assistance with making choices
- Family members can play an important role in supporting people with developmental disabilities but are not entitled to substitute their own interests and wishes for those of a family member with a disability
- Individuals with disabilities do not choose institutions or mini-institutions when they have real knowledge and experience of alternatives
- People with disabilities sometimes make ineffective or harmful choices, like other members of society; disability is not a reason for depriving an individual of the right to make the same choices other people have the right to make, but, choice should never be used to justify neglect
- The best safeguard against ineffective or harmful choices is a network of trusted, caring relationships; choice is not typically a solitary activity and is usually undertaken within the context of a network of close relationships of people

In sum, all people, irrespective of disability, should be able to make informed decisions regarding various aspects of their lives including friendships, intimacy, daily routines, employment, leisure pursuits, activities and associations, communities and neighborhoods they wish to live in, whether to live alone or with others, and, in the case of the latter, the specific person or persons with whom they wish to live. Choices regarding personal assistance, medical treatment, and therapeutic interventions should be within each person's purview as well.

---

[7] The Michigan Department of Community Health has had significant stakeholder involvement in policy development starting with the 1992 federal Community-Supported Living Arrangements (CSLA) demonstration initiative which awarded grants to Michigan and seven other states to provide supported living services (including personal assistance, habilitation services, and assistive technology) as an optional State Plan service to persons with developmental disabilities. The CSLA grants paid for services from 1992 through 1995 to individuals living in their own or their family's home or an apartment or other rental unit in which no more than three individuals receiving these services resided.

SELF DETERMINATION

Self-determination is an approach (rather than a model or program) to helping individuals create meaningful lives with effectual opportunities for developing and attaining valued life goals. It offers people the right to select and direct their own services and providers within a personal budget based on needs (rather than available services), make decisions regarding their health and welfare, and freedom from involuntary treatment. Self-determination also promotes consumers' roles in the design, delivery, and evaluation of services and supports. The development of a personal-centered plan and an individualized budget to procure services and supports are hallmarks of self-determination.

Early work in self-determination focused on consumer choice in daily activities, individual service planning, and values (i.e., freedom and choice) training for staff and program administrators. However, while progress was achieved in promoting self-direction, it became evident that the economic balance of power between consumers and providers needed to be modified to effect meaningful and enduring change. In response, a number of efforts were initiated to demonstrate the impact of changes in funding in the service system, most of which were sparked by the Monadnock Self-Determination for People with Disabilities Project in New Hampshire funded in 1993 by The Robert Wood Johnson Foundation (RWJF). RWJF convened a group to plan for an expansion of the program in 1995 and issued a call for proposals in 1996 which led to funding of the RWJF Self-Determination Initiative in 1997. This initiative funded planning efforts in Arizona, Connecticut, Florida, Hawaii, Iowa, Kansas, Maryland, Massachusetts, Michigan, Minnesota, Ohio, Oregon, Pennsylvania, Texas, Utah, Vermont, Washington, and Wisconsin. Ten other states received smaller technical assistance grants. Two additional RWJF grants provided up to five years of grant support to two projects in self-determination for people with developmental disabilities in Florida and Massachusetts to more specifically replicate the Monadnock Project. Since that time, numerous programs have implemented self-direction and individual budgeting using Medicaid funds through Home and Community Based 1915(c) waivers.

PRINCIPLES OF SELF-DETERMINATION	
FREEDOM	The ability of an individual together with freely chosen family and friends to plan a life with necessary support rather than purchase a program
AUTHORITY	The ability of a person (with a social support network or circle if needed) to control a certain sum of dollars in order to purchase services
SUPPORT	The arranging of resources and personnel, both formal and informal, that will assist an individual to live a life in the community rich in community affiliations
RESPONSIBILITY	The acceptance of a valued role in a person's community through competitive employment, organizational affiliations, spiritual development, and general caring of others in the community, as well as accountability for spending public dollars in ways that are life-enhancing
CONFIRMATION/ PARTICIPATION	The opportunity for service recipients to participate in decision-making regarding the care delivery system

The human services system has traditionally been based on the creation of congregate day and residential programs by provider agencies that offer slots to individuals with disabilities. This model does not lend itself to opportunities for consumers to exercise the freedom to determine where and with whom they live, work, and socialize. Self-Determination shifts power over resources directly to individuals and their families/supporters, and, as such, requires fundamental

structural changes (e.g., fiscal management agencies, independent brokering, and individually allocated personal budgets) that promote freedom and responsibility while achieving better value for public funds. It requires a new way of thinking and operating and can be perceived as a threat to traditional providers whose revenue streams have been dependent on the monetary value of serving people with disabilities. Implementation of self-determination is thus often met with resistance from traditional providers.

Studies indicate that the transfer of personal planning and budgeting from professionally dominated teams to consumers and their close allies and friends results in greater satisfaction and significant improvements in quality of life in all areas, including health and safety. Research also has demonstrated that self-determination leads to beneficial outcomes for young adults including independent living, maintaining a bank account, job training, and employment. Self-determination has also been shown to lead to cost efficiencies and increased service quality. Studies suggest that the adoption of service system-wide approaches to self-determination have a significant positive impact on total system costs for individuals who opt for self-determination as well as those who do not. States and projects report current costs at or below those of typical human services. The original demonstration project which included forty five individuals saved $300,000.00 annually. Studies of Michigan's[8] experience with self-determination have found that the higher current costs are in the traditional system, the greater the reduction in costs are achieved under self-determination with an average savings, adjusted for inflation, of sixteen percent.

Studies of self-determination projects have also shown that participants were significantly more successful in finding and retaining workers for the hours and assigned tasks desired. Evaluations conducted in Michigan, Minnesota, New Jersey, and Oregon indicated that direct support workforce issues such as recruitment, wage, and turnover challenges were often more effectively managed by individuals in control of their own budgets. Many consumers and families reported they were able to find and retain higher quality personnel and committed people (e.g., friends and family) for support when they could exercise control over who they hired and fired. Studies have also found that DSPs (direct support professionals) are often paid higher wages when they work for people who individually control their budgets because of the flexibility to pay higher hourly wages and use fewer hours. In addition, some families received more hours of support when they located their own staff rather than relied on sometimes scarce agency-directed support staff.

SELF-DIRECTED HEALTH CARE

Self-directed health care is derived from self-determination and is emerging as part of a national effort to transform the health care system that has been driven by increases in costs for health insurance and health care services as well as inconsistent quality. Self-directed care is a system in which funds that would customarily be paid to service providers are transferred to consumers using various formulas to account for direct, administrative, and other costs. Sources of financial support for self-direction include Ticket to Work, Social Security, and IDAs (Individual

---

[8] Michigan was one of the first states to pioneer self-determination in both rural and urban areas.

Development Accounts)[9]. The principles and values of self-directed care include freedom of choice, control over one's own life, personal responsibility, and access to services and supports at the individual level,. At the system level, its values include consumer satisfaction, service quality, efficiency and effectiveness, and cost effectiveness. According to the Centers for Medicare and Medicaid Services (CMS) there are four essential elements of self-directed care:

❶ **Person-centered planning:** a comprehensive strategy for putting necessary services and supports into place to help people achieve their goals
❷ **Individual budgeting:** enables people who need assistance to have some control over how funds used for their care are to be spent
❸ **Financial management services:** includes tracking and monitoring budgets, performing payroll services, and handling billing and documentation
❹ **Supports brokerage:** education and operational assistance to help individuals design and manage their own self-directed care plans

The most fundamental change that self-directed care engenders is a shift in power within the treatment system from one that is dominated by the needs, concerns, and interests of payers and providers to one that focuses explicitly on the needs of individuals. Self-directed care requires a transfer of control from providers to control shared with consumers as active participants in service and support planning. Providers function as coaches rather than directors and facilitators rather than managers, and furnish decision support. Opportunities for an increased use of nontraditional providers of services are engendered.

The values and principles of self-directed care include:

➤ **Protection of civil liberties**, the rights and freedoms that citizens enjoy in a democratic society which are often abridged for individuals with disabilities. Self-directed care programs enhance participants' civil rights, (e.g., freedom from discrimination, the right to due process, and the right of personal autonomy) through making purchasing decisions on their own behalf.
➤ **Fairness**, so that individuals with disabilities are enabled to manage their own lives in ways that are more similar to those of individuals without disabilities.
➤ **Freedom from implicit and explicit coercion**. Implicit coercion occurs when people are presented with little or no choice of services and are thus coerced into accepting those that are available. Explicit coercion arises when people are mandated to receive treatments/services they do not desire, or are treated against their will. Self-directed care programs can reduce explicit coercion by helping individuals design their own crisis management plans and define actions to be taken when they are unable to act on their own behalf.
➤ **Use of free market forces** to enable individuals with disabilities to become active in the marketplace and negotiate with funders and providers, thus enhancing their integration into the larger society. Participants become true consumers because funds and purchasing power are shifted from providers to individuals; providers need to sell themselves and their services to consumers.

---

[9] **Individual Development Accounts (IDAs)** are matched savings accounts that enable individuals/families with low incomes to save, build assets, and enter the financial mainstream. IDAs reward monthly savings of families who are working-poor and trying to amass funds to purchase assets such as a first home, a post-secondary education, or start a small business.

Self-directed care programs[10] have been demonstrated to be cost-effective and efficient by empowering individuals to evaluate their own needs and select only those services required to meet them. It has been found that individuals who are responsible for managing their own accounts regard the funding as an asset rather than an entitlement. Studies have also found that consumer satisfaction with self-directed services and levels of choice are significantly greater than found with traditionally delivered services.

SELF-DIRECTED SUPPORT CORPORATIONS (SDSCs) AND MICROBOARDS

Self-directed support corporations are small, legally incorporated, nonprofit entities established to negotiate, receive funds, organize and manage supports for one person and/or their family. The individual controls and directs the supports. A board of directors comprised of trusted allies of the person provides oversight of the SDSC and serves as part of a personal support circle. The person may elect to be the president of the board, a voting board member, or not serve on the board. The board receives its direction from the person, determines supports needed, and how supports are used to meet the person's desires, dreams, and needs. SDSCs must adhere to state and federal guidelines, procedures, and regulations for long-term care providers although the supports are designed for only one person rather than numerous individuals. Thus, an SDSC is accountable for public dollars spent and to the person who is being served with those public dollars.

A Microboard is a non-profit organization/corporation organized to support an individual that is comprised of people who know and care about that person and established to provide assistance in planning for and obtaining needed supports. It is operated by a volunteer board of directors that governs a non-profit provider agency which receives Medicaid waiver funds. In addition to receiving direct funding from the state in which it is incorporated, the Microboard is the employer of record responsible for responsible for human resource management (i.e., recruiting, screening, hiring, training, directing, disciplining, terminating, employee benefits, and payment of wages) as well as accounting. Microboards independently purchase goods and services. For example, a Microboard may want to purchase payroll services (from a bank, commercial payroll service, or private bookkeeper) rather than spending time managing payroll. Or, a Microboard can join with other Microboards to form a cooperative payroll service.

Self-Directed Support Corporations and Microboards share the same philosophy. They are both small legal providers for a single person with a disability, placing control and direction of supports in the hands of that person. Both follow an incorporation process and develop a not for profit agency. A board of directors, comprised of trusted allies of the person with the disability oversees SDSCs and Microboards. Microboards and Self-Directed Support Corporations represent the antithesis of models of congregate (i.e., residential, day program, and other support services) programming in which funding is allocated to an agency to operate a certain number of program spaces or slots.

---

[10] Cash and Counseling programs were developed in three states with funding from the Robert Wood Johnson Foundation and the U.S Department of Health and Human Services to provide self-directed personal care services for people with developmental and physical disabilities and older adults. Evaluations of these programs conducted by Mathematica found that outcomes were as beneficial, or even more so, than for persons in traditional fee-for-service (FFS) programs and the cost was the same or less. Cash and Counseling participants received more services than their FFS counterparts, but, by the end of the second year of the program, budget neutrality was attained.

The first Microboards were created in Manitoba, Canada in 1984 and the first application outside of Manitoba was developed in Colorado. The first large-scale application was developed by Vela Microboard Association in British Columbia. SDSCs and Microboards are increasingly being formed across the country for developing personal support services for individuals with disabilities. Microboards have been adapted to serve families with young children, couples, siblings without parents who share households, and households in which people with disabilities share residences. It should be noted that personal empowerment, citizen involvement, service flexibility, and individualized direct funding can be accomplished without Self-Directed Support Corporations, Microboards, or other formally incorporated organizations through the provision funding directly to individuals and families with personal support networks.

Microboards have been found to be as administratively efficient and cost effective as larger provider agencies. Cost offsets can be derived through economies of scale including:

> ▶ Creative use of generic services (e.g. automated payroll services)
> ▶ Membership in business associations that offer group benefit packages (e.g. insurance plans offered by Chambers of Commerce)
> ▶ Creative relationships with existing providers (e.g. contracting with a local provider for assistance with staff recruitment, screening and training)
> ▶ Cooperation among Microboards (e.g. sharing data processing, billing and accountability functions)

The literature recommends that Microboards and SDSCs have access to resources for development, training, technical support, and assistance with initial formation, planning, managing resources, recruiting, screening and training staff, managing challenging human resource situations, budgeting, evaluation, accountability, and advocacy. Adequate start-up financing for the development and initial operation of a support system anchored in the community (rather than the traditional service system) is also recommended. Traditional agencies and Microboard associations can provide some of the technical assistance and other supports that individual Microboards may need on a fee-for service basis. The functions of Microboard associations include:

1. The provision of assistance and support to start individual Microboards:
   a. Information, education and consultation about becoming a Microboard
   b. Training in planning, community building, and Microboard operations
   c. Assistance in organizing, incorporation, and approval as a provider
   d. Assistance with individual planning and creation of plans and budgets for the state
2. Ongoing training, consultation, advice, and technical assistance.
3. Purchase of ongoing support services through general purchase-of-service agreements
4. Obtaining voluntary support from individual Microboards for Microboard Associations in:
   a. Educating families, communities and the state about the Microboard model
   b. Helping to start new Microboards
   c. Shared learning (i.e., creating a learning community)
   d. Offering community service (e.g., helping schools, community groups, faith-based organizations, and families that not directly connected with a Microboard)

PERSON-CENTERED PLANNING (PCP)

Person-centered planning is an individualized planning process that is driven by people's strengths, choices, and preferences. The process is controlled by individuals with disabilities (or by families for children with disabilities) and results in a plan that details the issues important to each person/family, is managed in all important aspects by that person/family with freely chosen support when necessary, and that specifies what will constitute both quality and specific outcomes sought. It differs sharply from traditional program-centered planning in which individuals with disabilities are provided with pre-existing services that agencies make available thereby preventing individuals from determining where and with whom they live, work, and socialize. Implementing person-centered planning in behavioral health systems involves a major shift in the culture, training, and activities of the professionals in the system. As a result, organizations and professionals are often challenged to evaluate existing programs, services, practices, and policies.

In person-centered planning, the specific needs and goals of the individual drive the creation of new service matrices that are carefully tailored to address their unique characteristics and needs within the context of normalization and inclusion emphasizing community participation, meaningful social relationships, enhancement of opportunities for choice, roles that engender respect from others, and continued development of personal competencies.

Person Directed	An individual's plan is their vision of what they would like to be and do. The plan is not static, but changes as new opportunities and obstacles arise.
Capacity Building	Planning focuses on an individual's gifts, talents, and skills rather than deficits, and builds upon their capacities and affords opportunities that will reasonably encourage them to engage in activities that promote a sense of belonging in the community.
Person Centered	The plan consistently focuses on the individual rather than placement in available program slots; the individual's choices and preference are honored.
Network Building	The planning process joins people who care and are committed to helping an individual to articulate their vision of a desirable future. They learn together and formulate a course of action to make the vision a reality.
Outcome Based	The plan focuses on increasing any or all of the following experiences valued by the individual: • Growing in relationships or having friends • Contributing or performing functional/meaningful activities • Sharing ordinary places or being part of their community • Gaining respect or having a valued role which expresses the individual's gifts and talents • Making choices that are meaningful and express individual identity
Community Accountability	The plan assures adequate supports while respecting and according complete dignity to the person as a fully participating member of the community while concomitantly addressing issues of health and safety.

Person-centered planning began in Michigan in the Community-Supported Living Arrangements (CSLA) program and was the cornerstone of that program. Michigan has required community mental health programs to use person-centered planning since 1996, when the legislature enacted this requirement as an amendment to the Michigan Mental Health Code. The essential elements of person-centered planning for Michigan's community mental health system include:

- A specified pre-planning meeting format in which consumers are given the opportunity to express their wishes and needs

- Allowing consumers to select facilitators of planning meetings and use facilitators external to the local community mental health service system
- Inclusion of consumers' families, friends, and other informal supports in the planning process
- Allowing consumers to modify the planning process at any time
- Discussion of all potential treatment and support options with consumers
- The provision of continuous opportunities for consumers to express their needs and wishes as well as give feedback

A number of different roles and responsibilities critical to the success of the person-centered planning process have been identified including:

- Conducting a pre-meeting with the consumer to identify their needs and strengths
- Recording information in an understandable, concise format
- Facilitating meetings through the use of penetrating yet sensitive, open-ended questions, and encouraging brainstorming, problem-solving, action steps, conflict resolution, and taking direction from the consumer
- Providing assistance in locating resources
- Facilitating activities and assigning some action steps
- Following up and documenting progress

Studies of individuals who have undergone PCP indicate improvements in quality of life indicators (e.g., autonomy, choice-making, daily activities, and relationships), quality of supports received, and satisfaction. In addition, participants display increases in social networks, contacts with family members and friends, number and variety of activities, and level of community involvement. Studies also indicate that person-centered planning is relatively cost neutral.

Person-centered plans can be put into any format that is accessible to the individual (e.g., a document, drawing, or recorded oral plan). Multimedia techniques are increasingly being used as technology becomes more readily available. Research has shown that PCP tools are effective methods for focused listening, creative thinking, and alliance building that make a significant impact in the lives of people with disabilities and are a way of planning with people who often experience challenges in planning for their lives, or who find that other people and services are planning their lives for them.

Seven characteristics of effective person-centered planning teams have been identified:

1. **Productive meeting strategies:** Effective and efficient formats for conducting meetings and team problem-solving are used to enhance focus and productivity thereby allowing for more frequent meetings (if needed) and continual redesign of strategies for action.
2. **Problem-solving tools and technologies:** Group graphics, videos, and other visual tools are used as aids in reviewing accomplishments and planning.
3. **Focus on accomplishments:** Accomplishments, opportunities, successes, and work to pursue are reviewed at the start of each meeting to determine effective strategies.
4. **Fostering of leadership skills:** Leadership roles are shared by all team members who are empowered to act and make many more day-to-day decisions.
5. **Respect for and inclusion of all appropriate people:** Consumers, families, staff, and advocates are involved in the planning and implementation process in order to discover and build on ideas and information they have provided.
6. **Development of a greater capacity to solve problems:** Skills needed to solve increasingly complex problems and the ability to change existing organizational structures and processes are developed and used.
7. **Development of organizational effectiveness:** Effective groups obtain resources from the formal service system to improve the consumer's quality of life. In addition, they inform

and include agency management and administration in planning efforts, and receive recognition and support from management.

A number of different approaches to PCP have evolved. Current person-centered planning approaches include Making Action Plans or the McGill Action Planning System (MAPS), Group Action Planning (GAP), Essential Lifestyle Planning (ELP), and Planning Alternative Tomorrows with Hope (PATH). While each of these approaches has unique features and differs in the way in which information is amassed and whether the focus is on developing long term future plans or day-to-day details, all focus on individuals' gifts, capacities, and personal dreams, and make use of circles of committed friends, family, and community members to help individuals achieve their dreams and move toward full citizenship.

Biographical Timeline Process

The Biographical Timeline Process, also known as Biography, Timeline, or Life Line, is a facilitated process through which a team of people presents events, passages, and interventions in a person's life in a linear fashion in order to correlate information in a meaningful manner. The timeline is a prelude to person-centered planning; it is not a person-centered plan but can be used in preparation for other person-centered planning processes. The biographical timeline process can be used for assessment to aid in building supports for an individual who has unmet needs and/or presents with behavioral challenges, or a mental illness. It can also help team members clarify their mission and focus, while building empathy for the person who is the focus of support. In addition, it can be used by agencies and service systems to identify problems within support services and the effects of decisions on the lives of individuals who are provided with assistance. Teams ask consumers for permission to hold biographical timeline meetings and offer them the opportunities to attend. Individuals are also asked who they would like to attend the meeting and who they would definitely not want to be in attendance. Preferences are honored if at all feasible.

More information on the Biological Timeline Process can be downloaded from http://www.nasddds.org/pdf/LearningFromAPerson.pdf.

Personal Futures Planning (PFP)

Personal Futures Planning is designed to assist groups in focusing on opportunities for people with disabilities to develop personal relationships, enjoy positive roles in community life, experience increased control over their own lives, and develop skills and abilities needed to achieve their goals. PFP emphasizes the process of planning rather than the product and is both a plan and problem-solving process.

A Personal Futures Plan consists of a focus person's vision of what they would like to be and do and emphasizes their positive attributes (i.e., gifts, talents, abilities, and skills) rather than deficits, deficiencies, limitations, or problems. In addition, it considers things that need to happen in order for the person to fully participate in society rather than on what services are available in the community. The vision of the future is continually revised as new barriers and opportunities arise.

In PFP, a group of people, known as a circle of support, comprised of family, friends, advocates, neighbors, service providers and others who care about and are close to the focus person, as well the focus person, meet regularly to plan strategies, solve problems, and make commitments to take action. Individuals who do not have friends or family and rely on paid support staff can use a person-centered team for this purpose.

Information regarding the focus person's personal preferences (i.e., activities the individual most enjoys doing and motivate, and interest them) as well as those that are boring, frustrating or undesirable is collected during the first meeting. Ways that positive experiences be increased and

negative experiences decreased are explored. In addition, images the person has for the future, including unrecognized hopes and dreams (i.e., what the person wants in life) are ascertained. A process called group graphics is used to organize and portray the information with symbols to make it meaningful, stimulate creativity, and encourage the participation of people who have difficulty using words. A facilitator interviews the group and records all comments using colors, symbols, and words producing a series of pictures and symbols called maps which illustrate the patterns of a person's life and form the foundation for futures planning.

The Personal Futures Planning process consists of three steps: (1) the creation of a personal profile representing comprehensive information about the individual that is developed through a group interview; (2) the development of a plan for the person based on the information gathered from the group; and (3) the commitment by a group of individuals to form a network of support to help the person carry out the plan.

❶ **Creating a personal profile** that includes comprehensive information about the focus person, including, but not limited to, past events, future ideas and desires, opportunities, and obstacles. It is a recording of an individual's life including past events, relationships, places, preferences, ideas about the future, obstacles and opportunities that is developed through a group interview at a meeting of the focus person, a few others who care about and know them well, and a facilitator. The interview, sometimes called a capacity search, is a process for getting to know the focus person and building a description of the person that clearly defines their capacities and opportunities. During the meeting the facilitator interviews the focus person and a few other people close to the person to collect information regarding the person's background, including positive and negative experiences, major moves, critical events and current dynamics that are affecting the person's immediate future; family issues; general health; and ethnic and community ties. The quality of the focus person's life is described with information including the person's accomplishments, routines, and lifestyle patterns. Five areas of essential accomplishments are explored and the information provided forms the second part of the personal profile:

➲ **Community participation** including people the focus person spends the most time with, the number of those do not have a disability as well as their connections and networks to which the focus person could access.

➲ **Community presence** which gives information related to community environments that are frequented on a regular basis and with whom (e.g., alone, in small groups, or large groups).

➲ **Choices/Rights** include issues such as decisions the person makes independently and those made for the person by others.

➲ **Respect** describes how the person behaves in ways that reduce stereotypes, the kind of environments the person is in, and valued community roles they engage in each day.

➲ **Competence** includes the person's skills, those needed and wanted by others, and contributions made to other people's lives.

The development of the personal profile meeting usually occurs several days prior to the planning meeting in order for participants to have time to reflect on information that was shared. This meeting takes about two hours and is held in a very comfortable informal setting that the focus person is familiar with.

Background, People, Places, Preferences, and Images of the Future maps are used to create a personal profile. Additional maps can be used including choices, communication, capacities, health concerns, contributions, responsibilities, "nightmares", or other pertinent

issues. The facilitator or scribe draws simple illustrations in a variety of colors to make the maps easier for the participants to reference (e.g., green for positive experiences and opportunities; red for negative experiences and barriers; yellow for highlights, etc.).

Basic Frameworks	
Relationship Map	Identifies opportunities for personal support and assistance
Places Map	Describes the pattern of current daily life
Background Map	Provides an overview of the life experiences of the person and family
Preferences Map	Describes personal preferences, gifts and interests, as well as conditions to avoid
Dreams Map	Describes ideas about personal dreams and desires for the future. Determines time frame for work
Hopes and Fears	Describes how people feel about the opportunities and obstacles they see to making things happen
Optional Maps	
Choices Map	Describes decisions made by the person and decisions made by other people and clarifies needs for personal assistance
Health Map	Describes conditions that promote or threaten health
Respect Map	Describes personal characteristics that can create barriers to community acceptance
Other	Other maps created by the facilitator to help describe the patterns in a person's life

❷ **Planning:** Following completion of the personal profile, the group develops an action plan based on the image/dream of the future that has been developed. The facilitator leads the group to determine opportunities to be explored and obstacles to overcome to make the dream a reality. From this discussion the group develops strategies or action steps that group members agree to work on prior to the next meeting. A facilitator guides the group through seven basic steps for plan development:

Step 1: **Reviewing the Personal Profile:** The facilitator begins the meeting by reviewing the information collected during the personal profile process and the group has an opportunity to make additional comments and observations.

Step 2: **Reviewing Trends in the Environment:** Participants identify ongoing events in the environment that are likely to affect the focus person in a positive or negative manner. These events may be specific to the individual (e.g., graduation from high school, family changes, or financial issues) or trends in the larger environment (e.g., the closing of a service program, the development of a new assistive technology, or access to transportation). and can function as opportunities or obstacles to planning and implementation.

Step 3: **Finding Desirable Images of the Future:** Members of the group share their ideas about the future in various areas (e.g., home, work, school, or other valued roles, community activities, and relationships).

Step 4: **Identifying Obstacles and Opportunities**: The group prioritizes the order of areas of life to work on.

Step 5: **Identifying Strategies:** Strategies are action steps for implementing the vision developed during Step 3.

Step 6: **Getting Started:** Participants identify up to five action steps they can voluntarily commit to completing within a short time. (It is critical to ensure that many small steps occur quickly and the group reconvenes in the near future to assess the progress.)

Step 7: **Identifying the Need for System Change**

A plan is developed based on information gathered by reviewing the personal profile, considering environmental trends (e.g., economic issues that may impact funding availability), and identifying obstacles, opportunities, and strategies for getting started by the key people in the focus person's life. It includes: steps to be taken, the person or persons who will be working on each step, and a time-line. The format for each individual's plan is unique to their circumstances.

❸ **Commitment.** The group forms a support network to help the focus person accomplish the plan and ensure it comes to fruition. The support network is typically comprised of friends, family, neighbors, and others in the community.

The initial plan can take four to six hours to develop during two planning sessions. In addition, the planning team usually holds hour-long monthly follow-up meetings during the initial implementation phase, and meets as often as needed thereafter.

MAKING ACTION PLANS (MAPS)

The MAPS process starts with the person's history which is used to define dreams, acknowledge issues, and develop a profile of their gifts and talents. One person facilitates the discussion and another records it. The focus of MAPS planning meetings is on sharing answers to the following questions:

1. What is the person's history/story?
2. What is the person's dream?
3. What is the person's nightmare?
4. Who is this person?
5. What are the person's strengths and talents?
6. What does the person need to achieve their dream and avoid their nightmare?
7. What is the plan of action?

Planning and developing goals entails:

1. Describing a desirable future for the individual
2. Delineating a schedule of activities and support to move to a new outcome
3. Accepting responsibility for using available resources and dealing with reality

Information on MAPS can be obtained from http://www.inclusion.com/maps.html.

PLANNING ALTERNATIVE TOMORROWS WITH HOPE (PATH)

The PATH process starts with a person's dream five to ten years in the future (in contrast to MAPS) and works back to the present while identifying the progression of steps needed to realize the person's dreams. It is based on the person's strengths, interests, values, aspirations, and choices. A clear description of a potential, positive, and desired life is described. To accomplish this, the focus person is asked to select where he\she wants to live and with whom, where he\she will be working, and how he\she will be involved in the community, including friendships, recreation, and transportation. The individual's preferences and choices then become the basis for a clearly defined series of steps to make that dream come true (e.g., what kind of job the person would like to have; how the person can gain current experience that could lead to a future job; and who on the person's team will take responsibility for making arrangements for them to gain this experience). This process is designed to result in a strong commitment by team members to take specific actions now to help the individual progress along their path to the future.

The eight steps in PATH are:

1. Touching the Dream (the North Star, or the place in the future the individual imagines in their most optimistic expectations)
2. Setting the Goal
3. Grounding in the Now
4. Identifying People to Enroll
5. Recognizing Ways to Build Strengths
6. Charting Actions for the Next Few Months
7. Planning the Next Month's Work
8. Committing to the First Step
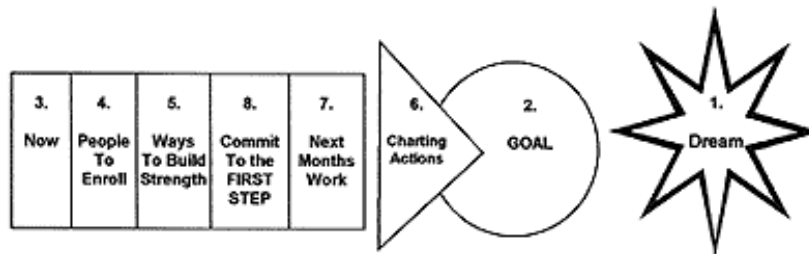
A specific format and color graphics are used with this planning tool. One person facilitates the process while a second person records what is said. Information can be obtained from http://www.inclusion.com/path.html.

ESSENTIAL LIFESTYLE PLANNING (ELP)

Essential Lifestyle Planning, which began in the late 1980s at the University of Maryland to help people return to their home communities from institutions and residential schools, is a guided process for learning how individuals wish to live and developing plans to assist in bringing those desires to fruition. An essential lifestyle plan identifies and differentiates what is important to a person from what others view as important for them. Plans thus reflect the perceptions of the focus person and those who know and care about them. Essential Lifestyle Plans are used to discover what is important to a person in everyday life (i.e., daily rituals); identify what support the person requires and any issues of health or safety from that person's perspective and describe what has been learned in a manner that is easily understood by those who will enable the person to obtain what is important to them. It is a flexible process that can be used in combination with other person centered planning techniques by self-advocates, families, friends, and paid support staff.

The development of an essential lifestyle plan is comprised of five stages: (1) think about what you want to learn and how to learn it; (2) gather the information; (3) develop and review a first plan; (4) put what has been learned into practice; and (5) on-going learning. The plan contains four basic sections:

❶ **Administrative section:** consists of basic information about whom the plan belongs to, who was involved in producing it, when it was done, and why the plan was done/what you want to learn.

❷ **Person's section:** consists of an introduction to the person (i.e., positive reputation, what people like and admire about the person) and what is important to the person. Three prioritized lists in order of importance to the person are created which generally reflect what is important in relationships and interactions; things to do and things to have; rhythm or pace of life; and positive rituals or routines.

❸ **Support section:** describes what support the person requires, and what people who know and care about the person believe are important for the person to be healthy and safe. Characteristics of people who support the person may also be included. This section omits things the person can do for themselves and those that are not important to the person (which are accounted for elsewhere in the plan). Optional parts of this section can be included and used as needed (e.g., describing how the person communicates and what others need to do to help the person maintain health and safety):

- **Communication section** is designed to support people who do not communicate with words, have difficulty communicating with words, or use words to talk but are difficult to understand, and recording how others communicate with them. This section is comprised of two subsections: How others think the person is communicating with them and how others are trying to communicate with them (e.g., using augmentative communication strategies such as object cues).

- **Routines** for persons who require extensive physical assistance are detailed under specific headings (e.g. morning, arriving home, and bedtime routines) and made available to others who actually provide, plan for, or oversee the support.

❹ **Action plan section:** reflects the discrepancy between what is described in the plan and what is happening in the person's life at the moment (i.e., something that is important to the person that is not present in their life), and an action to change this. The action plan section is recorded and addressed during the essential lifestyle planning meeting and includes:

- Issues to work out (i.e., unresolved issues) which consists of a running list of things to work out and questions to be answered.

- A designation of individuals and their agreed-upon tasks to help the person move toward the life that they want and remain healthy and safe (e.g., what needs to be maintained as well as what will be changed). It is developed by comparing the person's current life to what is important to them.

GROUP ACTION PLANNING (GAP)

Group Action Planning is a process of fostering a reliable alliance between an individual with a disability, family members, friends, and professionals (known as an action group) to create a vision of full citizenship characterized by interdependence, empowerment, and productivity and consistent with the preferences of the focus person. Action Groups are directed by the individual's and family's preferences rather than by agencies or professionals. They are comprised of individuals representing each of the individual's/family's valued settings (home, neighborhood, job or school setting, and community), the individual and family members (in contrast with typical individualized team meetings that are dominated primarily by professionals) in order to create a context for social connectedness and interdependent caring and build relationships. Action Groups are characterized by their use of problem-solving skills, adherence to family-centered principles of support, and self-determination.

Group Action Planning is comprised of five major components:

1. Inviting support

2. Creating connections (Group Action Planning places strong priorities on creating social and emotional connectedness among all group members, especially with the individual with the disability.)
3. Envisioning great expectations
4. Solving problems
5. Celebrating success

A group facilitator is selected to lead the group through problem solving steps:

- ➲ Analyzing preferences, strengths, and needs
- ➲ Brainstorming a wide range of options
- ➲ Carefully evaluating each option
- ➲ Selecting the preferred option in developing a detailed action plan
- ➲ Implementing the plan
- ➲ Evaluating the outcomes of the plan

The facilitator summarizes the specific steps that need to occur prior to the next meeting and a designation of responsibility at the end of every meeting, No unique guidelines for Action Groups have been established; the process can be tailored to particular situations.

Action Groups appear to work more effectively when expectations are set high because the challenge of reaching goals that many people view as unreachable can provide motivation for group members to surpass expectations. Stating positives about the individual (e.g., strengths or gifts) during meetings can enhance expectations, help al members of the group become familiar with the unique resources the individual has to build upon, and serve as positive affirmations for individuals with disabilities and their families. During meetings, time is taken to acknowledge progress, express gratitude, and celebrate rather than always engaging in problem-solving.

ALTERNATIVES TO GUARDIANSHIP

All people should be presumed competent to make choices regarding their lives, irrespective of disability. Although some individuals may have a limited ability to express their choices, people who know them well should make every effort to ascertain their preferences. Surrogates (i.e., parents, family members, and other supporters) sometimes need to make decisions on a person's behalf when it is impossible to determine their desires. The choices made in such circumstances should be limited to the range of choices and opportunities available to persons who do not have a disability.

It should be noted that individuals with disabilities experience the same vulnerabilities as all others, but often have less power to deal with them. Furthermore, it is impossible for anyone to exercise control over all threats to their own or another person's safety and well-being. According to the developmental disability literature, the most significant predictor for health and safety risks is the absence of long term enduring relationships with individuals without disabilities. Critical security measures that have been identified include long term committed relationships, strong community connections, and the ability to generate some private income and have control over who provides supports and services. Various strategies have been identified to help promote consumer safety and welfare including:

- ♦ Authority and control (to reduce vulnerability)
- ♦ Staff within provider agencies who know each consumer well
- ♦ Explicit rights and due process mechanisms for consumers and their families
- ♦ Independent investigation of claims of abuse claims and punishment of those found guilty of abusive practices

♦ Staff training to (to prevent abuse)
♦ A **natural support system** consisting of a network of committed family members, friends, and circles of support that are fully aware of a person's strengths, wishes, and character traits can assure that decisions are not made in a void or by paid service providers. In addition, a support system can distribute tasks and supports in a shared fashion so that no single person bears full responsibility. Consideration should be given for a **release of information or advocacy authorization** to allow family and other supporters access to medical records and receive routine invitations to participate in person-centered planning meetings.
♦ The provision of **community assistance** for support and observation including, but not limited to:

- Postal service checks for piled up mail
- Unpaid utility bills and meter reader observation
- Telephone reassurance programs
- Home visitors and pets on wheels
- Meals on wheels
- Food/meal and prescription medication delivery
- Home sharing/roommate
- Personal assistance / home health care
- Service animals

Guardianship is an extreme and intrusive form of oversight of an individual's life. Guardianship can also be a potentially lethal health risk for many people with significant disabilities residing in nursing homes, institutions, and community group homes who have do not resuscitate orders as part of their permanent medical record. These orders are typically given by legally appointed guardians and often when the person is not dying or even near death. Thus, the same medical interventions that persons without a disability might expect can be denied to individuals with disabilities. It is recommended that least restrictive alternatives always be considered prior to removing a person's civil and legal rights to independent decision-making. Alternatives that enhance a person's ability to live more independently in the community should be given first consideration to allow for the maintenance of as much autonomy and self-determination as possible while providing only the level of protection and supervision necessary.

ASSISTANCE WITH FINANCES

A number of alternatives are available to provide assistance with finances for people who have difficulty managing their funds. A **representative payee** is a person designated by the Social Security Administration, the Veteran's Administration, and other government agencies to receive and manage monthly benefit checks on behalf of a beneficiary when the beneficiary is determined incapable of managing the funds themselves. The payee maintains control over the benefits, signs all checks, and spends the money to meet the beneficiary's basic needs. Social Security, the Veteran's Administration, and other government agencies have procedures for appointing representative payees and must be contacted to have a representative payee appointed for someone. The appointment only applies to specific benefit programs.

Bill payer programs serve individuals with limited incomes who are in control of their own financial affairs but need some help organizing their bills and checkbook. A bill payer assists the person in organizing monthly income and expenditures, writes checks for the person's signature, and assists the person with paperwork related to bill paying. **Banking arrangements** and **dual signature accounts** can be used as alternatives to conservatorship. A person can often retain control of their own affairs with the help of automatic deposits and withdrawals for bills or banking by mail or phone. Another method often used is the establishment of a joint bank account in which a trusted friend or family member's name is added to an account. Caution is recommended because both persons on the account have ownership of the account. A **limited bank account** that requires a co-signor to access funds, write checks, or transact business is another banking

option. Yet another related option is the establishment of a **joint property arrangement** where two or more people share ownership of real estate or bank accounts for managing property.

POWERS OF ATTORNEY

A **Power of Attorney** allows an individual (the principal) to designate a person (the attorney-in-fact) to discuss and make decisions regarding medical decisions, living situations, confidentiality issues, and others. The power of attorney allows the individual to confer that power and remove it if they become dissatisfied with the decisions being made. There are general powers of attorney that convey a broad range of authority and limited powers of attorney that convey power over specific activities.

A **General Power of Attorney** gives a person the authority to perform any action for another person. It authorizes the attorney-in-fact to act on the person's behalf in all personal affairs and financial transactions. The authorization ceases upon death. Unless the document is a durable power of attorney, it also terminates upon disability or incapacity. A **Limited Power of Attorney** gives a person the power to perform a specific action and can act on the person's behalf only in matters specifically designated in the written document. The authorization ceases upon death. Unless the document is a durable power of attorney, it also terminates upon disability or incapacity.

A **Financial (Durable) Power of Attorney**, or **Power of Attorney For Financial Matters,** grants authority to the attorney-in-fact to transact business on the person's behalf (i.e., make financial decisions and/or handle financial transactions for the person). The power of attorney can grant the attorney-in-fact one or all of the following:

- Open, maintain or close bank accounts or brokerage accounts
- Sell, convey, lease or maintain real estate
- Access safe deposit boxes and their contents
- Make financial investments
- Borrow money, mortgage property, or renew or extend debts
- Prepare and file federal and state income tax returns
- Vote at corporate meetings
- Purchase insurance for the principal's benefit
- Initiate, defend, prosecute, or settle lawsuits
- Start or carry on a business
- Employ professional and business assistances including lawyers, accountants, real estate agents, etc
- Apply for benefits and participate in governmental programs
- Transfer any and all property to a trustee
- Disclaim part or all of an inheritance

Durable and **Standby Powers of Attorney** continue to be effective even in the event of disability or incapacity. Furthermore, a durable power of attorney can be made effective upon occurrence of a certain date or event such as a diagnosis by a physician of disability or incapacity. Because the effective date is delayed, this type of durable power of attorney is referred to as a standby power of attorney. Financial and medical Powers of Attorney can be made durable. A **Medical (Durable) Power of Attorney** is a type of Power of Attorney that appoints an agent to provide informed consent for surgery, medical treatment, personal care, and other medical or health matters. A Medical Durable Power of Attorney covers a broader spectrum of medical procedures than a Living Will. A **Protective Medical Decisions Document (PMDD)** is a durable power of attorney for health care that gives a person named (the agent) to make health care decisions (i.e., the authority to act on another person's behalf). A PMDD does not give the agent authority to approve the direct and intentional ending of life and specifically prohibits euthanasia and assisted suicide.

A **health care proxy** can be designated to make health care decisions for an individual who lacks the capacity to make such decisions themselves. A **living will**, also called a director or declaration, is a legal document that is often used in conjunction with a health care proxy. It is used to express wishes for medical decisions about withholding or withdrawing life-sustaining treatment for a person who lacks capacity to make such decisions. A living will, signed while the

person is competent, instructs doctors to withdraw or withhold artificial life support if the person becomes medically terminal. Living wills only apply to artificial life sustaining procedures. An **Advanced Directive** names a proxy and provides guidance about a person's wishes and essentially combines a health care power of attorney (or health care proxy) and a living will. Advance directives are oral or written instructions an adult gives to health care providers and family/loved ones while able to communicate in order to ensure their wishes regarding health care are followed in the event they are unable to communicate with providers.

CONSERVATORSHIPS

A **conservator** is appointed by the court and is responsible for making decisions regarding the financial affairs (e.g., such as stocks, bonds, bank accounts, cash and real estate) of a ward. In general, the conservator controls all of the ward's income and property, pays bills, and handles other financial matters. A conservator takes possession of the ward's real and personal property and establishes a bank account for all of the ward's income. Conservators have a duty to preserve and protect the property of the ward. Powers that a conservator can exercise without prior court approval include: collecting principal and income from any source; suing or defending claims in favor of, or against, the ward; selling or transferring perishable personal property; voting for the ward at corporate meetings; and receiving additional property from any source. Powers that a conservator can exercise only with the court's prior approval include: making payments to or for the benefit of the ward, including payments for nursing homes and medical expenses; investing the ward's funds; executing leases on behalf of the ward; applying any part of the ward's income or property for the support of another person; settling a legal claim; selling any of the ward's property; canceling contracts entered into by the ward that are no longer beneficial to the ward; and making gifts. A **limited conservatorship** gives only those specific powers that are set forth in a court order; the ward can still make decisions in all other matters. A general or **full conservatorship**, in contrast, gives the conservator the authority to make all but a few decisions on behalf of the ward. The court must attempt to give the conservator the fewest powers necessary to meet the needs of the ward by law.

A person of "sound mind" can establish a **standby conservatorship** to plan for circumstances in which they may be unable to handle their affairs without ceding present control over their property. A verified petition must be executed for the voluntary appointment of a conservator to establish a standby conservatorship. The petition contains the express condition that it is acted upon by the court only upon the occurrence of a specified event or the presence of a described condition of mental or physical health of the petitioner. The occurrence of the event, or the existence of such condition, must be established in the manner directed by the petition. The petitioner can revoke the petition provided the petitioner is of "sound mind" prior to the appointment.

TRUSTS

People with developmental disabilities have lifelong needs. Proactive financial planning is critical for families who have a child or sibling with a developmental disability. Families can set up **Special Needs Trusts**[11] **(SNTs)** that adhere to Social Security, SSI (Supplemental Security Income) and Medicaid rules to ensure their family member with a developmental disability has available resources after parents or other caretakers are no longer available. Funds in Special Needs Trusts are not counted as part of an individual's income (unlike funds in traditional savings accounts) and thus provide a safeguard for benefits such as Medicaid and Social Security. People with developmental disabilities can also set up trusts on their own behalf.

An **amenities trust** is designed to supplement means-tested entitlement benefits**[12]** (e.g., SSI, SSDI, and Medicaid) that are essential for securing personal assistance and medical treatment. Amenities trusts provide a resource for purchasing amenities to enhance the person's quality of life without hindering their access to essential public benefits. Funds in an amenities trust can be used to purchase a residence[13] for the beneficiary and ensure the beneficiary's needs are monitored subsequent to the deaths of parents or other caregivers. An amenities trust is typically a subtrust to a family or credit shelter trust funded upon the death of the grantor and grantor's spouse. A fiduciary is required to manage the assets throughout the beneficiary's lifetime. The grantors determine the disposition of any remaining trust assets subsequent to the death of the beneficiary. Allowable amenities include, but are not limited to:

- Acupuncture/acupressure
- Insurance (automobile and/or possessions)
- Appliances (TV, VCR, stereo, microwave, stove, refrigerator, washer/dryer)
- Linens and towels
- Bottled water
- Massage
- Bus pass/public transportation fees
- Musical instruments (including lessons)
- Clothing
- Clubs and club dues (record clubs, book clubs, health clubs, service clubs)
- Over-the-counter medications (including

- Dry cleaning and laundry services
- Private counseling
- Elective surgery
- Repair services (appliance, automobile, bicycle, household)
- Fitness equipment
- Retail store charge accounts (gift stores, craft stores, hardware stores, pet stores)
- Furniture, home furnishings
- Sporting goods/equipment
- Gasoline for automobile
- Taxi cab scrip
- Haircuts/salon services

---

[11] A **trust** is a legal relationship in which one person (a trustee) holds real or personal property (e.g., money, real estate, stocks, bonds, collections, business interests, personal possessions, and other tangible assets) for the benefit of another person (the beneficiary). Trusts that can be changed or terminated at any time by the grantor are **revocable**. Trusts that cannot be changed or terminated before the time specified in the trust itself are **irrevocable**. The trustee holds legal title to the property transferred to the trust and has a legal duty to use the property as provided in the trust agreement as permitted by law. The beneficiary retains equitable title (i.e., the right to benefit from the property as specified in the trust).

[12] Any outright inheritance or distribution received by an individual with a developmental disability (or mental illness) can interfere with the flow of means-tested benefits such as SSI or Medicaid.

[13] If the beneficiary pays rent to the trust and the rent payment constitutes a reasonable share of the expenses for maintaining the home, the provision that the trust not be used for shelter is satisfied. The amenities trust can purchase the home in the beneficiary's name if their income is sufficient to pay for basic utilities and property taxes. If the beneficiary opts to include roommates, the expenses associated with home maintenance can be shared with them.

vitamins or herbs)
- Computer (hardware, software, programs, Internet service)
- Personal assistance
- Courses or classes (academic or recreational)
- Pets, pet supplies
- Curtains, blinds, drapes
- Physician specialists

- Telephone, internet, cable, or satellite television
- House cleaning/maid services
- Tickets to concerts or events (for beneficiary and accompanying companion)
- Transportation (automobile, motorcycle, bicycle, moped)
- Vacation (including paying for a companion to accompany the beneficiary)
- Nonfood grocery items (household cleaning and laundry products, soap, bleach, fabric softener, deodorant, personal hygiene products, paper towels, napkins, tissue, toilet paper)

"Solely for the benefit of" trusts are created for the benefit of persons who are disabled under federal law and are in the amenities trust format. The transfer of assets to the trust (typically by a parent) is used to qualify the parent for Medicaid without disqualifying the person with a developmental disability (or mental illness) from also receiving Medicaid. Thus, the assets are transferred to the trust and removed from the parent's countable assets and are not a divestment subject to the look-back period with respect to the parent's Medicaid application. A parent who is moving toward long-term care and may need to qualify for Medicaid can create a trust that is solely for the benefit of his/her child with a development disability (or mental illness) and can fund the trust during the parent's lifetime. The parent thus becomes immediately eligible for medical assistance and the beneficiary of the trust does not have to count the trust assets or income generated by the trust. This type of trust can be effective in estate planning when a parent's estate is at risk for depletion due to medical and long-term care needs.

OBRA 93 trusts are used to shelter the assets of a person with a developmental disability (or mental illness) while protecting their eligibility for Medicaid. Such assets are typically in the form of accounts created for the person prior to reaching the age of majority and can be established for the receipt of unexpected distributions such as inheritances, gifts from relatives, or personal injury settlements. OBRA 93 trust provisions must require that the income and principal be unavailable to provide support to the beneficiary. These trusts must also specifically authorize that the state of Michigan will receive all amounts remaining in the trust upon the death of recipient up to an amount equal to the total medical expenditures paid on their behalf, including benefits received prior to the creation of the trust. An exception allows the assets to be retained by the trust subsequent to the death of the beneficiary by a trustee that is a nonprofit organization which can then use the retained assets for the benefit of persons with disabilities.

WORKING WITH FAMILIES

Adapting to a child who has a disability is an ongoing, lifelong process replete with anxieties, conflicts, and stressors that are manifested in different ways within and among families. Conflicted family situations can become exacerbated or strengthened by the presence of a child with a developmental disability. The time and attention needed to coordinate services and supports and manage behavioral challenges can diminish time for attention to siblings. Community and family outings can be restricted due to behavioral issues and parents can find themselves placed in situations of educating bystanders about their child's disability subsequent to public displays of problem behaviors (e.g., tantrums or outbursts). Contacts with friends can be reduced thereby curtailing social support. Families may need to make accommodations such as changing sleep habits, changing work hours or jobs, working fewer hours, quitting work, or not accepting a job. Families incur higher costs for children with special needs (due to medical care, therapy, equipment, transportation, and childcare) which can lead to financial strain. It is recommended that all family members receive support and education regarding the specific disability and potential coping strategies.

Families and other supporters have evolved from a passive role in which they receive instruction from an expert, into one that is active and in which they provide valuable qualitative perspectives for assessment, determinations regarding whether proposed intervention strategies are relevant, practical, likely to lead to beneficial outcomes, and congruent with their values, needs, and preferences. Such a family-centered perspective emphasizes parents and caregivers as the most knowledgeable sources of information about their children's strengths, needs, and challenges. It is based on the recognition that families' perceptions of their children's challenges and prognosis may diverge significantly from those of professionals, and that interventions may fail to be implemented and sustained when they are incompatible with families' goals, values, and beliefs, or daily routines. Families are now viewed as equal partners in diagnosis, assessment, and intervention processes and included in all aspects of treatment and service planning.

The literature indicates that the majority of parents desire clarity regarding the nature of their children's difficulties and studies demonstrate parents portray accurate developmental concerns about their children. Parents report the highest levels of stress prior to and during the process of securing a diagnosis for their child. For example, parents of children with autistic spectrum disorders frequently express concerns regarding their child's development prior to eighteen months of age. But, a considerable gap existed until recently between the time parents first reported concerns and subsequent referral and the establishment of a definitive diagnosis. Lengthy and cumbersome referral and diagnostic processes contribute to significant levels of parental anxiety, places unneeded stress on parents and families, and wastes valuable time for the initiation of intervention.

The majority of people (about sixty percent) with mental retardation reside with their families throughout their lives. Families often serve as brokers for health and other services. Longer life spans engender changes in the roles parents and siblings play in brokering services. Many older adults living with their elderly parents have Down syndrome which is associated with premature aging and a high risk for Alzheimer's disease (as noted previously in the section on older adults). As both parents and children age, their needs for respite care, long-term financial planning, and determination of future residential options become more critical. Finding and maintaining a safe, caring, respectful, and permanent residence is one of the major concerns and challenges that parents face. Prior planning can help mitigate disruptions in care that occur when parents are no longer able to provide support or die.

The National Family Caregiver Support Program, part of the Older Americans Act Amendments of 2000, is designed to help family members provide care for elderly persons at home including persons with developmental disabilities. The United States Administration on Aging awarded a grant to The Arc of the United States to help older parents and other caregivers obtain supports and services from local aging agencies to implement this provision. Many area agencies on aging and other agencies that focus on older adults have not traditionally seen this group of caregivers as part of their province.[14] The Arc of the United States has been working on a project that is designed to enhance the abilities of area agencies on aging to conduct outreach and provide services to older caregivers of persons with developmental disabilities to ensure that area agencies on aging include this group within their mandate. The focus of the project has been on encouraging local chapters of The Arc and area agencies on aging to collaborate in the provision of support to older caregivers following identification from outreach and casework initiatives of area agencies on aging.

A variety of family support services have been developed to assist families in maintaining a child or adult with a developmental disability in their own home. Services are provided to the entire family unit, individually tailored to the unique needs of each family, and include intensive family intervention, family services coordination, parent or other caregiver training, habilitation skills training, psychological/behavioral treatment, other training services, permanency planning and adoption services, respite, and cash subsidy programs.

Respite

Respite offers temporary relief to families and caregivers with children who have disabilities, chronic or terminal illnesses, and/or are at risk of abuse and neglect. Respite can be provided in the home or a variety of out-of-home settings for any length of time depending upon a family's needs and resources that are available. Respite care programs emerged in the late 1960's as a result of the deinstitutionalization movement which was based on the belief that the best place to care for children with disabilities was in their homes and the communities.

According to the National Respite Guidelines, respite service options need to be flexible and responsive to the changing needs of families, available during the day, for overnight care, and for extended periods of time if necessary. These guidelines also recommend the provision of respite in generic community settings where families receive other services, on a planned or immediate basis, with family choice of providers and options to request changes of providers.

Respite services can be provided through interagency collaboration efforts. Providers may be employed by agencies, work as self-employed independent contractors, or be individually selected and employed by families. Many respite programs offer additional services to enhance the respite experience and meet other needs of families including:

♦ Transportation
♦ Parent education
♦ Parent, sibling, and family support groups
♦ Counseling and therapy services

---

[14] It is estimated that almost two million persons with developmental disabilities live at home or with a family caregiver, and about twenty-six percent of these caregivers are aged sixty or older. Approximately fifty percent of these families remain unidentified until a concerted outreach effort is undertaken to identify them.

♦ Case management or service coordination
♦ Early intervention services

In-home Programs	Services are provided in a family's home or care provider's home
Center-Based Programs	Families bring their child to a facility in their community to receive respite care
Child Care Settings	Child care centers or family day care homes designed to provide respite care in addition to regular child care services
Recreational Programs	Parks and recreation departments and YMCA agencies provide recreational programs that offer families respite breaks
Generic Community Programs	Children receiving respite services are integrated into programs provided for all children
Summer Camps	Provide day or overnight options
Residential and Group Home Programs	
Licensed Foster Homes for Children	
Emergency Shelters	Shelters for children and individuals who are homeless
Hospital-Based Programs	
Cash Assistance or Parent Subsidy Programs	Families use funds to pay for and access respite care options of their choice
Registries	Lists of providers for families to use to make their own decisions regarding providers

Respite has been demonstrated to be critical in the continuum of family support, family preservation, and prevention services. Respite has been shown to reduce family stress, prevent or delay lengthy and costly out-of-home placements, and reduce the potential for violence, abuse, and neglect. Research has shown that respite leads to improved family functioning, satisfaction with life, and attitudes toward a family member with a disability. Studies have clearly demonstrated significant reductions in somatic complaints of primary caregivers of children with chronic illnesses, number of hospitalizations and hospital days required by children, number of medical care claims (which decrease in proportion to respite care day increases), and a significant decrease in foster care placements for children with developmental disabilities. It is the service option that families and caregivers request most often for child care, elder care, and comprehensive family support. Unfortunately, despite high demand, respite is in significantly short supply for all age groups, families in crisis, and caregivers of older adults and individuals with disabilities.

CRISIS NURSERIES

Crisis nurseries are a type of respite for children who are at risk of abuse and/or neglect that emerged during the 1970s. Crisis nurseries provide temporary child care and services for families and caregivers experiencing significant stress. They provide a safe and supportive environment for children and offer an array of support services and for families and caregivers. Crisis nursery programs generally serve children from birth to eighteen years of age. Some programs serve a particular age group (e.g., birth to age three or preschoolers).

Like other types of respite services, crisis nurseries help prevent out-of-home placements and potential abuse and neglect as well as preserve the family unit, and support family stability. Crisis nursery services can provide in in-home or out-of-home care in a variety of settings for various lengths of time in accordance with families' needs and available resources. Most programs offer child care free of charge for a maximum of thirty days per year that is usually available twenty four

hours a day and accept children at any time, day or night, in order to relieve a potential or existing family emergency. Some programs utilize existing day care centers, private homes (which are licensed similar to foster care homes), or emergency shelter facilities, while others are located in facilities specifically designated as crisis nurseries. Federally funded crisis nursery programs are required to provide referrals for support services. The majority of programs, irrespective of funding source, provide support services within their own service delivery systems. Support services provided by crisis nursery programs, or by community agencies through informal or formal collaborative agreements, include:

- Family counseling
- Individual counseling
- Service coordination (case management)
- Parenting classes
- Access to medical services

- Home management training
- Employment training
- Help lines
- Substance abuse prevention counseling
- Developmental assessments

Crisis nursery program models differ in accordance with the needs of the families within each local service area. For example, some serve families in situational emergencies (e.g., families involved in a divorce or extended hospital stay), while others focus on serving children and families where potential abuse or neglect has been identified.

Center-Based Crisis Nursery Facility	Center-based crises nurseries may be located within a larger organizations (e.g.,, child welfare agencies) or licensed child care facilities specifically designated as crisis nurseries and usually provide services twenty four hours a day, three hundred sixty five days a year. State requirements for food preparation, staff to child ratio, health and safety, and other licensing requirements must be adhered to. Funding for professional and paraprofessional staff is required. A variety of programs (e.g., substance abuse prevention and teenage mother assistance programs) may be offered.
Center-Based Day Care Facility	Many crisis nursery programs contract with existing day care centers. This is a cost effective model that utilizes day care centers that already meet state licensing requirements and have staff that are trained to provide developmentally appropriate activities for children. Day care staff members receive additional training (e.g., working with children at risk for abuse and neglect). Additional family support services are provided by the crisis nursery program and community agencies as needed. This model may not be able to offer temporary child care services twenty four hours a day due to licensing requirements and hours of operation of the daycare facility.
Center-Based Crisis Shelter	This model is similar to the day care facility model in which center-based crisis shelter administrative staff contracts with crisis or women's shelters to provide crisis nursery care for children and additional support services for parents. Families served in this type of program usually have an identified abuse or neglect situation.
Community-Center Multiple Site	This model, often used in rural areas, provides temporary child care by utilizing a variety of existing community facilities (e.g., community centers and churches) in one or more geographical locations. Facilities are provided through informal or formal agreements. This model may not be able to offer temporary child care services twenty four hours a day due to limited use of the community facility. Often, family support services (e.g., parent support groups or parenting classes) are offered for part of the time during which children are receiving care. Trained volunteer families within the community can be providers in this model. This model fosters interagency collaboration and coordination.
Family Care Home	In this decentralized model, family care homes with foster care licensing provide care for children. Crisis nursery child care is usually provided up to seventy two hours per stay. Families within a community commit time each month to care for

	children in crisis on a formal basis and may be on call for certain segments of the month. All providers are screened and licensed, and receive training and a stipend to help offset expenses for food and necessary supplies. Some providers work as volunteers, while others are paid. In addition to family care home providers, agencies use staff in the community to help with transportation, intake, and other duties integral to the operation of the program. This model is effective for rural areas.
In-Home Crisis Nursery	In-home programs provide some or all crisis nursery services within a family's home to make child care relief available with minimal disruption to routine activities. Services can include support counseling, activities to enhance parenting or other skills in accordance with individual families' needs, and assistance in accessing identified resources. Some in-home models provide temporary child care outside the home and parent support services within the home.

CRISIS NURSERIES FOR INFANTS AND CHILDREN WHO ARE MEDICALLY FRAGILE

Crisis nursery care for infants and children who are medically fragile is designed to provide a supportive, nurturing environment for children who have special medical problems requiring twenty four-hour observation or treatment. These crisis nurseries offer medically supervised child care to families in collaboration with medical facilities for infants and children whose health care needs are beyond the typical care needs of other children within the same age group, or require specialized health care plans directed by physicians and/or nurses for daily care. Criteria for children identified as medically fragile include:

♦ Infants on apnea monitors
♦ Infants born prenatally exposed to alcohol or drugs (e.g., infants with Fetal Alcohol Syndrome or crack/cocaine exposure)
♦ Children admitted directly from a hospital subsequent to receiving care for a significant injury or illness
♦ Children with breathing problems requiring significant care
♦ Children who require ongoing alterations in daily routines due to a medical condition
♦ Children in Spica Casts (i.e., body casts from waist to feet)
♦ Children with specialized feeding problems (e.g., feeding tubes, cleft lip or palate)
♦ Children with infectious or contagious diseases (e.g., hepatitis, sexually transmitted diseases, and HIV-related conditions)
♦ Children with chronic health problems (e.g., diabetes, asthma, or seizure disorders)

Individualized child care plans are developed to accommodate each child's specific physical problem(s). The organization of each child's day takes into consideration physical mobility, age and size, prescribed medications (and their effects on the child's waking and sleeping patterns), and specific medical issues. For example, toddlers or elementary school aged children may require shorter school schedules. Infants who are medically fragile typically need a lower staff to child ratio in accordance with the level of care required. A one to three staff ratio is typical, but some infants and children may require one-to-one care during specific times.

Specific staffing, ongoing training, and medical protocols are critical to crisis nursery operations for infants and children who are medically fragile, particularly those that mainstream children who are medically fragile with healthy children as a way to increase capacity. Staff training must adhere to state licensing requirements, include discussion of the types of physical problems to be encountered; the use of cardiopulmonary resuscitation; specialized medical equipment (e.g., inhalers or apnea monitors, feeding tubes, etc.), medication administration; charting of medication and physical symptoms, emergency procedures, universal medical precautions (including training

on the use of plastic gloves, proper handling of diapers, bedding, and any blood stained clothing or items), and incorporate practice in using various pieces of equipment and various procedures.

Medical care plans must be developed in conjunction with a physician and/or nurse, depending on the severity of the medical problem. Crisis nursery care must be supervised by medical staff. Collaboration with a medical service (e.g., hospital, clinic, or private physicians) which has a basic program of medical care is essential. Components of care include:

♦ Initial medical examination and assessment
♦ Medical history and prescribed treatment from a referring entity (Infants referred from hospitals are more likely to have this information available.)
♦ A weekly clinic in which medical examinations are conducted by a physician, treatment revisions are made as needed, and staff concerns are addressed
♦ The availability of a physician for emergency consultations during evenings and weekends
♦ A separate medical exam room for medical and nursing examinations, monitoring children who are ill, and storage of medications (in locked cabinets and refrigerators), medical supplies, and equipment
♦ Referral procedures that specify when, how, and where to refer children requiring urgent medical treatment
♦ Medical staff to teach older children how to care for their own medical conditions

Programs for Parents with Intellectual Disabilities

Accurate and reliable data regarding the number of parents who have an intellectual disability is lacking. Contrary to popular beliefs, intellectual disability does not inevitably result in parental inadequacy or child neglect or abuse. In fact, virtually all studies indicate that a significant proportion of parents with intellectual disabilities provide an acceptable level of care by community standards. Despite these findings, parents with intellectual disabilities are at high risk for losing custody of their children with rates of removal of children ranging from thirty to eighty percent.

Research indicates that an intellectual disability per se is unlikely to increase risk for child abuse or neglect. Studies have consistently found that IQ (as measured on standardized intelligence tests) is a poor predictor of parenting competence. Indeed, the literature indicates that parents with an intellectual disability appear to be no more likely than other parents who are socioeconomically disadvantaged to abuse their children. While child neglect is encountered more often than abuse, it is most often attributable to lack of experience, parenting training, and the provision of appropriate supports.

There is significant evidence in the literature that parents with intellectual disabilities are subjected to prejudicial and discriminatory treatment from child protection agencies and courts in matters of child protection due to false presumptions, inadequate legal representation, and culturally biased views regarding family and parenting competence. They have been found to be at a significant disadvantage in child protection and court process by rules of evidence and procedures and are less likely to receive support (e.g., parenting skills training) in correcting the conditions leading to termination. They are more likely to have their competence as parents judged against stricter criteria or harsher standards than other parents and be subjected to termination of parental responsibility on the basis of evidence that would not hold up against parents who do not have a disability.

Children of parents with intellectual disabilities can be at risk for neglectful care that leads to health, developmental, and behavioral problems due to parenting skill deficiencies, rather than purposeful abuse or neglect. Many such parents (who come to the attention of social service and child protection agencies) lack essential knowledge and skills for providing adequate instrumental

child care, a safe home environment, proper nutrition, and nurturing interactions. In addition, parents with intellectual disabilities may experience difficulties with problem-solving, recognizing and treating medical emergencies, and comprehending basic child development information.

Research demonstrates that parents with intellectual disabilities can acquire and generalize parenting skills and unlearn ineffective behaviors[15]. In other words, parenting difficulties can be overcome with appropriate education and support; parents who have intellectual disabilities can adapt and learn new skills, and create safe, supportive environments for their children. But without such support, their children can be at risk for accidental injury and serious illness, developmental delay, or behavioral and psychiatric disorders.

Studies have shown the use of teaching methods matched to learning needs results in parents with intellectual disabilities acquiring, retaining, and using effective parenting skills. Critical elements of effective parenting knowledge and skill acquisition have been identified including:

- ➤ Teaching and learning in the setting in which the skills are needed (i.e., the family home) and that includes both parents/partners
- ➤ Building trust and rapport for positive relationships (to increase participation) between trainers and parents
- ➤ Focusing on parents' demonstrations, rather than only discussions, of skills
- ➤ Teaching strategies that involve breaking complex tasks down into small, discrete, and concrete steps, as well as giving clear instructions, demonstrating the skill, giving concrete examples from the parent's everyday life, providing immediate feedback, prompting, a lot of practice, and ample positive feedback
- ➤ A range of teaching aides (e.g., pictorial manuals, photographs, audio and video recordings) that support learning when used in conjunction with face-to-face teaching
- ➤ Flexible, long-term programs with plans for the skills to be used (Parents with intellectual disabilities have been found to be more likely to use newly acquired skills if they are taught in the home using everyday interactions parents experience with their children as teaching opportunities and multiple examples of the same skill or concept are taught.)
- ➤ Providing intensive, consistent, and continuous (rather than irregular, infrequent and provided by different agencies or staff) training. Periodic and ongoing refresher support to maintain learned skills over the long-term

Effective parent training typically involves frequent (e.g., weekly) instruction in the home (or a homelike setting) by specially trained parent educators on an individualized basis through direct instruction methods including task analysis, illustrations, prompting, modeling, feedback, and reinforcement. Such training has been found to enhance child health and development and significantly reduces the need for child custody intervention. However, despite the development of evidence-based parent educational practices for parents with intellectual disabilities, there is a paucity of specialized programs available.

---

[15] Project Parenting at the University of California at Los Angeles and the Parent Education Project at Surry Place Centre in Toronto, Canada are examples of parenting programs that have demonstrated significant positive outcomes in training parents with intellectual disabilities in several parenting activities including child care, home safety and emergencies, parent-child interactions, and decision-making.

Meta-analytic studies support the effectiveness of self-administered parent training. Instructional parenting manuals and videotapes have been shown to be effective and as effective (and more cost-effective) than therapist-led training for parents of children with a variety of issues including behavior problems at home and in the community, sleep problems, fears, enuresis, and self-care skill deficits. In addition, research shows that persons with intellectual disabilities are able to learn relatively complex repertoires (e.g., domestic tasks, cooking, computer use, Internet access, academic skills, self-care, and vocational skills) through self-instruction methods using audio or visual cues.

PARENT ENHANCEMENT PROGRAM (PEP)

PEP is a parent training program targeted to parents with an intellectual disability. Self instructional materials are used to cover the contents of child care checklists which consist of task analyses of basic essential child care, health, safety, and interactional skills. Pictorial manuals illustrate each checklist item for twenty-five basic parenting skills relevant to children aged zero to five. Pictures in the manuals are line drawings traced from photographs. (The use of these types of pictures is based on research findings demonstrating that parents with limited literacy skills prefer and readily understand line drawings.) The manuals are written at a third grade level on average, and contain no material that is higher than a sixth grade level. Parents who are unable to read the text use supplementary audio recordings. Pictorial manuals are available for the following parenting skills:

Home safety and prevention	Cribs and bedtime	First aid & medical emergencies
Objects out of reach*	Crib safety*	Diaper rash treatment*
Kitchen safety*	Bedtime safety*	When to call the doctor*
Cuts, burns, & bruises*	Choosing a crib	When to call 911*
Suffocation*	Getting the crib ready	*Bathing*
Electric shock*	Bedtime routine	Preparing the bath*
Cosmetic poisoning*	*Feeding*	Bathing an infant*
Household poisoning*	Cleaning baby bottles*	Washing baby's hair*
Choking	Sterilizing baby bottles*	Bathing supplies
Medicinal poisoning	Nutrition*	*Other*
Poisonous plants	Burping baby*	Diapering*
Serious falls and wandering away	Preventing spitting up formula	Giving clear instructions*

Some manuals are constructed as discrimination tasks. For example, the home safety manuals have two pictures side-by-side on each page because not all skills lend themselves to task analysis. The one on the left, titled, *Find*, illustrates a safety hazard (e.g., a plastic bag within reach of the child) and the picture on the right, titled, *Fix*, illustrates the parent placing the hazard out of reach of the child (e.g., placing the bag on the top shelf of a cupboard). Below these two pictures are illustrations of generalization items (i.e., different types of bags).

The program starts with an assessment which is conducted by observing the parent caring for their child on a typical day or at different times over several days in the home. As the parent performs a particular task (e.g., diapering), the relevant child-care checklist is completed. The home is inspected for hazards by the trainer along with the parent in order to ascertain its safety and the parent's ability to identify household hazards. Several checklists of knowledge and skills that cannot be readily observed during a home visit (e.g., responding to medical emergencies and

treatment of common childhood ailments) are administered orally and the parent's verbal responses are documented. Correct and incorrect responses are noted on each step of the checklist. Several home visits are scheduled to monitor baseline performance after the parenting skills assessment is completed. The parents are then given information regarding skills they performed adequately and skills that can be improved.

Training in the use of the manuals is provided by initially reading the manual with the parent. The parent is asked to describe each picture and read the accompanying text to the best of their ability. Next, the parent is asked some comprehension questions to determine if they fully understand the contents of the manual. This instruction typically takes approximately thirty minutes. Parents are routinely offered audio recordings that orally present the manual text, and then asked to listen to the recording while reading along (silently), and pointing to the picture being described on the tape. Parents are asked to review the materials just before needing to complete the task.

Weekly home visits are scheduled to observe the parent performing the designated child-care skills. The child care checklists are used to monitor performance. No prompting or feedback is initially provided to the parent. If the parent does not display substantive progress after three to four visits, a two-level least-to-most prompting procedure conducted over several weeks is instituted. Level one entails gentle reminders to use the materials. Level two prompts consist of more assertive recommendations to review the materials each time the parent needs to perform the task.

Follow-up consists of continued weekly monitoring visits until the parent meets criterion (i.e., eighty percent over two consecutive visits) on the skill being taught. Observations of the skill are then gradually faded from once a week to once a month, then once every to three months, and finally, to once every six months. Full training is offered if a parent does not meet criterion or respond to prompts by the seventh monitoring visit. Full training consists of supplementing the self-directed learning with trainer-directed teaching including verbal prompting, modeling the specific steps the parent is not performing correctly, praise for correct responses, and corrective feedback.

PREVENTION AND EARLY INTERVENTION

Efforts to prevent mental retardation focus on educating women and families regarding the need for behaviors such as abstinence from alcohol and other substances that cause fetal harm during pregnancy, folic acid supplementation during pregnancy to prevent neural tube defects, and immunizations for congenital rubella or measles. Prevention of lead poisoning and the use of child car seats and bicycle helmets are examples of primary prevention efforts aimed at reducing the incidence of childhood injuries that can result in developmental problems. In addition, specific treatment of underlying conditions to prevent or to minimize insults to the brain that result in mental retardation (e.g., diet for Phenylketonuria and shunting for hydrocephalus) as well as treat or prevent general medical conditions that complicate certain mental retardation syndromes and reduce functioning, (e.g., congenital cataracts and deafness in children with Down syndrome, seizures and otitis or other painful conditions that may induce self injury in persons who are nonverbal) are secondary prevention measures. Finally, treatment and prevention of psychosocial difficulties, including mental illnesses, are considered essential since co-occurring mental disorders contribute significantly to adjustment difficulties. The provision of early intervention, education, habilitation, and ancillary therapies (e.g., physical, occupational, and language therapies), family support, and other services as needed to minimize functional delays and maximize abilities are considered tertiary prevention measures.

The literature recommends that primary care providers address parental concerns and inquiries regarding developmental concerns during every well-child visit[16] as well as during sick-child visits. However, professionals other than primary care physicians often identify young children with developmental difficulties. These include child protective services workers, audiologists, speech and language pathologists, occupational therapists, physical therapists, nurses and other public health providers, hospitals/attending physicians, early intervention specialists, daycare providers, licensed marriage and family therapists, and licensed clinical social workers. It is therefore recommended that all professional encounters with young children be viewed as opportunities to elicit developmental information. In addition, visits with daycare providers and school personnel also offer opportunities to identify developmental issues.

Since the first signs of mental retardation are usually displayed during early childhood, most often within the first or second year of life, it is important for parents, pediatricians, and other providers to recognize signs and symptoms (e.g., lagging in reaching developmental milestones such as sitting up, walking, talking, decreased interest in the environment and responsiveness to others); early intervention is critical to maximizing opportunities for development and quality of life. Early intervention includes education, physical, occupational, and language therapies along with family support and services that ensure comprehensive care is provided within the home, school, and community.

---

[16] The **Early and Periodic Screening, Diagnosis, and Treatment (EPSDT)** program is designed to determine potential or existing health and/or developmental problems in children as early as possible to assure early diagnostic and treatment interventions. EPSDT is a federally mandated Medicaid program component and EPSDT visits, also known as well-child visits, are a covered benefit for all eligible Medicaid beneficiaries under the age of twenty one. Providers must complete all testing components at the specific ages indicated on the periodicity schedule which can be found in the Michigan Medicaid Provider Manual.

Early diagnosis of autistic spectrum disorders (ASD) is considered critical in order to initiate services as soon as possible. However, diagnosis and treatment have often been found to be delayed. Clinicians often have different understandings of autism spectrum disorders. In addition, coordinating treatment can be challenging. Both the education and developmental disabilities systems serve children with ASD and these systems may be fragmented with their own processes and standards for diagnosing and serving children with ASD. Moreover, while the core impairments in individuals with autistic disorder are commonly identified in early childhood, other spectrum disorders (e.g., Asperger's disorder and Pervasive Developmental Disorder Not Otherwise Specified or PDD-NOS) may be identified much later. It is therefore recommended that assessment be ongoing and responsive to changes associated with intervention effects, maturation, family dynamics, and other factors.

Numerous studies of the outcomes of early intervention have delineated the benefits of early identification and intervention for young children with developmental disabilities. Early identification and diagnosis enhance opportunities for effective educational and behavioral intervention. On the other hand, lack of services has been shown to exacerbate the problems of children with developmental disabilities resulting in increased severity of the disability or learning delays. Research indicates that the lack of services and supports can exacerbate the difficulties experienced by children with developmental disabilities resulting in increased severity of disability and learning delays. Furthermore, lack of services may also lead to greater levels of dependence, social isolation, and reductions in self-esteem and productivity.

One significant benefit of early intervention is its positive impact on families' abilities to interact in developmentally appropriate ways with their children and gain a greater understanding of a disability and the manner in which it interacts with family life. Research shows that specific services and supports provided to families with young children can also help prevent children and their families from requiring more costly, intrusive, or longer-term services. Respite and family training regarding intervention strategies have been found to be especially beneficial. In addition, there is robust evidence of the effectiveness of early and intensive behavioral programs for young children with autistic spectrum disorders. While the precise teaching strategies and components of such programs are often a source of controversy, it is generally agreed that early diagnosis and intervention combined with program intensity can lead to significant improvements in functioning.

UCLA YOUNG AUTISM PROJECT (YAP)

The UCLA YAP is a promising forty-hour per week, three-year, manualized, Early Intensive Behavioral Intervention (EIBI) program for pre-school aged children with autism. The first year consists of discrete trial training that involves short, clear instructions and prompts for successfully following instructions, immediate reinforcement for each correct response during one-to-one sessions, then fading of the prompts. Subsequent to the evidence of progress, the format shifts to naturalistic instruction in group settings (e.g., classrooms). Parental involvement is a key component of the program. Parents work with therapists in implementing discrete trial training for five hours a week during the first three to four months of the program, recruit peers to participate in play dates, contact school districts regarding placements for their children, and communicate with teachers regarding their children's progress. Weekly meetings are held with parents to review progress. Children move from preschool to a kindergarten class for children with typical development if they display the majority of skills exhibited by classmates and are ready to begin the fading of a one-on-one aide. Preschool is repeated for children who are not ready in order to have additional time to adjust to school settings and be with peers who are closer in developmental level. One-to-one instruction at home is continued. Kindergarten is also repeated if necessary. Services are usually terminated during first grade but can continue for an additional year (to about age eight) to enhance skill retention and school adjustment.

UCLA YAP Treatment Stages

Stage	Length	Teaching Method(s)	Goals
1. Establishing a teaching relationship	2 – 4 weeks	Primarily discrete trial training (DTT)	Following one-step directions (e.g., "sit", "come here"), reducing interfering behaviors (e.g., tantrums)
2. Teaching foundational skills	1 – 4 months	Primarily DTT	Discriminating between one-step directions, imitating gross motor actions, matching, receptively identifying objects, dressing, beginning play with toys
3. Beginning communication	6+ months		Imitating speech sounds, expressively labeling objects, receptively identifying action and pictures, expanding self-help and play skills, starting visual communication for children who are slow to acquire speech (picture communication systems or reading and writing)
4. Expanding communication, beginning peer interaction	12 months	DTT, incidental teaching, dyads with typical peers	Labeling colors and shapes, beginning language concepts such big/little and yes/no, recognizing emotions, beginning sentence such as "I want_____" and "I see _____, " beginning pretend play and peer interaction, toilet training
5. Advanced communication, adjusting to school	12 months	DTT, incidental teaching, small group, regular education preschool	Using language concepts (e.g., prepositions, pronouns, past tense), conversing with others, describing objects and events, comprehending stories, understanding perspective of others, learning from models, working independently, helping with chores

(Lovaas and Smith 2003)

Outcome studies indicate that some participants in YAP achieve some gains in IQ and school adjustment. However, studies of social and emotional functioning are lacking, and limited generalization from EIBI programs such as YAP to other areas of functioning have been noted in the literature.

Learning Experiences: An Alternative Program for Preschoolers and Parents (LEAP)

LEAP is a developmentally integrated preschool for typically developing children and peers with autism. It offers a comprehensive parent education program to provide supports in home and community settings. This promising program is designed to facilitate the development of functional skills, independent play and work skills, social interaction skills, language skills, and adaptive behavior in children aged three to five who attend LEAP pre-schools fifteen hours during weekdays on a year-round basis for two to three years. Student ratios are typically three students with autism to ten typically developing children. LEAP preschools provide behavioral skills training for families including basic principles of behavior management and strategies for teaching children new skills. Peer, family, and staff interactions are used in the program's intervention components:

- Teaching typically developing peers to facilitate social and language skills in children with autistic spectrum disorders (e.g., using social scripts such as "getting your friend's attention")

- Embedding numerous learning opportunities during each day within typical preschool routines
- Employing a transdisciplinary service delivery model to promote generalization of skills among settings
- Systematic daily collection of data regarding Individual Education Program (IEP) objectives to determine instructional plans for each day
- Addressing problem behaviors by teaching more adaptive skills (e.g. language and self-regulation)
- Teaching behavioral skills to adult family members in home and community settings
- Using only practices that are evidence-based

Studies indicate that typically developing peers as young as thirty six months can be readily taught to utilize facilitative social and communicative initiations with peers who have autism and that these facilitative strategies result in higher rates of communicative interaction in preschoolers with autism. Many children who receive peer-mediated intervention develop a level of social participation that falls within the typical range for their age cohorts. The naturalistic or incidental teaching used in LEAP to influence cognitive outcomes has been shown to lead to a gain of approximately two months for each month enrolled. Children who begin the program early have been found to display better outcomes. The LEAP incidental teaching model also produces more active engagement and more complex developmental skills by children with autistic spectrum disorders and their typical peers when compared to one-to-one tutorial instruction. Gains are maintained subsequent to participation. Typically developing children show positive outcomes (e.g. improved social skills and fewer disruptive behaviors) and no demonstrable negative outcomes. Information on the program can be found at http://prekese.dadeschools.net/leap.html.

CEDEN Family Resource Center

CEDEN (Center for Development, Education and Nutrition) is a SAMHSA model program that provides family support and targets socioeconomically challenged families with children aged zero to five who have developmental delays or are at risk for developmental delays. CEDEN provides prenatal, early childhood, and parenting education to improve birth outcomes of pregnant adolescents and women who are at risk through the provision of information designed to reduce the incidence of premature births and babies with low birth weights. Services are also provided to prevent and reverse developmental delays, increase positive parenting behaviors, reduce injuries, and ensure timely immunizations.

CEDEN also offers an early childhood intervention program for children who have severe developmental delays or medical conditions that are likely to result in developmental delays. Home and community-based services are provided to accommodate family needs by working with children at child care centers, relatives' homes, shelters for homeless or battered women, and other community shelters. The frequency of home visits is based on family needs and ranges from weekly to monthly. Parent educators deliver a series of educational materials including early childhood stimulation activities, age-appropriate activities, basic health and nutrition care, home safety, and a Pro-Family Curriculum focusing on child development, behavior, and skill building. Parenting classes and support groups are conducted to help reduce social isolation of mothers by facilitating friendships and fostering enhanced self-esteem.

Services provided by CEDEN include:

- ▶ Early Childhood intervention services (in-home speech, physical or occupational therapy for children with serious developmental delays or medical conditions
- ▶ Pre and post-natal education and infant developmental screenings

▶ Parenting education and child development activities for families of children with mild developmental delays, or are at high risk for developing delays.
▶ Community education (monthly training for child care providers, bilingual childbirth and parenting classes, informal ESL and GED tutoring)

Outcome evaluations have demonstrated that participation in CEDEN's programs leads to improvements in the developmental status of young children with delays. Children participating in the program maintain up-to-date immunizations at a higher level than average for their community. Parents report significant levels of satisfaction from learning and using alternative disciplinary methods, and report they have a better understanding of their children.

CEDEN provides a one-day training that costs $500.00 for up to ten people and travel costs if conducted outside of Austin, Texas. Program materials are purchased separately from training. Follow-up training is available upon request. Attending training in Austin allows for observation of home visits conducted by CEDEN's staff. CEDEN's materials are available in English and Spanish. More information is available from www.main.org/ceden/educ.mat.

THE LET'S PREVENT ABUSE PROGRAM (LPA)

LPA is designed to help children with disabilities and adults gain information about child physical and sexual abuse, as well as help children develop personal safety skills. It features four multi-racial, child-size puppets that portray children with and without disabilities. Throughout the program children interact with the puppets through dialogue and role plays. The scripts, geared for children in first through fourth grades, focus on the definitions of physical and sexual abuse, how to get help and who to tell, the need for children to talk about abuse if it is experienced, and feelings of guilt, isolation and shame associated with abuse. In addition to the puppets, the program includes *Let's Prevent Abuse: A Prevention Handbook for People Working with Young Families,* which reviews child maltreatment risk factors, indicators, laws, prevention approaches, and resources. The handbook includes service issues unique to families of children with disabilities, and Hmong, and Spanish-speaking families. The program also offers *Let's Prevent Abuse Coordinator's Handbook* which is a guidebook for organizations to use in developing a program. Information can be obtained from the PACER Center at www.pacer.org.

Additional information on family support prevention programs can be found in *A Guide to Evidence-Based Practices for Children, Adolescents and their Families*.

CRISIS PREVENTION AND RESPONSE

Many individuals with developmental disabilities exhibit difficult behaviors in response to pain or illness and can stem from untreated medical and psychiatric disorders. Difficult behaviors can also result from unmet needs including a lack of meaningful relationships and enjoyment, a sense of safety, well-being, value and self-worth. It has been postulated that most behavioral crises (e.g., aggression toward others, self-injury, property destruction, public disrobing, sexual predation, and other behaviors) can be anticipated. The literature indicates that crises should occur infrequently; occurrences on a regular basis indicate that the person's support plan is not meeting their needs. It is recommended that each crisis be viewed as an opportunity to acquire important information about the person that can be used to prevent or mitigate future displays of the behavior.

Behavior training programs and psychotropic medications have been the primary strategies for reducing the frequency and intensity of challenging behaviors. In addition, many communities have developed behavior support and crisis prevention and response programs/teams to provide individuals and their families/supporters with immediate and ongoing support and intervention that allow them to remain in the community. Such teams often have well-staffed respite residences

where individuals can be stabilized to avert hospitalization or (re)institutionalization. In some locales, public institutions maintain open beds for crises (e.g., death or illness of the primary care provider, or unexpected and immediate expulsion from community settings). Some crisis response systems recruit parents to assist other parents in developing and implementing crisis plans. Others recruit and train self-advocates in crisis planning and implementation. In general, community-based resource networks and crisis/emergency response systems are designed to address the reasons people are initially institutionalized.

Supporters and caregivers have been found to benefit from specific action plans to help them anticipate a crisis and avert it or to establish safety when a crisis is full blown. A crisis plan clearly describes the behavior(s) of concern and specifies actions that should be taken during an emergency. It is recommended that, when feasible, consumers be involved in deciding strategies to relieve stress and inform their caregivers what they want to practice concretely. Thus, people's preferences can be ascertained and issues of health and safety can be addressed within the contexts of what is important to them in a collaborative, power-sharing manner.

The provision of crisis services where individuals actually live and work by behavior analysts, nurses, and other behavior support and crisis service personnel who observe the interactions between the individual and others in their environment by travelling to settings where the person's challenging behaviors actually occur is considered most effective.

Community behavior support and crisis response systems have been demonstrated to be effective in addressing challenging behavior and preventing (re)institutionalization. They have also been shown to be cost-effective. Studies show that effective crisis response services lead to reductions in law enforcement intervention, use of emergency room services, 911 calls, hospital days, exclusions from residential settings, and the use of medication, restraint, and other coercive control procedures.

SYSTEMS COLLABORATION

Human service systems often fail to meet the various needs of individuals with developmental disabilities and their families despite the availability of numerous public and private resources. Individuals and families may require several services (e.g., medical care, personal assistance, psychiatric services, educational and vocational supports, and others) but many human service systems focus on addressing one primary need. Moreover, no single organization or service system has the resources or capacity to comprehensively address all needs.

Collaboration[17] among various service systems and agencies confers a number of benefits including sharing scarce resources and alleviation of duplicative efforts leading to cost reductions and efficiencies. Moreover, collaboration allows for divergent perspectives to be incorporated into support and service plans.

- **Communication Supports to facilitate individual ways of communicating including assistive devices, interpreters, and other communications assistance devices**
- **Transportation Supports including individually designed wheelchairs, accessible transportation, and access to transportation for recreation, leisure, work, school, and medical and other appointments**
- **Educational and Personal Growth Supports (e.g., marriage counseling, parenting skills development, money management, home maintenance, meal preparation)**
- **Personal Care Assistance to help with activities of daily living and community participation**
- **Homemaking Assistance**
- **Respite Care**
- **Financial Assistance**
- **Employment Supports that include career planning and job coaches**
- **Supports That Connect People with their communities through circles of friends, personal friendships, self-advocacy groups, recreational and civic groups, and houses of worship**
- **Housing that is affordable, safe and accessible**
- **Advocacy Supports that promote learning to make decisions, assertiveness and protection of rights which can be provided through self-advocacy groups, as well as personal and legal advocacy**
- **Health and/or Mental Health Care**

---

[17] For example, collaborations are mandated in the provision of services and supports to older adults with developmental disabilities by the National Family Caregiver Support Program (NFCSP). The Older Americans Act mandates that states prioritize services for older individuals who provide care and support to persons with mental retardation and related developmental disabilities.

EDUCATION

The educational achievements of youth who have disabilities have been found to be significantly lower than that of their peers. Studies have shown that significantly fewer of these students receive high school diplomas and enroll in postsecondary school (thirty seven percent) when compared to their peers without disabilities (seventy eight percent). Although dropout rates among high school students with disabilities have been decreasing, only slightly more than half graduate from high school and, of those that graduate, eleven percent receive a certificate rather than a diploma.

Historically, children and youth with developmental disabilities were educated in segregated settings that isolated them from peers without disabilities and limiting their opportunities for social interaction and community inclusion. Concerted efforts to provide education for children with disabilities began during the nineteenth century. In 1818 the American Asylum for the Deaf and Dumb in Hartford, Connecticut was established to teach "idiot" children. Residential schools for children who were blind and "mentally defective" were established by Dr. Samuel Gridley Howe in 1848 and, by 1876, eight states had developed twelve training schools. Often established in the face of public opposition, these institutions were conceived primarily for education and release rather than as custodial asylums.

Special classes for children with intellectual disabilities were established in some states as early as 1870 spurred by work of the then new profession of psychology, particularly that of Alfred Binet and Theodore Simon who constructed a method to test intelligence. The newly developed tests led to the discovery of a group of students of children deemed "mentally deficient" and "morons" (later called "high grades, "borderlines" or "educables"). These tests revealed that these children, who were seen as burdens to educational settings, had subnormal I.Q.s and lacked the capacity to participate in regular classes. This led to the establishment of special classes within school systems across the country during the late 1800s and early 1900s.

Congressional hearings in the 1970s revealed that two and a half million children with disabilities were not receiving an education that met their needs, and almost two million others were not receiving any formal education at all. At that time laws in most states allowed school districts to refuse to enroll any student considered "uneducable" by local school administrators. Some children with disabilities were admitted to public schools and placed in regular education with no special services while others were served in special programs that often lacked adequate services and supports. Congress responded with the passage of Public Law 94–142, the Education of All Handicapped Children Act, now known as The National Adoption Information Clearinghouse offers information on state-funded adoption assistance programs which can be obtained from http://naic.acf.hhs.gov., which required that all students with disabilities receive a free and appropriate public education (FAPE) and related services in the least restrictive environment (LRE) tailored to their individual needs. This act also required schools to consider modifications in regular classrooms prior to moving children into more restrictive placements.

The relative merits and shortcomings of special education are of considerable debate in the literature. It has been criticized for being expensive, ineffective, inadequately coordinated with regular education, and culturally biased. For example, African American students (particularly those from economically challenged families) are more than twice as likely as Caucasian students to be diagnosed with mild mental retardation and disproportionately represented in special education within the category of mild mental retardation while Hispanics/Latinos are ostensibly underrepresented in most categories of special education. An additional concern is that many students are placed in special education due to the inability of general educational settings to accommodate their needs. On the other hand, special education has been cited for positive

benefits including the improved academic performance and self-esteem demonstrated by some students. Studies show that placement in regular education is associated both with better and worse post-school outcomes. In general, students with sensory or motor disabilities appear to benefit from regular education placement. But, more time in regular education is also associated with a higher likelihood of course failure and is a strong predictor of dropping out of school for many students with disabilities.

There has been increasing pressure to serve more students in regular classrooms for fiscal, educational, and social reasons. Special education funding is a shared responsibility of the federal government (about eight percent), states (on average fifty six percent with a range from eleven to ninety five percent), and local school districts. Funding structures in most states create fiscal incentives for school districts to label students as disabled with certain diagnoses or use placements that may not be in their best interests. Constrained school budgets have led school boards and administrators to consider pooling resources for special education with regular education in ways that confer educational and social benefits for all students. Reasons cited to shift more responsibility to regular education include reducing disruptive pull-out programs, increasing social interaction between regular education and special education students, and benefits that accrue to entire classrooms (e.g., smaller class sizes).

Advocates for students with disabilities seek greater integration into regular classrooms and note that every child has a right to belong to a community and share common experiences with family, neighbors, and friends. Indeed, research indicates that community membership at age ten is predictive of community membership during adulthood. Thus, the more separate children's educational settings are at age ten, the more likely they will be in the same types of settings at age twenty-five. An additional argument made is that working with peers who have varied skills and strengths helps all children to develop the skills needed to live within diverse communities.

Mainstreaming and inclusion have been instituted to promote integration. Mainstreaming is the integration of children with disabilities into general education with their peers based on individual assessments and is associated with the least restrictive environment (LRE) mandate in the Individuals with Disabilities Act (IDEA) and a full continuum of services. Mainstreaming occurs when an interdisciplinary team (including parents) determines that, given all available placement options, the child should participate in general education for some part of the school day. Inclusion, on the other hand, implies that most children with disabilities will be educated in general education classrooms for most, if not all, of the school day. Full inclusion means that all children with disabilities, irrespective of the nature or severity of their disabilities, are educated in general education settings; separate special education placements do not exist in full inclusion educational systems. Inclusion can be controversial due to its emphasis on placement (i.e., the classroom to which a student is assigned) rather than what transpires in that classroom. In general, the educational approach has changed in recent years from that of mainstreaming children in regular schools to inclusion, or placement of all children with disabilities in age-appropriate classrooms. Behavioral problems have been found to be the primary reason for the failure of some of these placements.

A variety of strategies have been developed to provide an appropriate education for special education students in general education settings. However, no interventions provided in either regular or special education have been found to be uniformly effective for students with special needs. Although most of the strategies demonstrate some promise, none have been shown to produce significant or consistent positive outcomes for all students. In other words, no intervention eliminates the impact of having a disability on level of achievement. Students with disabilities are a heterogeneous group with a variety of types and severity of disability, temperament, intelligence, and family characteristics. Moreover, students with the same disability and about the same degree of severity can vary tremendously in personality, motivation, social and family

support systems, and compensatory strengths. In general, students with special educational needs have been found to require more consistency and intensity of instruction, individualization of both academic content and pacing (to reduce behavior problems associated with fatigue and frustration), and a focus on behavior management (to help with the development of positive self-management skills).

Educational practices for children with disabilities in general education settings include individualized and intensive approaches to student instruction, teaching to multiple intelligences, using functional assessments, frequent monitoring of student progress, cooperative learning groups, and the incorporation of assistive technology. Additional services and supports that may be required include transportation, physical therapy, occupational therapy, speech therapy, psychological services, school health services, social work services, social-skills training, recreation programs, and parent counseling and training. The incorporation of aides, assistants, or paraprofessionals in classrooms is designed to help ensure students achieve success in inclusive classrooms through the provision of tutoring, implementation of teacher-developed instruction, provision of personal care, and observation of student performance.

A number of instructional methods appear to lead to modest improvements in academic outcomes for students with disabilities in general classrooms as well as improve relationships between students with and without disabilities and reduce referrals for special education. Promising programs entail the use of lengthy (often multiyear) teacher training, teacher planning time, administrative support, and additional instructional staff. All require significant resources for implementation including smaller class sizes, supplementary curricular and training manuals, expert technical assistance with extensive and frequent consultation with psychologists and other professionals to design interventions or adaptations for individual students, additional planning time for teachers, teacher's aides, and ongoing, intensive teacher training.

PREREFERRAL INTERVENTIONS	Individualized accommodations and adaptations made in general classrooms designed to avoid referrals to special education. Although prereferral interventions are widely recommended and are required in many states, there is little data demonstrating that they lead to long-term academic improvement for students struggling academically. However, pre-referral interventions appear to reduce the number of students referred to special education. Prereferral interventions include: • Individualized behavior-modification programs • Changed seating arrangements • Teaching in small steps • Increased monitoring of student progress.
TEACHER CONSULTATION	• Assistance (e.g., suggestions for teaching strategies) provided by special educators to general educators targeted to general education students experiencing problems (and potentially requiring referral to special education) or to special education students in general education classes. • Postreferral consultation to enable general educators to deliver special education services in general education classrooms rather than sending special education students to resource rooms for part of the day. Special educators consult with general educators regarding students' special needs and suggest modified teaching techniques such as behavior management strategies or modified reading instruction. Research on the impact of teacher consultation for students with disabilities is scant and inconclusive. • Mainstream Assistance Teams, in which general education teachers consult with special education teachers to design interventions. Studies show that teachers are initially concerned that extensive consultations

	leading to individualized programs for selected students are too complex and demand too much time; shorter, less complex forms of consultation have been found to be equally effective in achieving positive outcomes.
MODIFIED INSTRUCTIONAL METHODS (IN GENERAL CLASSROOMS)	• **Direct instruction (DI)** is a comprehensive curriculum (rather than a supplement to an existing curriculum), classroom management, and teaching system that entails teaching skills in small sequenced steps, the provision of immediate feedback, and frequent student and teacher interaction. It requires the use of trained supervisors working in classrooms. Research indicates direct instruction appears most advantageous for students with disabilities when they respond to many questions during the course of a lesson and the teacher provides step-by-step instruction. • **Cooperative learning** such as grouping students heterogeneously and holding the groups responsible for the performance of all students. Studies of whole schools using cooperative learning have shown positive academic and social outcomes with increases in learning and peer relationships. However, implementation of cooperative learning requires special curricular materials, extensive training, substantial time for planning and problem-solving among teachers, and substantial administrative support. • **Peer tutoring** in which students work in pairs or teams where one serves as a tutor. This method has been found to increase learning levels and peer relationships in both tutors and tutees. • **Cognitive strategy instruction** in which students are taught specific learning strategies.
TRANSENVIRONMENTAL PROGRAMMING (TP)[18]	Special educators and general educators coordinate their efforts to support individual students as they leave special education settings and reintegrate into general education. Transenvironmental programming is designed to increase the similarity of the instruction, curriculum materials, and behavioral expectations between general and special education classrooms. TP appears to improve student academic progress initially, but there is some question regarding whether faithful adherence to TP is feasible in general education.
WHOLE SCHOOL MODELS	Models designed to enhance the capacity of schools to address the needs of students with disabilities that entail intensive use of resources.

Research has shown that inclusive education can confer academic, behavioral and social benefits. Students with disabilities educated in inclusive school settings demonstrate higher levels of engagement in school activities, initiation and engagement in social interactions with peers and adults, enduring social networks of peers without disabilities, acquisition of community living skills and improvements in vocabulary, reading, and language. Students without disabilities have also been shown to experience positive outcomes including development of positive attitudes, greater understanding and empathy, growth in moral and ethical principals, self-esteem, patience, and

---

[18] **Transenvironmental programming** is designed to assist students in special education classrooms reintegrate into general education classrooms. In this model, special education teachers determine academic and behavioral skills needed by students to succeed in general education and teach those skills to students in special education. Special educators monitor whether the skills are used by students in general classrooms subsequent to transitions into general classrooms via frequent testing. Transenvironmental programming appears to improve student academic progress initially but has not been shown to be uniformly sustainable in general classrooms.

comfort level with people with disabilities. Studies indicate that students without disabilities do not experience any adverse effects from being in classes that include students with disabilities. Teachers in inclusive settings have been found to develop positive attitudes and increased confidence in their abilities to accommodate more diverse learners in classrooms when training and administrative support are provided.

It is difficult to reach conclusions about the effectiveness of special education because research in this area is rather weak. Many studies lack comparisons to similar control groups and most of those that include control groups lack random assignment. Moreover, the majority of studies are limited to short-term interventions and short-term outcomes. It is also difficult to determine the effectiveness of inclusion which requires significant resources (e.g., training and assistance for teachers, planning time, access to additional supportive services, and administrative support) to achieve somewhat modest beneficial effects for some students with disabilities. In general, one can conclude that research does not provide unequivocal support for full time inclusion for all students with disabilities; special education has been found to lead to positive academic gains for some students. However, the provision of adequate resources has been found to help many students function successfully in general education settings. Thus, it appears that placement per se is not the most critical factor in academic or social success, but rather hinges on the classroom environment and quality of instruction (i.e., well-trained teachers who provide sustained, intensive instruction). Finally, it should be noted that research has demonstrated that a concentration in vocational courses is robustly associated with completion of school and employment for students with disabilities.

Early diagnosis and educational programming are considered critical for children with autism and other pervasive developmental disorders. Preschool program components found to be critical for beneficial outcomes for children with autism spectrum disorders include:

- Entry into intervention programs as soon a diagnosis is seriously considered
- Active engagement in intensive instructional programming for a minimum of the equivalent of a full school day, five days a week, for at least twenty hours per week, with full year programming varied in accordance with each child's chronological age and developmental level
- Repeated, planned teaching opportunities for brief periods of time (e.g., fifteen to twenty minute intervals) for younger children, including sufficient amounts of adult attention in one-to-one and small group instruction to meet individualized goals
- Inclusion of a family component including parent training
- Low student to teacher ratios with no more than two young children with autistic spectrum disorders for each adult in the classroom
- Ongoing program evaluation, assessments of individual progress, and adjustments in programming as indicated

TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children)

The TEACCH program provides community-based services to children with autism and related disorders from preschool age through adulthood. The school program offers individualized instruction emphasizing skills appropriate for the child's age and developmental level within a highly structured learning environment. General domains targeted for skill development include communication, socialization, practical skills, and fostering independence and preparation for adulthood. Preschool aged children may attend half-day or full-day programs in classrooms with six students with autism, one teacher, and one assistant teacher. Additional related services such

as speech-language therapy may be provided at school. The key elements of structured teaching include:

➤ Highly structured learning environments with clearly defined concrete physical boundaries in which separate areas are designed for specific activities including independent work stations, play areas, and group work areas. Work areas are free of distractions. Visual organization, visual clarity, and visual instruction are stressed throughout the environment and routine.

➤ Daily individual schedules which are designed for each student and displayed visually through picture symbols, photographs, line drawings, and written words in a top to bottom or left to right progression. Students are taught to manipulate their schedules independently. Activities within the schedule may be color-coded (e.g., yellow for independent work and red for circle time).

➤ Individual work systems in which work tasks for specific skills are physically displayed in baskets with the "work" to be completed placed to the student's left. The student completes tasks independently and places the materials in a basket to his/her right. The exact task and amount of work are clearly defined. Initial tasks are taught utilizing chaining and shaping techniques until independence is achieved. The student refers to their individual schedule after completing work to transition to the next activity. As students progress, work tasks are changed frequently. Work tasks for younger children include matching, sorting and sequencing activities, assembly activities, and functional academics (pre-math and pre-reading).

➤ The curriculum is developmentally sequenced and functionally based and includes functional communication, vocational and independence training, community-based instruction, and leisure and social training.

➤ Family involvement is a key component. Family members receive training to continue activities at home. In addition, the home environment may be modified to provide visual structure. Families can request packets of activities for completion in the home environment. These packets contain instructions, material lists, and feedback forms. Frequent, ongoing communication between the home and school is accomplished through direct contact or communication notebooks.

A range of studies indicates that TEACCH is effective for autistic disorders, but studies do not meet all the criteria to establish the approach as a fully evidence-based practice. In addition, concerns have been raised about the influence on intervention outcomes from staff member skills and experience). It has been suggested that there is a need for more controlled, larger systematic independent studies conducted on TEACCH programs. Information on this approach can be found at http://www.teacch.com/.

INCIDENTAL TEACHING

Incidental teaching is an alternate teaching strategy that has a substantial base of research support. Incidental teaching programs are designed to capitalize on objects or activities that are of particular interest to each child in order to encourage skills such as communication by setting up situations in the natural environment that encourage a child to initiate communication and then respond in ways that require additional language from them (e.g., arranging toys in sight but out of reach and using the opportunity to teach requesting when the child reaches for a toy, or to require increasingly complex requests or elaborate on other learned skills [e.g., attributes]). Incidental teaching can initially focus on encouraging a child to request objects or activities and also be used

to teach a variety of other language skills (e.g., seeking help, using syntax such as prepositions, and asking for missing items that are needed to complete a task or activity). The instructor may wait expectantly in order to prompt the child, (a procedure called time delay) or ask a question (e.g., "What do you want"). The desired object (e.g., a toy) is given to child if the request is made correctly. A favorite object may be hidden from a child, so that the child must ask, "What is it?" or "Where is it?" to gain access to the object. A person or action figure can be hidden so that the child is encouraged to ask, "Who is it?"

EMPLOYMENT

Finding and maintaining reliable gainful employment is critical to achieving personal and financial independence. However, this can be significantly more challenging for individuals with developmental disabilities. According to national data, approximately sixty six percent of people with disabilities are unemployed, twenty percent hold full-time jobs, and twelve percent work part-time. Approximately one-half to two-thirds of young people with disabilities who are employed only work part-time. Many employed adults with disabilities do not receive health benefits, vacation time, or sick leave, and many have incomes near the poverty level. In recent years there has been increasing focus on helping individuals with developmental disabilities achieve and maintain gainful employment. Employment (like education) is essential because it provides a foundation of competency and self-sufficiency. People who receive support in individual community jobs earn far greater wages than those participating in sheltered employment or off-site groups settings (e.g., enclaves or crews). Integrated working settings also increase opportunities to access other community activities, contribute meaningfully to the community, and reduce dependence on social services.

Three primary approaches have been used to increase employment opportunities for persons with developmental disabilities:

1. Conversion of sheltered employment programs to supported employment
2. Development of new programs that provide supported employment services
3. Focusing on consumer choice and control of funding and the job search process

SUPPORTED / CUSTOMIZED EMPLOYMENT

Supported Employment (SE)[19] has been a model for employment services since the early 1980s and is a model for assisting individuals with disabilities obtain and maintain paid, competitive, employment in a full-time or part-time job/career in integrated work settings where co-workers are persons without disabilities. Supported employment provides needed supports to insure success and has been found to benefit persons with disabilities for whom competitive employment has not typically been available, or who, due to their disability, require intensive support services or extended services to maintain gainful employment. Employment Specialists assist job seekers with disabilities in job exploration to discover their work interests and abilities. They also provide job development services to help individuals find jobs that match their interests. Employment Specialists also provide work-site job coaching to help consumers learn the skills of a particular

---

[19] A complete description of the SE model can be found in *A Guide to Evidence-Based Practices for Adults with Mental Illness*.

job and ongoing job supports to assist both workers and employers with issues related to job performance in order to achieve ongoing success.

Real work	Work that would be performed by someone without a disability
Real wages	Wages commensurate to wages paid for comparable work performed by someone without a disability
Integrated work environments	Most co-workers are people without disabilities who work in close proximity and regularly interact with employees who have disabilities
Time-limited supports	The provision of job development or assistance in getting a job, intensive job training, and adaptive aids and devices
On-going supports	Supported employment assumes that people with developmental disabilities will need support over time, even if that support is provided by a co-worker. The provision of on-going supports to maintain a job include training and technical assistance to co-workers and employers to maximize natural supports, employment consultation, transportation and/or mobility assistance, and personal assistance services, etc.

Customized Employment entails the identification of accommodations and supports that allow an individual to perform the functions of a job. In customized employment, jobs are individually negotiated and developed, based on individualized determinations of consumers' strengths, expressed needs and interests, and designed to meet the specific business needs of employers. Customized employment strategies result in individually designed services, supports, and jobs negotiated to fit the needs of a specific job seeker or employee. These strategies may include aspects of other employment approaches, such as:

- Supported employment services
- Supported entrepreneurship services, microenterprises, or small businesses
- Individualized job development
- Job carving and restructuring
- The development of microboards

The first step in the customized employment process is an exploration of job seekers' dreams, goals, personal preferences, life experiences, and needs in order to develop an individualized career profile and customized employment plan. Information obtained during exploration is documented in a profile, portfolio, or other record to capture the information for use as the basis of the customized planning process. In addition to information obtained from the job seeker, family members, friends and other supporters are interviewed. Tasks, skills, and other potential contributions are observed and discussed with the job seeker. A Task List is constructed as part of the customized plan and used during employer negotiations to target specific duties of an applicant's customized job description.

The types of supports and the methods used to provide supports are unique to each Customized Employment position and business. Job duties or employee expectations are negotiated with employers to align the job seeker's skills and interests with an employer's needs. The negotiation process addresses areas such as job duties, terms of employment, hours of employment, productivity and outcome expectations, and services and supports necessary to perform the duties of the job. This process results in a job description that describes a customized relationship between employer and employee. Options include:

- **Job carving** in which a job description is created by modifying an existing job description; the carved job description contains one or more, but not all, of the tasks contained in the original job description.
- **Negotiating a job description** in which the job seeker and personal representative select tasks from all those performed at the workplace to create a new individualized job description.
- **Job creation** in which a newly created job description is negotiated based on unmet needs in the workplace.
- **Job sharing** in which two or more employees share the tasks and responsibilities of a job based on their strengths and skills.

- ♦ **The job seeker is fully involved in the planning process, decides who will participate, and directs their own blueprint for job development**
- ♦ **The plan is developed with the job seeker's vision of their interests and career goals**
- ♦ **The focus is on the job seeker's preferences, talents, life experiences, and dreams, rather than their challenges or limitations**
- ♦ **Family, friends, and natural social networks serve as a secondary source of input, opinions, and support; the job seeker is always the primary source of information**
- ♦ **Concerns and complexities are considered solvable through negotiation and support, and must not be used to rule out career options**
- ♦ **The planning process always focuses on obtaining community-based, integrated, employment that pays the prevailing wage**
- ♦ **Work occurs in integrated, individualized work situations in the community or personal businesses alongside people who do not have disabilities**
- ♦ **Job or business outcomes are individualized with no grouping of persons unless they are co-owners of a business venture**
- ♦ **Employment outcomes may include creating a job through self-employment**
- ♦ **The process is facilitated through a blend of services, supports, and resources that include the workforce system and other public and private partners (e.g., disability service providers) that are coordinated to meet the job seeker's needs**
- ♦ **The employee has a personalized job description and/or other employer expectations that did not exist prior to the negotiation process**
- ♦ **The individual makes a tangible contribution to the business enterprise**
- ♦ **The individual is hired and paid directly by the employer**
- ♦ **A job developer is available to assist the job seeker in negotiating with employers**
- ♦ **An array of strategies that allow job duties to be tailored to satisfy both job seeker and employer needs are used**
- ♦ **Personal budgets, individual training accounts, and other forms of individualized funding that provide choice and control to the person and promote self-determination are used**
- ♦ **All individually designed services and supports needed by the job seeker for success are offered by the employer, workforce system, and/or funders of services**
- ♦ **The employer voluntarily negotiates specific job duties or employee expectations**
- ♦ **The negotiated employment relationship meets the unique needs, strengths, and interests of the job seeker/employee and the specific needs** of the employer

---

In sum, the customized employment process is a flexible blend of strategies, services, and supports designed to increase employment options for job seekers with complex needs through voluntary negotiation of employment relationships. It is based on established principles, services, supports, and strategies (e.g., supported employment) that have been shown to result in employment success for job seekers with disabilities. Customized Employment can be used either prior to finding a job or subsequent to employment as a strategy to modify job duties and/or other employer expectations for an individual who has complex needs.

Customized Employment has been found to benefit job seekers in competitive job markets who experience barriers to employment (e.g., limited skills or education, inadequate childcare or transportation resources, disabilities, histories of chronic underemployment/unemployment. or cultural or language differences). It has also be found to effective for job seekers and current employees with changing circumstances that require negotiation to customize employment tasks, expectations, or working conditions.

RISE (REACH INDEPENDENCE THROUGH SELF-EMPLOYMENT) PROGRAM

RISE, operated by Maryland's Division of Rehabilitation Services, assists consumers in determining whether owning a business is a realistic vocational option, obtaining market information for selecting the appropriate industry, developing a comprehensive business plan, accessing financial resources, and ongoing individualized technical assistance. The program offers a two-session course, called *Exploring Entrepreneurship*, that provides information regarding the realities and the myths of small business ownership, including consideration of personality factors, and a comparison of self employment to working for another person, information on financial resources, and selecting the appropriate industry is provided. Another offering, *Business Plan Development,* is a semester-long course during which participants develop business plans. These plans for proposed ventures include information about the prospective business owner, business concept, industry and product market research and analysis; marketing plan; operations and management plan; critical risks and potential problems; community benefits; and financial projections.

The Maryland Division of Rehabilitation Services also provides limited funding for consumer-owned enterprises after business plans have favorable reviews by the RISE Advisory Committee and approved by the Division of Rehabilitation Services. In addition, businesses must comply with all relevant federal, state and local laws and regulations, organized as for profit, not involve speculative activities, and involve majority ownership and management of the business by an individual eligible to be served by the Maryland Division of Rehabilitation Services, The Supported Business Enterprise is an option for individuals who require supports in the operation of their venture. Identification of supports and funding commitment from an extended service provider is required. Individuals in this initiative are expected to perform a core function in the operation of the business. Information on RISE can be found at http://www.riseprogram.com/.

FLORIDA FREEDOM INITIATIVE (FFI)

The Florida Freedom Initiative is a cutting edge demonstration program that allows people with disabilities who work to set aside income in interest-bearing Individual Development Accounts (IDAs), called Freedom Savings Accounts, to save for housing (i.e., purchase, lease, or modify a home), additional education (i.e., pursue additional education without defining an employment goal until the last six months before completion), transportation (i.e., lease or maintain a car even if the person cannot drive), or develop a small business. IDAs can generate up to $800.00 for every dollar saved up to a maximum contribution of $10,000.00 per year. Thus, participants have the ability to create real assets and establish a credit history with a financial institution. Participants are also able to protect the first $280.00 of earned income from being counted as a resource for Social Security benefits. The program is open to Individuals who are enrolled in the Florida Agency for Persons with Disabilities' Consumer Directed Care Plus program, receive SSI; work or want to work, or increase their earnings, or want to own a micro enterprise are eligible for participation.

This promising program is designed to provide a means for persons with developmental disabilities to build assets and break the poverty cycle. It is predicated on the fact that people who own their homes enjoy an enhanced quality of living and generate significant savings when

compared to individuals who require publically funded housing. Moreover, individuals who control their transportation generate savings in public dollars expended on expensive and seldom reliable transportation systems that all too often serve people with disabilities poorly. In addition, financial institutions benefit from access to a growing and untapped market. Information on the Florida Freedom Initiative can be found at http://apd.myflorida.com/ffi/how-works.htm.

BENEFIT PLANNING

Benefit Planning is critical to helping people obtain and maintain employment over time. The risk of losing benefits that are essential to well-being needs to addressed at the outset of employment planning activities. A number of work incentives and supports that preserve needed benefits are described in the paragraphs that follow.

TICKET TO WORK AND SELF-SUFFICIENCY PROGRAM

The Ticket to Work and Self-Sufficiency Program is an employment program for people with disabilities who are interested in working. It is part of the Ticket to Work and Work Incentives Improvement Act of 1999 which was designed to eliminate barriers to employment stemming from loss of health care coverage. The program offers opportunities for individuals receiving Social Security Disability to obtain employment, vocational rehabilitation, and other support services from public and private providers, employers, and other organizations. Under the Ticket to Work Program, the Social Security Administration provides disability beneficiaries with a Ticket they can use to obtain the services and jobs they need from organizations called Employment Networks (ENs). The Ticket To Work Program serves individuals aged eighteen to sixty four. Youth aged eighteen to twenty being served by secondary education institutions can benefit from the Ticket To Work Program through secondary education institutions that become a Ticket to Work Employment Network. While an individual is using a Ticket to Work, the Social Security Administration suspends continuing disability reviews (which are used ascertain whether a beneficiary's' condition has improved medically). Information regarding the program can be obtained from http://www.ssa.gov/pubs/10061.html, http://www.yourtickettowork.com/youth, and http://www.yourtickettowork.com/program_info.

PLAN FOR ACHIEVING SELF-SUPPORT (PASS)

PASS is a Supplemental Security Income (SSI)[20] work incentive that is designed to help people compete effectively in the labor market. PASS allows persons with disabilities to set aside income and/or resources to use to achieve specific work goals. To qualify for a PASS, an individual must be less than sixty five years of age, be disabled or blind, meet all eligibility requirements for SSI with the exception of the income and resources test, and have earnings, unearned income, or resources to set aside in the PASS. (Examples of unearned income include Social Security, private pension, monetary support or gifts from family or friends). It is not necessary for individuals to have income and/or resources available when applying for PASS; a PASS can be submitted based on projected earnings. Approval from the Social Security Administration (SSA) for a PASS is contingent on a reasonable chance that the individual can achieve his/her vocational goal. PASS is a means to acquire services and items needed for starting work; funds cannot be used for ongoing costs.

---

[20] SSI eligibility hinges on meeting an income and resources test,

The income and/or resources set aside in a PASS are not counted in determining eligibility for SSI or in calculating the amount of the SSI benefit that an individual will receive. The SSI amount is increased for individuals who would otherwise be eligible are rendered eligible for SSI by excluding certain income or assets (i.e., resources) which would have to be counted under the regular SSI rules. The extra SSI helps pay for other living expenses (i.e. food, clothing, and shelter). The requirements for a PASS approval are as follows:

- A feasible occupational (i.e., work) goal that matches the person's interests, preferences, abilities, and support needs
- A viable plan that details short-term interval steps, milestones, and time frames to move the person toward and assist them in achieving their work goal
- A savings/spending plan that outlines income and resources to be set aside, how the income or resources will be spent, where they will be located, and other information (e.g., reasonableness of cost and /or cost estimates)

The PASS must be submitted in writing (on SSA form SSA-545 which is used to complete a Comprehensive Plan) and must state how money set aside will be spent to achieve the occupational objective. A list of monthly planned expenditures by grouping or category with an explanation of their connection to the occupational objective must be included. Items that can qualify as PASS expenditures include:

- Preparation fees for developing a PASS
- Supported employment services such as job coaching and job development services (i.e., supports needed to obtain and/or maintain employment)
- Operational or access modifications to buildings or vehicles to accommodate disabilities
- Equipment, supplies, operating capital, and inventory required to establish a business
- Vocational evaluation
- Tuition, books, supplies and all fees and costs imposed by or in connection with an educational or occupational training facility including tutoring, counseling, etc.
- Attendant care and child care
- Additional costs incurred for room and board away from a principal residence that are need for attendance at educational, training, employment, trade or business activities
- Equipment or tools either specific to individuals' conditions or designed for general use
- Dues and publications for academic or professional purposes
- Basic life skills training if the person is currently pursuing an occupational objective and the training is necessary for attaining the objective
- Medical and social services
- Transportation-related expenses (e.g., public transportation, private or commercial carriers, and assistance with purchase of a private vehicle)
- Licenses, certifications, and permits required for employment; government imposed penalties, fines, or income taxes are not allowable
- Job-related equipment (e.g., uniforms, specialized clothing, and safety equipment)
- Any other services and equipment needed for work

MEDICAID BUY-IN PROGRAM

The Medicaid Buy-In program is designed to make it easier for people with disabilities to work without losing health benefits. Authorized by the Balanced Budget Act of 1997 (BBA) and the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA), the Buy-In program

allows states to expand Medicaid coverage to workers who have a disability and whose incomes and assets would normally render them ineligible for Medicaid. Eligibility for participation is limited to persons with disabilities (as defined by the Social Security Administration) who have earned income and meet other financial eligibility requirements established by each state.

Michigan's **Freedom to Work Program (FTW)**, implemented in 2004, offers individuals with Medicaid who meet Social Security criteria for a disability an opportunity to earn meaningful wages and retain Medicaid health care benefits. Eligibility requirements include United States citizenship or qualified alien status, Michigan residency, a social security number, and a disability (as defined by the Social Security Administration). In addition, the person cannot reside in an institutional setting, must be between the ages of sixteen and sixty four, eligible for Medicaid without a spend down, be employed or self-employed, and have net unearned countable income that does not exceed one hundred percent of the Federal Poverty Level (FPL). Information on this program can be obtained from www.freedomtoworkmedicaid.com.

It has been noted that, because many Buy-In participants face a number of barriers to employment, the Medicaid Buy-In program alone may not provide enough support to foster substantial increases in employment for people with disabilities. The risk of losing disability benefits when earnings exceed SGA function as a financial disincentive for some participants to earn above the Substantial Gainful Activity (SGA)[21] level. In addition, findings suggest Buy-In participants with low earnings may be constrained from working or improving their earning potential by factors other than a lack of health insurance (e.g., the risk of losing disability cash benefits). On the other hand, participants who have made the commitment to competitive employment and who already earn above the SGA level before Buy-In enrollment are likely to further increase their earnings afterwards thus helping individuals take the next step toward independence. Studies of programs designed to increase employment for people with disabilities consistently show that younger individuals are more likely to participate in the programs, become employed, and are more successful in the labor market than older participants.

Trial Work Period (TWP)

The Trial Work Period allows beneficiaries of Social Security Disability Insurance (SSDI) to work for up to nine months while continuing to receive full SSDI cash benefits. In 2008, any month in which countable earnings exceed $670.00 (gross) is counted as a month of work. Once an individual reports wages over $670.00 a month they are enrolled in the in the nine-month TWP. The Trial Work Period ends when nine months of work (that do not have to be consecutive) within a rolling sixty-month window (i.e., the sixty months prior to the current month) has been recorded.

The **Extended Period of Eligibility (EPE)** starts subsequent to the Trial Work Period and allows beneficiaries to remain eligible for reinstatement of SSDI benefits for an additional thirty six months subsequent to the Trial Work Period. In the EPE, benefits are suspended during months when income is earned above the substantial gainful activity level (which is $1500.00 per month for beneficiaries with blindness and $940.00 per month for beneficiaries without blindness in 2008

---

[21] Substantial Gainful Activity (SGA) is the maximum amount of earnings a person can have and continue to receive Social Security Disability Insurance (SSDI).

and $1570.00 for those whose primary disability is blindness). Cash benefits are reinstated during any month of employment below the SGA level. The **Expedited Reinstatement (EXR)** allows an individual to have their benefits restarted If their benefits are terminated due to work activity, without a new application within five years if they are unable to work at SGA due to a medical condition and the impairment is the same as or related to their previous impairment.

Earned Income Tax Credit (EITC)

The Earned Income Tax Credit is a refundable federal tax credit for individuals and families who work and have low and moderate incomes. The EITC reduces the amount of taxes such persons owe. Eligibility is based on family income and number of children with a maximum amount that each family can receive. The income limits change annually. Married workers must file a joint tax return to qualify. The credit is available to families with biological, adopted, or foster children of any age who have total and permanent disabilities and a social security number. Adult children who have mental retardation may automatically qualify if their physical or mental condition prevents them from working. Information on eligibility can found on the Web at http://www.irs.gov/ind_info/eitc4.html. Additional information can be found in the IRS Publication 596. Forms can be downloaded from http://www.irs.gov.

Student Earned Income Exclusion (SEIE)

The Student Earned Income Exclusion allows students under the age of twenty two who receive SSI and are regularly attending school to exclude a portion of their earned income each month, up to a maximum so that earnings will not cause any reduction in SSI benefits. In order to be considered regularly attending school the student must take one or more courses of study and attend classes in a college or university for at least eight hours a week, or be in grades seventh through twelfth for at least twelve hours a week or for less if for reasons beyond the person's control (e.g., due to an illness).

Another program that can help students with employment is the **Continued payment under a program of vocational rehabilitation, employment services, or other support services (Section 301)** which started in July 2005 when the Social Security Administration extended the continuation of payments for students whose disability or blindness medically ceases between the ages of eighteen through twenty one and are participating in an individualized education program (IEP). Under this program, benefits continue until the student completes the IEP or stops participating for any reason. It is designed to provide students the opportunity to continue receiving benefits while they complete school.

Impairment Related Work Expenses (IRWE)

In this program, out-of-pocket costs for certain impairment-related items or services necessary for employment are deducted from countable earnings when the Social Security Administration determines whether work performed is at the SGA level. These expenses are also subtracted from earned income for determining the SSI monthly payment amount. The expenses must be paid while a beneficiary is working, not be reimbursed by another party, and at the reasonable and standard charge for those items or services in a beneficiary's community. The **Blind Work Expenses (BWE)** option is available to Supplemental Security Income (SSI) beneficiaries who are statutorily blind and employed in which SSA does not count any earned income that is used to meet expenses needed to earn income. The expenses do not have to be related to the individual's blindness.

Other work incentives include the **Special SSI Payments for People who Work (1619a)**, in which SSI beneficiaries can receive cash payments even when earned income is at the SGA

level. Under the **Medicaid While Working (1619b)** provision, SSI beneficiaries can retain Medicaid coverage even if earnings become too high for an SSI cash payment. Under the **Extended Medicare** provision Medicare coverage continues for at least eight and one half years after an individual first returns to work as long as their disabling condition continues. More information on work incentives can be found in the Social Security Administration's *Red Book*.

HOUSING

During the early part of the last century, people with developmental disabilities received services in large public institutions or were cared for by their families with very little publicly funded support. Historically, families that had a child with a disability either had to forgo supports at home or place their children in an institution to obtain assistance. A series of class action lawsuits and closer scrutiny of institutions by an increasingly vocal advocacy movement during the 1960s revealed the abysmal conditions and poor treatment of the residents of these institutions. Personal accounts of residents and independent research studies showed that residents were vulnerable to abuse, neglect, dehumanizing practices, segregated and isolated from community life, and denied basic human and civil rights (e.g., privacy, choice, and control), education, and access to assistive technologies.

Institutional reform became a focus during the 1970s with increasing legal challenges to not only improve conditions but eliminate unnecessary institutionalization as well. The 1980s saw an increased focus on institutional closures. In 1984, New Hampshire received a HCFA waiver to expand community-based services and made extensive use of Home and Community Based Services Waivers to provide case management, personal care and residential support, supported employment and environmental modifications such as home adaptations.

In 1991 New Hampshire and the District of Columbia closed their remaining institutions becoming the first state and jurisdiction to provide all publically funded services in the community. By 2000 there were one hundred twenty five closures or planned closures in thirty seven states. By 2001, Alaska, Vermont, Rhode Island, New Mexico, West Virginia, Hawaii, and Minnesota had closed all of their public institutions, and others such as Michigan, Minnesota, and Colorado significantly decreased the number of residents in large state-run institutions.

Michigan has been cited as an example of a state that has been persistently innovative in transforming its service delivery system. In 1979, eighty cents of every dollar spent on residential and community services in the state was allocated to state institutions. By 1996 ninety five percent of Michigan's total mental retardation resources were shifted to family support and community care (compared to a national figure of seventy two percent). Today the state has one large congregate institution. A number of developments helped transform Michigan's delivery system into what has been termed a model for other states to emulate in decreasing reliance on institutions: (1) litigation (*Michigan Association for Retarded Citizens vs. Smith*) which focused on the conditions found in the Plymouth Center, a large state institution; (2) the Macomb-Oakland Regional Center, opened in 1973, which focused on the provision family support services, family preservation, and permanency planning, and helped avert unnecessary institutional placement when support and services could be found in a community setting; (3) the Community Mental Health Act, enacted by the Michigan Legislature, which provided financial incentives to county mental health boards to provide community services by reallocating funds saved from closures to finance community services and supports; and (4) the Michigan cash subsidy program which provided $250.00 per month for families earning up to $60,000.00 to pay for clothing, education aids, out-of-pocket medical expenses, and transportation allowing people with developmental disabilities to combine their cash subsidy with their SSI benefits (and thus eliminating the routine

practice of reducing benefits from public programs when persons with developmental disabilities receive additional benefits from other programs).

As people left institutions they were placed into group homes owned and/or operated by provider agencies or other entities placing the locus of control of where and with whom they lived in the hands of those entities. As it became clear that group home living could not contribute to the achievement of a full life in the community, numerous alternatives to congregate living were developed. Options have included assistance with renting and purchasing homes and receiving supports from neighbors, roommates, landlords and others who do not have disabilities with back-up assistance and safeguards from formal service systems.

The benefits of community living have been demonstrated over and over again in significantly enhanced daily living skills, levels of community participation, and satisfaction. Research studies have found improvements in overall adaptive behavior including self-care, academic skills, community living skills, language/communication skills, motor/physical skills, leisure/recreation skills, self-care/domestic skills, social skills, vocational skills, and domestic skills, as well as reductions in challenging behavior. In addition, parents and other caregivers, who often initially oppose community integration, almost always express satisfaction. Finally, it has been shown that the cost of supporting a person in their own home can be less than supporting them in a congregate home. Some people who move into their own homes also decide to work in the community as opposed to segregated programs thus generating further savings.

It is now abundantly clear that, with carefully tailored and individualized supports and services, people can grow and develop in housing they control. Individuals who have complex needs (e.g., feeding tubes, ventilators, difficult-to-control seizures or other potentially deleterious problems, or have other medical conditions requiring sophisticated medical expertise and technology, and require suctioning and frequent positioning,) are living in the community, attending school, going on vacations, and working, thus demonstrating that level of care does not pertain to a site or real estate, but rather the provision of what each person chooses based on their preferences and desires.

Unfortunately, the realization of community living for all individuals with developmental disabilities has yet to be achieved. Institutional closures have been accomplished primarily through transfers to mini-institutions (e.g., group and foster care homes) in the community. In addition, considerable numbers of individuals with developmental disabilities live in substandard or unsafe housing which constitutes a significant risk to health and safety. Safe, independent, accessible, and affordable housing provides individuals with freedom and self-sufficiency as well as offering the opportunity to achieve independence and become part of a community. Lack of affordable and accessible housing is the most significant barrier to community integration for people with developmental disabilities. High unemployment rates for persons with significant disabilities (typically sixty to ninety percent) engender continued reliance on public benefits. People with disabilities who receive SSI cannot afford housing because they are among the most economically disadvantaged in this country. In fact, they constitute the low-income group with the highest level of unmet need for housing assistance. In addition, Medicaid, the principal source of funding for services and supports, does not allow its funds to be used for housing-related costs. Persons with disabilities whose incomes depend on such benefits need housing subsidies[22] or shared housing

---

[22] *A Guide to Evidence-Based Practices for Adults with Mental Illness* offers more information on housing subsidies and affordability issues.

arrangements in order to live in the community. But, federally subsidized housing programs and the various Section 8 housing subsidy programs are disproportionately not targeted to persons with developmental disabilities and are funded at a relatively modest amount.

CENTERS FOR INDEPENDENT LIVING (CILs)

Centers for Independent Living were developed during the early 1970s by people with disabilities to provide individuals with disabilities assistance in developing independent living skills, are authorized under Title VII of the federal Rehabilitation Act, and receive funding from a variety of federal, state, and local sources. Most are non-residential, private and nonprofit, consumer controlled and operated, community-based organizations that provide services and advocacy by and for persons with all types of disabilities. The majority of the membership of their governing boards, staff, and individuals in other decision-making positions are held by persons with disabilities.

Information and Referral Services	• Employment services and information • Spectran paratransit rider certification • Emergency services and support information • Housing information (subsidized and barrier-free) • Obtaining adaptive equipment and assistive technology • Social Security and other supportive funding information • Recreation and volunteer opportunities
Community Awareness and Advocacy	• Self-advocacy and assertiveness training • Working with employers to provide job accommodations • Accessible housing development • Public speaking to groups, schools, employees, churches, etc. • Legislation - speaking before Michigan legislature and national advocacy • Americans With Disabilities Act - teaching seminars and one-on-one training assistance
Individual Skills Development	• Supervision of personal assistants • Hygiene • Academic skills • Résumé preparation and job search preparation and support • Job readiness skill-building • Rehabilitation nursing assessments and follow-up services • Independent living assessments and skills training • One-on-one training for individuals with specific needs • School-to-work transition services for students with disabilities • Cooking, menu planning, and comparison shopping • Money management
Peer Support	• Matching people with disabilities as mentors for people with new disabilities • Matching people with similar disabilities for support and information sharing

Each CIL is unique; programs offered can vary among different CILs. However, most provide assistance with transition to community based living, housing advocacy, transportation advocacy, and leadership training. Many CILs provide transition services targeted to students between the ages of eighteen and twenty that are designed to foster more active participation in their IEPs and transition planning processes. In addition, many offer leadership and personal development training curricula to assist students to prepare for life after high school as well as peer mentor services that match young people who have disabilities with trained mentors who also have disabilities and can provide assistance with personal and social skills development. Some CILs

also offer personal assistance services to help with personal care needs. Michigan's CILs provide information regarding disability issues, outreach, and recruitment activities. Information on CILs can be obtained from the [National Council on Independent Living](#).

PERSONAL ASSISTANCE SERVICES (PAS)

Personal assistance services encompass a range of human and mechanical supports for individuals who require help with routine activities of daily living and health maintenance. Some individuals require minimal personal assistance to help them live independently and maintain employment, while others need intensive medical interventions, life-sustaining therapies and technologies, ongoing therapeutic services (e.g., physical therapy), and immediate access to emergency medical support.

DIRECT SUPPORT STAFF

Personal assistance workers provide home and community-based care for persons with disabilities. These workers are known by a variety of names, including home care aide, personal care attendant, personal attendant, personal assistant, and direct support professional. Home health aides assist with personal as well as some clinical care. Home health aides are required by federal law to undergo seventy five hours of training and work under the supervision of a registered nurse.. Personal assistance workers provide personal care (e.g., toileting, bathing, eating, and transferring) and help with activities such as housekeeping, meal preparation, shopping, and bill paying.

Research indicates that it is challenging to find and retrain direct-care staff even when unemployment rates are relatively high.. In addition to being interested in assisting people with disabilities, workers must be able to handle the physical demands of the job, be mature, reliable, and sensitive to other people's preferences and needs, as well as be adept at prioritizing tasks, solving problems, and negotiating a variety of situations. In addition, specific technical skills, such as monitoring vital signs or complex medical equipment, may be required. This work can be physically and emotionally demanding and it offers few opportunities for career advancement. Prevailing wages are generally low and comparable to earnings from far less demanding work in fast-food restaurants, hotels, and other service industries. Direct care positions often lack affordable health coverage making it unappealing to many, particularly people who have families/children[23] to support. In fact, personal assistance workers often live near or below the poverty level. Many are single parents who hold two or more jobs to survive economically. In addition, this type of work is not highly regarded by the general public. It is viewed by some employers as unskilled (i.e., work anyone can perform after a few days of training). Consequently, personal assistance staff are often not involved in care related decision-making and or treated with due respect. High rates of vacancies and turnover in direct care staff often result in poorer outcomes and poorer quality of services including loss of understanding of the manner in which an individual communicates (particularly when in distress), lack of understanding of antecedent

---

[23] The traditional pool of direct care staff is comprised of women between the ages of twenty five and forty four.

behavior (which can lead to increased behavioral risks), and inability to make appropriate judgments related to acceptable risks based on knowledge of the person being served.

The literature recommends affording recognition and respect for the work performed by direct support staff as well as the provision of opportunities for learning and professional development, guaranteed work hours and schedules that meet workers' needs. Tapping into faith and community-based organizations for potential candidates is also recommended. And, as noted previously, self-determination has been shown to be an effective recruitment and retention strategy. Evaluations of programs using self-direction and individual budgets reveal that offering significant choice, control, and responsibility for hiring direct support staff leads to improvements in service quality, an expansion of the pool of potential direct care workers, offers flexibility in the design of supports and services to better meet participants' needs, and enhances participant satisfaction.

ADAPTIVE EQUIPMENT, ASSISTIVE TECHNOLOGY (AT), AND ENVIRONMENTAL MODIFICATIONS (E-MODS)

Environmental modifications (e.g., wheelchair ramps, lifts, handrails, etc.) and adaptive equipment enable individuals with physical challenges to lead more productive lives. Alterations in the design or structure of residences can make them accessible and have been shown to sustain families for many years. Assistive technology promotes greater levels of independence for adults with disabilities enabling them to perform tasks that were formerly difficult or unable to be accomplished by providing enhancements or altered methods of interacting with the technology needed to accomplish such tasks. Assistive technology enables infants and young children with disabilities to participate in daily routines and activities and facilitates mobility, communication, and other functions. AT can facilitate active participation in educational activities[24] (e.g., access to and mastery of curricula), assessments, extracurricular activities, and typical routines. Various types of assistive technology enable students to participate in and benefit from education.

The design and selection of assistive devices is unique to each person. Various considerations in the selection and design of assistive technology for children have been shown to be of importance in successful use including durability, cosmesis, cost, function, and acceptability by children and caregivers. The selection of the most appropriate device for a particular child is based on assessments conducted to determine the needs of the child and matching those needs with devices. AT devices range from readily available, off-the-shelf and generally low cost devices to those with limited availability designed to address issues related to specific disabilities. Readily available low-tech items include bath seats, car seats, strollers, and other positioning equipment as well as toys, spoons and bowls, and other items used by young children. Specialized high-tech devices are generally more complex and include computer-based communication devices, highly specialized switch interfaces, power wheelchairs, computerized toys and other devices not readily available for use by the general population. Practice to maximize skill generalization in naturally occurring routines at home, school, and the community has been shown to lead to increases in

---

[24] By law, a student's assistive technology needs must be considered in development of their individualized education program (IEP). The Individuals with Disabilities Education Act (IDEA) requires consideration of the need for assistive technology devices and services referral, evaluation, and IEP development as an integral part of the educational process.

successful use of adaptive devices in children. However, there is a paucity of evidence-based AT teaching practices in the literature.

Augmentative and Alternative Communication (AAC)	- Low-tech systems: simple paper or object based systems (that do not require a battery) - Light-tech systems: simple voice output devices, which require a battery but no sophisticated charging mechanism - High-tech systems: sophisticated voice output devices which require a battery as well as training and ongoing support - Communication board/book with pictures/objects/letters/words - Eye gaze board/frame - Simple voice output device (e.g., BIGmack, Cheap Talk, Voice-in-a-Box, and MicroVoice) - Voice output device with levels (e.g., Tech Speak, Macaw,) - Voice output device with icon sequencing (e.g., Vanguard II, Chatbox) - Voice output device with dynamic display (e.g., Dynavox, Speaking Dynamically Pro with laptop computer, Portable Impact Handheld) - Device with speech synthesis for typing (e.g., Cannon Communicator, Link, Write:Out Loud with laptop computer) - VOCA (Voice output Communication Aid) + teacher-directed natural instructional strategies[25]
Computer Access	- Ergonomic keyboards to reduce the discomfort and strain of typing - Chorded keyboards (which have a handful of keys [one per digit per hand] to type by chords which produce different letters and keys) - Expanded keyboards with larger, more widely-spaced keys - Compact and miniature keyboards - Dvorak Simplified Keyboard layout (in which the most common keys are located at either the left or right side of the keyboard) - Input devices: - Keyboards with lowercase keys - Keyboards with big keys - Large print keyboard with high contrast colors (e.g., white on black, black on white, and black on ivory) - Large print adhesive keyboard stickers in high contrast colors (e.g., white on black, black on white, and black on yellow) - Embossed locator dots to help find the home keys, F and J, on the keyboard - Scroll wheels on mice to alleviate the need to locate the scrolling interface on the computer screen - Replacement of the keyboard and mouse with trackballs, joysticks, graphics tablets, touchpads, touch screens, a microphone with speech recognition software, sip-and-puff input, and switch access

---

[25] A naturalistic instructional strategy is typically comprised of using child-preferred stimuli available within natural routine, child-initiated responses as the point of intervention, and verbal and gestural prompts with minimal use of physical guidance. Natural cues (e.g., expectant delay, questioning looks with eye contact, and physical approach techniques) are modeled by the instructor. ACC/VOCA in combination with naturalistic instruction strategy has been shown to lead to increased communicative interactions.

	- Software for input devices - Keyboard shortcuts - MouseKeys - Macro recorders - StickyKeys - ClickLock - Customization of mouse or mouse alternatives' responsiveness to movement, double-clicking, etc. - ToggleKeys - Customization of pointer appearance (e.g., size, color and shape) - Predictive text - Spell and grammar checkers
Activities of Daily Living	- Nonslip materials to hold objects in place - Universal cuff/strap to hold items in hand - Color coded items for easier locating and identifying - Adaptive eating devices (e.g., foam handles, deep sides) - Adaptive drinking devices (e.g., a cup with a cut out rim) - Adaptive dressing equipment (e.g., button hook, elastic shoe laces, Velcro instead of buttons, etc.) - Adaptive devices for hygiene (e.g., adapted toothbrushes, raised toilet seat.) - Adaptive bathing devices - Adaptive equipment for cooking - Adaptive driving equipment
Electronic Aids for Daily Living (EADLs)	- Light switch extensions - Interface and switch to activate battery operated devices - Interface and switch to turn on electrical appliances (e.g., radio, fan, blender, etc.) - Radio/ultra sound to remotely control appliances - Electronic aids to daily living to control the environment in connection with an augmentative communication device
Home or Building Access	- Ramps - Elevators - Lifts - Hand rails
Learning Supports	Color highlights on text to improve reading skills
Memory Aids	- Wearable computer-based memory aids - Memo recorders - Talking watches
Mobility	- Walker - Grab bars and rails - Manual wheelchair - Powered mobility toy (e.g., GoBot) - Powered scooter or cart - Powered wheelchair with joystick or other control - Adapted vehicle for driving
Recreation and Leisure	- Adapted sports - Travel accommodations - Toys adapted with Velcro, magnets, handles, etc. - Toys adapted for single switch operation - Adaptive sporting equipment (e.g., lighted or beeping ball) - Universal cuff or strap to hold crayons, markers, etc.

	• Modified utensils (rubber stamps, rollers, brushes) • Arm support for drawing/painting (e.g., Ergo Rest) • Electronic aids to control/operate TVs, DVD/CD players, etc. • Software to complete art activities • Computer games • Other computer software

Sensory Aids	• Hearing
	  ▪ Audiometer
	  ▪ Captioning
	  ▪ Fire alarm paging system
	  ▪ Loop system (portable and fixed)
	  ▪ Radio aids
	  ▪ Telecommunications device for the deaf[26]
	  ▪ Teletext
	  ▪ Video cassette recorders that can read and record subtitles
	  ▪ Vibrating fire alarm placed under pillow when asleep
	  ▪ Door bell lighting system
	• Vision
	  ▪ Large computer monitors
	  ▪ Adjustable task lamp with a fluorescent bulb that shines directly onto the paper and can be adjusted
	  ▪ Adjustable copyholder to keep printed material in a near vertical position for easier reading
	  ▪ Closed circuit television (CCTV) or video magnifiers in which printed materials and objects are placed under a camera and the magnified image is displayed onto a screen
	  ▪ Modified cassette recorders to record a lecture, one's own thoughts, ideas, notes etc.
	  ▪ Desktop compact cassette dictation systems that allow audio cassette playback with the aid of a foot pedal
	  ▪ Fusers to produce tactile materials (e.g., diagrams and maps) by applying heat to special swell paper
	  ▪ Scanners used in conjunction with optical character recognition (OCR) software to scan and convert printed documents into electronic text which can then be displayed on screen as recognizable text
	  ▪ Standalone reading aids which integrate a scanner, OCR software, and speech software in a single machine without a separate PC
	  ▪ Refreshable Braille display (which is an electronic tactile device placed under a computer keyboard in which a line of cells move up and down to represent a line of text on the computer screen to enable the user to read the contents of the computer screen in Braille)
	  ▪ Electronic Notetaker (a portable computer with a Braille or QWERTY keyboard and

---

[26] A TDD ([Telephone Device for the Deaf] called a TTY [TeleTYpewriter]) converts typed characters into tones that can be sent over the telephone line allowing immediate communication at a distance. When used in tandem with relay services, in which an operator reads what a person with deafness types and types what a hearing person says, all telephones can be made accessible (not just text telephones).

	synthetic speech; some models have an integrated Braille display)
	▪ Braille embossers (which emboss Braille output from a computer by punching dots onto paper via a connection to a computer in the same way as a text printer) ▪ Perkins Brailler (which manually emboss Grade 1 or 2 Braille) ▪ Customization of graphical user interfaces to alter the colors and size of desktops, short-cut icons, menu bars and scroll bars ▪ Screen magnifiers ▪ Screen readers ▪ Self-voicing applications ▪ Optical character recognition (OCR) which converts the printed word into text via a scanner. ▪ Braille translation (which converts the printed word into Braille and can then be embossed via a Braille embosser)
Switches and Switch Operated Devices[27]	Switches are a basic technology that can be used to help young children with disabilities learn various skills and are effective tools for early intervention with children with severe disabilities. These have been found to be an essential component in the creation of responsive environments because they produce contingencies between actions and outcomes. The importance of contingency experiences using assistive technology for sensory-motor development of children with disabilities has been cited. In general, switches or comparable AT are first presented to children with the help of participating parents and teachers and without feedback in order to reduce fear/anxiety. The children are then given time to familiarize themselves with the devices and discover their respective reinforcements or consequences. Studies show that children from birth through age five with cognitive/physical disabilities become skilled at controlling their environments and making choices by learning about cause-and-effect relationships through the use of switches subsequent to practice and intermittent feedback (i.e., reinforcement).
Telecommunications	• Voice recognition systems • Text reading systems • Telecommunication Relay Service • TTY (Teletype) devices
Transportation	• Steering Devices • Left-foot accelerator • Pedal extenders • Hand controls • Steering column extension • Joy-stick system • Gear selection • Remote switches • Wheelchair/scooter lift • Automatic door openers • Wheelchair carrier • Quad key-holder/turner

[27] Switches control the flow of electrical power to a device that the user wants to turn on or off. Switches can be activated by almost any part of the body a person is able to voluntarily and reliably control (e.g., arm, hand, finger, leg, foot, head, chin, movements of the eyebrow, and rib cage through controlled breathing).

Research indicates that while cost and maintenance issues may be associated with assistive technology devices, they allow children with disabilities to explore their environments and achieve higher levels of independence. Studies have demonstrated that teaching infants and young children to use AT results in improved involvement and engagement in daily activities and routines. In addition, different types of AT, including power mobility, augmentative and alternative communication (AAC) devices, switch activation, and computers can be used by children with disabilities to accomplish functional tasks and enhance social, emotional, intellectual, and locomotor development. Studies show that the use of AAC (e.g., Voice Output Communication Aid [VOCA]) in combination with teacher guidance and naturalistic teaching procedures can promote the development of effective communication and enhance communicative interactions during classroom routines.

Transportation

Although physical accessibility is frequently viewed in terms of access to buildings, transportation is also a critical aspect of accessibility, particularly for individuals with mobility challenges. Many individuals with developmental disabilities lack access to transportation or must depend on family or friends for transportation. Reliable and accessible transportation not only helps with gaining access to available community services, but offers a means to find and maintain employment, consult health care professionals, reside in locations of choice, shop for groceries, pay bills, and participate in community-based activities. Thus, transportation is key to a more independent and self-sufficient life; unavailable or inadequate transportation results in isolation and unmet needs. It is recommended that individual budgets have a sufficient allocation of funding to ensure control of personal transportation needs, including the purchase of a personal vehicle if necessary (irrespective of the person's ability to drive).

Recreation and Leisure

Opportunities for people with disabilities to participate in recreation and leisure activities can be quite limited. Obstacles include lack of transportation and skills or ability to participate in certain activities. Activities that require multiple participants (e.g., tennis, basketball, chess, card games, etc.) necessitate the availability of friends who are willing and able to participate in activities.

A number of benefits to participation in recreational and leisure pursuits have been identified for persons with developmental disabilities including enhanced community integration, breaks from usual daily routines, exposure to a variety of interesting and pleasant experiences, opportunities for socialization, and acquisition of new skills that increase self-confidence.

Advocates stress inclusive recreation and participation However, the Special Olympics, after school programs that provide daily, time-limited, temporary care for individuals with disabilities, and camp/recreation services which offer day, evening, weekend and/or overnight programs for recreation, social activities, and care have been developed for persons with developmental disabilities. Such programs have been found to be effective in developing skills and providing respite for families. For example, studies of the Special Olympics indicate athletes, coaches, and family members note significant improvement in athletes' self confidence, self-esteem, social skills, social interactions, health, and increases in employment.

CO-OCCURRING MENTAL HEALTH AND MEDICAL DISORDERS

It is estimated that thirty three percent to seventy percent of persons with developmental disabilities experience co-occurring medical and psychiatric disorders including seizure disorders, neuromotor problems (e.g., tics), attention deficit disorders, conduct disorders, behavior disorders, mood disorders (particularly depression and bipolar disorder), posttraumatic stress disorder, language disorders, anxiety disorders (particularly obsessive-compulsive disorder), feeding disorders (in children), schizophrenia, and auditory, and visual impairments. Numerous studies have shown that children and adolescents with autistic spectrum disorders (ASD) experience higher rates of affective disorders and behavior problems. In addition, approximately seventy five percent of children with autism are also diagnosed with mental retardation. However, it should be noted that the majority of children with mental retardation do not display significant impairments in reciprocal social interaction typically present in pervasive developmental disorders such as autism. Children with more severe mental retardation have been found to display increased aggressiveness, feeding disorders, stereotyped movements, and self-injurious behavior. The latter is more common in certain syndromes (e.g., Lesch-Nyhan and Prader-Willi).

A number of factors have been attributed to the significant incidence of co-occurring psychiatric disorders in person with developmental disorders. These include: the increased likelihood of experiencing traumatic events (e.g., abandonment by loved ones, abuse, bullying and harassment) and social restrictions (e.g., lack of education and poverty, as well as limited opportunities for employment, fulfilling relationships, and meaningful activities). Biological factors (e.g., brain injury, epilepsy, illicit and prescribed drug and alcohol misuse); and developmental factors (e.g., lack of understanding of social norms and appropriate behavior and societal misunderstanding of expressions of grief and other emotions displayed by persons with developmental disabilities) have also been attributed to the development of co-occurring psychiatric disorders.

Posttraumatic Stress Disorder (PTSD) is thought to be significantly under diagnosed in persons with developmental disabilities. Such individuals are vulnerable to abuse due to their high levels of dependency, a tendency to want to please others, lack of understanding of their rights, and limited communication skills which may prevent reporting incidents of abuse. Individuals with development disabilities have historically been unduly subjected to other types of traumatic events including separation from primary relationships at an early age, frequent moves from residential placements, institutionalization, degradation, significant medical problems/procedures, and extended hospitalizations, In addition, aversive treatment procedures (e.g., facial screening or exposure to noxious substances) are thought to contribute to symptoms of PTSD. Early intervention is recommended, but studies point to delays in psychiatric diagnosis and inadequate or lack of treatment for co-occurring psychiatric disorders.

People with intellectual disabilities been have found to experience more serious health problems than the general population including epilepsy, sensory problems (e.g., visual and auditory impairments), dental problems (i.e., tooth decay), below normal bone mineral density (BMD), foot diseases or conditions (e.g., bunions, corns, calluses, fungal infections, ingrown nails, etc.), obesity. Some syndromes are associated with increased risk for physical problems. For example, Down syndrome is associated with auditory impairment, cataracts, impaired cardiac functioning,

and thyroid disorders that can result in psychiatric symptoms. The life expectancy[28] for people with developmental disabilities is estimated to be twenty years below average, although this has been improving with advancements in adaptive and medical technologies and as people are leading healthier, more fulfilling lives. The multiplicity of disorders associated with mental retardation syndromes have been found to be disproportionately high in economically challenged communities in which residents experience social and economic disparities when seeking health care.

Individuals with developmental disabilities and their families experience significant barriers to accessing primary and specialty health care services and are more likely to receive inappropriate and inadequate treatment, or be denied care altogether. In addition, they are all too likely to encounter dismissive and inexpert health care providers, gaps in available services, insurance coverage limitation, transportation problems, and a lack of coordination among multiple service systems. Opportunities to promote healthy lifestyle practices and prevent diseases are often overlooked. Providers often lack knowledge regarding the distinctive needs of patients with developmental disabilities. These barriers are even more overwhelming for individuals from minority communities whose cultures and primary languages may not be reflected in available health services.

Transportation, communication, and other problems commonly experienced by persons with disabilities only increase the challenges faced by providers. Individuals with developmental and intellectual disabilities may need assistance in filling out insurance forms, filing claims, making medical decisions, securing transportation to and from appointments, and finding a qualified medical professional with the training to work effectively with them.

Physical illnesses can be overlooked in persons with intellectual disability due to difficulties in reporting symptoms. Individuals with severe communication difficulties may find it difficult to articulate their health needs, and, without adequate support and education, may not recognize ill health. These problems can be exacerbated by high turnover rates of personal care staff and gaps in medical records. High rates of turnover in personal care staff can lead to lack of knowledge of medical history and concerns as well as lack of ability to assist consumers and their health care providers in communication, adherence to courses of treatment, and recognition of symptoms that require attention.

Many medical illnesses have psychiatric symptoms. For example, hyperthyroidism can present with anxiety, depression, or manic symptoms, and hyperactivity can be prominent in lead poisoning. Medical illnesses may also result in nonspecific behavioral symptoms or exacerbate pre-existing ones. For example, a painful condition in a nonverbal person may lead to self-injurious behavior such as head banging related to otitis media or migraine, as well as to nonspecific aggression. In addition a number of medications can lead to manifestation of psychiatric symptomatology (e.g., beta blockers may produce depressive symptoms, phenobarbital may result in impulsive, aggressive behavior, and estrogen and progesterone preparations and corticosteroids can produce affective symptoms).

Care for individuals with multiple conditions may be fragmented (e.g., different specialists may be managing seizures, a gastrointestinal disorder, and self-injurious behaviors), resulting in adverse

---

[28] Individuals with Down syndrome often experience an early onset of aging.

drug interactions or chronic drug toxicity. Age-related changes in health care needs may further complicate care if additional or different providers are needed. Moreover, as age-related health needs change with the various stages of life, transitions from one health care system to another can be difficult to navigate and continuity of care may be disrupted.

Studies show that children, adolescents, and adults with intellectual disabilities receive fewer routine health examinations, immunizations, mental health care, prophylaxis and treatment, and have fewer opportunities for physical exercise and athletic participation. Individuals with verbal communication challenges have been found to be at higher risk for overmedication, injury, inadequate nutrition, and abuse, all of which may go undetected.

Providers may omit screening individuals with developmental disabilities for dietary and nutritional status, exercise habits, oral diseases, substance use/abuse, and depression and other mental illnesses, cancer, abuse or neglect, domestic violence, or occupational hazards. Routine preventive services including periodic oral prophylaxis and restoration, cancer screening, immunizations, and early intervention in emerging mental illnesses, critical to prevention of more serious conditions and secondary disability, may not be provided. Nutrition and weight control; exercise; oral health; family planning; safe sex; strategies for protection from rape, domestic violence, and sexual abuse; maintaining treatment regimens; avoiding medication errors; recognizing and seeking care for emerging disorders; and age-related changes in, and risks to, health status and other educative and self care skills may also be neglected.

Providers may not have the specialized training and equipment needed to provide preventive interventions, such as oral prophylaxis and applications of protective materials to tooth surfaces. Providers may overlook the need for immunizations and opportunities to educate individuals and families about behaviors that promote health. Physicians, dentists, and other health care providers frequently cite lack of training and experience in treating individuals with developmental disabilities as well as reluctance to assume clinical responsibility for care. An additional factor often cited is inadequate compensation for the additional time that may be required for care. Research shows that providers who receive training regarding the health care needs of individuals with developmental disabilities display increased willingness to treat such patients which can improve access to care.

Developmental monitoring and initiation of referrals in a timely manner is critical to early identification and the effectiveness of intervention programs. It is therefore recommended that developmental surveillance and screening (i.e., routine monitoring and tracking of specific developmental milestones) for specific disorders start during in infancy and be performed by primary care providers during well-child visits. In addition, information should be obtained using reliable standardized instruments, parental and professional observations and judgment. Concerns raised by developmental surveillance should result in screening or referral for diagnostic evaluation.

Research shows that screening is manageable within current primary care practice parameters in terms of time and cost. The American Academy of Pediatrics Practice Guidelines and the federal and state Early and Periodic Screening, Diagnosis and Treatment (EPSDT) schedules indicate routine developmental surveillance should be conducted during each well-child visit. However, numerous studies have shown that this does not occur in most health care practices due to time constraints. Parents may not voice developmental concerns unless specifically elicited by the primary care provider. Moreover, studies have shown that even when parents raise developmental concerns, some providers respond by waiting to see if delays will resolve spontaneously or discount parental observations.

It is recommended that all children be screened specifically for ASD at eighteen and twenty four months since research indicates that a significant number of the features of ASD are present by

eighteen months of age. In addition, since some children with ASD evidence regression in skills between the ages of fifteen and twenty four months (and rarely after two years), screening at age two facilitates the identification of these children. Screening younger siblings and educating their parents about the increased risks for ASD for subsequent children is also recommended.

Several general developmental screening tools have been developed to identify and track developmental progress in young children. These instruments vary in mode of administration, duration of time needed, ease of use, amount of information provided, reliability, validity, accuracy of developmental progress, and divergence from norms. A number of screening tools have been developed for detecting autism that can be used in primary care settings. These include, among others, the **Modified Checklist for Autism in Toddlers (M-CHAT)** which is a parent report version of the **Checklist for Autism in Toddlers (CHAT)** designed to identify children at eighteen months who are at risk for ASD. The M-CHAT is used as part of clinician-guided child health surveillance for eighteen to twenty four-month old children. It is a twenty three-item checklist that consists of items in a yes/no format that parents can easily fill out in a waiting room and does not require health care staff observation. This instrument has demonstrated validity in identifying the majority of children with ASD and developmental delay at twenty four months of age. It is available free of charge in English and Spanish and can be downloaded in English from http://www.utmem.edu/pediatrics/general/clinical/m-chat.pdf.

The **Pervasive Developmental Disorders Screening Test-II (PDDST-II)** is a parent report measure designed to indicate the likelihood of global and pervasive developmental disorders in children from birth through age three. The scale consists of seventy-one true/false items presented in six-month age intervals. Cutoff algorithms have been established for differentiating children with the likelihood of ASD from children with other developmental challenges. Parents are asked to rate items as "usually true" or "usually false" for their child. The instrument takes fifteen to thirty minutes to complete depending on the age of the child. It is available at no cost in English and Spanish and can be downloaded from http://www.co-brass.com/pddsii.pdf in English. Other instruments for early detection of ASD include the **Screening Test for Autism in Toddlers (STAT)**, the **Social Communication Questionnaire (SCQ)** for preschoolers and elementary-aged children, the **First Year Inventory (FYI)** for infants aged twelve months, and the **Early Screening for Autism Questionnaire (ESAT)** for infants aged twelve months.

CHILD WELFARE

Studies indicate that children with disabilities are more likely to experience abuse or neglect and are at increased risk for becoming involved in the child welfare system. While prevalence rates are unknown because disability is not always recorded, risk factors have been well documented. Children with developmental disabilities are less likely to live with both parents and more likely to live in families with below poverty level incomes. As noted previously, the presence of a child with a disability increases stress for many families, and for some, the combination of stressors and other problems (e.g., social isolation, emotional stress, and time pressures as they coordinate care for the behavioral, medical, or educational needs of their children) leads to involvement with the child welfare system.

Permanency planning for children and youth with disabilities has supplanted out-of-home placements which were common prior to the mid 1970s and once widely viewed as beneficial to both families and children. A number of social reforms have promoted options for children with disabilities to benefit from family life. The Adoption Assistance Program of 1980 was designed to ensure that families adopting foster children with special needs could do so without reducing or exhausting their resources. This federal adoption subsidy program[29] entitles all families adopting children from foster care with special needs who cannot meet their needs to obtain subsidy support. In addition, Supplemental Security Income (SSI) became available to provide financial support for families of children with disabilities with low incomes. A free and appropriate education for children with disabilities in their own communities was mandated by Individuals with Disabilities Act (IDEA). The Medicaid Home and Community Based Services, respite care, personal care, and other services can also be used to support permanency planning efforts.

A number of barriers to providing services to children and youth with disabilities in the child welfare system have been identified. Families involved in the child protection system often receive mandated services from the child protection system as well as voluntary services from the disability service system. These two systems have different philosophies, separate legislation, rules, and bureaucratic procedures and are typically not well integrated. In addition, there are differing eligibility requirements and age cut-offs for disability services and the child protective system and screening for disabilities at time of intake into the child protective system is often lacking. There has historically been little recognition in the child welfare and disability service systems of the vulnerability of children with disabilities for maltreatment. Knowledge regarding disabilities, financial resources and funding for needed parenting supports for parenting, and a lack of child welfare providers with expertise in both child welfare and disabilities have also been lacking in the child welfare system. Moreover, federal and state laws mandating child protection services usually do not provide for disability accommodations. For example, the timeframes mandated by the Adoption and Safe Families Act can create challenges because longer timeframes may be needed to obtain services or for families to comply with orders from child protective services.

The literature recommends training regarding recognition of disabilities in the child welfare system as well as the provision of treatment, preventive services (e.g., parenting support groups, respite, child abuse hotlines) that address the needs and concerns of families of children with disabilities, and crisis intervention. In addition, ongoing collaboration between child welfare and the disability service system throughout a family's child welfare involvement has been identified as important. This includes gathering collateral information regarding a child's and family's strengths and challenges, current and prior service participation during the early stages of a case, and involvement in the service planning process if a family is determined to require ongoing child welfare services. Professionals with expertise in working with families and children with disabilities can provide consultation regarding communication techniques for interviewing children with communication challenges, appropriate care tailored to specific disabilities, and accommodation issues. For example, a child may need a medical evaluation to determine the etiology of marks, bruises, or other physical conditions pertinent to allegations of abuse. Disability professionals can also provide assistance with accessing and securing funding for resources (e.g., respite care, personal assistance, and home modifications), locating or designing accessible family services

---

[29] The National Adoption Information Clearinghouse offers information on state-funded adoption assistance programs which can be obtained from http://naic.acf.hhs.gov.

(e.g., parenting skill training geared towards parenting children with disabilities), as well as assessing risk, parental functioning, and safety in families in which a parent has an intellectual disability.

- **All children, regardless of disability, belong with families and need enduring relationships with adults. Children have a right to a nurturing home and consistent relationships with adults.**
- **Families should receive the supports necessary to maintain their children at home. Family support services should be flexible, individualized, designed to meet the diverse needs of families, and based on the principle of "whatever it takes".**
- **Family supports should build on, strengthen, and expand existing social networks and natural sources of support (e.g., neighbors, extended families, friends, and community associations) and these should be preferred over agency programs and professional services. When natural sources of support cannot meet the needs of families, professional or agency-operated support services should be available.**
- **Family supports should maximize every family's control over the services and supports they receive. Families are in the best position to determine their own needs.**
- **Family supports should support the entire family including children with disabilities, parents, and siblings.**
- **Family support services should be designed to maximize the integration and participation of children with disabilities in the community.**
- **Consistent with the philosophy of permanency planning, children should live with their families whenever possible. When children must leave their families due to family crisis or other circumstances, efforts should be directed at encouraging and enabling families to be reunited.**
- **Adoption should be aggressively pursued when families cannot be reunited or active parental involvement is absent. Families should be involved in adoption planning whenever possible and be treated with sensitivity and respect. The possibility of open adoption whereby families maintain involvement with their children should be seriously considered.**
- **Foster care should only be pursued when children cannot live with their families or adoptive families.**

Adapted from the Center on Human Policy, Syracuse University, Syracuse, New York (http://thechp.syr.edu/famstate.htm)

Some public child welfare agencies have formalized collaborative arrangements with disability service providers. A number of models entail the use of two case workers, one from child protection and one from the developmental disabilities services system, who work together on all cases involving a child with a disability who has an open child protection case. Other child protection units team all of their cases with staff from the disability services system which can facilitate the identification of children who may be eligible for disability services.

Although research on best practices for serving children with disabilities and their families who are involved in the child welfare system is rather limited, some effective strategies have been identified to help families and prevent out-of-home placements:

> ► **Support Families** provide shared parenting and are an alternative to foster care or residential placement and function as a prevention strategy for the child welfare system. Support families are recruited specifically for children with disabilities and make long-term commitments to those children. Birth parents can share parenting with support families without ceding their rights. Support Families receive training in the care specific to each individual child.

►   **Respite** programs provide temporary care by specifically trained individuals for children with disabilities and give families a break from care-giving, reduce family stress, and create time for other activities. Respite can be provided in a family's home or out of home (e.g., provider's home, a day care center, a group foster home, and homes of a circle of families that provide respite for each other).

►   **Parent Training and Support** includes parent training and education programs, support groups, and other family support services designed to assist parents in learning about their child's disability, build care-giving skills, focus on family life, and obtain peer support from other parents of children with disabilities.

Many public child welfare agencies offer services such as alternative response and family group decision-making. Alternative response provides flexibility in responding to families at lower risk and providing services to create stable and safe situations. The focus of alternate response is on assessing the strengths and needs of the family and child while ensuring the child's safety, usually without requiring a determination regarding maltreatment. Families may receive services through diversion to community agencies. In other words, families reported for suspected child abuse or neglect may receive either a traditional investigation or an assessment alternative, depending on the severity of the allegation and other considerations. Family group decision-making typically involves extended family members in case planning to take advantage of resources within families to plan for the safety and well-being of their children (e.g., brainstorming ways in family members can work together to support children and their parents).

The Justice System

Studies suggest that individuals with developmental disabilities are overrepresented in correctional systems. However, research also indicates that people with developmental disabilities frequently go through the justice system unrecognized. Individuals with intellectual disabilities are most often taken into custody for sex offenses, arson, and property offenses.

Rates of sex offenses among offenders who have intellectual disabilities are four to six times greater than found in the general offender population. Many of these offenses appear to stem from limited information about sexual relationships and courtship skills, limited impulse control, sexual naiveté, and a lack of normal sexual outlets. It is recommended that individuals with intellectual disabilities be provided with basic sex education and information about laws and social codes related to sexual behaviors. Treatment regimens that involve learning arousal control skills, cognitive restructuring, group therapy, anger management, and social skills training in various combinations have been found to be effective for individuals with IQs ranging from fifty five to eighty five.

It has been suggested that criminal investigation, court-ordered intervention, and concrete consequences can be effective for sex offenders with developmental disabilities, particularly those who do not accept or readily understand the connection between their behavior and involvement in the criminal justice system. Creative sentencing options can be used to encourage actual behavior change rather than a jail or prison sentence; those who serve time in jail or prison face a high chance of reoffending due the lack of provision of quality sex education and related services in the criminal justice system. Sanctions/consequences can include twenty four to forty eight-hour incarceration in a safe environment, confinement to a residential facility for a specific period of time or required treatment along with sex/relationship training, and restitution for damages. This type of personalized justice plan (PJP) has found to be helpful for persons with developmental disabilities.

Fire setting is also overrepresented in the population of offenders with intellectual disabilities and is associated with impaired communication and emotional expression as well as a response to stress. Prison-based recommended interventions focus on helping individuals evaluate antecedents to fire setting and teaching skills to reduce stress and improve coping. In addition, it is recommended that these individuals are closely monitored, housed in lower stress living environments, and searched frequently.

Property offenses appear to be related to low frustration tolerance, exposure to delinquent peers, and disturbed family environments. Anger management techniques such as relaxation training and the use of cognitive self-statements (e.g., "calm down") have been shown to be of benefit to offenders with intellectual disabilities. In addition, psychopharmacological agents can be effective but must be used judiciously due to potential adverse effects for individuals with underlying brain disorders. Neuroleptics, antiepileptics, lithium, and beta-adrenergic blockers have been found to be effective in reducing episodic violence.

Individuals with developmental disabilities have been shown to be disadvantaged in criminal justice system processes. Individuals with intellectual disabilities are more vulnerable to false confessions during interrogative interviews because of a heightened propensity towards acquiescence, suggestibility, biased responding to leading questions (i.e., answering in the affirmative or negative given the demands of the question), and assumption of blame in an effort to please a questioner. Individuals with developmental disabilities may have difficulty processing large chunks of information and there is evidence that they have difficulty understanding their MIRANDA rights. A review of the literature reveals that, when compared to defendants without developmental disabilities, individuals with developmental disabilities confess and plead guilty more often, plea bargain less often, are defended by court-appointed counsel more often, make fewer appeals, serve longer sentences, are denied parole more often, and receive less time off for good behavior.

Criminal justice systems have been found to be ill prepared to meet the needs of people with developmental disabilities (both as perpetrators and victims of crimes). Correctional environments often lack the resources needed to address the treatment and programming needs of this group of offenders; correctional staffs lack knowledge about this population, and there is typically a lack of interagency agreements and collaboration efforts between the justice and disability systems.

In general, services designed to assist persons with developmental disabilities who are involved with the justice system focus on identifying offenders with developmental disabilities and targeting points of diversion from the standard adjudication track once in the court system, providing transition options out of the justice system and into appropriate education and/or community service and support systems that offer programs that can respond to behaviors and needs in ways that can reduce the likelihood of recidivism. These programs often operate side-by-side but separately from community crisis response programs.

Prison-based programs for offenders with intellectual disabilities typically focus on building social skills, and educational training. Token economy systems are used to reward desirable behaviors; unwanted behaviors result in loss of tokens and timeouts or seclusion (usually in response to violent behaviors).These programs usually offer structured training programs and operate with higher staffing ratios and multidisciplinary teams that include nursing staff. In addition, safeguards to prevent risk of victimization from other offenders are instituted when inmates with developmental disabilities are integrated into general prison populations.

A number of jurisdictions use case management to address the needs of offenders with developmental disabilities and provide assistance with community re-entry. Case management has been found to reduce recidivism and the costs of supervision. Literature concerning the use of sanctions as a tool emphasizes the need for graduated sanctions and less rigid enforcement for

offenders with developmental disabilities as these individuals are more likely to experience difficulties complying with treatment goals or the conditions of their release. Information on justice system sanctions and diversion options can be found in the SCCMHA publication, *A Guide to Evidence-Based Practices for Individuals with Substance Use Disorders*.

SPECIAL OFFENDER SERVICES PROGRAM (SOS)

The Special Offenders Services is model program for the treatment of offenders with developmental disabilities or at least three deficits in essential adaptive skills or behaviors who are on probation or parole that was developed during the mid-1980s in Lancaster County, Pennsylvania. The program provides education to criminal justice personnel, facilitates the use of social services (through case management), focuses on enhancing the self-esteem of participants (by rewarding small successes and not placing unreasonable demands on its clients). It offers education to clients regarding their rights and responsibilities, and skills training in a variety of areas including recreational activities. Outcome evaluations indicate that participation leads to a ninety five percent reduction in recidivism.

The Lancaster County Office of Special Offender Services also operates programs that use case management targeted to adult and juvenile offenders with mental retardation. It is a collaborative endeavor that was established in 1981 by the Lancaster County Court of Common Pleas (Probation/Parole) and the Lancaster County Office of Mental Health and Retardation. The Office of Special Offenders Services provides intensive probation/parole and case management services to adults with mental retardation. Probation officers and case managers work conjointly to determine consumers' functional levels and case management goals in the Adult Offenders with Mental Retardation Program. Case managers provide intensive supervision and counseling to help offenders develop self-esteem and confidence; build decision-making, social, and independent living skills; and obtain employment. Subsequent to successful completion of probation, offenders are linked to the county's mental health/mental retardation department for continued case management which is provided as long as needed.

A specially trained team of probation officers and case workers in the Juvenile Division of the Office of Special Offender Services addresses the needs of juvenile offenders with developmental disabilities who might otherwise fall through the cracks of the juvenile justice system. The program, which is partially funded by the Pennsylvania Juvenile Court Judges, works to reduce recidivism and the cost of placement through developing skills necessary to live independently or with families, comply with laws, and function in the community. Case management includes intensive supervision (consisting of daily meetings until stabilization occurs and several meetings per week thereafter); meetings with families, school officials, and employers; and an intensive education program that addresses drug and alcohol issues, legal rights and responsibilities, money management, social skills, recreational activities (as a reward for program compliance), and other training related to daily living skills. Participants spend an average of nine to twelve months in the program. In addition, case managers from Office of Special Offender Services and a probation officer teach a school truancy prevention program targeted to youth with developmental disabilities in mainstreamed educational settings who may not adequately understand the law or criminal justice system. This three-hour program, which is provided during two morning and two afternoon sessions per week, focuses on community behavioral standards, personal responsibility, decision-making, and the consequences of breaking the law.

FAITH-BASED ORGANIZATIONS

People with disabilities have historically been denied access to houses of worship and the fellowship that participation in faith-based community activities offers. It has typically been assumed that people with developmental disabilities required caring rather than inclusion among those who offer care. For example, until fairly recently, Jewish children with developmental disabilities were seldom included in preparations for Bar or Bat Mitzvahs. Membership in faith communities continues to be a challenge for individuals with developmental disabilities but significant strides have been made to welcome them into faith communities. National religious organizations (e.g., the Catholic Conference of Bishops, National Council of Churches of Christ, and Union of American Hebrew Congregations) have adopted new or updated position papers or statements on ministry and people with disabilities. In addition, community bridge building efforts in various churches, synagogues, and other congregations have been found to effectively promote community inclusion.

Faith-based organizations have the potential to function as familiar and welcoming places where persons with disabilities can feel valued and included. In addition, members of faith-based organizations can offer connections to the community-at-large and help foster opportunities for meeting people and building friendships. Collaborative efforts with families and other supporters (e.g., paid support staff) can help minimize health and safety risks.

Congregations can play a key role in promoting inclusion through the provision of opportunities for full participation and personal connections through established committees or groups (e.g., men's groups, women's groups, choir, church decorating, ushers, etc.). Members of congregations can reach out to support expansion of the social networks of adults with disabilities who live with their parents and are somewhat isolated within the family structure. Additionally, congregation members can extend themselves in individual friendships, both within religious institutions and the wider community. Some social ministry programs identify congregation members who are more isolated and provide fellowship and friendship.

Bridges to Faith is an example of a collaborative, interfaith effort that provides opportunities for persons with developmental disabilities to worship in chosen faith communities as well support to faith communities. The Robert Wood Johnson's Faith in Action[30] initiative demonstrated that congregations can offer services and supports to people with developmental disabilities and their families including:

- Friendly visiting and telephone reassurance
- Transportation
- Meal preparation and delivery
- Shopping

- Minor chores and household repairs
- Respite for family caregivers
- Personal care
- Linkage to community services

---

[30] Faith in Action supports the establishment of local interfaith coalitions of volunteer caregivers consisting of diverse religious congregations, as well as health, social service, and civic organizations, which come together to provide informal care and support for communities' residents who are homebound and have a chronic illness or disability (e.g., dementia, physical disability, mental illness, substance use disorders, and HIV/AIDS). Services are provided by volunteers recruited primarily from participating congregations and the community at large.

A number of parochial day schools offer a range of supports for students with developmental disabilities. Young children with disabilities are increasingly being enrolled in regular congregational nursery school or daycare programs Some are part-time programs that supplement public school early childhood special education programs, while others offer supports from specialists within religious institutions' programs in which classroom aides help with school integration and provide assistance to classroom teachers.

Research points to the importance of addressing spiritual needs and preferences as part of the provision of services and supports to persons with developmental disabilities. It is recommended that interest in spiritual expression and religious activities be made part of person-centered planning and that consumers be asked if they want their pastor, priest, rabbi, imam, or someone else from their congregation to participate in planning meetings.

Individual faith profiles can be used to explore and document faith traditions, congregation membership, rites or sacraments that have been received or desired, faith involvement (i.e., worship, religious education, congregational programs, and prayer), as well as areas of support needed for effective inclusion. Spirituality profiles are also used to describe spiritual interests and needs which are then delineated in individualized plans for supporting spirituality. One format developed for interdisciplinary teams in healthcare settings is George Fitchett's 7x7 Model for Spiritual Assessment which outlines seven dimensions of holistic assessment: and seven areas of spiritual assessment to be explored:

The 7 x 7 Model for Spiritual Assessment

Holistic Assessment	Spiritual Assessment
Medical (Biological) Dimension: What significant medical problems has the person had in the past? What problems do they have now? What treatment is the person receiving?	**Beliefs and Meaning:** What beliefs does the person have which give meaning and purpose to their life? What major symbols reflect or express meaning for this person? What is the person's story? Do any current problems have a specific meaning or alter established meaning? Is the person presently or have they in the past been affiliated with a formal system of belief (e.g., church)?
Psychological Dimension: Are there any significant psychological problems? Are they being treated? If so, how?	**Vocation and Obligations:** Do the persons' beliefs and sense of meaning in life create a sense of duty, vocation, calling or moral obligation? Will any current problems cause conflict or compromise in their perception of their ability to fulfill these duties? Are any current problems viewed as a sacrifice or atonement or otherwise essential to this person's sense of duty?
Family Systems Dimension: Are there at present, or have there been in the past, patterns within the person's relationships with other family members which have contributed to or perpetuated present problems?	**Experience and Emotions:** What direct contacts with the sacred, divine, or demonic has the person had? What emotions or moods are predominantly associated with these contacts and with the person's beliefs, meaning in life and associated sense of vocation?
Psychosocial Dimension: What is the history of the person's life, including, place of birth and childhood home, family of origin, education, work history, and other important activities and relationships. What is the person's present living situation and what are their financial resources?	**Courage and Growth:** Must the meaning of new experiences, including any current problems, be fit into existing beliefs and symbols? Can the person let go of existing beliefs and symbols in order to allow new ones to emerge?
Ethnic, Racial, Cultural Dimension: What is the person's racial, ethnic or cultural background. How does	**Rituals and Practice:** What are the rituals and practices associated with the person's beliefs and meaning in life?

it contribute to the person's way of addressing any current concerns?	Will current problems, if any, cause a change in the rituals or practices they feel they require or in their ability to perform or participate in those which are important to them?
Social Issues Dimension: Are the present problems of the person created by or compounded by larger social problems?	**Community:** Is the person part of one or more, formal or informal, communities of shared belief, meaning in life, ritual or practice? What is the style of the person's participation in these communities?
Spiritual Dimension	**Authority and Guidance:** Where does the person find the authority for their beliefs, meaning in life, for their vocation, their rituals and practices? When faced with doubt, confusion, tragedy or conflict where do they look for guidance? To what extent does the person look within or without for guidance?

Another format for a spiritual assessment, developed by Christina Puchalski, M.D., et al, uses the acronym FICA to signify the format for an initial exploration of faith:

F   Faith or Beliefs (What is a person's faith or belief? What gives meaning? Does this person consider himself/herself to be spiritual or religious?)

I   Importance (How important is spirituality for this person?)

C   Community (What kind of communal expression does this take, or would the person want it to take?)

A   Address (How does this person/family want health and human service providers, to address these needs and interests?)

SERVICE COORDINATION

CASE MANAGEMENT / SUPPORTS COORDINATION

Over the past several years efforts have been made to transform case management from placing people in programs to supporting individuals in their efforts to build opportunities and relationships in their communities. Case managers are increasingly referred to as Service Coordinators or Supports Coordinators to signify the transformation of their role from that of a manager of "cases" to one of a coordinator of services and supports for individuals and their families in accordance with consumer-directed services and supports. Supports Coordinators provide advocacy, serve as community liaisons, and coordinate resources. They not only provide assistance in navigating various service systems and agencies to ensure individuals obtain need supports, but also teach people how to coordinate their own supports. Their roles are vital to the overall effectiveness of service delivery both within and external to the developmental disability service system. In recent years supports coordination has been evolving into personal agentry.

PERSONAL AGENTRY

Personal agentry is described as a hybrid of support coordination and brokering. Personal agents are based outside of the service delivery system (i.e., separate from funding agencies) and usually work in private nonprofit units. Personal Agents (PAs) are contracted to provide a variety of supports and act at the behest and discretion of consumers. They help consumers navigate the service delivery system rather than represent it. Personal Agents who are not responsive to the concerns of consumers and their circles of supports can lose their contracts.

Personal Agents provide information, education, and technical assistance to consumers and their families. They provide leadership to circles or networks of support by fostering increased communication, eliciting information, and helping with problem-solving. Personal Agents can help identify goals, build support networks, ascertain the availability of services and supports, coordinate resources, and provide assistance with the selection of service providers. PAs are given the authority (with the concurrence of consumers and their circles) to enter into contractual arrangements to procure resources. They assist consumers in planning and negotiating the use of individualized funding to purchase services and supports that meet their needs in accordance with consumers' priorities. This brokerage role is designed assist consumers in investing their resources in optimal means of support. In some instances, Case Managers/Supports Coordinators provide parts of the support coordination role (primarily paperwork and monitoring for a larger number of consumers) while personal agents provide other aspects of support.

It has been noted that working independently can create challenges including isolation, staying abreast of changes in available services and supports, accessing training, and reduced understanding and influence regarding funding. However, strong working relationships with Case Managers/Support Coordinators and others within services systems can help bridge gaps.

INDEPENDENT BROKERS

Independent Brokers work independently of service systems to provide linkages to community supports and may provide expertise in only one area or in a variety of areas. Brokers charge hourly or daily rates, or a lump sum for service provision. Brokers can work solo as independent contractors or as part of a collaborative that shares business operations (e.g., clerical and bookkeeping services). Brokers may also work as a unit similar to that of Personal Agents. In addition, brokers may not be human service system focused. For example, realtors offer brokerage services for dwellings and employment specialists offer brokerage services for jobs. More than one broker may be involved since one individual or type of broker may not be able to provide expertise in all areas of need for a consumer.

INDEPENDENT FACILITATION

Facilitation of person-centered planning independent of organizations that provide services and supports is designed to ensure no conflicts of interest exist for service professionals who assist individuals in planning for their futures. Independent Facilitators thus have a vested interest in outcomes for consumers but are not employed by the service organizations that consumers access. In other works, Independent facilitators work for individuals, not service organizations. Independent facilitation services can include the provision of structure and support for the person-centered planning process, information regarding resources, assistance in the identification or development of natural supports and community relationships, as well as negotiating and contracting for services and supports.

Independent facilitators can also provide assistance to Microboards through the person-centered planning process as well as in specific areas requested by a board apart from the person-centered process (e.g., resources, bridge building within the community, or troubleshooting). The option for assistance with specific areas can be used when a consumer is satisfied with their relationship with a service professional already providing assistance with the development of a person-centered plan. An Independent facilitator can enter into the process at the point of designing services and supports in order to relieve a service professional of a conflict of interest. Microboards may hire several Independent Facilitators throughout the process to facilitate the person-centered planning based on areas of expertise. For example, one facilitator particularly skilled in person-centered planning can be hired for a few sessions and a different facilitator can

be hired to assist with resource development, and a third facilitator can be hired to assist with contract negotiations.

FISCAL INTERMEDIARIES

Fiscal intermediaries (or fiscal management agencies) hold individual budget allocations for consumers and pay bills, taxes, and benefits based on approved individual budgets. They provide regular reports to funding authorities and consumers and relieve consumers of concerns about federal, state and other tax and benefit liabilities. The functions carried out by a fiscal intermediary include, but are not limited to, check writing for all bills and personal costs, tax withholding, paying worker's compensation, health insurance, and other tax and benefits that might be appropriate depending on the individual's budget. Fiscal intermediaries work for individuals and remain accountable for ensuring compliance with all federal and state laws.

Fiscal intermediaries can function as payroll agents for direct support personnel employed by consumers, payment agents for consumer-held agreements to purchase services from providers, and provide timely periodic reports on individual budgets, accounting to the local public mental health authority for the funds transferred to it, and other supportive services that strengthen the role of the consumer as an employer. In some cases they may perform other functions including function as the employer of record.

It is recommended that fiscal intermediaries maintain individual budgets separate from other provider contracts, have no other duties that conflict with their role, and be independent of service provision. In addition, it is recommended that fiscal intermediaries be generic neighborhood community organizations so that people with disabilities are enabled to create relationships with personnel (e.g., a neighborhood bank).

CIRCLES OF SUPPORT

A circle of support, also called a circle of friends, is a group of people who meet on a regular basis to assist an individual accomplish personal life goals. A circle of support can include family members, friends, peers, teachers, other supporters and community members, and service providers central to person-centered planning. Members of circles of support are usually not paid but are involved because they care about the focus person and want to expend time and energy helping that person overcome obstacles and expand available options. Determinations regarding the composition of circles are made by the focus person (and/or their representative if needed). A relationship map that includes information regarding best friends, who the person cares about the most, people who care about them the most, and so forth, can be used to guide the selection process to determine who the person would like to include in planning and the manner in which these people will be invited to attend meetings.

The focus person determines the scope of the circle's efforts which are driven by goals set forth by that person. A facilitator can be selected from within the circle or be external to the group. Meetings are held to build relationships with the focus person and explore their strengths and interests, and develop cohesion. A comprehensive plan for the individual's future is constructed in a major planning session that can last from two to four hours. New, previously unidentified opportunities and possibilities that arise from the membership lead to regularly revisiting plans to ensure they are effective.

ONE-STOP CENTERS

One-stop centers have been developed across the country with grant funding from the U.S. Department of Health and Human Services. Twenty one Family Support 360 five-year

implementation grants (2004 through 2008) have been awarded, including one in Detroit in conjunction with the Developmental Disabilities Institute/Wayne State University to develop one-stop centers. These centers are designed to function as a centralized location where a wide range of services can be accessed by families. They are designed to improve access to comprehensive systems of family support services for families who are typically unserved and underserved. Services offered include; (1) family-centered planning, (2) information and referral, (3) education and training for parents and families, and (4) assistance with obtaining eligibility for other services. Outreach activities are also conducted to assist additional families each year of the project.

Family Support 360 implementation grantees had to be designated as the recipient by the governor in the application, have a public entity as the fiscal agent, involve a local elected official or their designee, and agree to work with other grantees in a state in the operation of the one-stop center. Other state grantees include the State Developmental Disabilities Council, the State Protection and Advocacy Agency, and the University Center(s) for Excellence in Developmental Disabilities. Families are also involved in the design, implementation and ongoing operation of a one-stop.

Families are actively engaged in the assessment and development of individual family plans. Plans include needed services and supports (e.g., health and/or mental health care, housing, counseling and/or marriage education, parenting skills development, child care, employment, transportation, respite care, personal assistance care, financial assistance and/or management) that can be provided by public and/or private human service agencies and/or faith-based groups. Services and supports are for any family member as needed, not just the member with a developmental disability. In addition, relevant human services agencies and/or private groups and organizations participate in the development of family plans. Families that encounter problems as their plans are implemented have access to assistance from a navigator employed by the one-stop who helps resolve problem. Information on this model can be obtained from http://www.addfamilysupport360.org/3_10/index.html and http://ddi.wayne.edu/detroit360.php.

TRANSITION SERVICES: PREPARING FOR ADULTHOOD

Adolescence can be particularly challenging for families who have teens with disabilities, who, like most parents, often find themselves at odds with teens who want to experience life, develop individual values, and achieve independence. Parents of teens with more significant intellectual challenges can feel the need to provide more supervision and oversight due to perceived safety risks which can result in a lack of needed maturational opportunities and mentoring and resulting in sheltered life activities. Although transition to adulthood planning during adolescence often focuses on academic and vocational development, moving into adulthood also includes psychological, social, emotional, and sexual development. Teens with disabilities want and need to experience the same things as all adolescents, no matter how significant their disability.

The post graduation period can be challenging for any young adult who is learning to live independently, manage finances, and make decisions affecting their future. Young adults are expected to live independently, continue their education, pursue careers, establish relationships, and participate in the community. Students with developmental disabilities often face unique challenges in transitioning to adulthood not encountered by their peers within the general population. Opportunities can be diminished by low expectations, discrimination in employment and housing, and lack of supports needed to function successfully in the community. The latter can lead to loss of self-help and socialization skills gained during the school years. Students with developmental disabilities often require additional services and supports to make smooth transitions to institutions of higher education and/or employment.

Changes in the labor market[31] have increased the importance of postsecondary education and training to maximize opportunities for obtaining meaningful employment for all students, particularly those with disabilities. However, students exiting special education do not enjoy the same success as their peers without disabilities. Many do not complete high school or obtain postsecondary education and are at increased risk for underemployment or unemployment. According to the National Longitudinal Transition Study of Special Education Students, eight percent drop out before entering high school and thirty percent drop out during high school. Only twenty five percent of students with disabilities graduate with a standard high school diploma and only thirty seven percent of high school graduates with disabilities attend a postsecondary school. While less than sixteen percent (15.6%) of persons with disabilities who have less than a high school diploma participate in the labor force, that participation doubles (30.2%) with completion of high school, triples (45.1%) with some postsecondary education, and increases to over fifty percent (50.3%) with at least four years of college education.

Poverty tends to exacerbate the impact of a disability and studies have found that students with disabilities are significantly more likely to be socioeconomically challenged. Students with disabilities from impoverished families are less likely than students with disabilities from families that are more economically advantaged to attend postsecondary education and training programs that could enable them to break out of poverty. Moreover, students with disabilities from more economically disadvantaged families who are employed earn significantly less per year than those

---

[31] Individuals with disabilities are negatively and disproportionately affected by changes in general employment trends and are frequently in the position of last-hired and first-fired.

from wealthier families and thus have less opportunity to overcome the pervasive effects of family poverty.

Six factors have been found to result in improved opportunities for students with disabilities:

❶ Participation via paid work experiences in the community during the last two years of high school
❷ Competence in:
   ➲ Functional academic skills (e.g., reading, math, writing, and problem-solving)
   ➲ Community living skills (e.g., money management, community access)
   ➲ Personal/social skills (e.g., getting along with others)
   ➲ Vocational skills (e.g., career awareness, job search)
   ➲ Self-determination skills (e.g., self-advocacy, goal setting)
❸ Participation in transition planning
❹ Participation in vocational education classes[32] during the last two years of high school, especially classes that offer occupationally-specific instruction
❺ Graduation from high school
❻ Absence of continuing instructional needs in functional academic, vocational, and personal-social areas after leaving school

Evidence-based research on effective transition planning is limited and there is a paucity of scientifically-based studies of programs found to be of benefit in improving the educational outcomes for students with disabilities. Several studies, meta-analysis, and an emerging consensus on the principles of effective high schools and factors that increase student achievement for secondary school students can be used to guide effective transition planning efforts.

The active involvement of the youth in transition planning has been found to be fundamental to the process to ensure that aspirations, desires, and needs reflect those of the youth and their family rather than available services and supports. In addition, research demonstrates that parental involvement increases success in transition planning. And, in many instances, family members maintain the only consistent relationships in a youth's life. Transition teams can include school personnel, service agencies for adults, current service and support providers, community members, employers, and members of the youth's informal network of support. Transition coordinators ensure that various resources are garnered and foster interagency collaboration.

Services and supports in the following areas are considered essential to effective transitions:

♦ Health (medical needs and healthful lifestyle)
♦ Post-secondary education and training
♦ Living arrangements
♦ Employment
♦ Recreation/leisure

---

[32] Employment success and increased earnings for students with disabilities have been found to be strongly associated with taking a concentration (i.e., four courses) in vocational education. The 1994 School-to-Work Transition Act (Public Law 103–239) supports students in acquiring high-end vocational skills and transitioning to the kinds of jobs needed in an increasingly information-based economy. Provisions in this legislation also explicitly require states to include students with disabilities in the plans they develop for school-to-work programs.

- ♦ Daily living (self-care, shopping, meal preparation, etc.)
- ♦ Finances and money management
- ♦ Friendships and socialization

- ♦ Community involvement (including spirituality and volunteerism)
- ♦ Legal and advocacy needs
- ♦ Transportation

It is recommended that transition planning activities include a review of accomplishments and visions for the future as well as identify opportunities and experiences that support preparation for adulthood using a person-centered planning process. The process assists students in identifying opportunities and experiences during school years that help prepare for life as an adult and should be an integral component of IEPs. Information related to the student's preferences, goals, hopes, skills, community and cultural connections, language skills, communication style, and health/medical and functional information should also be collected.

IDEA requires schools to develop an Individual Transition Plan (ITP), initiated through the student's Individualized Education Plan (IEP), beginning with the IEP at age sixteen. However, the literature recommends that transition planning begin as early as possible and it can start as early as fourteen years of age and continue past the age of nineteen.

Timeline for Transition Planning	
Age	**Activities**
11-14	• The IEP (Individualized Education Plan) should include social, communication, and self-help skills with at least functional math and functional reading in regular classroom settings (if appropriate)
By 14	• Begin Transition Planning (focusing on the student's course of study) • Ascertain exit options to ensure the student will be able to reach their goals (e.g., attending college or entering military service)
No Later than 16	• Transition planning (focusing on interagency responsibilities and needed linkages) • Identify job interests, abilities, and job training needs • Begin to identify community services that provide job training and placement • Prepare job placement file with references and skills that have been acquired • Begin application to adult service agencies • Consider summer employment or participation in volunteer experiences

16-18	• Contact adult services programs:
	   · Colleges, vocational or technical schools
	   · Social Security Administration
	   · Residential or independent living services
	   · Recreation/leisure groups
	   · Medical services

17-18*	• Begin to consider and research alternatives to guardianship • Continue to review and update the Transition Plan • If college-bound, take ACT or SAT tests, visit colleges and their disability services offices, and register with the disability service office of the preferred school by the end of senior year
18-21*	• Continue to review and update the Transition Plan • Establish needed health benefits • Develop long-term financial support plan (e.g., SSI)
21 and beyond	• Support is available to adults with dreams for the future.
* Some students may remain in school and continue working on transition goals through age 21 or as defined by state law such as Michigan which requires special education services for children ages to age 26.	

(adapted from Impact 2006)

TRANSITIONING FROM FOSTER CARE

As noted above, the transition to adult life can be challenging for youth with disabilities due to social, academic, health, and environmental issues. The additional challenges posed by transitioning out of foster can significantly reduce opportunities for achieving successful outcomes for youth with disabilities. Youth with disabilities in foster care have been found to experience significant challenges to academic success due to poor academic performance and lags in academic achievement. They are less likely to be employed, graduate from high school, have social support, or be self-sufficient. Studies have shown these youth are at risk for a number of adversities including lack of enrollment in education or training programs, underemployment (which undermines financial security), lack of adequate nutrition, homelessness, substance use disorders, chronic medical problems, unplanned pregnancies, and involvement in the justice system. Youth in foster youth experience many disruptions while growing up and often require extensive supports during the transition to adulthood. It is recommended that basic, critical needs (e.g., housing or medical care) be addressed immediately. In addition, it has been found that coordination of transition planning among key agencies and systems is critical for youth in foster care with disabilities aging out of the child welfare system. Critical elements of transition planning that have been identified include:

- ⮫ **Youth involvement** in planning and the promotion of self-determination, communication, and problem-solving skills with opportunities for practice of skills, feedback, and self-assessment
- ⮫ **Collaboration** that includes linkages between the child welfare system, educational institutions, medical and mental health services, foster care providers, and other human service and community agencies
- ⮫ **Cultural competence** that includes sensitivity to race, ethnicity, disability, sexual orientation, religion, and gender and reflects diverse backgrounds, strengths, unique cultural issues, and traditions of youth and their families
- ⮫ **Family and community connections** that are maintained and strengthened through participation in the transition planning process. Optimal independent living planning should be family-centered and include existing relationships both inside and outside the family of origin. In many cases, youth are the best resource for identifying relationships that can serve as primary, ongoing connections
- ⮫ **Concrete, integrated transition plans** that contain specific goals, action steps, and clear designation of responsibility. Services need to be integrated and be built upon available resources including education/training vouchers, independent living programs, income supports (e.g., SSI), health services (e.g., Medicaid), and other supports. Transition plans need to include information pertinent to employment, education, housing, life skills, personal and community engagement, personal and cultural identity, physical and mental health, and legal issues.
- ⮫ **Educational surrogates** (i.e., stable, committed adults) who ensure youth receive coordinated comprehensive services and prevent disruptions in the educational process engendered by disruptions in foster placements. A consistent, informed, and involved advocate can ensure smoother transitions and continuity. In addition, the consistent presence of a single caring adult has been shown to have a significant positive impact on a young person's growth and development.

THERAPY

In general, interventions for intellectual disabilities focus on normalization and community integration[33]. A number of factors are considered in the selection of treatment including cognitive and communication abilities and concurrent medical disorders. For example, a lack of communication skills indicates that verbally based interventions (e.g., psychotherapy) are unlikely to be of benefit, whereas behavior modification and educational accommodations could be effective. Treatments are adapted based on age progression.

All states are required by federal law to offer early intervention programs for children with mental retardation from the time of birth and make special education programs available by age three. Special education programs and services are driven by an Individual Family Services Plan (IFSP) that can include special education services, recreational activities, child counseling, nutrition counseling, transportation, and parent education and training, as well as assistive technology, transportation, case management, nursing intervention, and occupational, physical and language therapies. Services must be provided in the least restrictive setting feasible and typically focus on enhancing self-care skills (e.g., toilet training, feeding, and dressing), language and communication skills, and ameliorating physical difficulties. Services can be home-based or center-based (e.g., preschool program or Head Start Center), or a combination of the two. Special educations programs for older children focus on daily living and academic skill building. In addition, medical care for comorbid conditions (e.g., seizure disorders, motor skill deficits, sensory impairments) and intervention for psychosocial difficulties and co-occurring psychiatric disorders are provided.

While no single approach or specific intervention has been found to be effective for all individuals in alleviating symptoms of autistic disorders, highly structured, individually tailored, intensive programs instituted early in life, and provided in a comprehensive, coordinated, and ongoing manner using positive reinforcement, with a focus on generalization of skills to all settings, have shown to be of benefit. Studies have found that applied behavioral methods are effective in decreasing inappropriate behaviors and increasing social and communication skill, facilitating learning, and the acquisition of appropriate social behaviors as well as minimizing behaviors that impede functioning and learning. Behavioral interventions are the primary empirically validated interventions for children with autism. Research shows that when implemented early, prior to age five, and in an intensive manner, more than twenty hours per week for two years or longer, such intensive behavioral intervention (EIBI) leads to significant improvements.

APPLIED BEHAVIORAL ANALYSIS (ABA)

ABA is one of the most widely used and well established methods for treating behavioral excesses and deficits associated with autistic spectrum disorders and pervasive developmental disorders. ABA principles have been found to be applicable to a range issues including developmental delays, significant behavioral problems, and undesirable habits or behaviors. It is used to increase communication, play, social, academic, self-care, work, and community living

---

[33] The majority of individuals with intellectual disabilities reside in the community with families and in foster care, groups homes, and independent living programs; no more than ten percent have ever resided in institutions.

skills and decrease problem behaviors. The approach teaches social, motor, verbal behaviors and reasoning skills through behavioral observation and positive reinforcement or prompting for each step of a behavior. Intensive training of clinicians and extensive time (twenty to forty hours per week) are required to conduct ABA therapy effectively

ABA is applicable to individuals of all ages with autistic spectrum disorders and it can be applied in a variety of settings including home, school, and clinical office. Some ABA techniques involve highly structured instruction directed by adults, while others use the person's natural interests and follow their initiations. Some techniques entail teaching skills within the context of ongoing activities. Applied Behavior Analysis focuses on proactive, preventative approaches as well as strategies for intervention subsequent to the occurrence of a behavior.

In ABA, skills to be learned are broken down into small steps or components. Numerous repeated opportunities to learn and practice skills in a variety of settings and abundant positive reinforcement are provided. Intervention goals and specific types of instructions and reinforcers used are tailored to the strengths and needs of the individual. Performance is measured continuously by direct observation and intervention is modified if the data indicate lack of progress. ABA includes the use of direct observation, measurement, and functional analysis of the relationships between environment and behavior. The key components of ABA include:

- Observation of current behavior for topography (i.e., what the movement looks like), frequency, antecedents, and consequences. A functional analysis of behavior is used to understand how individuals who display challenging behavior function successfully in their environments. This entails a detailed analysis of antecedents and/or setting events[34] that predict the behaviors, concrete descriptions of the behaviors, and the consequences that maintain the behaviors.
- Breaking down desired skills into steps
- Teaching the steps through repeated presentation of discrete trials
- Data on performance is tracked to show changes over time

APPLIED BEHAVIOR ANALYSIS TECHNIQUES	
Chaining	The skill to be learned is broken down into the smallest units for ease of learning (e.g., a child learning to independently brush his/her teeth may start with learning to unscrew the toothpaste cap and, once this has been mastered, the next step may be squeezing the tube, and so forth).
Prompting	Assistance to encourage the desired response. Prompts are faded systematically and as quickly as possible from a more intrusive prompt to the least intrusive prompt (e.g., starting with physical guidance, then pointing, and finally, a verbal request), with completely independent responding as the goal. Prompts include: • **Physical prompts** which typically start with full physical prompting and are gradually spatially faded • **Modeling** (e.g., showing the person how a specific action is done) • **Gestural prompts** (e.g., pointing at the toothpaste) • **Verbal prompts** should be avoided when possible as these are the hardest to fade

---

[34] Ecological events or conditions (e.g. lack of sleep, change in routine, noisy environment, crowds, allergies, illness, etc.) that increase the likelihood that challenging behavior may occur.

Fading	Prompts and reinforcers are gradually faded out as new behavior is learned
Generalization	ABA is conducted in both table and natural environments depending on the person's progress and needs. Once a skill has been mastered at the table, further training is provided in a natural environment (e.g., house or school) for generalization of the skill.
Shaping	Shaping entails gradually modifying an existing behavior into a desired behavior.
Differential reinforcement	The level of reinforcement varies depending on the response (e.g., difficult tasks may receive a lot of reinforcement while easy tasks may be reinforced less heavily). Reinforcement is changed systematically to foster appropriate responses under naturally occurring (i.e., occasional) schedules of reinforcement with natural (i.e., social) types of reinforcers.
Video Modeling	Video modeling (i.e., the use of taped sequences as exemplars of behavior) is a teaching technique that has been found to be effective for some children in the acquisition of verbal and motor responses and long chains of behavior. (Modeling can also be presented in vivo or imaginally).

Applied behavior analysis interventions (e.g., Functional Communication Training, choice-making, noncontingent reinforcement, and extinction) have a robust base of evidence. However, limitations include the challenge of maintaining twenty to forty hours per week of intervention, the need for qualified supervisors, and the difficulty of replicating study findings in non-research settings. In addition ABA has been criticized by advocates when aversive techniques (to reduce potentially injurious behaviors) are used as well as efforts that focus on rendering individuals indistinguishable from their peers through the elimination of harmless behaviors.

DISCRETE TRIAL TRAINING (DTT)

The discrete trials method is a therapy for children with developmental delays and autistic spectrum disorders that is designed to assist with the acquisition of a variety of skills. Discrete trials entail breaking a behavior down into its most basic functional units and presenting these units in a series. A discrete trial typically consists of an antecedent, sometimes combined with a prompt (i.e., a non-essential element used to assist learning or correct responding), the behavior, and a consequence. If the behavior is desired, the consequence is positive (e.g., food, candy, a game, or praise, etc.). If the behavior is not correct, the correct answer is offered, the trial is repeated, and more prompting is provided if needed. An inter-trial interval of a few seconds to separate each trial is provided to allow for processing the information, teaching participants to wait, and to make the onset of the next trial more discrete. Discrete trials can be used to develop most skills including cognitive, verbal communication, play, social, and self-help skills.

Discrete Trial Instruction (DTI) is used in educational settings for students who require information to be taught in small repeated steps in order to learn new skills. It can be used during adult to student, one-to-one teaching situations. Data collection is an important part of the DTI format as it supports decision-making when planning a student's program. Data is collected on a planned schedule to gather specific information about skill acquisition, beginning skill levels, and determine progress, problems, skill acquisition, generalization, and advancement to the next skill level. The steps of discrete trial instruction include gaining the student's attention and presenting them with an instruction followed by a prompt, if needed, to elicit the correct response followed by reinforcement from the teacher.

Discrete Trial Training is a highly structured teaching format in which each learning trial has five parts:

❶ **CUE:** A discriminative stimulus, or S^D, that consists of the presentation of a brief, clear instruction or question (e.g., "Do this" or "What is it?")

❷ **PROMPT:** Assistance is provided in responding correctly to the cue at the same time as the cue is presented or immediately after (e.g., taking the student's hand and guiding them in performing the response, or modeling the response). This assistance is gradually faded out and ultimately eliminated as progress is made (e.g., guiding the student through less and less of the response) to facilitate learning to respond to the cue alone.

A number of prompts can be used in DTT programs (e.g., modeling the correct response, using positional cues, placing the correct object or picture closer to the participant than other items, and gesturing). Studies have shown that within stimulus prompts (i.e., prompts that are incorporated into the materials or S^D) are more readily faded than extra stimulus prompts (i.e., prompts that are separate from the materials or S^D). For example, when selection of a picture for a preferred item is taught, its picture can be in color while pictures for non-preferred items can be in black and white. Or, in teaching differentiation between the letters "b" and "d", the loops on each letter can be exaggerated.

PROMPTING PROCEDURES			
Type of Prompt*	Definition	Example	Advantages/ Disadvantages
Gestural	Using a visual gesture, such as a point, to indicate the correct response	In a program for identifying objects, pointing to the correct object while giving the S^D, "Give me [object]"	Easy to implement and fade out
Verbal	Providing part or all of a response audibly	Immediately after asking "What is it?" while holding up a cookie, saying the word or providing the first sound ("c")	Easy to implement but can be the most difficult to fade
Modeling	Showing the correct response, or part of a response	While giving the S^D "Clap hands", the instructor performs the action	Easy to implement and fade out but requires that student has well-developed imitation skills
Positional	Modifying the placement of materials	In a program for matching words to corresponding pictures, placing the correct picture closer than other pictures to the student	Easy to implement and fade out
Physical	Placing one's hand on the child's hand, wrist, elbow, etc., to guide the student to complete a response or perform a task	When teaching a child follow the instruction "Stand up", placing hands on the back of child's shoulders and lightly nudging the shoulders; when shadowing the child during a group activity, sitting behind the child and providing handover-hand guidance as needed to complete tasks	Often useful for motor activities and for activities in which it is advantageous for the child to complete tasks without orienting to instructor (e.g., self-help activities or group lessons). May be aversive to some children
Pictorial	Pictures used to represent objects, actions, and tasks	When teaching a long response chain such as making microwave popcorn, using a picture to represent each individual step	Helpful for children who have good visual skills. Useful for cueing child to perform activities without relying on verbal prompts from adults
Textual	A written cue such as a checklist, label, written	Placing a written instruction next to a picture depicting a	Useful for cueing child to perform activities without relying on verbal

	instruction or script	game for a child to read when asking a caregiver or peer to play the game	prompts from adults. Requires the child to have reading skills.
Time Delay	Providing a prompt after a designated period of time following the instruction (S^D); the time can be increased as child progresses	When starting to teach a new expressive label, saying the word immediately after presenting the S^D, "What is it?" As the child progresses, the time between the S^D and prompt (saying the word) is gradually increased	Beneficial in promoting initiation of communication without verbal cues from adults. However, student may simply wait for prompt unless S^D is already effective
Tactile	A devise such as a vibrating pager (a gentle reminder) that is activated remotely at designated time intervals to cue the child to engage in a specific behavior	When a classroom teacher asks a question during Circle Time, pager is activated to prompt the child to raise his/ her hand	Useful for encouraging child to respond without an adult nearby
Within Stimulus	Using the physical properties of a target response as a relevant stimulus to help increase the likelihood of a correct response	When teaching a child to identify the word blue, teaching the color "blue" having the word surrounded by a blue border, and gradually decreasing the size of the border as the child progresses	Within stimulus prompts are often the easiest of all prompts to fade out. However, it may be time-consuming to prepare materials.

* A combination of prompts may be used   (*Ferraioli, Hughes, and Smith*)

Prompt Hierarchy

● **Most-to-Least Prompting:** Entails starting with a very salient prompt and gradually using less salient prompts as progress is made and is typically used for teaching new skills. Examples include:

  ● **Graduated guidance:** Progressively reducing physical guidance (e.g., starting by placing a hand on the student's hand, then fading by placing the hand on the wrist, then on the arm, the shoulder, etc. when teaching a writing task)

  ● **Progressive Time Delay:** Systematically increasing the length of time between the S^D and prompt as the student acquires a skill (e.g., starting with a zero second delay, then increasing to two seconds, then five seconds, and so forth)

  ● **Combination procedures:** Starting with a full physical prompt (i.e., hand-over-hand guidance), then using a lesser physical prompt, then using modeling or gestures, and finally using no prompts

● **Least-to-Most Prompting:** No prompt is given at the outset, then increasingly greater levels of prompting are provided until the response is successfully completed. This is typically used for skills the student has previously mastered. Examples include:

  ● **Physical prompts:** Manual guidance is provided as needed

  ● **Time delay-verbal-modeling:** Waiting expectantly, then, giving a verbal prompt if there is no response (e.g., asking, "What do you

want?") and next demonstrating the response if a response is still not received (e.g., saying, "I want puzzle")

❸ **RESPONSE:** An intratrial response time is allotted for emitting the behavior that is cued. The duration of this interval is typically one to three seconds but may be adjusted based on the student's learning style and skill being taught. (For example, it can be extended to three to five seconds for students who tend to respond slowly or for skills that involve carrying out a sequence of actions, or it can be shortened for skills already mastered.)

❹ **CONSEQUENCE:** Correct responses are immediately reinforced (e.g., praise, small bites of food, access to toys, or other enjoyable activities). Incorrect responses are responded to with a verbal "no", looking away, removal of teaching materials, modeling or guiding the student to perform the correct response, or otherwise signaling that the response was incorrect.

❺ **INTERTRIAL INTERVAL:** Following the consequence, the instructor pauses briefly (for one to five seconds) prior to presenting the cue for the next trial.

Discrete trials are incorporated into instructional programs that focus on a specific teaching objective (e.g., identifying body parts or tying shoes). A sequence of steps or phases for meeting the objective is integrated into each trial (e.g., teaching identification of an individual body part or working on a particular component of shoe tying). Clear definitions of the target behavior(s) being taught, as well as procedures for administering cues, prompts, and consequences are included. Baseline data is collected to determine the level of mastery attained prior to instruction. A typical teaching session consists of ten trials, with one to two sessions per day for each instructional program in the student's current curriculum, but the number of trials per session and sessions per day can vary depending on the specific participant's learning and other traits (e.g., children who are just starting DTT and become frustrated quickly or are inattentive may receive fewer trials per session while those who are more advanced may receive twenty trials per session or multiple sessions per day). Data from eight to ten sessions is used to indicate whether or not progress is occurring. One month may constitute the maximum amount of time to continue an instructional program without signs of progress. In some instances data from a one week period (e.g., five sessions) or from a period of up to one month is reviewed to determine progress.

PICTURE EXCHANGE COMMUNICATION SYSTEM (PECS)

PECS is an augmentative/alternative communication (AAC) technique and modified applied behavior analysis program that teaches communication using picture cards. It is designed for individuals with limited or no verbal skills. Although PECS is primarily used with individuals who are nonverbal, it can also be used with individuals who primarily display echolalia, unintelligible speech, or have only a small set of meaningful words or signs in their repertoires. And, while it is designed to teach speech, speech is encouraged indirectly. While PECS is applicable to individuals of any age, the focus of much of the literature on PECS is on children since it was developed for young nonverbal children and those with limited functional speech who have autistic spectrum disorders or other social communication challenges.

PECS training is provided during typical activities within natural settings (e.g., home and classroom). Techniques used include strategies such as chaining, prompting/cuing, modeling, and environmental engineering. Pictures are used by the participant to vocalize a desire, observation, or feeling. Participants are taught to give a picture of a desired item to a communicative partner in exchange for the item in order to initiate a communicative behavior for an actual outcome. The program consists of six phases each of which is approached and taught sequentially, although

there may be times when a student is working on two or more phases simultaneously during transitions between phases.

Phase I: A communication trainer/teacher/family member works with a child/student and their caregivers to help decide which images would be most motivating (e.g., images of food). Cards are then created (or provided through a pre-made book) with those images. Trainers and caregivers help the child discover that, by handing over a picture, a desired object can be obtained. A reward is immediately given upon receipt of the picture along with an appropriate comment (e.g. "Oh, you want an M&M"). Physical assistance is provided in picking up the picture and handing it to the trainer if needed. This assistance faded out until the picture is exchanged for the item independently.

Phase II: The caregiver/trainer moves farther away from the child when showing the picture so the child must approach and give the card to the trainer in order to receive the reward. This phase is designed to promote the ability to seek and obtain another person's attention in order to build a full vocabulary and structure for using recently learned words.

Phase III: In this phase the student learns to select the target picture from a choice of multiple pictures that differ in various dimensions. Error correction strategies are used for incorrect responses.

Phase IV: The student combines the object picture with the phrase "I want" on a sentence strip and gives the strip to the trainer. In addition, discrimination between and making requests for a variety of items, people, and environments is focused on. The program then begins to focus on sentence structure. The child is taught to use sentence strips to make longer requests by combining a picture for "I want" with a picture of the requested item or activity. The two pictures are then attached to a sentence strip and the entire strip is exchanged with the trainer for the pictured item or activity.

Phase V: This phase focuses on requesting behavior with the student learning to respond to the question "What do you want?" by exchanging the sentence strip and extending the sentence structure work begun in Phase IV. Adjectives and other words can be added to the child's repertoire to further refine requests (e.g., moving from "I want candy" to "I want two red candies").

Phase VI: This phase focuses on commenting behavior with the student learning to respond to questions "What do you want?" versus "What do you see?" versus "What do you have?" In addition, the child is taught to comment on elements of his/her environment through the use of pictures for "I see", "I hear", "I feel", "I smell", etc.

PECS has been found to lead to improvements in independent communication skills and spoken language for children, adolescents, and adults who display a variety of communicative, cognitive, and physical difficulties. In addition, it has been found to effective for people with autism who learn visually. Some children begin to spontaneously use speech while participating in the program. PECS is especially successful when integrated into behavior programs that offer opportunities for structured and naturalistic language learning. The program may take several months or several years to complete.

Professional training is required to implement PECS with fidelity. Training is typically provided during a two-day workshop. While speech pathologists can function as the primary PECS program coordinators, it is helpful to have others (e.g., parents, teachers, and classroom assistants) also attend the two-day trainings since they play important roles in identifying new

vocabulary, can help construct some of the picture display symbols, and provide opportunities to learn and use the new vocabulary. A manualized training program that takes caregivers and children through the various phases of the program is available from Pyramid Products at www.pyramidproducts.com. (Other manuals, sources of training, and resources are also available and images can be obtained from magazines, photos, or other media.)

FUNCTIONAL COMMUNICATION TRAINING (FCT)

Functional Communication Training is a reinforcement-based behavioral strategy that is designed to teach individuals with autistic spectrum disorders to use signs or other AAC techniques as substitutes for messages underlying their challenging behaviors (e.g., self-injury and aggression). It is predicated on research suggesting that one of the most common functions of such behaviors is escape from undesired demands, tasks, and social situations. Interventions focus on teaching the communication of one or more functional messages and a positive alternative to challenging behavior.

FCT teaches individuals appropriate alternative responses (or mands, or manding behaviors, such as signing, verbalizations, and pointing to word cards) to obtain reinforcement and which replace challenging behaviors. A number of types of mands have been shown to be effective including verbalizations, manual signs, word or picture cards, and micro switches. It is recommended that trained mands be functionally relevant to the situations that occasion challenging behavior and reinforcers be relevant to the contexts in which behaviors occur (i.e., matched to the correct establishing operations and to the function of challenging behavior).

Numerous studies have demonstrated that individuals with autistic spectrum disorders display immediate and substantial reductions in challenging behaviors subsequent to the initiation of FCT, and gains are maintained for as long as twelve months subsequent to the termination of the interventions. FCT is currently considered to be a treatment of choice in the management of challenging behaviors in children and is one of the most frequently recommended ABA interventions for challenging behavior. Studies show it is most effective and efficient when the treatment is matched to the results of a functional analysis and is more effective when combined with extinction procedures.

PIVOTAL RESPONSE TRAINING (PRT)

Pivotal Response Training, formerly known as Natural Language Paradigm (NLP) is a manualized intervention for children with autistic spectrum disorders that focuses on motivation[35] and self-initiated social interactions. It targets behaviors that are taught in natural environments using items that are age appropriate and reinforcing to the child[36]. PRT is designed to enhance the relationship between social communication responses and consequent reinforcers to increase the rate of responding, correct responses, response attempts, and positive affect to promote cognitive, language, and social development. Examples include beginning a new verbal or

---

[35] Studies show that learning is accelerated, disruptive behaviors are reduced or eliminated, and general family affect is improved when motivational procedures are incorporated into intervention plans via parent training.

[36] Child choice, task variation, interspersing maintenance tasks, reinforcement of response attempts, and using natural and direct reinforcers have been found to increase motivation of children with autism and produce significant improvements in core symptoms of the disorder.

nonverbal social interaction (e.g., taking a toy to a parent or pointing to a toy), self-initiating a task that results in social interactions (e.g., verbalizing the word "play"), or altering the direction of an interaction (e.g., bringing a new toy to a parent during play).

PRT uses the discrete trial format along with the provision of antecedent stimuli and consequences contingent upon response. A key area of intervention is communication. Children are taught to respond to multiple cues and stimuli, increase self-management capacity, and increase self-initiations[37]. Teaching self-initiation targets language skills and social interactional behavior. Sessions are comprised of the following elements:

- The child selects the object used for instruction to increase motivation
- Clear and uninterrupted instructions or opportunities are provided to ensure the child is attending
- Reinforcement is delivered for all approximations/attempts
- Reinforcers have a specific relationship to the desired behavior (e.g., "ball" results the ball rather than praise or another reinforcer)
- Multiple examples or multiple components are presented to increase responsiveness to multiple cues. (e.g., using two different objects but the same verb such as "roll car", then "roll ball", then "throw ball")

Parents function as interventionists[38] and are taught how to present clear instructions and questions, employ child-selected stimulus materials, natural reinforcers, and intersperse previously learned tasks with new acquisition tasks. They are provided with feedback on their performance. PRT has been used to improve manipulative and symbolic play skills (e.g., teaching appropriate use of a train on a train track) as well as language (e.g., making the train noise prior to intersections, identifying train colors, and familiar verbalizations such as "all aboard", and "choo- choo" sounds).

Outcomes studies indicate PRT is effective in helping some children with autistic spectrum disorders learn to use verbal communication as their primary mode of communication. It has been shown to reduce social avoidance and other disruptive behaviors, and increase verbal accuracy. When PRT is embedded within teaching activities it has been shown to increase the rate of target behavior acquisition and positive child affect. However, although each of the components of PRT (e.g., task interspersal, direct reinforcement, and choice) has been tested extensively, randomized trials comparing PRT to another intervention model are lacking. A PRT manual can be downloaded from http://www.users.qwest.net/~tbharris/prt.htm.

VIDEO MODELING

Video modeling generally involves a person observing a video of a model engaging in a behavior that is subsequently imitated and practiced. Another technique is self-modeling in which the person is initially prompted on video to demonstrate a target behavior with instruction or prompts.

---

[37] Research indicates that improvements in self-initiated social interactions lead to concomitant improvements in academic, social and communication behaviors as well as decreases in aggressive and self-injurious behaviors as well as tantrums.

[38] Such parent education programs have been demonstrated to increase communication skills, reduce disruptive behaviors, increase generalization of gains, and decrease family stress. In addition, they offer natural teaching opportunities throughout the day thereby expanding the quantity of intervention.

The sequences are edited together to display only the target behavior and then shown to the person. Target behavior that involves interactions with others, (e.g., social and play skills for children) can also include the use of peer models or siblings.

Numerous studies using standardized intelligence tests show that individuals with autistic spectrum disorders often benefit from visually cued instruction and display ability in processing visual rather than verbal information. Features of autism (e.g., over-selective attention, a restricted field of focus, preference for visual stimuli, and avoidance of face-to-face attention) can be used to advantage in video modeling. Further, children with autism exhibit atypical responses to the social environment and may selectively avoid attending to socially relevant stimuli. Using visually cued instruction such as that found in video modeling restricts the field of focus while not imposing too much demand on social attention or interaction.

Video modeling offers a way to learn through social models without initial face-to face interactions. In addition, a television or video monitor provides a restricted field of focus thereby improving the attention of individuals with autism through selective focus of attention on relevant stimuli and removal of extraneous visual and auditory stimuli. Retention is facilitated through repetition of the target behavior since all video modeling interventions include presenting repeated exposures of the event that help to establish and maintain the behavior in memory; video allows for the repetition of the same model and precise procedures leading to the production of the behavior (the next essential component of observational learning). Additional components of video modeling interventions include rewards for repeating scripted and unscripted play comments from videos. Behavioral practice is also a key element of many video modeling procedures.

Video modeling has been found to be effective in teaching a variety of skills including vocalization and pronunciation, social and play skills, emotion process, use of schedules to guide activities, activities of daily living such as bathing, and community skills such as making purchases. Research shows that video modeling leads to more rapid acquisition of skills, greater generalization and maintenance of skills across settings and stimuli, generative skill acquisition, as well as spontaneous, unscripted verbal behavior in children with autism. Video procedures also offer significant time and cost saving benefits since they take approximately one third of the time at half the cost of in vivo procedures. Moreover, because video watching is typically associated with recreation, it is inherently motivating and thus may be engaged in with greater receptivity and enthusiasm.

INTENSIVE BEHAVIORAL INTERVENTION (IBI)

Intensive Behavioral Intervention is an evidence-based teaching method for children with autistic spectrum disorders. It employs methods based on applied behavior analysis (ABA) to develop effective behavioral repertoires and decrease problematic ones. Small, measurable units of behavior are taught systematically; each skill is broken down into small steps. Each step is taught by presenting an instruction (Sd) and a prompt (P) if needed. Appropriate responses (R) are followed by consequences (Sr) that have been found to function effectively as reinforcers. Prompts and reinforcers are faded as learning occurs during repeated trials. The principles of IBI include:

- ➲ Making learning reinforcing so that it is enjoyable.
- ➲ Teaching how to discriminate among many different stimuli (e.g., distinguishing one's name from other spoken words, differentiating colors, shapes, letters, numbers, and the like from one another, and discerning appropriate from inappropriate behavior).
- ➲ Problematic responses (e.g., tantrums, stereotypies, self-injury, or withdrawal) are explicitly not reinforced (i.e., put on extinction). This requires systematic analyses to determine events that function as reinforcers for problematic responses.

➲ Guiding engagement in appropriate responses that are incompatible with problematic responses (i.e., redirection).

➲ Strongly reinforcing spontaneous positive behaviors and differential reinforcement of other desired behaviors (DRO).

Emerging skills are practiced and reinforced in numerous and less structured situations to facilitate generalization. In addition, instruction gradually progresses from one-to-one to small group and then to large groups so that learning takes place in natural environments and from typically developing peers.

EARLY AND INTENSIVE BEHAVIORAL INTERVENTION (EIBI)

Early and Intensive Behavioral Intervention has been demonstrated to be one of the most effective interventions for autistic spectrum disorders during early childhood. The EIBI model (also known as the Lovaas approach), includes discrete-trial instruction, intensive treatment delivery, and a curriculum that is developmentally sequenced. Each instructional program is implemented with a child at least three to four times per week.

An alternative EIBI manualized model, Applied Verbal Behavior (i.e., the VB approach), has been developed. It also includes treatment intensity, hierarchically organized curricula, operant training techniques, teaching expressive/speaker and receptive/listener behaviors, facilitation of specific and frequent daily training opportunities, and use of a discrete-trial training format for the presentation of instructions and consequences. In the Lovaas approach, discrete-trial instruction is the modal format in which training is conducted. In the VB approach, on the other hand, discrete-trial instruction is used in conjunction with Natural Environment Training (NET[39]). The VB approach employs a functional account of language to teach children multiple functions of language (e.g., mand, tact, and intraverbal) and each function using the ultimate controlling variables specific to that function. However, although VB has been widely disseminated, it has only a modest base of research support for outcomes related to the acquisition of verbal operants.

SOCIAL STORIES

Social stories, a promising practice, can be used to teach social skills (e.g., sharing and asking a friend to play, etc.) including understanding, interpreting, and responding appropriately in social situations (e.g., predicting outcomes, preparing for change, coping, and problem-solving) to children with autistic spectrum disorders. A social story consists of a simple description of an everyday social situation, written in first person and present tense by a parent, teacher, therapist, or counselor, from the child's perspective, matched to the child's vocabulary and comprehension level, and put into a booklet format. The story is rehearsed by the child with an adult so that when the situation that is depicted transpires, the child can use the story to help guide their behavior.

Social stories are used to help children prepare for upcoming changes in routine, illuminate social interactions, and relate academic skills to real-life experiences. Accurate information regarding situations that may be difficult or confusing is provided. A situation is described in detail with a focus on a few significant points including important social cues, events and reactions that might

---

[39] NET is designed to continue language training in the presence of stimuli and motivative variables that eventually control and maintain the person's verbal behavior. It targets generalization of acquired responses and variations of those responses across a variety of appropriate captured and contrived stimulus conditions.

be expected to occur in the situation, actions as well as reactions that might be expected of the child and why. The story is designed to increase understanding and comfort, as well as suggest some appropriate responses to the situation.

Social Stories attempt to address the theory of mind impairment[40] by providing perspectives on the thoughts, emotions, and behaviors of others. They are designed to help an individual better predict the actions and assumptions of others. They also present information regarding social situations in a structured and consistent manner providing social information through pictures and text rather than speech or observation. Social Stories provide distance between teaching and potential stresses of a social situation itself and offer the opportunity to practice skills often.

Six types of sentences used to present the information in a social story:

1. Descriptive sentences (De) objectively address where the situation takes place, who is involved, what they are doing, and why they may be doing it so the child can recognize the situation when it transpires.
2. Perspective sentences (P) describe one of the child's possible feelings or responses.
3. Affirmative sentences (A) provide details about emotions and thoughts of other people.
4. Directive sentences (Di) suggest appropriate desired responses to the situation that are tailored to the individual.
5. Control sentences (Cn) are created by the child to aid in remembering effective strategies. These are not used in every story and are typically used only with children who have sufficient cognitive capability.
6. Cooperative sentences (Co) describe how other people will help out in a given situation.

An example of social story using all six sentence types is as follows:

(De): When we go to the toy store, there will be many toys to choose from.
(P):   I might not know which toy I like.
(A):   That is okay with everyone.
(Cn): I can hold onto my string while I decide.
(Di): When I decide about the toys, I will tell the grown-up.
(Co): The grown-up will go get the toy for me.

The story is read with the child at least twice even if the child is capable of reading it. The adult then verifies that the child understands the important elements using a checklist or role play. The child then reviews the story each day on a consistent basis. Audio and/or video recordings of the story can be made for children who have difficulties with reading. In addition, stories can be presented through illustrations or photographs, or augmented with picture symbols (e.g., PECS), or with story boxes in which a child and an adult act out scenes from stories. The effectiveness of each story is monitored and the story is gradually faded out (or changed to meet emerging needs) when the behavior has been learned. The story is rewritten and motivation is reassessed if there

---

[40] The theory of mind impairment is a lack of understanding that other people have their own thoughts, feelings, plans, and points of view which results in difficulties understanding other individuals' expectations and an inability to predict what others will say or do in social situations.

is minimal progress. As each story is mastered it is kept visible (e.g., in a notebook) in the child's environment for review when needed.

JARS (JOINT ACTION ROUTINES)

JARs is a promising practice that is designed to encourage communication skills in children that is primarily used to develop spontaneous conversation and increase social understanding. In JARs, teachers or parents encourage communication by providing frequent repetition and rehearsal of target language within a functional or motivating activity through a familiar and predictable routine, Three types of joint action routines[41] are used In JARS: routines that include an outcome or end product (e.g., setting the table), routines that are developed around a story line (e.g., shopping at a supermarket), and routines that involve turn-taking (e.g., playing a board game). The principal elements of JARs are:

➤ **A unifying theme or purpose:** The themes of effective routines are motivating and meaningful and understood by the participants. The purpose or theme of routines can vary and be simple or elaborate (e.g., stacking blocks or role playing a phone call to a friend). Themes are often set around normally occurring events. The activity needs to be meaningful and motivating. There are generally three types of routines:

    1. Preparation or assembly of a project or product (e.g., cooking applesauce, building a block tower)
    2. Cooperative turn-taking games or routines (e.g., playing tickle, blowing bubbles, water play, cooperative team games)
    3. Routines organized around a story or plot (e.g., role playing *The Three Bears* or pretending to be firefighters)

➤ **Joint focus and interaction:** A joint focus (i.e., participants attending to the same event and responding accordingly) and opportunity for turn taking are necessary. Interaction is required so that increased opportunities for practice of language and social responses are available. Participants' parts need to relate to one another to make interactional sense. Examples of activities that increase the likelihood of shared attention and turn taking include using a puppet, building a tower, or blowing up a balloon. Such activities allow partners to attend to and comment on a common scene or activity and share vocabulary and concepts. Puzzle play is frequently a parallel/solitary activity with few opportunities for interaction, but is motivating for children with autism and can be modified to create an effective JAR by (a) using a common floor puzzle rather than individual puzzles; (b) creating a common pile of pieces controlled by the adult to require repeated opportunities for requesting and negotiation; or (c) selecting a puzzle that is slightly too difficult for the child so that teamwork and joint interaction are encouraged.

➤ **Logical sequence of events and structure for turn taking:** A logical sequence to an activity is needed to make a routine as predictable and repeatable as possible, Activities that entail steps that follow a specific sequence (e.g., preparing a peanut butter sandwich, setting the table, or making a bed) and that can easily be repeated in the exact sequence each time the activity occurs are most effective. These result in the child being able to

---

[41] A joint action routine is a routine interaction between two or more people that follows a predictable and logical sequence of events wherein the activity relies on routine verbal exchanges by those involved.

predict what to do during each step rather than open-ended activities (e.g., block or water play, or play at the sand table) which are far less predictable as materials and props can be used in different ways and in varied order resulting in more difficulty creating repeated opportunities to model target language or concepts.

➤ **Clearly defined roles:** In simple routines one partner may act as the requester and the adult functions as the keeper of the items (e.g., snack time or playing wind-up toys where the adult repeatedly winds up the toy while the child always gets to let it go). Clearly defined routine roles enable children to learn how to speak or act differently based on the role they are given. In more complex routines children can learn to play different roles within the same activity thus learning the give-and-take nature of interaction (e.g., a child may play a customer at a candy store one time and next take the role of the clerk). During an opening group time a child may take on several roles (e.g., only taking the role of a responder to predictable teacher questions, and later taking the role of asking the same questions to peers and adults in the group.)

➤ **Planned repetition and variation:** Repetition of words or actions is planned into routines to help children anticipate what to say or do. The degree of repetition may vary; some children need the exact script of specific words/phrases to use until they are able to use those words or actions independently.

➤ **Controlled variation:** While a JAR is predictable by design, variation and expansion are required because children with ASD can easily become locked into what they say or do and have difficulty expanding their responses. Controlled variation of a routine is critical as it gives children the opportunity to change what they say or do within the structure of a comfortable routine. Routines can be varied by introducing new materials and new vocabulary, omitting necessary materials (e.g., :losing" one or two pieces of a puzzle being completed or "forgetting" the cups while setting a table), offering an unexpected response (e.g., offering a less preferred food in response to a sign for more of a preferred one thereby allowing for "no" response from the child), making objects inaccessible, using objects that do not work or are not appropriate for a given activity, or interrupting/violating a routine. Variation is individualized for each child. Routines may need to be varied numerous times for children who do not offer different responses more immediately. Very small changes may be needed for children who respond very negatively to even the smallest change in a routine.

Sample JAR Plan format:

Date of Plan

Routine Name (theme): _____

Props Needed: _____

Roles:

Receptive/Expressive Vocabulary:

Basic Sequence:	Planned Variation:

Language Target/s of Opportunities

Completed JAR plan:

Date of Plan: 9-22-01

Routine Name (theme): Fast food restaruant

Props Needed: Menus, money, pictures of food, pretended food, tray, utensils

Roles: Customer

Receptive/Expressive Vocabulary:

- Names of food or items
- Employee/waitress
- Concepts
- Understanding of simple questio forms
- General money concepts

Basic Sequence:	Planned Variation:
• Customer walks to the counter • Employe greets customer • Customer responds • Employee asks for order • Customer makes order • Employee restate order • If correct, customer pays • Employee gives food and thanks customer	• Vary food available • Change the restaurant • Vary the prices • Customer gets different • Amount of money to spend • Particular items may not be available • Wrong order is given • Food is spilled • Transfer to real restaurant

Language Target/# of Opportunities

- Greeting
- Placing order, taking order
- Requesting with complete sentences minimally 10 opportunities
- Response to simple questions to make requests and respond
- Routine can be repeated

Once the JAR is trained, data must be collected on target language skills. Data may include the accuracy of language responses compared to the target model, and frequency of spontaneous target language behaviors per opportunity. When other skills (cognitive, motor, etc.) are targeted, data must also be collected on accuracy of responses.

DIR (DEVELOPMENTAL, INDIVIDUAL-DIFFERENCE, RELATIONSHIP-BASED) MODEL

The DIR model focuses on helping children with communication disorders improve social reciprocity and functional/pragmatic communication. It is one of a number of social-pragmatic programs (e.g., Floortime and PLAY Project) designed to help children with autism spectrum and related disorders master developmental milestones to achieve emotional and intellectual growth. The DIR model provides supports to parents as their children's primary play partners and offers naturalistic play-based interactions that engage the child's affect. It also provides a comprehensive framework for understanding and treating children challenged by autism spectrum and related disorders:

D: Developmental: Understanding where the child is developmentally in order to plan a treatment program. The six developmental milestones children master for healthy emotional and intellectual growth are:

1. Self regulation and interest in the world
2. Intimacy
3. Two-way communication
4. Complex communication
5. Emotional ideas
6. Emotional thinking

I: Individual-Difference: Each child's unique way of understanding the world (e.g., sights, sounds, touch, etc) and responding to it. Biological challenges include

various processing issues that make up a child's individual differences and may be interfering with the ability to grow and learn.

R: Relationship-Based: Building relationships with primary caregivers is a critical element in helping a child return to a healthy developmental path. Floortime, a centerpiece of the DIR approach, encourages parents and others important in children's lives to interact with them in a manner that promotes developmental progress.

Comprehensive DIR programs can also include the incorporation of speech therapy for receptive and expressive language, occupational therapy for sensory modulation and processing, and motor planning, as well as physical therapy for significant motor problems. Many children have been found to benefit from educational programs that provide services for children with special needs and access to other children who do not have disabilities which provide opportunities for spontaneous communicative skills and interactions. Many children can also benefit from devices that enhance communication (e.g., learning signs, pictures or picture-exchange systems, and various types of talkers) used as part of spontaneous communication and Floortime activities (e.g., to help a child create a make-believe story or negotiate their needs). It is recommended that approaches be individualized in accordance with age, cognitive and language levels, behavioral needs, and family priorities.

Social-pragmatic program approaches are widely used but have a limited base of scientific evidence of effectiveness; they are more difficult to operationalize and quantify than behavioral approaches. While there is evidence that DIR interventions lead to improvements, a clear, direct relationship between any specific component and progress has yet to be established. Although most children in comprehensive programs make significant progress in at least some developmental domains, methodological limitations preclude definitive attribution of progress to specific procedures. Furthermore, there is a lack of adequate comparisons of different comprehensive programs and data on the relative merit of one model over another.

FLOORTIME

The Floortime program is a social approach to the treatment of autistic spectrum disorders. It is a form of therapeutic play that entails working directly children's interests (rather than considering those interests as a means for rewarding desired behaviors). Floortime is designed to address speech, motor, and cognitive skills by integrating a focus on emotional development rather than addressing it in a separate manner. The intervention is called Floortime because parents get down on the floor with their children to engage them at their level.

Floortime consists of therapists/parents entering and joining into children's preferred play activities without making any demands (i.e., requiring the child to engage in a structured activity) in order to develop an activity into an affective interaction, build awareness of self and other, and enhance emotional self-understanding (rather than the ability to communicate per se). The therapist/parent follows the child's cues and works within their interests, gradually introducing observation, parallel play and, ultimately, turn taking and interaction. Parents are taught how to help their children progress toward increasingly complex interactions in a process of opening and closing circles of communication through a mutually shared engagement. For example, a parent may begin to take turns with their child who is lining up cars until the child begins to expect and wait for the parent's turn. Then the parent may place a car in the wrong spot, tempting the child to open and close a circle of communication while correcting this "error". There are five steps in the process:

1. Observation of the child at play and noting their interests and mood.

2. Building on the child's interest in their chosen activities through words and gestures without disturbing the flow of their play.
3. Following the child's lead.
4. Praising the child's play, unobtrusively joining the activity, and helping the child navigate through everyday activities by explaining the activities so the child knows what to expect and what is expected of them (e.g., using verbal cues such as "my turn" to help a child wait in line). This is designed to help the child reference other people, initiate interactions, and use language to indicate wants and needs through this process of joining and subtle reinforcement.
5. The child starts to reference the therapist/parent and use words and gestures to reciprocate and initiate interactions over time.

As a child becomes more verbal and capable of linking ideas, reality-based problem-solving discussions, including anticipating future challenges, are added to the daily routine (e.g., dialogue about school, friends, favorite foods, toys). Problem-solving time, empathy for the child's perspective, breaking challenges into small component parts, setting limits, and extra Floortime are incorporated as a part of the daily routine. Extra practice with adults and peers through scheduled play dates is provided. As progress is made more subtle problems (e.g., controlling aggression, competitiveness, jealousy, and learning to respect others) are addressed. Problems can be addressed through the provision of extra practice in the situations that evoke the problematic behaviors (e.g., (e.g., pulling toys away from friends, wanting one's own way all the time, or excessively demanding attention). Problem-solving strategies (e.g., talking it through, rehearsing, and practice) as well as the provision of structure, limits, and encouragement can be provided by parents at the home and used by the child in school and other settings.

Many children with autism spectrum disorders, particularly those who have severe challenges in communicating and relating, often require six to ten, twenty to thirty-minute, Floor-time sessions per day. Floortime can be implemented by parents with minimal training. Siblings, as well as friends, other caregivers or students can be a part of a Floortime team. The home-based Floortime component is time intensive and requires effort but can be implemented with a relatively small financial expenditure through the help of students, volunteers, relatives, or extended-family members work. More information on Floortime is available from http://www.floortime.org/ and http://www.polyxo.com/floortime/.

PLAY (PLAY AND LANGUAGE FOR AUTISTIC YOUNGSTERS)

The PLAY Project, based on the DIR Model, is an eight to twelve month comprehensive, intensive, and multidisciplinary program that includes early referrals for speech and language, occupational therapy, and other services. The PLAY Project is comprised of four clinical components:

1. Medical consultation (at the Ann Arbor Center for Developmental and Behavioral Pediatrics clinic and referrals to community resources)
2. Training that includes community-based workshops for parents, pediatricians and other professionals, and agency trainings in The PLAY Project Home Consultation model
3. Parent support and advocacy services called the Michigan Autism Partnership (MAP)
4. The PLAY Project Home Consultation (PPHC) program

PLAY Project Home Consultation (PPHC) program

The PLAY Project Home Consultation (PPHC) program trains parents of children with autistic spectrum disorders using the DIR/Floortime model. Families with young children aged one and a half to six years who reside in southeast Michigan are eligible to receive services from the project's three child development home-based consultants (consisting of one MSW and two recreational therapists). The home consultants make monthly, half-day (three to four-hour) visits to families' homes to teach parents how to provide intensive, one-on-one, play-based (i.e., social-pragmatic) interventions for their children. Contingent and reciprocal engagement of children by their parents occurs for a minimum of fifteen hours per week in structured sessions (e.g. twenty-minute play periods) or during incidental daily activities (e.g., mealtimes, bath times, and bedtimes). The home consultants use a seven-step skill sequence to train parents in a supportive, non-critical, and outcome focused manner:

Step 1: Parents are taught the principles of play-based intervention and how to apply them strategically to their child's preferred way of relating, sensory motor preferences and deficits, and current level of functional development.

Step 2: Parent learn to assess their child's unique profile using the play-based intervention principles and strategies.

Step 3: A list of activities that are likely to be engaging is generated.

Step 4: Parents are taught methods for observing their child's cues, following their lead, and understanding their child's intentions in order to increase reciprocal interaction.

Step 5: Parents observe the consultants modeling the skill sequence and are taught specific techniques that enhance the basic methods of following the child's lead.

Step 6: Video assessment is provided to give immediate feedback to parents who can review how they are relating with their child.

Step 7: Parents are helped to refine the curriculum, methods, and techniques used as their child progresses up the functional developmental hierarchy. The skill sequence is repeated continuously so that methods are synchronized with the child's progress.

Monthly home visits incorporate modeling, coaching, video assessment, and written objectives to help implement and then refine the skill sequence. Modeling entails demonstrations of the use of the strategies, methods, and techniques of the play-based approach by the home consultants. Coaching entails consultant observation of the parents as they play with their child and providing positive feedback regarding their performance. Video assessments of parents' interactions occur at the end of the sessions. Written objectives are derived from the Pre-School Autism Rating Scale (PARS) which profiles the child's functioning in key areas that are synchronized with the DIR model (i.e., communication, reciprocal interaction, social skills, and repetitive behaviors). The home consultants review selected cases and video segments with the project's medical director on a weekly basis. Observations and suggestions are recorded on a feedback form and shared with parents during subsequent visits (and serve as further training for the PLAY home consultants).

Fifteen agencies in Michigan and fifty agencies in seventeen states currently use the model. The average cost per family per year for this manualized program is between $2500.00 and $3000.00 depending on the number of annual visits (e.g. ten visits per year = $2500.00). Information can be obtained from http://www.playproject.org/.

POSITIVE BEHAVIOR SUPPORT (PBS)

Positive Behavior Support is a promising multi-component practice designed to ameliorate difficult behaviors. PBS arose from applied behavior analysis, normalization, the inclusion movement, and person-centered values. It is predicated on the belief that most difficult behaviors are purposeful and that people who display difficult behaviors should be treated with compassion and respect, and are entitled to lives of quality. PBS is designed to gain an understanding of the purpose of challenging behavior and construct a plan to promote the development of new skills and decrease the need to engage in adverse behavior. It focuses on assisting individuals to accomplish comprehensive lifestyle changes to improve their own quality of life and that of people who provide support to them. PBS is the antithesis of coercion (i.e., control through the use of threats or escape from unpleasant events to manage behavior) which reduces dignity, self-control, and autonomy, can provoke retaliation, requires increasing intensity due to habituation, and can cause physical or psychological harm

PBS entails rearranging the environment and building skills (e.g., communicative competence) to increase opportunities for choice, improve quality of life, and modify the setting events to alter the valence of reinforcers for significant behaviors, rather than directly reducing problem behavior per se. In other words, the focus is on fixing problem contexts rather than problem behaviors. PBS takes a lifespan perspective because efforts to achieve meaningful change can often take years. Thus, intervention is an ongoing process that evolves as different challenges arise during different stages of life; new PBS strategies may have to be added and previously used ones modified.

Effective behavior intervention plans entail teaching or reinforcing positive behaviors. Consumers and their supporters (e.g., parents, siblings, neighbors, teachers, job coaches, friends, and roommates) function as active participants and collaborators with professionals in a process of reciprocal information exchange. Thus, typical intervention agents (e.g., parents, teachers, and job coaches) who support individuals in typical settings (e.g., home, neighborhood, school, and workplace) for protracted periods of time in all relevant venues are involved. Intervention is provided in the absence of problem behaviors in order to prevent recurrence. The components of Positive Behavior Support are as follows:

❶ **Functional Behavioral Analysis (FBA)** to understand behavior. FBA is a systematic process for describing challenging behavior, identifying environmental factors and setting events that predict the behavior, and developing behavior support plans. A comprehensive FBA includes:

- **Clear description of the Behavior** to detail aspects of the target behavior (e.g., what the challenging behavior appears and sounds like, whether it occurs in conjunction with other behaviors or in isolation, any prior warning, duration of occurrence, and length of time it has been a problem). An alternative desirable behavior is described in terms of what it would look and sound like.

- **Typical Routines** to provide information regarding circumstances in which the target behavior occurs including when it is more likely to occur, less likely to occur, activities or expectations, and with whom it occurs. The "who, what, when and where" of the alternative desirable behavior is also determined.

- **Rationale** to provide information regarding why the target behavior is deemed difficult and requires change. Minor problems may be viewed as significant by one person but as insignificant by others. Thus, it should be determined whether the behavior is harmful to self or others or is merely distracting (i.e., who the problem belongs to).

- **Strengths/Needs** to ascertain skills the person has that could become a source of success and esteem. These are often the specific behaviors viewed as difficult (e.g., a student with a high level of energy who may be unable to sit still in class but can effectively help clean the cafeteria). Limitations that prevent the accomplishment of simple tasks and getting recognition that others take for granted are also reviewed.

- **Likes/Dislikes** to determine preferences (e.g., events, books, movies, foods, or music) the person enjoys and aversions (i.e., things the person detests). Some behavior challenges function as statements of preference or refusal for individuals who do not communicate verbally. Enjoyable activities can help to break up the day and serve as a means to connect with others.

- **Values/Culture** to depict role models' values/behaviors, family rituals/routines, loyalties, and cultural beliefs.

- **Biomedical/Physical Factors** can contribute to many behaviors (e.g., head banging, chronic whining, striking out at others, or running out of a room). Responses to ear infections, stomach aches and headaches, over-sensitivity to certain sounds, hunger, fatigue, over-stimulation, boredom, or the way things feel to the touch can vary among individuals. Diet, medications, depression, attention deficits, seizure disorders, and others are also important considerations. Understanding specific disabilities and their impact on behavior is an essential component of FBA.

- **Environmental Factors** to ascertain whether the challenging behavior occurs more or less frequently in some settings than in others, taking into account physical and social environments.

- **Motivation** to determine what is gained from the challenging behavior (e.g., attention, assistance, and desired food or objects) and what is escaped or avoided (e.g., avoidance of chores), as well as gains from engaging in appropriate behavior (e.g., evoking an immediate reaction to inappropriate behavior while appropriate behavior goes unnoticed). A description of the setting events, antecedents, and consequences of the behavior is documented.

- **Intervention History** to provide information to ascertain what has been effective and what has not, as well as persons who have been helpful and those have not. Issues related to the experience of trauma are also noted.

- **Learning History** to ascertain what the person has been learning through displays of difficult behavior (e.g., learning that desired behavior goes unnoticed while inappropriate behavior receives an immediate response, or that the longer the person persists at complaining, fighting, or tantruming, the more likely they are to obtain what they want).

- **Learning Style** to ascertain how the person learns best (e.g., visually, tactilely, through practice, or teaching others), whether they are able to follow simple or complex instructions, and translate what is heard into action (or ignore verbal instructions).

- **Relationships** to determine what types of people the person is attracted to and avoided. Many people with developmental disabilities who display difficult behaviors have few meaningful peer relationships. Most relationships tend to be hierarchical, inequitable rather than equitable, and involve people in their lives who

❷ **Preventing Challenging Behavior by Enhancing Quality of Life:** PBS views challenging behaviors as logical reactions to lack of choice and/or control over one's environment (e.g., where and with whom one lives, daily activities, and food). Thus, the provision of assistance in attaining life goals that most people take for granted can significantly reduce challenging behavior. The preventive approaches listed below are used within the context of natural settings (e.g., classroom, home, automobile, park, and supermarket). If skills are taught in clinical settings, specific strategies are needed to ensure generalization to natural settings.

- **Person-Centered or Family-Centered Planning** that focuses on the strengths of individuals, their families, and other supporters.

- **Exposure to Options** so that informed choice is based on experience rather than mere communication of information regarding various living arrangements, jobs, entertainment options, and other available life choices.

- **Exposure to Appropriate Role Models** using peers and caregivers as examples in school, work, and community settings.

- **Exercising Choice** regarding daily activities and life goals. Such choices are respected and opportunities for repeated practice are provided to build a sense of competence.

- **Assistive Technology and Supports** to reduce dependence on others for reminders, personal hygiene, transportation, information, communication, and entertainment.

- **A Sense of Belonging** or feeling accepted by others in all venues (e.g., school and neighborhood).

- **Altering the Environment** to avoid antecedent events that provoke challenging behavior and consequences that reinforce the target behavior (e.g., minimizing distractions, using space to denote various activities such as designated eating space, leisure activities, and private space).

- **Addressing Biomedical or Physical Factors** including medications to control seizures, impulsiveness, infections, depression or hyperactivity; adequate sleep, proper nutrition, physical exercise, and pain management. Sensory integration techniques (e.g., deep pressure, joint compression, brushing or swinging) may also be included.

❸ **Teaching/Encouraging Desirable Behavior** entails:

- **Establishing Helpful Routines** which entails assistance with establishing predictable routines around personal care, eating, dressing, working, and transitions. Printed or picture schedules can be used to communicate scheduled activities.

- **Building a New History of Success** by helping individuals recognize and celebrate their successes (no matter how small), increase their openness to attempts, and enhance self-esteem through the use of rewards for accomplishments that often go unnoticed (rather than corrections for challenging behaviors).

- **Setting Realistic Expectations** including those that are not so low that challenges are lacking as well as raising expectations when new skills are learned.

- **Clarifying Expectations** to ensure expectations are understood (e.g., using pictures or objects that represent the steps in an individual's schedule).

- **Teaching and Reinforcing Effective Alternative Behavior** to decrease the need for using challenging behavior to get one's needs met.

- **Teaching Behaviors that are Naturally Reinforced** by others in everyday situations.

- **Fading Supports Needed for Desirable Behavior** by first fading prompts and then rewards in order to foster lasting behavior change.

❹ **Intervening when Challenging Behavior occurs** within the context of natural/everyday settings (e.g., classroom, home, car, street, park, or supermarket) rather than clinical settings. If skills are taught in clinical settings specific strategies to ensure generalization to natural settings are used. Strategies include:

- **Preparing Oneself for Challenging Behavior** entails knowledge of behaviors and situations that challenge the person and planning for managing those situations.

- **Minimizing the Power of Challenging Behavior** by not acknowledging it, allowing it to interrupt or alter the current focus, providing a reaction, or giving in to the individual's demands in order to minimize the power of the challenging behavior or diffuse a dangerous situation.

- **Interrupting Challenging Behavior (if necessary)** to help the individual stop the challenging behavior or minimize the harm caused by the challenging behavior in a gentle, safe, and calm manner (e.g., removing someone from a room to stop the disruption the behavior is causing others or blocking blows to the head to minimize self-injury).

- **Redirecting to Effective Alternative Behavior** by giving reminders regarding what could be done instead to get needs met (e.g., verbal reminders, pointing to the person's schedule, or handing the person their coat).

- **Reinforcing Effective Alternative Behavior** to increase and maintain desired performance.

- **Using Consequences (if necessary)** that are planned in advance, rather than imposed as retaliatory measures, and include the focus person in discussions and determinations of the consequences. Consequences for challenging behavior should be relevant to the behavior (e.g., cleaning up a mess the person made), respectful (i.e., do not shame or humiliate the person), and reasonable (e.g., losing video watching privileges for the rest of the day rather than the rest of the month), and should provide opportunities for the person to practice the desirable behavior more often. For example, a consequence for bullying might be supervised practice helping others (e.g., turn taking, holding the door open, or offering complements).

❺ **Managing Crisis Situations (if necessary)** in natural settings including:

- **Stopping Harm to Self or Others** including removal from the situation in calm manner and without excessive force.

- **Seeking Help from Others** and determining when supporters' responses are not effective as well as including them in the development and implementation of behavior plans.

- **Dealing with Others' Expectations** to minimize caregiver actual or perceived influence from external observers (particularly in public settings).

❻ **Evaluating Behavior Support Efforts** so that changes to PBS plans are based on effectiveness or lack thereof, or changes in the individual's behavior or life circumstances. Monitoring, evaluating, and revising PBS plans should include the following:

- **Objective, Observable, Measurable Data** are used to ascertain the effectiveness of PBS plans.

- **Continuous Monitoring** on a regular basis. Data is collected every day and graphed or summarized each week. Baseline data (prior to the inception of a PBS plan) needs to be collected over time and compared to intervention data (subsequent to implementation of a PBS plan) to ensure that determinations are based on consistent data gathered over time (rather than single and subjective observations or impressions).

- **Revised when Data Indicate and Team Decides** based on data and made in collaboration with the other team members rather than by individual caregivers. Frequent changes to PBS plans are not recommended as it often takes several days or weeks to determine whether the elements of a plan are working. It is also important to ascertain if a plan has been implemented as intended.

❼ **Supporting Caregivers** including parents, teachers, and direct support personnel and involving them in the assessment process as well as in the development and evaluation of plans. Ongoing support is provided to assist with recollection of planned actions, cope with difficulties, and provide relief.

- **Involving Caregivers in Plan Development** and giving them the opportunity to have their opinions considered or their questions answered. Caregivers need to understand why they are to ignore some behaviors and respond to others in order to prevent errors.

- **Understanding Caregiver Values/Culture/Beliefs** to help them cope with stressors encountered when they are expected to compromise their own values (e.g., asking someone who has strong objections to cursing to ignore such behavior).

- **Providing Training and Technical Assistance** so that caregivers have opportunities to ask questions, view demonstrations, and receive reminders and feedback regarding their performance.

- **Providing Effective Role Models** so caregivers can focus on the quality of the care they provide as source of satisfaction rather than only on desired changes in the other person's behavior.

- **Providing Frequent and Relevant Feedback** including charts and graphs that document improvements and offer feedback regarding caregiver behavior.

- **Ensuring Caregivers have Ongoing Emotional Support** to provide opportunities to share frustrations and distresses, commemorate successes, and avoid burn-out. Such support can be provided through parent groups, relationships with

- **Responding to Caregiver Requests in a Timely Fashion** to provide immediate assistance when necessary.

- **Providing Opportunities for Professional/Personal Growth** to enhance skills.

PBS has been shown to lead to significant improvements that have long-term effects on lifestyle, functional communication skills, and problem behaviors. Research on PBS indicates that it is widely applicable to people with developmental disabilities and to severe problem behaviors within typical/everyday settings by direct support providers. Its effectiveness is significantly enhanced when intervention is based on functional assessment, and when implemented by typical agents.

School-Based PBS

PBS can be targeted to individual students or entire schools because it does not focus exclusively on individual students, but also includes altering environmental variables (e.g., physical setting, task demands, curricula, instructional pace, and individualized reinforcement).

In most instances of school-based PBS, a plan is developed that typically includes skills training to increase appropriate behavior, changes that will be made in classrooms or other environments to reduce or eliminate problem behaviors, strategies to replace problem behaviors with appropriate behaviors that serve the same function for the child, and supports for the child to use the appropriate behaviors. Examples of behavioral intervention strategies include:

➤ **Stop, Relax, and Think** teaches children how to think about the problem they are having and find a solution using the following steps:

1. Define the problem
2. Decide who "owns" the problem
3. Think of as many solutions as possible to solve the problem
4. Select a solution to try
5. Use the solution
6. Evaluate its success

After the steps are understood, role playing and practice are used to foster inculcation of the process. Children are also helped to recognize their own responses to stress (e.g., clenched hands or tone of voice).

➤ **Planned ignoring** which is designed to stop behaviors that are annoying and attention-seeking. It should be noted that attention-seeking behaviors often become exacerbated before they eventually dissipate. Also, planned ignoring is not appropriate for behaviors that are extremely disruptive and may not be effective if other children laugh at the problem behaviors the adult is trying to ignore. Some behaviors, including those that are unsafe or involve peer issues (e.g., arguing), can quickly escalate into more serious behaviors and thus may not be possible to ignore. Planned ignoring is contraindicated for unsafe behaviors. Planned ignoring is less effective as children grow older and desire more attention from friends than adults.

➤ **Preventive cueing** (also called signal interference) is designed to inform a student they are behaving in an unacceptable manner. Teachers can frown, shake their heads, make eye contact, point to a seat for a student who is wandering, or snap their fingers to let the student know they need to pay attention or stop the problem behavior(s). Preventive cueing can be applied in steps in accordance with the

behaviors displayed, frequency of occurrence, and seriousness. For example, a hand motion may work the first time or two, but may need to be combined with eye contact or a shake of the head thereafter.

➤ **Proximity control** entails an adult moving closer to the child in a gentle manner to get their attention. For example, a teacher can move closer to a student or teach a lesson while standing near a child's desk.

➤ **Touch control** is a nonverbal guided intervention used to direct a student toward positive behavior (e.g., gently placing a hand on their shoulder to steer them back to their desk). Touch control is generally contraindicated for children who react angrily, are anxious, have a history of violence, abuse or maltreatment, or have a mental illness or psychosis.

➤ **Humor**, directed either at the teacher or the situation (not the child), can be used to defuse tension as well as for redirection. Humor is never used to demean or in a manner that might encourage other students to ridicule the child.

➤ **Nonverbal warnings** give children the opportunity to regain control without being singled out for a verbal reprimand.

➤ **Discipline privately** to prevent the student from gaining stature from peers by publicly refusing to obey a teacher. Also, children are more likely to accept discipline if their peers do not witness the process.

➤ **Positive phrasing** is used inform students of positive outcomes for using appropriate behaviors.

➤ **I-messages** are used to help children learn how their problem behaviors affect others and to demonstrate the importance of taking responsibility for one's own behavior. I-statements are ineffective in instances of dislike for the teacher and can help the student annoy the teacher more effectively.

➤ **Behavior shaping** entails rewarding small gains and reinforcing gains as they occur.

➤ **Clear routines and expectations** offer children information regarding rules and what comes next in their school day thereby reducing anxiety or fear. Teachers post and review the rules daily to establish expectations for behavior during the day.

Research has shown that school-based PBS is effective in promoting positive behavior and reducing the incidence of problem behaviors in individual students as well as on a school-wide basis. Schools that have implemented system-wide PBS interventions report increased time engaged in academic activities, improved academic performance, and reductions in discipline referrals.

MOTIVATION ENHANCEMENT TECHNIQUES

Children with autistic spectrum disorders often display a lack of motivation during teaching sessions. A number of techniques have been found to be helpful in increasing motivation including:

➤ **Preferred reinforcers:** Identification and selection of reinforcers using preference assessments in which an array of choices are presented on a choice board to elicit spoken words, gestures (e.g., pointing or visual systems such as PECS) in response to questions (e.g., "What do you want to work for?") and, if necessary,

prompts (e.g., "Do you want _____?") Children who are less verbal can be presented with two or three objects simultaneously and asked, "What do you want to work for?" The object the child reaches for or looks at is then determined to be preferred. Such procedures are used to identify a single reinforcer at the beginning of each instructional program to prevent satiation and allow for changes in preference. Access to the reinforcer is limited so its effectiveness is maintained (e.g., setting a timer for access to toys or giving only a small amount of a preferred food).

➤ **Altering schedules of reinforcement:** More regular and frequent reinforcement is used initially when teaching new or more difficult skills than when helping with maintenance of previously mastered skills. Incrementally increasing reinforcement schedules until there is evidence that performance has improved has been shown to be more effective than increasing reinforcers automatically by giving one reinforcer for each correct response, Enabling a child to anticipate when reinforcement will be given has also been found to be helpful.

➤ **Token economy systems** in which a certain number of pennies or stickers are earned and then exchanged for reinforcers, can be effective, particularly for children who can count.

➤ **Restricting access to reinforcers outside of instructional programs** can increase their potency (e.g., highly preferred snacks or toys can be used as reinforcers in instructional programs and stored out of sight at other times). Access to preferred foods or toys may be further restricted by limiting their use to new or difficult instructional programs.

➤ **Use of short constrained episodes of problem behaviors as reinforcers** when other preferred activities or items cannot be identified while attempting to reduce such behaviors during other parts of the day (e.g., relatively benign repetitive or perseverative activities such as hand flapping, lining up toys, gazing at spinning objects, and delayed echolalia [repeating scripts from favorite movies]).

➤ **Incorporating preferred materials into programs** can increase motivation (e.g., using a strong interest in trains to teach prepositions by asking the child put the train on top of or under another object or using preferred action figures to teach pronouns).

➤ **Turn taking** can be used to introduce variety into instructional sessions. (e.g., making a request of the child, then telling the child that it is their turn to make a request of the adult, etc.).

➤ **Task interspersal** involves incorporating previously learned skills into a new instructional program to add variety to sessions.

BEHAVIORAL INTERVENTIONS FOR CHILDHOOD SLEEP DISORDERS

Studies indicate that most children with developmental disabilities experience some form of sleep disturbance[42] and these problems are typically more severe and persistent than those of children without developmental disabilities. The most common are disorders of sleeplessness including difficulty falling asleep, bedtime refusal, co-sleeping, early waking, and night waking. These have been found to be more prevalent in children under the age of five.

Difficulties with sleep are associated with a number of adverse effects including behavior problems, compromised daytime functioning, cognitive deficits (e.g., impaired attention, memory, and creative thought), measurable decrements in academic performance, depressed mood, irritability, and physical issues (e.g., impaired growth and immune function). Moreover, children's sleep disturbances often have adverse effects on the sleep patterns and subsequent daytime functioning of other family members and have been found to be associated with general family stress, marital discord, and parenting difficulties. Many of these adverse effects can be reversed by eliminating or ameliorating the sleep disturbance. However, despite the prevalence of sleep problems in children with developmental disabilities, the literature on interventions for sleep disturbances for these children is scarce. Moreover, all too frequently no attempt is made to treat sleep disturbances in children with developmental disabilities.

A range of approaches are used to treat sleep disorders in children with developmental disabilities including teaching parents about environmental and lifestyle factors that can affect sleep; behavioral techniques to teach children appropriate sleep habits and/or correct inappropriately learned sleep-related behaviors; cognitive therapy; chronotherapy (i.e., altering sleep timing in specific, systematic ways to reset the body's clock); physical measures such as using bright light to alter sleep times; aids such as a nasal continuous positive airway pressure (NCPAP) device to help breathing during sleep; surgery (e.g., removal of tonsils and adenoids if they are causing an obstruction); and pharmacological approaches (e.g., sedatives, stimulants, and melatonin).

Intervention begins with obtaining a sleep history to assess the precise nature and course of the problem along with a developmental, medical, psychological, and family history. Sleep diaries in which parents systematically record sleep-related information are maintained. Questionnaires (for screening and obtaining detailed information regarding specific aspects of sleep for devising and monitoring treatment, as well as objective methods (e.g., video recordings, monitoring body movements with actigraphy [which can detect basic sleep wake patterns] and conducting polysomnography [PSG] in a laboratory or the home to record various physiological parameters which permit detailed analysis of sleep physiology according to standardized criteria) can also be used.

Approaches to treating sleep/wake rhythm disorders[43] generally involve resetting the circadian clock using chronobiological approaches including bright light treatment or altering sleep and

---

[42]. Over eighty different sleep disorders are listed in the International Classification of Sleep Disorders. There are three primary types of sleep problems: sleeplessness (dyssomnias), excessive sleepiness, and episodes that are associated with and/or intrude into sleep (i.e., parasomnias).

[43] Sleep-wake rhythm disorders are problems with the timing of sleep within the twenty four-hour day. Sleep may occur too early (i.e., be phase advanced), too late (i.e., be phase delayed), fragmented (i.e., occur irregularly throughout the twenty four hour day), or be free-running (i.e., dissociated from regular time cues) with sleep onset gradually delayed over successive nights thus moving the sleep period around the twenty four-hour clock over a period of days or weeks. The light-dark cycle is the most important zeitgeber

wake times behaviorally (i.e., chronotherapy) by successively phase delaying sleep until the desired bedtime is reached, or through the use of forced waking. Bright light therapy involves morning light exposure to cause a phase advance in the sleep-wake rhythm, or evening bright light exposure which results in a phase delay. Morning and evening are relative to the individual's own body clock time which does not necessarily correspond with actual clock-time. Research on bright light treatment is scant and appears to be effective for only a minority of the few reported cases in the literature. Another alternative is the neurohormone melatonin that is ingested prior to sleep onset. Strong social cues (i.e., regular meals, a daily routine, and a regular bedtime routine) that provide additional zeitgebers are also put in place.

Studies indicate that behavioral interventions are effective for a variety of different sleep disorders and are the treatment of choice for many of the most common pediatric sleep disorders in children with developmental disabilities because they entail nonverbal methods for modifying behavior. In addition, such interventions can be individually tailored to each child/family's particular needs and circumstances. Successful use of behavioral interventions has been associated with improvements in child behavior and various aspects of parental functioning. Extinction and graduated extinction with bedtime routines meet criteria for probably efficacious treatments for sleeplessness in children with developmental disabilities. Most of the literature on other behavioral interventions consists of case studies ranging from single subjects to multiple baseline designs.

Faded Bedtime with Response Cost	Faded Bedtime entails setting a bedtime routine during baseline and then establishing appropriate sleep length, onset, and wake time based on developmental norms. An initial bedtime when the child is likely to fall asleep quickly using baseline data for guidance is established. After following a bedtime routine, the child is put to bed at this time and awakened at a predetermined time the following morning. If the child does not fall asleep within fifteen minutes of bedtime, the child is kept out of bed and awake for an additional hour and then put back to bed. This procedure continues throughout the night until the child falls asleep within the allotted fifteen minutes. Fading from this initial bedtime then occurs by making bedtime thirty minutes earlier on nights following those where sleep was initiated within the prescribed fifteen minutes. If sleep does not occur within fifteen minutes, bedtime is delayed thirty minutes later the following night. Faded bedtime with response cost has been shown to be effecting in reducing hours of disturbed sleep
Extinction	Extinction entails ignoring or not rewarding undesirable behaviors (e.g., crying) after the child is put to bed. Extinction procedures include: • Setting and adhering to a regular bedtime for the child • Implementing a calming bedtime routine and setting the mood for sleep leading up to bedtime (i.e., no playing, remaining quiet and calm) • Placing the child in the bedroom rapidly and then leaving the room, ignoring the child thereafter (unless unwell), and intervening only to ask the child to return to the bedroom if they leave it or, if necessary, physically returning the child to the room as often as necessary. • Rewards for appropriate night time behavior An advantage of extinction is that problems often resolve within a week. However, a potential disadvantage is the occurrence of an extinction burst in which the undesired behavior is temporarily exacerbated prior to improving.
Parent	Parent training programs entail teaching behavioral principles, establishing a bedtime

(or time-cue) for resetting the sleep/wake rhythm to the twenty four-hour day with other environmental cues (e.g., regular social interactions and meals) functioning as secondary zeitgebers.

Training Programs	routine, implementation of extinction, and rewards the next day for "good" bedtime behavior. Differential reinforcement of incompatible behaviors (DRI) with response cost using a token economy can also be used to deal with disruptive night waking. Tokens earn desired activities and are removed for disruptive behavior. Extinction, and later mild punishment (closing the bedroom door all night), are added. Such programs have been shown to be effective and elicit a high level of parental satisfaction and approval.
Graduated Approaches	Graduated approaches include graduated extinction (i.e., gradually increasing the interval before checking on the child subsequent to being put to bed), ignoring with checking at fixed intervals, and stimulus fading (i.e., gradual fading of parental presence).
Fixed Approaches	In fixed interval attention approaches, a bedtime routine is put into place and attention is provided to the child by a parent for twenty minutes on a fixed five minute schedule until the child is asleep.
Sleep Restriction	An initial assessment of sleep problems is conducted, baseline data collected, and the initial bedtime is moved to a later time. A fixed wake time is employed. When the initial sleep disturbance is eliminated bedtime is faded back to an age-appropriate time. A bedtime routine can be added.

INTERVENTIONS FOR SEX OFFENDING BEHAVIOR

While it is increasingly recognized that individuals with developmental disabilities, like other members of society, have a right to healthy sexuality, negative social biases continue to impede appropriate sexual expression by people with developmental disabilities. Stereotypic views range from seeing such persons as having uncontrollable sexual desires to those that perceive them as innocent, naïve, and lacking sexual desire. Such views continue to cause significant restrictions on sexual expression and function as an impediment to the provision of accurate and effective sexually educative experiences which can lead to sexual knowledge inadvertently acquired that is subject to significant distortions and misinterpretations.

Inappropriate sexual behavior exhibited by persons with developmental disabilities has been postulated to stem from lack of opportunities for appropriate sexual expression and intimacy, ignorance regarding appropriate behaviors, inadequate social education, and poorly developed or absent self-control. Other factors cited include lack of social skills training and information about appropriate/safe sexual behavior and relationship development, a history of sexual or physical abuse, exposure to violence and/or pornography, limited or lack of available appropriate sexual partners, difficulty projecting consequences of behavior and recognizing and expressing emotions, and denial by significant others that such behavior is occurring. The latter can contribute to risk for reoffending and undermines the person's right to obtain assistance in developing appropriate sexuality. Many of these deficits stem from living in settings in which opportunities for learning about healthy relationships and appropriate sexual expression are absent. In addition, individuals with developmental disabilities who have experienced sexual exploitation or abuse may lack access to legal support or psychotherapy, alternatives that are available to individuals without disabilities. Cognitive limitations, expressive speech impairments, and limited adaptive skills can further complicate the experience of victimization.

The prevalence of sex offending behavior among individuals with developmental disabilities is unknown. Some studies have found that individuals with developmental disabilities are more likely to commit sexual offenses, while others have not. The disparate results found in prevalence studies are due to variations in inclusion criteria, sample sources, IQ determinations, and the effects of changing social and penal policies in areas where studies have been conducted. It should be noted that there is also no evidence to support a direct or causal association between intellectual functioning and sex offending behavior. Often persons with developmental disabilities charged with sexual offenses engage in socially acceptable sexual behaviors, but with an underage partner.

There is a dearth of research regarding treatment of sex offending behavior in persons with developmental disabilities and a paucity of outcome data on the efficacy of treatment programs. For example, there is significant evidence that interpersonal social skills deficits and mood disorders are related to sex offending, but little empirical research on the importance of risk factors in sex offenders with developmental disabilities has been conducted. However, the studies and program reports that do exist suggest that cognitive behavior therapy (CBT) with opportunities to generalize newly acquired skills in the community is a promising approach. In addition, contingency management systems that are designed to increase the likelihood of continued attendance in outpatient therapy sessions can augment treatment outcomes by reducing rates of reoffending and improving behavioral skills.

It is recommended that assessment techniques (e.g., polygraphic and phallometric testing) be used with caution in individuals with developmental delays due to the lack of normative data and invasiveness of these techniques. Few assessment instruments are appropriate for individuals with intellectual disabilities and many existing assessments are too linguistically complicated to ensure offenders with intellectual disabilities understand the requirements and items of the test. Penile plethysmography (PPG) is traditionally the most popular approach for assessing sexual arousal, and has been recommended for individuals with developmental disabilities.

Some assessment instruments have been found to be useful as well including the Sexual Abuser Treatment Progress Scale for Persons with Developmental Disabilities, the Multiphasic Sex Inventory II (MSI-II), the Socio-Sexual Knowledge and Attitude Test (SSKAT), and the Psychopathology Inventory for Mentally Retarded Adults. The Aberrant Behavior Checklist (ABC) appears to be useful in tracking the effects of psychopharmacological agents on persons who have moderate to severe mental retardation. The Reiss Screen for Maladaptive Behavior, the Reiss Profile of Fundamental Goals and Motivation Sensitivities for Persons with Mental Retardation, and the Modified Cognition Scale for the Developmentally Disabled Questionnaire on Attitudes Consistent with Sexual Offending (QACSO) can also be used.

The methods used to treat sex offenders who have developmental disabilities are based on those developed for sex offenders without developmental disabilities and adapted for use with persons who have developmental disabilities. In general, the treatment of sexual offending is designed to minimize risk to the community, foster control over sexual impulses, reduce sexual offending behaviors, and foster the development of appropriate social skills, including sexual expression.

Multi-component treatment programs consist of strategies aimed at arousal, cognitions, adaptive behavior, and interpersonal areas of vulnerability. Respondent conditioning techniques were among the first therapies adapted for sex offenders with intellectual disabilities. Such techniques typically include satiation, covert sensitization, and overt reconditioning techniques to decrease deviant arousal. Behavioral techniques (e.g., masturbatory reconditioning to increase arousal to appropriate stimuli), social skills training, and sex education are considered important elements of treatment for persons with intellectual disabilities. Improved outcomes have been found with treatment lasting at least two years. In addition, in vivo community training and contingency management are used to reduce inappropriate social behavior toward peers. Non-aversive procedures that focus on instructional control, manipulation of antecedents, fading, and positive reinforcement to increase adaptive socio-sexual behavior are also part of treatment models for this population. It has been found that positive reinforcement strategies can maintain gains when alternative sexually adaptive behavior is paired with the positive reinforcement.

Problem-solving is an important strategy for reducing impulsivity as part of a multi-component treatment package for sexual offenders with intellectual disabilities. The repetition and reinforcement of concepts, using visual aids, role playing, and community practice are recommended. It is also recommended that offenders with developmental disabilities receive

several hours of supported community practice for every hour of group or individual therapy since translating concepts from a classroom or therapy setting to real life practice can be quite challenging for this population. Community support activities offer opportunities to try out new skills and receive immediate feedback from support staff to reinforce or improve skills. In addition, various techniques or adaptations for people who do not read and write can be incorporated into treatment programs (e.g., photo collages and video or audio equipment to record plans). Posters, collages, graphics, videos, and role playing can be used during group treatment.

The components of standard sex offender treatment adapted for individuals with developmental disabilities are as follows:

◻ **Learning accurate information about sexuality:** It is recommended that Individuals with developmental disabilities who commit sexual offenses be given correct information about anatomy and physiology; hygiene; pregnancy; sexually transmitted diseases (STDs); HIV and AIDS; birth control; safe sex practices; sexual techniques; and sexual orientation. Additional topics for sexuality training include social and legal information, such as the legal age of consent; laws against engaging in sex with family members and minors; places where sex is not allowed (e.g., public space versus private space); laws against sex for hire/prostitution; and what constitutes sexual contact.

◻ **Social competence improvement:** Social skill and relationship training are essential elements in the treatment of sex offending, and the development of appropriate social and sexual skills are critical to reducing the risk for reoffending. It is recommended that education and training include concrete skill-building techniques regarding social interactions (e.g., how to initiate appropriate social contact and deal with rejection or respond to mutual interest) and sexual behavior (e.g., how to put on a condom), as well as information about sexuality. Structured activities and opportunities to practice basic socio-sexual skills may be needed to facilitate the development of healthy, responsible sexuality and positive, non-sexual social relationships with peers. In treatment, progress is evidenced by behavioral, cognitive, and attitudinal changes (e.g., acceptance of responsibility for one's behavior and the development of an understanding of the consequence one's actions have for others) which have been shown to lead to the reduction of risk for reoffending. It is recommended that such training be incorporated incrementally into the therapeutic process.

◻ **Control of sexual arousal:** A number of interventions/techniques are used including:

   ▪ **Orgasmic reconditioning:** Positive conditioning procedures in which the offender pairs appropriate sexual fantasies with masturbation and orgasm to eliminate abusive sexual fantasies while masturbating. Reconditioning techniques work by pairing healthy sexual images and fantasies with the pleasurable feelings of orgasm. Recordings, photos, or other materials with appropriate sexual images can be provided if help is needed to develop positive images.
   ▪ **Exposure:** Includes opportunities to view and enjoy movies, videos, and tapes with images of appropriate sexual partners, and loving, respectful relationships.
   ▪ **Avoidance** of pornography and other abusive images and masturbating to deviant thoughts.
   ▪ **Covert sensitization:** A counter-conditioning approach that pairs deviant fantasies with aversive or escape images and entails having the offender record or role play an abusive or high risk scene that could lead to offending (i.e., the chain of behaviors that led to past instances of sexual offending). When the individual reaches the point of committing an offense, they interrupt the scene by imaging or acting out a highly aversive consequence (e.g., being arrested and going to jail). A

variant entails substituting an escape script rather than an aversive scene (e.g., shouting "STOP" and practicing fantasies of successfully escaping before engaging in abusive behavior). Role plays with staff rather than recorded scripts may be more effective for sex offenders with developmental disabilities.

- **Verbal satiation:** A technique in which the individual repeatedly verbalizes their abusive fantasies until the sexually arousing properties of these fantasies have been extinguished through boredom.

- **Odor aversion:** A technique in which the individual uses a foul odor (e.g., ammonia) to interrupt sexually deviant urges or thoughts. Administration of foul odors by others (e.g., therapists) is considered an aversive procedure and therefore contraindicated.

- **Environmental controls:** Controlling a sex offender's environment by reducing access to stimuli (e.g., young children) that trigger deviant sexual urges.

- **Medications:** Pharmacotherapeutic interventions to reduce abusive sexual arousal including:

  - **SSRIs** (Selective Serotonin Reuptake Inhibitors), such as fluoxetine, paroxetine, sertraline, venlafaxine, and fluvoxamine, which are used primarily to treat depression or obsessive-compulsive disorder, but reduce libido in many people.

  - **Antiandrogens**, such as depot medroxyprogesterone Acetate (Depo-Provera) and leuprolide (Lupron), which reduce sexual arousal and libido. Side effects, including weight gain and loss of bone density, can occur but are eliminated by stopping administration. Particular caution needs to be exercised with adolescent males who have not reached physical or sexual maturity.

  - **Hormonal treatments**, such as medroxyprogesterone acetate (MPA) and cyproterone acetate (CPA) which attempt to decrease the effect of sex hormones on parts of the brain associated with the genesis and maintenance of sexual urges. CPA is not prescribed for men under age eighteen or whose bone or testicular development is not complete. However, caution is recommended for men with intellectual disabilities as they may not be as capable of reporting side effects and bodily changes.

  - Indirect intervention with **pharmacological regimes for comorbid conditions** including aggression, impulsivity, and psychiatric disorders (e.g., major depression or bipolar disorder) that can influence sexual disinhibition.

◻ **Learning emotional self-regulation skills:** Treatment programs for offenders with developmental disabilities teach emotional self regulation skills.

- **Anger management therapy** has been found to be of benefit to offenders with developmental disabilities because the urge to commit sexual offenses is often strongest when the person is feeling angry. A number of anger management programs have been developed and all share a number of common elements:

  - Recognizing and labeling anger: Individuals learn to identify the physical signs (e.g., muscle tension and clenched fists) that indicate anger in themselves and others
  - Identifying situations and cues that lead to anger

- Understanding the external circumstances as well the internal triggers that provoke anger
- Learning skills to reduce anger
- Learning to express anger in healthy, socially constructive ways
- Learning to relax using relaxation exercises and deep breathing

◻ **Relapse Prevention:** Relapse prevention skills development is a core component of sex offender treatment and studies have suggested it is one of the most effective forms of treatment for sex offending. Relapse prevention entails providing assistance to sex offenders in identifying their "cycle of abuse" (i.e., the series of life events, thoughts, and feelings that have been associated with past offending). Offenders are then taught to intervene in order to break the chain of antecedent events and avoid a potential relapse. This treatment is most effective when provided in the context of a systemic approach involving the offender, family, and other supporters.

In relapse prevention participants are taught that sexual behavior follows a predictable pattern and learn to identify risk factors and patterns; to avoid risk situations; and to escape or cope when they find themselves in a risk situation. An Escape and Avoidance Plan (also called a Risk Plan) can be used prior to any outing. This plan provides the individual with an opportunity to define the risks that will be faced in the community, the precursors to inappropriate sexual activity, and how the person will act. A plan sheet is completed and placed in the individual's pocket to serve as their "conscience" during the outing.

To create a plan, two columns are placed on a sheet of paper. In one column things in the community that might be problematic (e.g., seeing children) or ways in which behaviors in the community may signal risk level (e.g., staring at children) are listed. Actions that can be taken by the person, or with a support person, to prevent or resist those possibilities and lower their risk level (e.g., looking away or leaving the situation) are listed in the opposite column.

Escape strategies for coping with risk situations include:

- Self talk ("Stop, Think, Decide")
- Deep breathing and other calming techniques
- Telling another person about the risk
- Looking away
- Leaving
- Developing appropriate social support networks[44]

Individuals with developmental disabilities are typically unable to absorb the multiple steps of the relapse prevention cycle as it is taught in most therapy programs for sex offenders. Teaching from the concrete to the abstract has been found to be more effective for people with developmental disabilities. Skills (e.g., risk awareness) are presented as a single

---

[44] Social support is a critical element in relapse prevention programs. Coping strategies learned as part of treatment are more likely to be used effectively if a positive social support is in place. Individuals who have positive social relationships are less likely to reoffend than those with negative and anti-social family and peer group relationships. Negative relationships and long separations from parents are associated with recidivism.

subject that is practiced and mastered before being integrated into a sequence. Focusing on more finite concepts and avoiding elaborate abstract sequences as well as a simpler three-stage sequence to describe the cycle (e.g., Fantasy→Plan→Action) appears to be more effective.

◘ **Family involvement:** Family education and treatment have been determined to be critical elements of sex offender therapy both when abuse occurs within a family as well as when an identified victim is external to the family. (Families are often one of the only social support networks outside the service system of sex offenders with developmental disabilities.) Various forms of family education and treatment are used including:

- Family therapy
- Multifamily therapy groups
- Multifamily psychoeducational groups
- Parent-peer support groups
- Couples therapy

Four factors have been identified as predictive of positive outcomes for sexual offenders with intellectual disabilities: a stable residence, regular employment[45], regular supervision, and support in the community. In general, supportive and positive approaches have been shown to be more effective than punitive approaches.

PROJECT STOP

Project STOP is an outpatient program that provides assessment and treatment for adults with intellectual disabilities who have been convicted of, or identified as being at risk for, engaging in sex offending behavior. It is a cognitive-behavioral, multi-component model that employs an individualized case formulation approach focusing on each sex offender's unique vulnerability factors. The program uses a problem-solving approach to decision-making, incorporates individual, group and family therapies, and a contingency management system to increase adherence.

The primary treatment approaches of Project STOP include applied behavior analysis, staff and family consultation, behavior therapy techniques such as relaxation, and masturbatory conditioning, and cognitive-behavior therapy (CBT) techniques including: problem-solving therapy, anger management, stress management, cognitive restructuring, interpersonal skills training, social and sexual education, and Functional Family Therapy[46]. A strong emphasis is placed on skills development and improving self-control (e.g., learning relaxation techniques to decrease anger arousal and self-instruction strategies to increase self-control) while families are learning how to reinforce the skills at home. In addition, family members may be provided with assistance to alter patterns of inadvertently reinforcing sexually aggressive behavior. Group treatment is designed to build adaptive, rehabilitative, and coping skills within the context of peer participation, feedback, and support. Different types of groups are offered: (a) a social skills training group; (b) a

---

[45] Employment is associated with progress in sex offender treatment; working is indicative of a willingness to be self-supporting, meet expectations and demands and contributes to self-worth, as well as offers opportunities to form new personal connections, build interpersonal skills, and demonstrate competence.
[46] Information on Functional Family Therapy can be found in *A Guide to Evidence-Based Mental Health Practices for Children, Adolescents and their Families*.

clinical "mapping group" to help participants identify and change patterns or "maps" of their offending behaviors; and (c) a problem-solving coping skills group.

Outcomes studies indicate that participation in Project STOP leads to positive changes in adaptive and target behaviors, and significant reductions in recidivism. Individuals who receive combined treatment demonstrate the most significant improvements. It is recommended that treatment extend beyond two years.

PSYCHOTHERAPY

The literature indicates that a number of psychotherapies can be effective for people with developmental disabilities:

▶ **Counseling** that is focused and structured has been found to be of benefit to children with Asperger's syndrome, especially during experiences of overwhelming sadness, negativism, anxiety, family functioning challenges, frustration related to vocational aspirations, as well as ongoing social adjustment issues.

▶ **Individual Therapy** has been found to be beneficial for children with intellectual disabilities who have higher cognitive skills and when conducted by therapists specifically trained in working with developmental disorders using techniques and activities adapted to chronological age, level of development, and include the provision of social support.

▶ **Family Therapy** typically focuses on caregivers' identification and support of their children's strengths and independence as well as the provision of opportunities for success. It can include educational and emotional support components. Families often benefit from assistance in recognizing strengths, avoiding feelings of guilt and overprotection, supporting their children's progress towards independence, and providing opportunities for success. Family therapy has been found to be effective for providing help in locating resources, services and entitlements, and concrete advice regarding disability management. **Multiple Family Group Therapy** has been found to be beneficial because it provides families and children with support in a context similar to society at large.

▶ **Group Therapy** has been found to be helpful for adolescents who have relatively good verbal skills as they often benefit from peer interaction and support.

▶ **Behavior Modification** has been found to be beneficial to children with developmental disabilities who lack social skills or demonstrate problem/challenging behaviors. This intervention provides a consistent and structured framework for teaching appropriate behavioral patterns and adaptive life skills. Interventions need to be generalized and consistent in all settings (e.g., home and school) and focus on teaching appropriate skills and behaviors to replace maladaptive ones rather than merely suppressing them. Behavior management to control behavior problems using positive behavioral techniques (rather than aversion) can produce significant improvements. Target behaviors include skill deficits, social and academic skills, and behavioral excesses (e.g., tics).

▶ **Social Skills Training** entails the gradual teaching of effective social interactions and appropriate social behavior and is used to prepare individuals for dealing with social and interpersonal expectations to enhance potential for the establishment of friendships. It is a cost-effective, time-limited approach that often produces noticeable improvements in quality of life and interpersonal behavior through gradual teaching of effective social interactions and appropriate social behavior and has been found to improve the integration of children with intellectual disabilities into the community.

➤ **Cognitive Therapy** focuses on teaching people with mild intellectual disabilities to recognize situations in which they get into trouble and develop alternative behaviors and

solutions to their problems. However, it has only fairly recently been adapted for use with this population so research regarding its effectiveness is limited.

➤ **Activity Therapy** including music and art therapy are used to help build positive experiences and enhance self-confidence.

PHARMACOTHERAPY

A number of concerns have been reported in the literature regarding the use of medication in individuals with developmental disabilities including lack of integration into overall treatment plans, and failure to collect follow-up data on behavior and monitor side effects. The latter is of particular significance since individuals with developmental disabilities may not be able to adequately report symptoms. The literature strongly advises that medication not be used for the convenience of caregivers or as a substitute for appropriate services and supports.

Individuals with developmental disabilities manifest increased susceptibility to paradoxical reactions to benzodiazepines and barbiturates, can experience cognitive impairments and/or toxic reactions to neuroleptics, and develop depression and nightmares from some beta blockers. Neuroleptics have been cited as a specific concern for persons with developmental disabilities who have posttraumatic stress disorder (PTSD) as many have histories of abuse experienced while receiving neuroleptics. In addition, neuroleptic effects can interfere with the ability to process trauma (by diminishing cognitive ability) and can also trigger a dissociative state.

Potential Side Effects of Psychotropics in Persons with Mental Retardation	
Drug	Side Effects
aminophylline (ethylenediamine)	Aggression
anticholinergic drugs	Greater likelihood of cognitive impairment, delirium in persons with Down Syndrome and elderly persons
carbamazepine	Inconspicuous elevation of carbamazepine-epoxide levels during polytherapy with seizure exacerbation, hyponatremia; hypovitaminosis D, folic acid and riboflavin deficiency in persons with marginal diet, irritability
clobazam	Aggression, agitation, self-injurious behavior (SIB), insomnia, hyperactivity
gabapentin	Aggression; choreoathetosis reported in persons with significant brain abnormality
lithium	Cognitive dulling, increased likelihood of toxicity due to erratic fluid intake or regulation of same
lorazepam, other benzodiazepines	Hyperactivity, SIB, withdrawal-induced manic symptoms
methylphenidate	Social withdrawal, motor tics, anxiety
neuroleptics	Greater likelihood for development of tardive and other dyskinesia, parkinsonism from first generation antipsychotics, withdrawal, irritability, self-injury, akathisia
phenobarbital	Irritability, self-injurious behavior, aggression, hyperactivity, propensity to osteomalacia
phenytoin	Increased susceptibility to intoxication, cerebellar atrophy, brain stem atrophy, osteomalacia
valproate	Pancreatitis, hepatotoxicity, myelodysplasia

*(*adapted from *AACAP 1999)*

Psychotropic medications, particularly antipsychotics, are frequently used to treat disruptive and destructive behaviors (e.g., self-injurious behaviors, hyperactivity, excitability, aggression, and stereotyped behaviors such as hand or finger twisting and aggression) despite the lack of uniform response (i.e., consistent effectiveness) to these agents and scarcity of well-controlled studies. For example, risperidone is often prescribed for co-occurring aggression, tantrums, and self injury and can be effective on a short-term basis. However, the drug has no effect on behavior following discontinuation and adverse effects such as weight gain require continuous monitoring.

Opiate receptor antagonists (e.g., naltrexone) have been found to be of benefit for self-biting, but results have not been consistent and self-injurious behaviors can be exacerbated initially by opiate blockers. Moreover, naltrexone appears to exacerbate stereotypic behaviors in some persons. Several studies have shown that clomipramine is effective for treating repetitive behaviors in children with autistic spectrum disorders and persons with intellectual disabilities. Lithium and beta blockers are sometimes used to treat aggression and a number of studies have shown high rates of response to lithium. However, lithium is used with caution due to its relatively narrow toxicity window and the erratic hydration status of some persons with developmental disabilities.

Psychostimulants are used to treat hyperactivity and inattention problems that co-occur with autistic spectrum disorders and have been shown to be effective. However, methylphenidate is associated with adverse effects including difficulty falling asleep, reduced appetite, irritability, and emotional outbursts. Serotonin-affecting medications have been shown to be effective in treating symptoms of autistic disorders with reductions in self-injury, anxiety, and increased socialization reported in the literature.

First-line treatments for co-occurring bipolar disorder include antiepileptic drugs (e.g., carbamazepine and valproic acid). Lithium may not be well tolerated because of the magnified significance of cognitive dulling. Newer anticonvulsants (e.g., gabapentin and lamotrigine) have shown some promise for persons with mental retardation, but there is a paucity of research available.

Co-occurring depression is typically treated with selective serotonin reuptake inhibitors (SSRIs) due to their relatively benign side effect profile. Tricyclics have potential adverse effects on seizure threshold, cardiac rhythm, and cognition which are significant issues for persons with mental retardation and comorbid medical conditions. Monoamine oxidase inhibitors (MAOIs) are rarely prescribed due to the difficulty in ensuring adherence to dietary restrictions.

First-line treatments for co-occurring schizophrenia and mental retardation are atypical (second generation) neuroleptics due to the increased susceptibility of such individuals to tardive dyskinesia, tardive akathisia, and other toxic effects of conventional (first generation) antipsychotic agents.

A noted previously, children with developmental disorders have a higher prevalence of sleep disturbances which are often chronic and more difficult to treat. Sleep disturbances can arise from multiple and interrelated factors including delayed brain maturation, sensory dysfunction (especially visual), and dysfunction of sleep centers. Medical problems including gastroesophageal reflux, pain, and epileptic seizures can also impair sleep. Individuals with mental retardation, particularly those with multiple impairments (e.g., congenital rubella syndrome and blindness) can experience sleep disturbances. Individuals with Smith Magenis syndrome can experience insomnia and those with Prader-Willi syndrome can experience excessive daytime somnolence.

There is increasing evidence that chronic sleep-wake disorders of children with neurodevelopmental disabilities are associated with an inability to synchronize the sleep-wake cycle generating system with environmental zeitgebers (or time-cues for resetting the sleep/wake rhythm to the twenty four-hour day) and resulting in atypical melatonin secretion. This has led to the increasingly widespread use of melatonin (a pineal hormone known to be important in the regulation of the circadian rhythm, including the sleep-wake cycle) which can reduce sleep latency in children with developmental disorders, particularly those with severe sleep disorders. However, there is no evidence for reductions in night-time awakenings or increases in total sleep time, while only modest evidence suggests that melatonin can reduce sleep latency, Short term use of

melatonin does not appear to cause adverse side effects, but data on its potential long term effects is lacking.

Sedatives and hypnotics lack empirical support and are contraindicated for sleeplessness due to their limited duration and side effects (e.g., disinhibition). In addition, these medications can lead to tolerance and paradoxical responses in persons with developmental disabilities. It is recommended that pharmacotherapy be used in conjunction with behavioral therapy for sleep disorders.

Benzodiazepines are not used as first-line treatments for anxiety disorders because individuals with mental retardation are sensitive to their cognitive and other effects (e.g., impaired acquisition of memory, interference with respiration, and disinhibition). Buspirone and antidepressants with anxiolytic effects (e.g., fluoxetine or paroxetine) as well as antiepileptic drugs, (e.g., carbamazepine) are often used for anxiety disorders. Clonidine and various beta blockers can be effective short term treatments for anxiety, but when used on a long term basis, produce side effects including depression, sleep disturbance, cardiac disturbances, and cognitive dulling. SSRIs are used for the treatment of co-occurring obsessive-compulsive disorder rather than clomipramine because of their more favorable side-effect profiles. However, pharmacological response can take from to four to six weeks.

Medications are used to ameliorate Tourette's disorder as a second-line treatment following behavior therapy. It is estimated that children with the disorder require medication for one to two years and that fifteen percent require long-term pharmacotherapy for control of tics. The use of stimulants to treat co-occurring ADHD[47] has been controversial due to reports of stimulants accelerating the onset or increasing the severity of tics in some persons.

Pharmacotherapy of Tourette's Disorder	
Tics	
Neuroleptics	
Haloperidol	Clonidine
Pimozide	Botulinum Toxin[48]
Fluphenazine	
Others	
Obsessive-Compulsive Disorder	
Clomipramine	Sertraline
Fluoxetine	
Attention Deficit Hyperactivity Disorder	Stimulants
Clonidine	Methylphenidate
Tricyclic antidepressants	Pemoline
	Dextroamphetamine

---

[47] Information on ADHD can be found in *A Guide to Evidence-Based Mental Health Practices for Children, Adolescents and their Families*.

[48] Recent studies have shown that a small number of individuals who do not respond to other medications may benefit from injections of botulinum toxin.

QUALITY OF LIFE OUTCOME MEASUREMENT

Contemporary outcome measurement focuses on quality of life and the evaluation of lives rather than assessment of service effectiveness. Current views hold that measurement systems should include outcomes that are of significance to recipients of services and are desired by any person irrespective of a disability. In other words, outcomes need to be assessed within the context of the expectations and aspirations shared by all, not just standards specific to the human service system or by comparing people receiving services to one another. Increasingly consumers are evaluating the quality of their own care and lives, and their perspectives are driving continuous quality improvement efforts.

Individual outcomes include the achievement of:

➲ Living where one desires (given available resources) and access to available resources
➲ A broad and diverse social support system of their own choosing
➲ The opportunity to be productive and do things that are personally meaningful
➲ A feeling of progress towards or achievement of economic self-sufficiency and security.

Service system-level measures take into account community presence, community participation, choice, respect, and competence and include:

➲ The provision of consumer and family-driven supports
➲ Consumers have control over their own budgets
➲ Consumers choose where and with whom they live
➲ Consumers choose what they do during the day
➲ Consumers choose personal goals for the future that are honored by the organization
➲ Consumers participate in community life in valued ways
➲ Consumers have friends and regular contact with family
➲ Consumers have the opportunity to exercise their constitutional rights (e.g., voting, respect for their privacy, etc.)

The state of Michigan has identified the following priority areas for its citizens with developmental disabilities:

➤ **Education activities and early intervention:** Individuals with developmental disabilities are able to access appropriate supports and modifications when needed to maximize their educational potential, benefit from lifelong educational activities, and be integrated and included in all facets of student life.
➤ **Child care-related activities** that result in families of children with developmental disabilities having access to and use of child care services, including before-school, after-school, and out-of-school services, in their communities.
➤ **Health-related activities:** Individuals with developmental disabilities have access to and use of coordinated health, dental, mental health, and other human and social services, including prevention activities in their communities.
➤ **Employment-related activities:** Individuals with developmental disabilities acquire, retain, or advance in paid employment, including supported employment or self-employment, in integrated settings in a community.
➤ **Housing-related activities:** Individuals with developmental disabilities have access to and use of housing and housing supports and services in their

> communities, including assistance related to renting, owning, or modifying an apartment or home. Michigan citizens with disabilities, senior citizens and members of other vulnerable populations, including those from culturally diverse backgrounds, live in the accessible, affordable, safe housing of their choice and get the services and supports they need to participate and contribute in inclusive communities.

The U.S. Department of Health and Human Services, Administration for Children and Families' **Developmental Disabilities Program Independent Evaluation (Ddpie) Project** has proposed measuring outcomes in terms of:

1. Informed choices
2. Employment
3. Housing
4. Health care
5. Transportation
6. Integrated community living
7. Freedom from abuse, neglect, financial and sexual exploitation
8. Freedom from violation of legal and human rights

The **Participant Experience Survey: Mental Retardation/Developmental Disabilities (PES MR/DD)** is an interview tool that captures data that can be used to gather information regarding program participants' experiences with the services and supports they receive under Medicaid Home and Community Based Services Waivers. The instrument provides indicators of program participants' experiences in four priority areas:

1. **Choice and Control:** Program participants have input into the types of services they receive and who provides them and can help make choices about where they live and how they spend their day.
2. **Respect/Dignity:** Program participants are treated with respect by providers.
3. **Access to Care:** Program participants' needs for personal assistance, adaptive equipment, and case manager access are being met.
4. **Community Integration/Inclusion:** Program participants participate in activities and events outside their homes when they want to and of their choosing.

Fifty one performance indicators within these priority areas can be calculated for quality monitoring and intervention for an entire sample, or different sub-samples (e.g., program participants served by different providers) and compared across groups. The tools and a user's guide are available from the Center for Medicaid & Medicare Services at
http://www.qualitytools.ahrq.gov/summary/summary.aspx?doc_id=7133.

A broad range of indicators of quality of life outcomes measures have been put forth. However, a consensual conceptualization of quality of life is still emerging; more than one hundred definitions and models of quality of life have been proposed. One of the most commonly used conceptualizations is the five valued experiences proposed by O'Brien and O'Brien: sharing ordinary places and activities; making choices; developing abilities and sharing personal gifts; being respected and having a valued social role; and growing in relationships. A number of definitions of quality of life have been used for research purposes and various studies have examined quality of life across domains such as:

Emotional well-being: Safety, happiness, spirituality, freedom from stress, self concept, contentment
Interpersonal relations: Intimacy, affection, family, interactions, friendships, support

Material well-being:	Ownership, financial security, food, employment, possession, social economic status, shelter
	Personal development: education, skills, fulfillment, personal competence, purposeful activity, advancement
Physical well-being:	Health, nutrition, recreation, mobility, health care, health insurance, leisure, activities of daily living
Self determination:	Autonomy, choice, decision-making, personal control, self-direction, personal goals/values
	Social inclusion: acceptance, status, supports, work environment, community activities, roles, volunteer activities, residential environment
Rights:	Privacy, voting, access, due process, ownership, civic responsibilities

CONCLUSIONS AND RECOMMENDATIONS

The past decades have witnessed progressively more individualization in the design of services and supports for people with developmental disabilities. Propelled by an increasingly strong advocacy movement, a transformation from institutionally-based models to segregated community-based options (e.g., group homes and sheltered workshops) was engendered. Driven by person-centered values and self-determination, consumer-directed supports, consumer-controlled housing, and other individually-oriented options, individuals with developmental disabilities have much greater opportunities for control over their lives. Innovations in the provision, design, and delivery of personal care, as well as vocational, educational, and recreational supports are now available to more consumers.

Despite progress, many challenges still exist. The majority of individuals with developmental disabilities served in the public sector still find their lives controlled by agencies that purport to provide supports for them to lead lives they desire. And, although more now live in smaller community-based residences, these residences are owned by others and do not offer choice in the selection of housemates or roommates. "Going home" all too often means visiting family on weekends or holidays rather than having a sense of one's own home. Moreover, although more people with developmental disabilities participate in supported employment, the majority still work in segregated programs, earning very modest wages and performing work that is not matched to their interests. And, the majority of people in their lives are people who are paid to be present.

A legacy of older, outdated service and support options compete with those that are newer and more progressive for a limited set of resources; scarce and valuable resources continue to be spent on outdated non-inclusive services and supports. Individuals with developmental disabilities still experience high rates of poverty, lack of access to affordable and accessible housing, shortages of personal assistance and direct support professionals, discrimination, and stigma. They are still all too often "placed" into congregate program or facility "slots" with others who have similar disabilities and in isolation from their communities.

Contemporary principles and values underlying the provision of services and supports for individuals with developmental disabilities and their families include:

- Children belong with their families. Families are the major decision-makers for their children. As children grow older, authority and power should shift to them as consumers in their own right with the assistance of family and friends.

- Adults should control where and with whom they live, and have opportunities to rent or purchase their own homes.

- The planning and provision of services and supports are based on needs, strengths, and abilities, and predicated on informed choice. People seldom choose options that they are unfamiliar with. Individuals with developmental disabilities and their supporters need clear and consistent information regarding services and supports and access to training and tools to enable them to make informed decisions, select service providers, and be able to appropriately and effectively manage their own services and supports.

- Individuals with developmental disabilities, their families, and community members should be able to access resources available in the community (e.g., jobs, houses, and friends) rather than resources provided solely by human service agencies and populated by people with disabilities and agency staff. The abilities of a

community's citizens can be harnessed to teach skills, help with participation, model appropriate behaviors, and for the development of relationships.

- Services and supports need to be coordinated around the life of an individual, rather than around the needs of agencies, staff, programs, and services.

Meeting the needs of people with developmental disabilities focuses on quality of life issues including presence in the community; health and safety; opportunities for personal growth and access to self-determination. A variety of services and supports are required including supported employment, housing, recreation and leisure activities, medical care, and transportation. Support and service planning needs to be coordinated among the various service systems, agencies, and programs that individuals with developmental disabilities and their supporters interface with. Collaborative alliances between agencies and service systems can reduce duplication and the need for one agency or service system to try to offer comprehensive services.

Effective interventions for persons with developmental disabilities are designed to build functional and adaptive coping skills or compensate for deficits. No single intervention has been found to be fully effective. Instead, optimal benefits are usually the result of the application of multi-component and multimodal interventions with various elements tailored to address individual needs. Skills training, wraparound supports for employment and community living, stimulus control, and contingencies of reinforcement are used. Ecological interventions (e.g., changes in physical environments to reduce over stimulation or criticism, and that engender congruency of fit between assets and deficits in employment and residential settings), positive programming to teach effective and socially acceptable ways of getting one's needs met, and coping skills for tolerating everyday frustrations have been found to be effective. Integration into traditional work and community life are the focus. This includes assistance with ameliorating problem behaviors that interfere with day-to-day living and addressing health, cognition, communication, sensory-motor skills, social integration, emotional/behavioral skills, and self-help skills.

The following recommendations are made based upon a review of current trends and research:

- Continue to promote and offer alternatives to services and supports organized around congregate models that isolate individuals from their community and include activities without social valence; continue to expand options for services and supports that are individualized, inclusive, highly regarded, and respect the wishes and the dreams of the individual and their supporters. For example, congregate day/rehabilitation programming alternatives include individually designed employment supports (or other meaningful activities) as the mainstay of a consumer's day. Where feasible and within available resource limits, continue to offer options for living arrangements that are freely chosen and personally controlled.

- Continue to expand self-determination so more consumers have access to individual budgets so that decision-making regarding expenditures of public dollars for the support and care of individual consumers are made by those consumers, their families, and trusted supporters.

- Continue to promote personal agentry so that agencies function less as administrators of specialized services and more as brokers for individuals and their families, providing assistance in locating and utilizing community resources.

- Review interventions currently in use to ascertain whether they meet the evidence-based practice criteria and eliminate those that do not by redirecting resources to implementing practices with a sufficient base of empirical support.

APPENDIX A: SELECTED REFERENCES

Abramson, W., Emanuel, E., Hayden, M, (Eds.) (2000). Feature Issue on Violence Against Women with Developmental or Other Disabilities. *Impact 13:* 1-28. Institute on Community Integration, University of Minnesota. Minneapolis, MN. [On-line]. Available: http://ici.umn.edu/products/impact/133/133.pdf.

Administration on Developmental Disabilities. (2004). *The American Dream Belongs to Everyone: A Report to Congress, the President, and the National Council on Disability Fiscal Years 2003-2004.* Administration on Developmental Disabilities, Administration for Children and Families, U.S. Department of Health and Human Services. Washington, DC.

Agosta, J. (2004). Pointers for Families and Individuals Who Want to Manage Their Own Services. *Impact 17:* 6-7.

Amado, A., McBride, M. (2001). *Increasing Person-Centered Thinking: Improving the Quality of Person-Centered Planning: A Manual for Person-Centered Planning Facilitators.* University of Minnesota, Institute on Community Integration. Minneapolis, MN.

American Academy of Child & Adolescent Psychiatry. (1999). *Facts for Families, Asperger's Disorder.* [Online]. Available: http://www.aacap.org/publications/factsfam/69.htm.

American Academy of Child and Adolescent Psychiatry. (1999). *Practice Parameters for the Assessment and Treatment of Children, Adolescents, and Adults with Autism and Other Pervasive Developmental Disorders.* [On-line]. Available: http://www.aacap.org/galleries/PracticeParameters/Autism.pdf.

American Academy of Child and Adolescent Psychiatry. (1999). *Practice Parameters for the Assessment and Treatment of Children, Adolescents, and Adults with Mental Retardation and Comorbid Mental Disorders.* [On-line]. Available: http://aacap.org/galleries/PracticeParameters/Mr.pdf.

American Academy of Child and Adolescent Psychiatry. (1998). *Practice Parameters for the Assessment and Treatment of Children and Adolescents with Language and Learning Disorders.* [Online]. Available: http://www.aacap.org/galleries/PracticeParameters/Lang.pdf.

American Academy of Family Physicians. (1999). *Information from Your Family Doctor. Understanding Tics and Tourette's Syndrome.* [On-line]. Available: www.aafp.org/afp/990415ap/990415f.html.

American Academy of Pediatrics. (2006). Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening. *Pediatrics 118:* 405-420.[On-line]. Available: http://aappolicy.aappublications.org/cgi/reprint/pediatrics;118/1/405.pdf.

American Psychiatric Association. (1994). Diagnostic and Statistical Manual of Mental Disorders - 4th edition (DSM-IV). American Psychiatric Association. Washington, D.C.

American Speech-Language-Hearing Association. (2005). The Prevalence and Incidence of Hearing Loss in Adults. American Speech-Language-Hearing Association. [On-line]. Available: www.asha.org/public/hearing/disorders/prevalence_adults.htm.

Anderson, L., Larson, S. (1995/96). Parental Attitudes Toward Deinstitutionalization. In Hayden, M., Lakin, K. Taylor, S. (Eds.). *IMPACT: Feature Issue on Institution Closures, 9.* Institute on Community Integration, University of Minnesota. Minneapolis, MN.

Andrews, K., Weathers, B. Liu, S. (2007). How Do Medicaid Buy-In Participants Who Collect Social Security Disability Insurance Benefits Use SSA Work Incentive Programs? Mathematica Policy Research, Inc. Washington, DC. [On-line]. Available: http://www.mathematica-mpr.com/publications/pdfs/WWDsocialsecurity.pdf.

Apolloni, T., Meucci, S., Triest, G. (1981). *Monitoring the Quality of Life Experienced in Living Arrangement: A Guide to Citizen Participation.* California State Council on Developmental Disabilities. Sacramento, CA.

Asmus, J., Ringdahl, J., Sellers, J., et al. (2004). Use of a Short-Term Inpatient Model to Evaluate Aberrant Behavior: Outcome Data Summaries from 1996 to 2001. J*ournal of Applied Behavior Analysis 37:* 283-304.

Autistic Children's Activity Program (ACAP). (2002). *What is Autism?* [Online]. Available: http://www.autism.com/acap/.

Autism Society of America. (2002). *What is Autism?* [Online]. Available: http://www.autismsocietyorg/whatisautism/autism.html.

Autism Spectrum Disorders. (2002). Overview of Autism Spectrum Disorders. [Online]. Available: http://www.geocities.com/Heartland/Fields/6979/.

Barwick, M., Boydell, K., Stasiulis, E., et al. (2005). *Knowledge Transfer and Evidence-Based Practice in Children's Mental Health.* Children's Mental Health Association. Toronto, ON. [On-line]. Available: www.cmho.org.

Baxley, D., Janicki, M., McCallion, P., Zendell, A. (Undated). *Aiding Older Caregivers of Persons with Intellectual and Developmental Disabilities: A Toolkit for State and Local Aging Agencies.* Center on Intellectual Disabilities, University at Albany. Albany, NY. [On-line]. Available: http://www.albany.edu/aging/IDD/documents/aidingoldercaregivers-toolkit.pdf.

Bebko, J., Wainwright, J., Brian, J., et al. (2006). Social Competence and Peer Relations in Children with Mental Retardation: Models of the Development of Peer Relations. *Journal on Developmental Disabilities 20th Anniversary Issue: 89-113.*

Benson, B.A. (1992). Teaching Anger Management to Persons with Mental Retardation. IDS Publications Corporation. Worthington, OH.

Berol, B. (2001). Learning from a Peron's Biography: An Introduction to the Biographical Timeline Process. *The Pennsylvania Journal on Positive Approaches 3:* 1-14. [On-line]. Available: http://www.nasddds.org/pdf/LearningFromAPerson.pdf.

Bazelon, E. (August 5, 2007). What Are Autistic Girls Made Of? *The New York Times Magazine: 3*8-43.

Biklen, S., Moseley, C. (1988). "Are you retarded?" "No, I'm Catholic.": Qualitative Methods in the Study of People with Severe Handicaps. *Journal of the Association for Persons with Severe Handicaps 13:* 155-162.

Borthwick-Duffy, S., Eyman, R. (1990). Who Are the Dually Diagnosed? *American Journal of Mental Retardation 94:* 586-595.

Braddock, D. (Ed.). (2002). *Disability at the Dawn of the 21st Century and the State of the States.* American Association on Mental Retardation. Washington, DC.

Bradley, V. (2004). The Impact of Self-Determination on Services and Supports. *Impact 17:* 2-3.

Brasic, J. (2002). Pervasive Developmental Disorder: Asperger Syndrome. *E-medicine.* [Online]. Available: http://www.emedicine.com/ped/topic147.htm#section~treatment.

Bregman, J.D. (1991). Current Developments in the Understanding of Mental Retardation, Part II: Psychopathology, *Journal of the American Academy of Child and Adolescent Psychiatry 31:* 861-872.

British Columbia Ministry of Children and Family Development. (Undated). *Transition Planning for Youth with Special Needs: A Community Support Guide.* British Columbia Ministry of Children and Family Development. BC, Ca. [On-line]. Available: http://www.mcf.gov.bc.ca/spec_needs/pdf/support_guide.pdf.

Brown, K., Wacker, D., Derby, K., et al. (2000). Evaluating the Effects of Functional Communication Training in the Presence and Absence of Establishing Operations. *Journal of Applied Behavior Analysis 33:* 53-71.

Burns, B., Hoagwood, K, Mrazek, P. (1999). *Effective Treatment for Mental Disorders in Children and Adolescents.* Clinical Child and Family Psychology Review 2(4).

Bush, G. W. (2001, June 19). *Executive Order 13217: Community Based Alternatives for Individuals with Disabilities.* The White House. Washington, DC. [On-line]. Available: http://whitehouse.gov/news/releases/2001/06/19/20010619.html.

Butler, C., Chambers, H., Goldstein, M., et al. (2006). *Evaluating Research in Developmental Disabilities: A Conceptual Framework for Reviewing Treatment Outcomes.* American Academy for Cerebral Palsy and Developmental Medicine. Rosemont, IL. [On-line]. Available: http://www.aacpdm.org/index?service=page/treatmentOutcomesReport.

California Department of Developmental Disabilities. (2002). *Autistic Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment.* California Department of Developmental Disabilities. Sacramento, CA.

Carey, B. (2008). Drugs Used on Aggression in Those With Low IQs Provide No Benefit, Study Says. *The New York Times: CLVII* A10.

Carlson, B. (1997). Mental Retardation and Domestic Violence: An Ecological Approach to Intervention. *Social Work 42:* 79-89.

Carlson, M. (2004). *With Open Hands: The Project Homecoming Guidebook for Faith Communities.* People First Wisconsin. Milwaukee, WI.

Carr, E., Dunlap, G., Horner, R., et al. (2002). Positive Behavior Support: Evolution of an Applied Science. *Journal of Positive Behavior Interventions 4:* 4-16.

Carr, E., Horner, R., Turnbull, A., et al. (1999). Positive Behavior Support for People with Developmental Disabilities: A Research Synthesis. *American Association on Mental Retardation Monograph Series.* American Association on Mental Retardation. Washington, DC. [On-line]. Available: http://rrtcpbs.fmhi.usf.edu/rrtcpbsweb/Products/research_synthesis_brief.pdf.

Carr, J., Firth, A. (2005). The Verbal Behavior Approach to Early and Intensive Behavioral Intervention for Autism: A Call for Additional Empirical Support. *Journal of Early and Intensive Behavior Intervention 2:* 18-27.

Center for Mental Health Services. (2005). *Free To Choose: Transforming Behavioral Health Care to Self-Direction.* Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.

Centers for Medicare & Medicaid Services. (2004). *Intermediate Care Facility for People with Mental Retardation Program (ICF/MR).* [On-line]. Available: http://www.cms.hhs.gov/medicaid/icfmr/default.asp.

Center on Human Policy, Syracuse University. (1979). *The Community Imperative: A Refutation of all Arguments in Support of Institutionalizing Anybody Because of Mental Retardation.* Center on Human Policy, Syracuse University. Syracuse, NY. [On-line]. Available: http://thechp.syr.edu/community_imperative.html.

Cheek, M. (2001, Spring). Serving Persons with MR/DD Who are Involved with State Criminal Justice Systems. In Hanson, R., Wiesler, N., Lakin, K. (Eds.). *IMPACT: Feature Issue on Behavior Support for Crisis Prevention and Response 14:* 22-23. Institute on Community Integration, University of Minnesota. Minneapolis, MN. [On-line]. Available: http://ici.umn.edu/products/impact/141/prof6.html.

Condon, E., Brown, K. (2008). Planning for Your Transition from High School to Adult Life: A Workbook to Help You Decide What You Want Your Life to Look Like After Graduation. The Rural Institute. Missoula, MT. [On-line]. Available: http://ruralinstitute.umt.edu/transition/Articles/PlanningWorkbook.pdf.

Corbett, B., Abdullah, M. (2005). Video Modeling: Why does it Work for Children with Autism? *Journal of Early and Intensive Behavior Intervention 2:* 2-8.

Daniles, R., Samis, M. (1995/1996). Inside and Out: Former Residents Reflect on Their Lives. *Impact 9.* Institute on Community Integration, University of Minnesota. Minneapolis, MN.

Davis, D., Fox-Grage, W., Gehshan, S. (2004). *Deinstitutionalization of Persons with Developmental Disabilities: A Technical Assistance Report for Legislators.* National Conference of State Legislatures. Denver & Washington, D.C. [On-line]. Available: http://www.ncsl.org/programs/health/Forum/pub6683.htm.

Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1994, P.L. 103-230, Section 101(a)(1).

Dobbs, D. (July 8, 2007). The Gregarious Brain. *The New York Times. CLVI*: 42-47.

duPree, K. (2004). Effective Interagency Collaboration for People with Co-Occurring Mental Illness and Developmental Disabilities. *National Association of the Dually Diagnosed Bulletin. 7:* 16.

Dugan, L. Millborne, S. Campbell, P., Wilcox, M. (2004). Evidence Based Practice in Assistive Technology. *Research Brief Volume 1, Number 5.* Tots n Tech Research Institute. [On-line]. Available: http://tnt.asu.edu.

Eaton, L., Menolascino, F. (1982). Psychiatric Disorder in the Mentally Retarded: Types, Problems, and Challenges. *American Journal of Psychiatry 139:* 1297-1303.

Eidelman, S., Pietrangelo, R. Gardner, J., et al. (2003). Let's Focus on the Real Issues. *Mental Retardation 41:* 126-129.

Elder, J.H. (2002). Current Treatments in Autism: Examining Scientific Evidence and Clinical Implications. *Journal of Neuroscience Nursing 34:* 2.

Feinstein, C. & Reiss, A.L. (1996). Psychiatric Disorder in Mentally Retarded Children and Adolescents: The Challenges of Meaningful Diagnosis. *Child and Adolescent Psychiatric Clinics of North America 5:* 827-52.

Feldman, M. (2006). Cost-Benefit of Effective Interventions. *Journal on Developmental Disabilities 20th Anniversary Issue:* 83-87.

Feldman, M. (2004). Self-Directed Learning of Child Care Skills by Parents with Intellectual Disabilities. *Infants and Young Children 17:* 17-31.

Feldman, M., Case, L., Garrick, M., et al. (1992). Teaching Child-Care Skills to Mothers with Developmental Disabilities. *Journal of Applied Behavior Analysis 25:* 205-215. [On-line]. Available: http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=1279667&blobtype=pdf.

Ferraioli, S., Hughes, C., Smith, T. (2005). A Model for Problem Solving in Discrete Trial Training for Children with Autism. *Journal of Early and Intensive Behavior Intervention 224:* 246.

Fombonne, E. (1997). Epidemiology of Autism and Related Conditions. In Volkar, F. (Ed.). *Autism and Pervasive Developmental Disorders:* 32-63. Cambridge University Press, England.

Gardner, J. (2003, Summer/Fall). Quality and Accountability for 7 Cents a Day. *Capstone 20:* 1, 3. The Council for Quality and Leadership. Towson, MD. [On-line]. Available: http://www.thecouncil.org/council/about/Capstones/summer03.pdf.

Garland, C., O'Hanlon, M. (November 21, 2006). Studying Autism Isn't Enough. *The New York Times.* A29.

Glassheim, B. (2005). *A Guide to Evidence-Based Practices for Adults with Mental Illness.* Saginaw County Community Mental Health Authority. Saginaw, MI. [On-line]. Available: SCCMHA - Quality.

Glassheim, B. (2006). *A Guide to Evidence-Based Mental Health Practices for Children, Adolescents and their Families.* Saginaw County Community Mental Health Authority. Saginaw, MI(. [On-line]. Available: SCCMHA - Quality.

Golden, J. (2004). Self-Directed Support Corporations: What a Difference They Can Make. *Impact 17:* 10, 30

Goode, D. (1998) *"And Now Let's Build A Better World": The Story of the Association for the Help of Retarded Children, New York City 1948 – 1998.*Association for the Help of Retarded Children. New York, NY. [On-line]. Available: http://www.ahrcnyc.org/pdf/ahrc_history.pdf

Grey, I., Hastings, R. (2005). Evidence-Based Practices in Intellectual Disability and Behaviour Disorders. *Current Opinion in Psychiatry 18:* 469-475.

Griswold, K., Goldstein. M. (1999). Issues Affecting the Lives of Older Persons with Developmental Disabilities. *Psychiatric Services 50:* 315-317.

Hanley, G., Iwata, B., McCord, B. (2003). Functional Analysis of Problem Behavior: A Review. *Journal of Applied Behavior Analysis 36:* 147-184.

Hanson, R., Wieseler, N., Lakin, K. (Eds.). (2002). *Crisis Prevention and Response in the Community.* American Association on Mental Retardation. Washington, DC.

Hanson, R., Wieseler, N., Lakin, K. (2000). *Impact: Feature Issue on Behavior Support for Crisis Prevention and Response.* Institute on Community Integration. University of Minnesota, Minneapolis. [On-line]. Available: http://ici.umn.edu/products/impact/141/.

Harris, J. (1995). *Developmental Neuropsychiatry*, Vols. 1-2. Oxford University Press. New York, NY.

Hassan, S., Gordon, R. (2003). *Developmental Disability, Crime, and Criminal Justice: A Literature Review.* Criminology Research Centre, Simon Fraser University. Burnaby, BC.

Hasselbring, T., Williams Glaser, C. (2000). Use of Computer Technology to Help Students with Special Needs. *The Future of Children: Children And Computer Technology.10: 10*2–122. [On-line]. Available: http://www.futureofchildren.org/usr_doc/vol10no2Art5.pdf.

Hawaii Department of Health. (2004). Summary of Evidence-Based Interventions for Youth with Behavioral and Emotional Disorders. Hawaii Department of Health, Child and Adolescent Mental Health Division. Honolulu, HW.

Hayden, M. (1997). *Living in the Freedom World: Personal Stories of Living in the Community by People who Once Lived in Oklahoma's Institutions.* University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration (UAP). Minneapolis, MN.

Healey, K. (February 1999). Case Management in the Criminal Justice System. *Research in Action.* U.S. Department of Justice, Office of Justice Programs. Washington, DC.

Heaton-Ward, A. (1977). Psychosis in Mental Handicap. *British Journal of Psychiatry 130:* 525-33.

Herrera, C., Pepper, S. (2000). *Faith in Action: Using Interfaith Coalitions to Support Voluntary Caregiving Efforts.* Public/Private Ventures. New York, NY.

Hewitt, A. (2004). Finding, Keeping and Training Staff When Individuals and Families Control the Budget. *Impact 17:* 8-9, 28-29.

Hieneman, M., Nolan, M., Presley, J., et al. (1999) *Facilitator's Guide, Positive Behavioral Support.* Florida Department of Education, Bureau of Instructional Support and Community Services. Tallahassee, FL. [On-line]. Available:
http://www.fmhi.usf.edu/cfs/cfspubs/pbsguide/facilitatorguidepbs.htm.

Hocutt, A. (1996). Effectiveness of Special Education: Is Placement the Critical Factor? *The Future of Children 6:* 77-102.

Holburn, S., Jacobson, J., Schwartz, A., et al. (2004). The Willowbrook Futures Project: A Longitudinal Analysis of Person-Centered Planning. *American Journal on Mental Retardation 1:* 63-76. [On-line]. Available:
http://coverpage.montclair.edu/media/generator/1602/user/Willowbrook_longitud.pdf.

Hollins, S., Sinason, V., & Thompson, S. (1994). Individual, Group, and Family Psychotherapy. In Bouras, N. (Ed.), *Mental Health in Mental Retardation:* 233-43. Cambridge University Press. New York.

Horowitz, S., Kerker, B., Owens, P., Zigler, E. (2001). *The Health Status and Needs of Individuals with Mental Retardation.* Yale University School of Medicine. New Haven: [On-line]. Available:
http://www.specialolympics.org/world_games/game_stories/Health%20Status.pdf.

Institute on Community Integration, University of Minnesota. (Winter 2001/02). Feature Issue on Faith Communities and Persons with Developmental Disabilities. *Impact: 14* 1-35. Institute on Community Integration (UCEDD) and the Research and Training Center on Community Living, College of Education and Human Development, University of Minnesota. [On-line]. Available:
http://ici.umn.edu/products/impact/143/143.pdf.

Institute on Community Integration, University of Minnesota. (Winter2005/06) Feature Issue on Children with Disabilities in the Child Welfare System. *Impact: 19:* 1-40. Institute on Community Integration (UCEDD) and the Research and Training Center on Community Living, College of Education and Human Development, University of Minnesota. Minneapolis, MN [On-line]. Available: http://ici.umn.edu/products/impact/191/191.pdf.

Institute on Community Integration, University of Minnesota. Spring/Summer 2006). Feature Issue on Parenting Teens and Young Adults with Disabilities. *Impact 19:* 1-28. Institute on Community Integration, University of Minnesota. Minneapolis, MN. [On-line]. Available:
http://ici.umn.edu/products/impact/192/192.pdf.

Jellinek, P. (2001). Faith In Action: Building Capacity For Interfaith Volunteer Caregiving. *Health Affairs 20:* 273-278.

Johnson, C., Hasko, D., Scheib, L. (2006). *Transition Guide for Washington State.* The Center for Change in Transition Services, Seattle University. Seattle, WA.

Kim, S., Larson, S., Lakin, K. (1999). *Behavioral Outcomes of Deinstitutionalization for People with Intellectual Disabilities: A Review of Studies Conducted Between 1980 and 1999. Policy Research Brief 10.* University of Minnesota, Institute on Community Integration. Minneapolis, MN. [On-line]. Available: http://ici.umn.edu/products/prb/101/default.html.

Kim, S., Larson, S., Lakin, K. (2001). Behavioural Outcomes of Deinstitutionalization for People with Intellectual Disability: A Review of US Studies Conducted Between 1980 and 1999. *Journal of Intellectual & Developmental Disability 26:* 35-50.

Kingsbury , L. (2005). Person Centered Planning and Communication of End-Of-Life Wishes With People Who Have Developmental Disabilities. *Journal of Religion, Disability and Health 9:* 81-90

Kirby, B. L. (2001). Asperger Syndrome Information and Support Web Page. *What is Asperger Syndrome?* [Online]. Available: http://www.udel.edu/bkirby/asperger.

Koegel, R., Koegel, L., Brookman, L. (2003). Empirically Supported Pivotal Response Interventions for Children with Autism. In Kazdin. A., Weiss, J. (Eds.). *Evidence-Based Psychotherapies for Children and Adolescents.* The Guildford Press. New York.

Kurlan, R. (2002). *Current Pharmacology of Tourette Syndrome.* Tourette Syndrome Association, Inc. [Online]. Available: http://www.tsa-usa.org.

Lakin, K. (Spring 2001). Community for All: Experiences in Behavior Support and Crisis Response. In Hanson, R., Wiesler, N. Lakin, K. (Eds.). *Impact: Feature Issue on Behavior Support for Crisis Prevention and Response 14:* 2-3, 27. Institute on Community Integration, University of Minnesota. Minneapolis, MN. [On-line]. Available: http://ici.umn.edu/products/impact/141/over2.html.

Lakin, K., Prouty, R., Polister, B., Coucouvanis, K. (2004). States' initial response to the President's New Freedom Initiative: Slowest Rates of Deinstitutionalization in 30 Years. *Mental Retardation 42:* 241-244.

Larson, S., Lakin, K. (1991). Parent Attitudes about Residential Placement Before and After Deinstitutionalization: A Research Synthesis. *JASH 16: 25-38.*

Laski, K., Charlop, M., Schreibman, L. (1988). Training Parents to use the Natural Language Paradigm to Increase Their Autistic Children's Speech. *Journal of Applied Behavior Analysis: 21:* 391-400.

LaVigna, G., Christian, L., Liberman, R., et al. (2002). Training Professionals in Use of Positive Methods for Community Integration of Persons with Developmental Disabilities. *Psychiatric Services 55:* 16-18.

Lewit, E., Baker, L. (1996). Children in Special Education. *The Future of Children 6:* 139-151.

Lindsay, W. (2002). Research and Literature on Sex Offenders with Intellectual and Developmental Disabilities. *Journal of Intellectual Disability Research 46 (supp.):* 74-85.

Liu, S., Weathers, B. (2007). Do Participants Increase Their Earnings After Enrolling in the Medicaid Buy-In Program? *Working with Disability, Earnings In Brief #4. Mathematica* Policy Research, Inc. Washington, DC. [On-line]. Available: http://www.mathematica-mpr.com/publications/PDFs/WWDparticipants.pdf.

Lovaas, I. , Smith, T. (2003). Early Intensive Behavioral Intervention in Autism. In Kazdin. A., Weiss, J. (Eds). *Evidence-Based Psychotherapies for Children and Adolescents.* The Guildford Press. New York.

Martin, E., Martin, R., Terman, D. (1996). The Legislative and Litigation History of Special Education. *The Future of Children 6:* 25-39.

Masi, G. (1998). Psychiatric Illness in Mentally Retarded Adolescents: Clinical Features. *Adolescence 33:* 425-35.

McCart, A., Juracek, D., (2007). Practical Strategies for Supporting Families in the Use of Positive Behavior Support. *Association for Positive Behavior Support Newsletter 5:* 1-4.

McConnell, D., Llewllyn, G. (1998). Parental Disability and the Threat of Child Removal. *Family Matters 51:* 33-36.

McLean, J., McLean, L., Brady, N., Etter, R. (1991). Communication Profiles of Two Types of Gestures using Nonverbal Persons with Severe to Profound Mental Retardation. *Journal of Speech and Hearing Research 34:* 294-308.

Medstat. (2004). *Money Follows the Person and Balancing Long-Term Care Systems: State Examples.* Centers for Medicare and Medicaid Services. Baltimore, MD. [On-line]. Available: http://www.cms.hhs.gov/PromisingPractices/Downloads/mfp92903.pdf.

Medstat. (2004). *Promising Practices in Long Term Care Systems Reform: Michigan's Managed Specialty Services System.* Centers for Medicare and Medicaid Services. Baltimore, MD. [On-line]. Available: http://www.cms.hhs.gov/PromisingPractices/Downloads/mimsss.pdf.

Medstat. (2002). The Right People for the Job: Recruiting Direct-Care Workers for Home and Community-Based Care. *Workforce Tools 1:* 1-8. [On-line]. Available: http://www.directcareclearinghouse.org/download/WorkforceTools_Vol1No1.pdf.

Mellum, J., Heffernan, K. (2004). Consumer-Directed Community Supports: A County Perspective on a New Service Option. *Impact 17:* 18-19, 31.

Michigan Department of Community Health (2008). Mental Health/Substance Abuse Medicaid Provider Manual. Michigan Department of Community Health. Lansing, MI. [On-line]. Available: http://www.mdch.state.mi.us/dch-medicaid/manuals/MedicaidProviderManual.pdf.

Michigan Department of Community Health. (2003). Self Determination Policy and Practice Guideline. Michigan Department of Community Health. Lansing, MI. [On-line]. Available: http://www.michigan.gov/documents/SelfDeterminationPolicy_70262_7.pdf.

Michigan Developmental Disabilities Council. (Undated). *Developmental Disabilities Five-Year Strategic Plan: Fiscal Years 2007-2011.* Michigan Developmental Disabilities Council. Lansing, MI. [On-line]. Available: http://www.michigan.gov/documents/mdch/5-yrstateplan_179395_7.pdf.

Michigan Developmental Disabilities Council. (Undated). Michigan Developmental Disabilities Council 2008 Public Policy Platform: *Our Community Includes Everyone.* Michigan Developmental Disabilities Council. Lansing,

Mistrett, S. (2001). *Synthesis on the Use of Assistive Technology with Infants and Toddlers (Birth through Age Two).* U.S Department of Education, Office of Special Education Programs, Division of Research to Practice. Washington, DC.

Moseley, C. (2004). Individual Budgeting, Control and Support: What Systems Need to Tell People. Institute on Community Integration, University of Minnesota. Minneapolis, MN. *Impact 17:* 4-5.

Moseley, C., Lakin, C., Hewitt, A. (Eds). (2004). *Consumer-Controlled Budgets and Persons with Disabilities.* Institute on Community Integration, University of Minnesota. Minneapolis, MN. *Impact 17:* 1-32. [On-line]. Available: http://ici.umn.edu/products/impact/171/default.html.

Moss, K., Wiley, D. (Undated). *A Brief Guide to Personal Futures Planning Workbook.* Texas School for the Blind and Visually Impaired. Austin, Tx.

Mount, B., Zwernik, K. (1988). *It's Never Too Early, It's Never Too Late: A Booklet about Personal Futures Planning.* Governor's Planning Council on Developmental Disabilities. St. Paul, MN. [On-line]. Available: http://www.mncdd.org/extra/publications/Never_too_Early.PDF.

National Alliance for Mental Health. (2002). *Tourette's Syndrome Fact Sheet.* [Online]. Available: http://www.nami.org/helpline/tourette.html.

National Association of Protection and Advocacy Systems (NAPAS). (2003). *Community Integration/Medicaid.* National Association of Protection and Advocacy Systems. Washington, DC. [On-line]. Available:
http://www.napas.org/I-3/I-3-D/community%20integrationmedicaid%20home.htm.

National Center for Special Education Research at the Institute of Education Sciences. (2003). LEAP – USA (Using Science-Based Approaches). Institute of Education Sciences. Washington, DC.

National Clearinghouse on Family Violence. (1998). *Addressing the Needs of Developmentally Delayed Sex Offenders: A Guide.* National Clearinghouse on Family Violence, Health Canada. Ottawa, Ont.

National Council on Disability. (2003). *Olmstead: Reclaiming Institutionalized Lives.* National Council on Disability. Washington, DC. [On-line]. Available:
http://www.ncd.gov/newsroom/publications/2003/reclaimlives.htm.

National Institute of Mental Health and Tourette Syndrome Association. (2000). *Warning About Two Therapies for Tourette's, OCD (Obsessive-Compulsive Disorder).* [Online]. Available: http://intramural.nihm.nih.gov/research/pdn/web.htm.

National Institute of Neurological Disorders and Stroke of the National Institutes of Health. (1995). *Tourette Syndrome.* [Online]. Available:
http://www.ninds.nih.gov/patients/disorder/tourette/tourette.htm.

National Institutes of Health. (September 2007). *NIH News in Health.* National Institutes of Health. Bethesda, MD. [On-line]. Available: nih.gov.

Nelis, T. (1995/96). The Realities of Institutions. In Hayden, M., Lakin, K., Taylor, S. (Eds.), *IMPACT 9:* 1, 27. Minneapolis: Institute on Community Integration, University of Minnesota.

Nerney, T. (2001). *Filthy Lucre: Creating Better Value in Long Term Supports.* Center for Self-Determination. Wayne, MI.

Nerney, T. (2004). *Quality Issues in Consumer/Family Direction.* (2004). Paper prepared for the SAMHSA Consumer Direction Summit, March 2004.

Nerney, T. (2007). *Self-Determination: Individual Costs, System Costs, and Quality of Life.* The Center for Self-Determination. Wayne, MI. [On-line]. Available: http://www.self-determination.com/articles/Cost_and_quality_data.pdf.

Nerney, T. (2004). *Lost Lives: Why we Need a New Approach to Quality.* Center for Self-Determination. Wayne, MI.

Nerney, T., Crowley, R., Kappel, B. (Undated). *An Affirmation of Community; A Revolution of Vision and Goals: Creating a Community to Support All People Including those with Disabilities.* Institute on Disability, University of New Hampshire. Durham, NH.

Nesbit, J. (1998). Creating the Capacity for Change: Lessons from the Evolution of the New Hampshire Developmental Service System. In *Toward a Community Support System for the Elderly.* Institute for Health, Law and Ethics, Franklin Pierce Law Center. Concord, NH.

Nezu, C., Greenberg, J., Nezu, A. (2005). Cognitive Behavioral Assessment and Treatment for Sex Offenders with Intellectual Disability. *International Journal of Behavioral Consultation and Therapy 1:* 191-203.

NINDS Asperger Syndrome Information Page. [Online]. Available: http://www.ninds.nih.gov/health_and_medical/disorders.

O'Brien, J. (1995, Winter). Issues and Challenges in Developing Individualized Supports. In *Individualized Services in New York State Policy Bulletin No. 4:* 20-22. Research and Training Center on Community Integration, Center on Human Policy, School of Education, Syracuse University. Syracuse, NY. [On-line]. Available: http://thechp.syr.edu/nysbisch.htm.

O'Brien, J., O'Brien, C. (1993). *Assistance with Integrity: The Search for Accountability and the Lives of People with Developmental Disabilities.* Responsive Systems Associates. Lithonia, GA. [On-line]. Available: http://thechp.syr.edu/!integri.pdf.

O'Brien, C., O'Brien, J. (2000). *The Origins of Person Centered Planning: A Community of Practice Perspective.* Responsive Systems Associates. Decatur, GA.

O'Brien, J., O'Brien, C., Schwartz, D. (Eds.) (1990). *What Can We Count on to Make and Keep People Safe? Perspectives on Creating Effective Safeguards for People with Developmental Disabilities.* Responsive Systems Associates. Lithonia, GA. [On-line]. Available: http://thechp.syr.edu/CountOn.pdf.

Oliver, C., Murphy, G.H., & Corbett, J.A. (1987). Self-Injurious Behavior in People with Mental Handicap: A Total Population Study. *Journal of Mental Deficiency Research 31:* 147-62.

Olson, E. (July 13, 2006). Disabilities No Barrier to the Entrepreneurial Spirit. *The New York Times.* C5.

Opsal, C. (Ed.). (2002, September). Health Status, Health Care Utilization Patterns, and Health Care Outcomes of Persons With Intellectual Disabilities: A Review of the Literature. *Policy Research Brief 13.* Institute on Community Integration, University of Minnesota Minneapolis, MN. [On-line]. Available: http://ici.umn.edu/products/prb/131/default.html.

Osburn, J. (1998). An Overview of Social Role Valorization Theory. *The International Social Role Valorization Journal/La revue internationale de la Valorisation des Roles Sociaux 3:* 7-12. [On-line]. Available: http://communitygateway.org/text/tutorials/srv.htm.

Perry, R., (1992). Differential Diagnosis of Functional Decline in Down's Syndrome. *University of Pittsburgh School of Medicine. The Habilitative Mental Healthcare Newsletter 11:* 37-41. [On-line]. Available: http://www.altonweb.com/cs/downsyndrome/declinepary.html.

Pennell, R. (2001). Self-Determination and Self-Advocacy: Shifting the Power. *Journal Of Disability Policy Studies 11:* 223-227.

Perry, A., Condillac, R. (2003). *Evidence-Based Practices for Children and Adolescents with Autism Spectrum Disorders: Reviews of the Literature and Practice Guide.* Children's Mental Health Ontario. Toronto, ON. [On-line]. Available: www.cmho.org.

Perry, A., Weiss, J. (2007). Evidence-Based Practice in Developmental Disabilities; What Is It and Why Does It Matter? *Journal on Developmental Disabilities 13:* 167-172.

Phillips, L., Appleton, R. (2004). Systematic Review of Melatonin Treatment in Children with Neurodevelopmental Disabilities and Sleep Impairment. *Developmental Medicine & Child Neurology 46:* 771-775.

Piazza, C., Fisher, W. (1991). A Faded Bedtime with Response Cost Protocol for Treatment of Multiple Sleep Problems in Children. *Journal of Applied Behavior Analysis 24:* 129-140. [On-line]. Available: http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=1279554&blobtype=pdf.

Pitonyak, D. (2005). *Supporting a Person Who is Experiencing Post Traumatic Stress Disorder (PTSD).* Imagine. Blacksburg, VA.

Pitonyak, D. (2007). *Toolbox for Change.* Imagine. Blacksburg, VA.

Pitonyak, D. (2007). *Upside Down and Inside Out: Supporting a Person in Crisis / Supporting the People Who Care.* Imagine. Blacksburg, VA.

Prouty, R., Smith, G., Lakin, K. (2007). *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2006.* University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, Minneapolis, MN.

Reed, P., Lahm, E. (2005). *A Resource Guide for Teachers and Administrators about Assistive Technology.* Wisconsin Assistive Technology Initiative. Milwaukee, WI. [On-line]. Available: http://www.wati.org/Products/pdf/resource%20guide%20-%20general.pdf.

Reiss, S. (1994) *Handbook of Challenging Behavior: Mental Health Aspects of Mental Retardation.* IDS Publishing. Worthington, OH.

Reiss, S. & Benson, B.A. (1985). Psychosocial Correlates of Depression in Mentally Retarded Adults: Minimal Social Support and Stigmatization. *American Journal of Mental Deficiency 89:* 331-37.

Reiss, S., Levitan, G., Szyszko, J. (1982). Emotional Disturbance and Mental Retardation: Diagnostic Overshadowing. *American Journal of Mental Deficiency 86:* 567-574.

Reiss, S., Trenn, E. (1984). Consumer Demand for Outpatient Mental Health Services for Mentally Retarded People. *Mental Retardation 22:* 112-115.

Richardson, S., Koller, H., Katz, M. (1985). Continuities and Change in Behavior Disturbance: A Follow-Up Study of Mildly Retarded Young People. *American Journal of Psychiatry 55:* 220-29.

Richdale, A., Wiggs, L. (2005). Behavioral Approaches to the Treatment of Sleep Problems in Children with Developmental Disorders: What is the State of the Art? *International Journal of Behavioral and Consultation Therapy 1:* 164-190.

Rimland, B. (1993). Plain Talk about PDD and the Diagnosis of Autism. *Autism Research Institute.* [Online]. Available: http://www.Autism.org/pdd.html.

Institute for Health Research. (2005). *The Impact of Person Centred Planning.* Institute for Health Research, Lancaster University. Lancaster, UK.

Sackett, D. (1996). Evidence-Based Medicine - What it is and What it isn't. *British Medical Journal 312:* 71-2. [On-line]. Available: http://www.cebm.net/ebm_is_isnt.asp.

Sattler, J. M. (1992). *Assessment of Children 3rd Edition.* Jerome M. Sattler, Publisher, Inc. San Diego, CA.

Sanderson, H., Smull, M. (2005). *Essential Lifestyle Planning for Everyone.* Helen Sanderson Associates, London.

Sara, S. (June 1 2008). Living Longer With Down syndrome, Only to Face another Struggle. *The New York Times CLVII:* 27.

Scandlen, G. (2003). *Consumer Driven Health Care: New Tools for a New Paradigm.* Galen Institute. Alexandria, VA. [On-line]. Available: http://www.galen.org/fileuploads/New_Tools.pdf.

Schalock, R. (2006). The Conceptualization and Measurement of Quality of Life: Current Status and Future Considerations. *Journal of Developmental Disabilities 20th Anniversary Issue:* 65-82.

Scottish Intercollegiate Guidelines Network. (2007). *Assessment, Diagnosis, and Clinical Interventions for Children and Young People with Autism Spectrum Disorders.* Scottish Intercollegiate Guidelines Network. Edinburgh, Scotland. [On-line]. Available: http://sign.ac.uk/pdf/sign98.pdf.

Shoultz, B., Walker, P., Hulgin, K., et al. (1999). *Closing Brandon Training School: A Vermont Story.* Center on Human Policy, Syracuse University. Syracuse, NY. [On-line-].Available: http://thechp.syr.edu/brandon.htm.

Siperstein, G., Norrins, J., Corbin, S., Shriver, T. (2003). *Multinational Study of Attitudes toward Individuals with Intellectual Disabilities.* Special Olympics Inc. Washington, D.C.

Siperstein G. (2001). *National Evaluation of the Special Olympics Unified Sports Program.* Special Olympics, Inc. Washington, D.C.

Smith, D. (2001) Health Care Management of Adults with Down Syndrome. *American Family Physician 64:* 1031-1038. [On-line]. Available: http://www.aafp.org/afp/20010915/1031.html.

Smull, M. (1989). *Crisis in the Community.* Developmental Disabilities Program of the University of Maryland, School of Medicine. Baltimore, MD. [On-line]. Available: http://www.elpnet.net/documents/crisisincommunity.pdf.

Smull, M. (2000). *Listen, Learn, Act: Selected Writings by Michael W. Smull on Essential Lifestyle Planning, Self-Determination, and Organizational Change.* Support Development Associates, Annapolis, MD. [On-line]. Available: http://learningcommunity.us/documents/listenlearnact.pdf.

Smull, M. (Spring 2001). A crisis is Not an Excuse. In Hanson, R., Wiesler, Lakin, K. (Eds.). *IMPACT 14:* 26-27. Institute on Community Integration, University of Minnesota. Minneapolis, MN. [On-line]. Available: http://ici.umn.edu/products/impact/141/over1.html.

Smull, M. (1995). *Revisiting Choice – Part 1 & Part 2.* Support Development Associates. Kensington, MD. [On-line]. Available: http://www.elpnet.net/choice.html.

Smull, M., Burke-Harrison, S. (1992). *Supporting People with Severe Reputations in the Community.* National Association of State Mental Retardation Program Directors. Alexandria, VA.

Sobsey, D., Doe, T. 1991. Patterns of Sexual Abuse and Assault. *Journal of Sexuality and Disability 9:* 243-59.

Social Security Administration. (2007) 2007 *Redbook: A Summary Guide to Employment Support for Individuals with Disabilities Under the Social Security Disability Insurance (SSDI) and Supplemental Security Income Program.* Social Security Administration. Baltimore, MD.

Solomon, R., Necheles, J., Ferch, C. Bruckman, D. (2007). Pilot study of a Parent Training Program for Young Children with Autism: The PLAY Project Home Consultation Program. *Autism 11:* 205-224.[On-line]. Available:

http://www.playproject.org/media/pdfs/PilotStudy_PLAYProject.pdf.

Sovner, R., Hurley, A.D. (1983). Do the Mentally Retarded Suffer from Affective Illness? *Archives of General Psychiatry 40:* 61-67.

Special Olympics, Inc. (2005). *Changing Attitudes, Changing the World, Changing Lives through Sport—A Report Card on the Impact of Special Olympics.* Special Olympics, Inc. Washington, DC.

Stancliffe, R., Lakin, K. (2004). *Costs and Outcomes of Community Services for Persons with Intellectual and Developmental Disabilities. Policy Research Brief, 15.* University of Minnesota, Institute on Community Integration. Minneapolis, MN. [On-line]. Available: http://ici.umn.edu/products/prb/151/default.html.

Stanford University School of Medicine Child and Adolescent Psychiatry, (2005) *Autism and Pervasive Developmental Disorders Research.* [Online]. Available: http://coy.state.va.us/Modalities2005/Pervasive05.pdf.

Stefan, S. (2004). *Competence Issues in Self-Directed Care.* Paper prepared for the SAMHSA Consumer Direction Summit, March 2004.

Steveley, J. (2005). Supported Employment for Oregonians with Developmental Disabilities: Recommendations for Action. Oregon Council on Developmental Disabilities. Salem, OR.

Sturmey, P. (1995). DSM-III-R and Persons with Dual Diagnoses: Conceptual Issues and Strategies for Future Research. *Journal of Intellectual Disability Research 39:* 357-364.

Substance Abuse and Mental Health Services Administration. (2005). *Independent Living for People with Fetal Alcohol Spectrum Disorders.* Substance Abuse and Mental Health Services Administration. Rockville, MD.

Swenson, S. (2004). *My Son or Daughter Is Not the Same As Yours: How to Answer that Question.* The Arc of The United States. Silver Spring, MD.

Szymanksi, L., Kiernan, W. (1983). Multiple Family Group Therapy with Developmentally Disabled Adolescents and Young Adults. *International Journal of Group Psychotherapy 33:* 521-34.

Szymanski, L., King, B. (1999). Practice Parameters for the Assessment and Treatment of Children, Adolescents, and Adults with Mental Retardation and Comorbid Mental Disorders. *Journal of the American Academy of Child and Adolescent Psychiatry 38:* 5S-31S.

Taylor, S. (2001). On Choice. *TASH Connections 27:* 8-10. [On-line]. Available: http://thechp.syr.edu/on_choice.htm.

Taylor, S. (2003). The Editor's Perspective on Institutional and Community Costs. *Mental Retardation 41:* 125-126.

Taylor, S. (1992). The Paradox of Regulations: A Commentary. *Mental Retardation 30:* 185-190.

Taylor, S., O'Brien, J., Hulgin, K. (Eds.). (1993). *Safeguards* [Policy Bulletin No. 3]. Research and Training Center on Community Integration, Center on Human Policy, School of Education, Syracuse University. Syracuse, NY. [On-line]. Available: http://thechp.syr.edu/bullsafe.htm.

Terman, D., Larner, M., Stevenson, C., Behrman, R. (1996). Special Education for Students with Disabilities: Analysis and Recommendations. *The Future of Children 6:* 4-24.

The Arc of the United States. (1999). *Availability of Community Services and Supports: Position Statement # 21.* [Online]. Available: http://www.thearc.org/posits/commser.html.

The Arc of the United States. (2003). *Family Resource Guide. Michigan.* The Arc. [On-line]. Available: http://www.thearc.org/NetCommunity/Page.aspx?&pid=1400&srcid=183.

The Elizabeth M. Boggs Center on Developmental Disabilities. (2005). *Dimensions of Faith and Congregational Ministries with Persons with Developmental Disabilities and Their Families: A Bibliography and Address Listing of Resources For Clergy, Laypersons, Families, and Service Providers.* The Elizabeth M. Boggs Center on Developmental Disabilities University of Medicine & Dentistry of New Jersey, Robert Wood Johnson Medical School Department of Pediatrics. New Brunswick, NJ.

The Medical Center Online. Child and Adolescent Mental Health. (2002). *What is Tourette's disorder?* [Online]. Available: http://www.mccg.org/childrenshealth/mentalhealth/tourette.asp.

Thomas, S. Wolfensberger, W. (1982). The Importance of Social Imagery in Interpreting Societally Devalued People to the Public. *Rehabilitation Literature 43:* 356-358.

Tourette Syndrome Association, Inc. (2002). What is Tourette's Syndrome? [Online]. Available: http://www.tsa-usa.org.

Turnbull, R., Turnbull, A., Warren, S., et al. (2002). Shakespeare Redux, or Romeo and Juliet Revisited: Embedding a Terminology and Name Change in a New Agenda for the Field of Mental Retardation. *Mental Retardation 40:* 65-70.

United States Centers for Medicare & Medicaid Services (CMS). (2007). Early Diagnosis of Autism Spectrum Disorders. *Promising Practices in Home and Community-Based Services.* United States Centers for Medicare & Medicaid Services (CMS). Baltimore, MD.

United States Centers for Medicare & Medicaid Services (CMS). (2003). Financial Security for People with Developmental Disabilities. *Promising Practices in Home and Community-Based Services.* United States Centers for Medicare & Medicaid Services (CMS). Baltimore, MD.

United States Centers for Medicare & Medicaid Services (CMS). (2003). IndependentChoices – The Arkansas Cash and Counseling Demonstration. *Promising Practices in Home and Community-Based Services.* United States Centers for Medicare & Medicaid Services (CMS). Baltimore, MD.

United States Centers for Medicare & Medicaid Services (CMS). (2007). Preparing Individuals for Employment. *Promising Practices in Home and Community-Based Services.* United States Centers for Medicare & Medicaid Services (CMS). Baltimore, MD.

United States Centers for Medicare & Medicaid Services (CMS). (2007). Supports for Adults with Autism Spectrum Disorders. *Promising Practices in Home and Community-Based Services.* United States Centers for Medicare & Medicaid Services (CMS). Baltimore, MD.

United States Department of Health and Human Services. (1999). *Mental Health: A Report of the Surgeon General.* Rockville, MD.

United States Department of Justice. (1999). Case Management in the Criminal Justice System. *National Institute of Justice Research in Action.* United States Department of Justice. Washington, DC.

United States Department of Justice. (2004). *Effective Prison Mental Health Services: Guidelines to Expand and Improvement Treatment.* United States Department of Justice, National Institute of Corrections. Washington, DC. [On-line]. Available: http://www.nicic.org/pubs/2004/018604.pdf

United States Public Health Service. (2002). *Closing the Gap: A National Blueprint for Improving the Health of Individuals with Mental Retardation. Report of the Surgeon General's Conference on*

Health Disparities and Mental Retardation. United States Department of Health and Human Services, Office of the Surgeon General. Washington, DC.

Veenstra-Vanderweele, J. (2004). Developmental Disabilities: Close the Training Gap. *Psychiatric News 39:* 4.

Vermont Agency of Human Services. (2005). *Vermont Best Practices Manual: Supervision and Treatment of Sex Offenders with Developmental Disabilities.* Vermont Agency of Human Services. Waterbury, VT. [On-line]. Available: http://www.dail.state.vt.us.

Voelker R. (2002). Improved Care for Neglected Population Must Be 'Rule Rather Than Exception'. *Journal of the American Medical Association 288:* 299–301.

Voice of the Retarded (VOR). (2002). *Executive Summary: Institutional and Community-Based Systems for People With Mental Retardation: A Review of the Cost Comparison Literature.* [On-line]. Available: http://www.vor.net/.

Wagner, M., Blackorby, J. (1996). Transition from High School to Work or College: How Special Education Students Fare. *The Future of Children 6:* 103-120.

White House. (2001, February 1). *Foreword by George W. Bush: Fulfilling America's Promise to Americans with Disabilities (press release).* White House. Washington, DC. [On-line]. Available: http://whitehouse.gov/news/freedominitiative/freedominitiative.html.

Wilkinson, H., Janicki, M. (2001). *Edinburgh Principles with Accompanying Guidelines and Recommendations.* The Edinburgh Working Group on Dementia Care Practices (EWGDCP). Stirling, Scotland. [On-line]. Available: http://www.uic.edu/orgs/rrtcamr/edinburgh.htm.

Wolfensberger, W. (1972). *The Principle of Normalization in Human Services.* National Institute on Mental Retardation. Toronto, ON.

Wolfensberger, W. (2001). What Advocates Have Said. *Citizen Advocacy Forum 11:* 4-27.

Woodill, G., Velche, D. (1995). From Charity and Exclusion to Emerging Independence: An Introduction to the History of Disabilities. *Journal on Developmental Disabilities 4:* 19-27.

APPENDIX B: SELECTED RESOURCES

Self-Determination:

Michigan Partners for Freedom
Bazelon Center for Mental Health Law (BCMHL): http://www.bazelon.org
Center for Self-Determination: http://www.self-determination.com
National Association of Protection & Advocacy Systems (NAPAS):
http://www.protectionandadvocacy.com
National Coalition on Self-Determination: http://www.nconsd.org/
Consumer-Directed Models of Personal Care: Lessons from Medicaid:
http://aspe.hhs.gov/daltcp/reports/lessons.htm
Independent Choices: A National Symposium on Consumer Direction and Self-Determination for the Elderly and Persons with Disabilities:
http://aspe.hhs.gov/daltcp/reports/01cfpack.htm
Oregon Health Sciences Center on Self-Determination: http://selfdeterminationohsu.org
LifePages.org: www.lifepages.org
QualityMall.org: QualityMall.org
New Hampshire Self-Direction Model: http://nhdds.org/programs
TASH: http://www.tash.org/
National Association of State Directors of Developmental Disabilities Services (NASDDDS):
http://www.nasddds.org/
Self Advocates Becoming Empowered: http://www.sabeusa.org
Self-Directed Support Corporation: www.self-determined.org
Robert Wood Johnson Foundation (RWJF): http://rwjf.org/reports/grr/PC379.htm

Assistive Technology:

Wisconsin Assistive Technology Initiative: http://www.wati.org/
AT devices: www.abledata.org, www.qiat.org
Computer related assistive devices: www.closingthegap.com.
Assistive technology assessment forms: www.wati.org.
AAC Intervention: www.aacintervention.com
US Office of Education: www.ed.gov/offices OSERS/techpack.html
National Center to Improve Practice (NCIP): www.edc.org
Family Village: www.familyvillage.wisc.edu
Special Education section of the Wisconsin Department of Public Instruction:
www.dpi.state.wi.us
World Institute on Disability: www.wid.org
Quality Indicators for Assistive Technology Services (QIAT):
http://natri.uky.edu/assoc_projects/qiat/

Employment:

Oregon Self-Directed Employment Toolkit
Partners in Employment
Customer Guide to Supported Employment working with VR and DD

Benefit Planning:

Social Security's Redbook
Cornell University's PASS
PASSplan.org

Microboards and Self-Directed Support Corporations:

Vela Microboard Association: http://www.microboard.org
http://www.tnmicroboards.org/
Self-Directed Support Corporation: www.self-determined.org

Person-Centered Planning:

Listen to Me (workbook): http://www.allenshea.com/documents/LTM.pdf
The Learning Community for Person-Centered Practices: http://www.elpnet.net/
My Life (workbook): http://www.learningcommunity.us/documents/MyLife.pdf
Families Planning Together: Starting Work on an Essential Lifestyle Plan (workbook available in English and Spanish): http://learningcommunity.us/documents/FPTGuide.11-03.pdf
Essential Lifestyle Planning: http://www.elpnet.net/
Family Futures Project: http://www.family-futures.org.uk/index.html
The Family Futures Project: http://www.family-futures.org.uk/Introduction%20to%20PCP.html

Advocacy:

ADAPT: http://www.adapt.org/
Michigan Protection and Advocacy Service, Inc: http://www.mpas.org/HomePage.asp
Michigan Protection and Advocacy Service, Client Assistance Program (CAP): http://www.mpas.org/AdvocacyServices.asp?TOPIC=10116
Michigan Commission on Disability Concerns: http://www.michigan.gov/dleg/0,1607,7-154-28077_28545-14846--,00.html
Advocacy Center, National Down Syndrome Society: http://www.ndss.org/content.cfm?fuseaction=AdvCen&article=79
American Association on Mental Retardation (AAMR): http://www.aamr.org
Americans with Disabilities Act/Olmstead Decision, Centers for Medicare & Medicaid Services: http://www.cms.hhs.gov/olmstead/default.asp
The Arc of the United States: http://www.thearc.org/
The Arc's Training Page: http://www.thearc.org/ga/trainmat.html
Assistance with Integrity: The Search for Accountability and the Lives of People with Developmental Disabilities: http://thechp.syr.edu/!integri.pdf
Center for an Accessible Society: http://accessiblesociety.org/
Center for Health Care Strategies (CHCS): http://www.chcs.org/info-url_nocat3961/info-url_nocat_show.htm?doc_id=206314
Center for the Study and Advancement of Disability Policy (CSADP): http://www.disabilitypolicycenter.org/
The Center on Human Policy: http://thechp.syr.edu
Centers for Medicare & Medicaid Services (ICF?MR Program): http://www.cms.hhs.gov/medicaid/icfmr/default.asp
The Council on Quality and Leadership: http://www.thecouncil.org
TASH: http://www.tash.org/govaffairs/
Center for the Study and Advancement of Disability Policy (CSADP): http://www.disabilitypolicycenter.org/

Associations and Organizations:

The American Association for Intellectual and Developmental Disabilities: AAIDD
Addup: ADDup.org
Administration on Developmental Disabilities
American Network of Community Options & Resources: ANCOR
The Association of University Centers on Disabilities: AUCD
The Arc of the United States: Arc/US or http://www.thearc.org/
The Consortium for Citizens with Disabilities: CCD
Families USA
The National Association of Developmental Disabilities Councils: NACDD or
http://www.nacdd.org/
The National Association for the Dually Diagnosed: NADD
The National Association of Protection & Advocacy System: NAPAS
Self Advocates Becoming Empowered: SABE or http://www.sabeusa.org/
The Robert Wood Johnson Foundation's National Program on Self-Determination for Persons with Developmental Disabilities: SDPDD
Institute on Disability at the University of New Hampshire.
The Association for Persons with Severe Handicaps), Disability Advocacy Worldwide: TASH
The Council on Quality and Leadership: The Council or http://www.thecouncil.org
Research and Training Center on Community Living (RTC): http://rtc.umn.edu/main/
American Academy for Cerebral Palsy and Developmental Medicine (AACPDM): http://www.aacpdm.org/index?service=page/Home
The National Association of Protection & Advocacy System: NAPAS
The Robert Wood Johnson Foundation's National Program on Self-Determination for Persons with Developmental Disabilities: SDPDD
Institute on Disability at the University of New Hampshire.
American Association on Health and Disability: http://www.aahd.us
Developmental Disabilities Nurses Association: http://www.ddna.org/
Family Voices: http://www.familyvoices.org/
National Alliance for Caregiving: http://www.caregiving.org/
National Association for the Dually Diagnosed: http://www.thenadd.org/
National Association of Qualified Mental Retardation Professionals: http://www.qmrp.org/
National Association of Protection and Advocacy Systems: http://www.napas.org/
National Association of State Directors of Developmental Disabilities Services: http://www.nasddds.org/index.shtml
National Down Syndrome Congress: http://www.ndsccenter.org/
Voice of the Retarded: http://www.vor.net/
National Center on Birth Defects and Developmental Disabilities, Center for Disease Control and Prevention: http://www.cdc.gov/ncbddd/
Social Security Administration, Office of Disability: http://www.ssa.gov/disability/
Department of Health and Human Services, Administration on Developmental Disabilities: http://www.acf.hhs.gov/programs/add/
President's Committee for People with Intellectual Disabilities: http://www.acf.hhs.gov/programs/pcpid/
Department of Education, Office of Special Education and Rehabilitative Services: http://www.ed.gov/about/offices/list/osers/osep/index.html
National Institute of Child Health and Human Development (NICHD): http://www.nichd.nih.gov/
National Council on Independent Living: www.ncil.org

National Guardianship Association: www.guardianship.org
The Center on Human Policy: http://thechp.syr.edu
The University of Minnesota's Research and Training Center on Community Living: http://rtc.umn.edu/
The Beach Center on Families and Disability: to http://www.beachcenter.org

Choice:

Advocating Change Together: http://www.selfadvocacy.com/
Self Advocates Becoming Empowered: http://www.sabeusa.org/
National Self-Determination Program Office: http://www.self-determination.org/
National Home of Your Own Alliance: http://alliance.unh.edu/
Institute on Community Integration, University of Minnesota: http://ici.umn.edu/

Recreation & Leisure:

Special Olympics, Inc.: http://www.specialolympics.org

State Government Resources:

University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCE) (formerly University Affiliated Program or UAP):
http://www.acf.dhhs.gov/programs/add and http://www.aucd.org
Parent Training Information (PTI) Center: http://www.ed.gov/Programs/bastmp/SPTIC.htm to and http://www.taalliance.org/PTIs.htm.
National Information Center for Children and Youth with Disabilities (NICHCY):
www.nichcy.org
National Center for Family Support: http://www.familysupport-hsri.org
U.S. Administration on Developmental Disabilities
Alabama Department of Mental Health and Mental Retardation: DDMED
National Association of State Mental Health Program Directors: NASMHPD
National Association of State Medicaid Directors (NASMD): NASMD
NASMHPD Research Institute
National Association of State Units on Aging: NASUA
Conference of State Legislatures: NCSL
National Governors Association: NGA

Federal Government Resources:

Administration on Developmental Disabilities: ADD
Centers for Medicare & Medicaid Services: CMS
Disabled and Elderly Health Programs Group: DEHPG
DisabilityInfo.gov
Department of Health and Human Services, Office for Civil Rights: OCR
Plain Language Action & Information Network: Plain Language
Social Security Administration: SSA
The White House
US Congress
US Supreme Court
HHS-Administration on Developmental Disabilities: http://www.acf.dhhs.gov/program/add/
Home and Community Based Services Network (HCBS): http://www.hcbs.org
DisAbility.Gov (New Freedom Initiative): http://www.disabilitydirect.org

Funding Sources:

Department of Health and Human Services, Administration on Developmental Disabilities: ADD

Association of University Centers on Disabilities: AUCD

Center for Disease Control, Birth Defects, Developmental Disabilities and Health Funding Opportunities: CDC

Catalog of Federal Domestic Assistance: CFDA

Department of Labor's (DOL) Disability Online Grants & Contracts: DOL

GRANTS.GOV

Department of Health and Human Services, Developmental Disabilities Funding Opportunities: HHS

National Institute of Child Health and Human Development, Funding Opportunities: **NICHD**

Department of Education (ED) Office of Special Education Programs Grants Resources: OSEP

Robert Wood Johnson Foundation: RWJ

Promising Practices:

CMS Promising Practices in HCBS
HCBS Promising Practices
Quality Mall

Early Care and Education (ECE):

Early Childhood Research Institute on Inclusion (ECRII): http://www.fpg.unc.edu/~ecrii/
National Early Childhood Technical Assistance Center (NEC*TAC): http://www.nectac.org/
Early Childhood Research Institute on Culturally and Linguistically Appropriate Services (CLAS): http://clas.uiuc.edu/
Eric Clearinghouse on Elementary and Early Childhood Education: http://www.ericeece.org/
Division of Early Childhood (DEC), Council for Exceptional Children: http://www.dec-sped.org
Infant Development Association: http://www.idaofcal.org
ZERO TO THREE: National Center for Infants, Toddlers and Families:
http://www.zerotothree.org/ and http://www.zerotothree.org/imh/
The National Center for Early Development & Learning (NCEDL): http://www.ncedl.org
Models of Inclusion in Child Care Project: http://www.rtc.pdx.edu/pgProjInclusion.php
Center for Effective Collaboration and Practice: http://cecp.air.org/
International Network for Children and Families: http://www.redirectingbehavior.com/
Center on the Social and Emotional Foundations for Early Learning:
http://csefel.uiuc.edu/index.html
Center for Evidence-Based Practice: Young Children with Challenging Behavior:
http://www.challengingbehavior.org
Project Support: http://www.calstatela.edu/faculty/dklein/project_support/
National Resource Center for Health and Safety in Child Care:
http://nrc.uchsc.edu/CFOC/index.html

Parenting/Family Support:

Family Village: http://www.familyvillage.wisc.edu/index.html
The National Parent Network on Disabilities (NPND): http://www.npnd.org/
The Federation for Children with Special Needs: http://www.fcsn.org/

The Beach Center on Families and Disability: http://www.beachcenter.org/
National Fathers Network: http://www.fathersnetwork.org
National Center on Low Incidence Disabilities: http://www.nclid.unco.edu/
The National Parent Information Network (NPIN): http://npin.org/

Health and Social Services:

Office of Special Education IDEA Home Page:
http://www.ed.gov/offices/OSERS/IDEA/index.html and http://www.ideapractices.org
Americans with Disabilities Act (ADA): http://www.usdoj.gov/crt/ada/adahom1.htm
ADA and Child Care Centers: http://www.usdoj.gov/crt/ada/childq%26a.htm
Department of Justice ADA Home Page: http://www.usdoj.gov/crt/ada/adahom1.htm
Child Care Law Center: http://www.childcarelaw.org/
The National Information Center for Children and Youth with Disabilities: http://nichcy.org
The National Organization for Rare Disorders (NORD): http://www.rarediseases.org/
Bright Futures in Practice: Mental Health: http://www.brightfutures.org/mentalhealth/

School Capacity:

Including Your Child: http://www.ed.gov/pubs/parents/Including/
Promising Practices Network (PPN): http://www.promisingpractices.net/
Positive Behavioral Interventions and Supports (PBIS): http://www.pbis.org/

Program Infrastructure, Administration and Evaluation:

The Grassroots Consortium on Disabilities: http://www.gcod.org/
Pacer Center: http://www.pacer.org/
Technical Assistance Alliance for Parent Centers: http://www.taalliance.org/
Disability is Natural: http://www.disabilityisnatural.com/

Aging:

American Association on Mental Retardation
National Association of Developmental Disabilities Councils
The Arc of the United States
National Down Syndrome Society
Self-Advocates Becoming Empowered
The National Center on Physical Activity and Disability (NCPAD)
The Waisman Mental Retardation Research Center
National Rehabilitation Information Center
National Center for the Dissemination of Disability Research
National Resource Center on Community Integration
RRTC on Health and Wellness
The Rehabilitation Research and Training Center on Aging with Developmental Disabilities
(RRTCADD): http://www.uic.edu/orgs/rrtcamr/index.html
Department on Disability and Human Development
The Institute on Community Integration
Internetwork Institute at San Diego State University
National Clearinghouse of Rehabilitation Materials
The University of Kansas SPED ON-LINE
Virginia Commonwealth University Rehabilitation Research and Training Center on Supported Employment

Rehabilitation Research & Training Center on Aging With a Disability
World Health Organization - Mental Health
Developmental Disabilities Center
The Center for International Rehabilitation Research Information and Exchange (CIRRIE)
International Network for Research in Elder Care (INREC)
Central England People First
Agency for Health Care Policy & Research
Elder Law Answers
Independent Living
The Able Project Seeks
The Center on Human Policy (CHP)
The GeroWeb Virtual Library on Aging
The Alzheimer's Association
Managed Care Clearinghouse Web Site
Resources on Managed Care for People with Disabilities
ASPE's Disabilities & Managed Care Web Site
Program Development Associates
The Family Village
The Disability Resource
Equip for Equality
The Illinois Planning Council on Developmental Disabilities (IPCDD)
American Society on Aging - Network on Environments, Services and Technologies to Maximize Independence (NEST)
AARP Research Information Center

Assistive Technology:

The National Center on Secondary Education and Transition (NCSET):
http://www.ncset.org/default.asp
QIAT Consortium: http://natri.uky.edu/assoc_projects/qiat/index.html
Michigan Assistive Technology Project: http://www.copower.org/AT/index.htm
AccessWorld®: Technology and People with Visual Impairments
Assistech WIKI
Breaking New Ground Resource Center (for farmers and other persons with disabilities in agriculture)
Assistive Technology for Students with Mild Disabilities
Assistive Technology Guide
American Foundation for the Blind: Assistive Technology Product Database
Disability and Rehabilitation: Assistive Technology Journal
Integrating Assistive Technology into the Standard Curriculum
Kids Together, Inc.
ACM SigAccess or **Association for Computing Machinery**
Disability Help Site
Assistivetech.net - Online database for assistive technology
Association of Assistive Technology Act Programs -ATAP
Assistive Technology Industry Association
Center for Assistive Technology and Environmental Access (CATEA) at Georgia Tech and
AT Wiki
Rehabilitation Engineering & Assistive Technology Society of North America
ABLEDATA Global database of AT and Rehab products
The Alliance for Technology Access

The Family Center on Technology and Disability
The Special Education Assistive Technology Center (SEAT Center)
The Nassau-Suffolk TRAID Center
University of Victoria Assistive Technology Team
Volunteers for Medical Engineering
Lekotek: http://www.lekotek.org/

Specific Disabilities Information:

Children and Adults with Attention Deficit/Hyperactivity Disorder: http://www.chadd.org/
United Cerebral Palsy: http://www.ucpa.org
Autism Resources (through the California Department of Developmental Services): http://www.dds.ca.gov/autism/autism_main.cfm
Unicorn Children's Foundation: http://www.eunicorn.com/
The M.I.N.D. Institute: http://www.ucdmc.ucdavis.edu/mindinstitute/
American Speech-Language-Hearing Association: http://www.asha.org/
Prader-Willi Syndrome Association USA: www.pwsausa.org
Michigan Commission for the Blind (MCB): http://www.michigan.gov/dleg/0,1607,7-154-28077_28313---,00.html
American Association on Mental Retardation: http://aamr.org
National Information Center for Children and Youth with Disabilities (NICHCY): http://www.nichcy.org
The Arc (formerly Association for Retarded Citizens): http://www.thearc.org
IDEA 1997 Statute on Implementing Regulations: contact the United States Department of Education: www.ed.gov/offices/OSERS/IDEA
National Down Syndrome Society: http://www.ndss.org/
Autism Spectrum Disorder Workgroup: http://cenmi.org/asd/
National Information Center for Children and Youth with Disabilities: www.nichcy.org
National Institute of Mental Health (NIMH): www.nimh.nih.gov
National Institute on Deafness and Other Communication Disorders Information Clearinghouse: www.nidcd.nih.gov
National Institute of Child Health and Human Development Clearinghouse: www.nichd.nih.gov
Families for Early Autism Treatment, Inc.: http://www.feat.org.
MAAP Services (For Autism, Asperger's Syndrome, and PDD): www.maapservices.org/index.html
Autism Research Institute (ARI): www.Autismresearchinstitute.com
Autism Society of America: http://www.Autism-society.org
Autism Society of Michigan: http://www.autism-mi.org/aboutautism/person.html
IAN, the Interactive Autism Network: http://www.ianproject.org/
Citizens United for Research in Epilepsy (CURE): info@CUREepilepsy.org and http://www.CUREepilepsy.org
Epilepsy Foundation: postmaster@efa.org and http://www.epilepsyfoundation.org
Epilepsy Institute: website@epilepsyinstitute.org and http://www.epilepsyinstitute.org
Parents Against Childhood Epilepsy (PACE): pacenyemail@aol.com and http://www.paceusa.org
Family Caregiver Alliance/ National Center on Caregiving: info@caregiver.org and http://www.caregiver.org
National Council on Patient Information and Education: ncpie@ncpie.info and http://www.talkaboutrx.org
National Family Caregivers Association: info@thefamilycaregiver.org and

http://www.thefamilycaregiver.org
National Organization for Rare Disorders (NORD): orphan@rarediseases.org and
http://www.rarediseases.org
International RadioSurgery Association: office1@irsa.org and http://www.irsa.org
Charlie Foundation to Help Cure Pediatric Epilepsy: ketoman@aol.com and
http://www.charliefoundation.org
Epilepsy Therapy Development Project: EpilepsyCure@aol.com and
http://www.epilepsytdp.org
Antiepileptic Drug Pregnancy Registry: ebaldwin@partners.org and
http://www.aedpregnancyregistry.org
Rehabilitation Services Administration:
www.ed.gov/about/offices/list/osers/rsa/index.html?src=mr
Job Accommodation Network, U.S. Department of Labor:
www.jan.wvu.edu/sbses/vocrehab.htm
National Council on Independent Living: www.ncil.org
U.S. Department of Housing and Urban Development: www.hud.gov
"F.A.S.: When the Children Grow Up":
www.knowledgenetwork.ca/know_tool/fas/resources/documentary/index.html
Tourette Syndrome Association, Inc.: www.tsa-usa.org
Tourette Syndrome Net: www.tourettesyndrome.net
National Alliance for the Mentally Ill (NAMI):
>   **Tourette's Syndrome Fact Sheet:** www.nami.org/helpline/tourette.html
>   **Attention-Deficit Disorder and Obsessive-Compulsive Disorder:**
>   www.vh.org/Patients/IHB/Psych/Tourette/Modifications.html

MiConnections
High School/High Tech
Michigan Department of Labor & Economic Growth: Michigan Rehabilitation Services.

Respite:

MN Board on Aging Caregiver Page: www.mnaging.org
DHS Aging Consumer Directed Page: www.dhs.state.mn.us/cdcswww.cdcs
Minnesota Help Network —consumer decision making tool: www.minnesotahelp.netwww.net
Administration on Aging Caregiver Resource Room: www.aoa.govwww.gov
Family Caregiver Alliance: www.caregiver.orgwww.org
National Family Caregiver Association: www.nfcacares.orgwww.org
Arch (Access to Respite Care and Help) Respite Program: www.archrespite.orgwww.org

Employment:

Michigan Rehabilitation Services (MRS): http://www.michigan.gov/mdcd/0,1607,7-122-25392---,00.html

Direct-Care Staffing:

Paraprofessional Healthcare Institute: www.directcareclearinghouse.org
Avoiding Attendants from HELL, by June Price: www.personalcareattendants.com
**Maine's Home-Based Care Program and Personal Attendant Management: Regular
Medicaid Program and Medicaid Waiver Program:**
www.hcbs.org/resources/one/one_protocols2.htm
Disability Gateshead: www.disabilitygateshead.org.uk/recruit/recruit.htm
Institute on Independent Living: www.independentliving.org

World Institute on Disability: www.wid.org/pages/halts/pas/PAS%20survey/statepas.htm
National Council on Independent Living: www.virtualcil.net/cils/
National Clearinghouse on the Direct Care Workforce:
http://www.directcareclearinghouse.org/a_index.jsp

Positive Behavioral Interventions:

PACER Center: www.pacer.org
Center on Positive Behavioral Interventions and Supports: www.pbis.org
American Institute for Research: www.air.org
Center on Positive Behavioral Interventions and Support: www.pbis.org

Disability and Faith Resources:

National Organization on Disability, Religion and Disability Program: www.nod.org
American Association on Mental Retardation, Religion and Spirituality Division:
www.aamr.org
Council for Jews with Special Needs, Inc: www.cjsn.org
National Apostolate for Inclusion Ministry: www.nafim.org
National Christian Resource Center: www.blhs.org/congregations/ncrc
Pathways Awareness Foundation: http://www.inclusioninworship.org/
L'Arche: http://www.larcheusa.org/
The Center for Religion and Disability: http://religionanddisability.org/

Resources for Sex Offenders with Developmental Disabilities:

Safer Society Press: www.safersociety.org
Diverse City Press Inc.: http://www.diverse-city.com/display.htm
YAI/National Institute for People with Disabilities Network video series on Friendships, Relationships and Sexuality: http://www.yai.org
Developmentally Disabled Offenders Program: www.arcnj.org
National clearinghouse for information about offenders with developmental disabilities.
Association for the Treatment of Sexual Abusers (ATSA): www.atsa.com
Center for Sex Offender Management (CSOM): www.csom.org

Violence Against Women with Disabilities:

MINCAVA: www.mincava.umn.edu
CAVNET: www.cavnet2.org
Center for Research on Women with Disabilities: www.bcm.edu/crowd
National Women's Health Information Center: http://www.4woman.gov/

Transition Planning:

Parent Training and Information Centers/Community Parent Resource Centers:
www.taalliance.org/centers
Bright Futures for Families: http://brightfuturesforfamilies.org
Family Voices: www.familyvoices.org
Kids as Self Advocates: www.fvkasa.org
The Self-Advocate Leadership Network: www.hsri.org/leaders
Family Village: www.familyvillage.wisc.edu
The National Youth Leadership Network: www.nyln.org

Partners in Policymaking: http://www.partnersinpolicymaking.com
National Center on Secondary Education and Transition (NCSET): www.ncset.org
Youthhood: www.youthhood.org
Quality Mall: www.qualitymall.org
Self-Advocacy Online: www.selfadvocacyonline.org

Alzheimer 's Disease and Intellectual Disability:

The ARC: http://www.thearc.org/NetCommunity/Document.Doc?&id=95
National Down Syndrome Society (NDSS): http://www.ndss.org
PCAD project (Preparing Community Agencies for Adults affected by Dementia):
http://www.uic.edu/orgs/rrtcamr/dementiaresources.pdf
eMedicine.com: http://www.emedicine.com/neuro/topic552.htm
Rehabilitation Research and Training Center on Aging with Developmental Disabilities:
http://www.uic.edu/orgs/rrtcamr/dbiblio.htm
American Association on Mental Retardation; International Association for the Scientific Study of Intellectual Disabilities (AAMR & IASSID): http://www.aamr.org/
Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTC): http://www.uic.edu/orgs/rrtcamr/index.html.

APPENDIX C: GLOSSARY

Asperger's Disorder is a type of pervasive developmental disorder (PDD) that is characterized by problems in the development of social skills and behavior that is usually discernable subsequent to age three. It differs from autism in more pronounced motor deficits and later onset. In addition, social skills deficiencies are exhibited without impairments in language and cognitive skills. Children with Asperger's Disorder can display a variety of characteristics and the disorder can range from mild to severe. Preferences for sameness and difficulties with change can be present. Other symptoms include sensitivity to sounds, tastes, smells, and sights, as well as preferences for soft clothing, certain foods, and intolerance to certain sounds or lights. Research has demonstrated that Asperger's Disorder is associated with Tourette's disorder. Other disorders can co-occur including obsessive-compulsive disorder, depression, attention deficit hyperactivity disorder (ADHD), and schizophrenia.

Assistive Technology (AT) is any item, piece of equipment, or product system, whether acquired commercially off-the-shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities. It is also a generic term that includes assistive, adaptive, and rehabilitative devices as well as the process used in selecting, locating, and using such devices.

Autistic Spectrum Disorders (ASD) refers to disorders with a pattern of behaviors involving three central features: impairments in socialization, impairments in verbal and nonverbal communication, and restricted and stereotyped actions that can vary widely in symptom expression, degree of impairment, and developmental onset. Conditions include Autistic disorder, Pervasive Developmental Disorders–Not Otherwise Specified (PDD-NOS), and Asperger's disorder. Autistic Spectrum Disorders affect multiple developmental domains. Research indicates a genetic component is associated with ASD and related developmental disabilities (i.e., mental retardation), lesser variants (i.e., language disorder and learning disability) and phenotype traits (i.e., schizotypal). Children with ASD vary widely in cognitive potential. Seventy to eighty percent are estimated to function in the mentally retarded range and approximately twenty to twenty five percent demonstrate normal to superior functioning in at least one major cognitive domain. There is controversy surrounding the "spectrum" concept primarily due to the questions regarding whether disorders within the autistic spectrum are, in fact, continuous. Children with a family history of autism have a somewhat higher risk for developing ASD. Early warning signs include:

- Not speaking one word by age sixteen months
- Not combining two words by age two
- Not responding to their name
- Appearing to lack awareness when being addressed, but responding to other sounds
- Apparent lack of knowledge of how to play with toys
- Excessive lining up of toys or other objects
- Lack of babbling, pointing or making meaningful gestures by the age of one
- Avoidance of eye contact
- Lack of smiling
- A desire to be alone
- Lack of pointing to object to demonstrate interest
- Not looking at objects when someone points at them
- Unusual reactions to the way things smell, taste, appear, feel, or sound

The number of children diagnosed with autism spectrum disorders has increased dramatically in recent decades. The Centers for Disease Control estimates that one of every one hundred fifty children has an ASD although it is unclear whether increasing rates are the result of increased prevalence or improved diagnosis.

Cerebral Palsy refers to a group of disorders affecting the ability to control posture and balance caused by a non-progressive brain abnormality. There are four main types of cerebral palsy. **Spastic cerebral palsy** is the most common type and affects seventy to eighty percent of people with the disorder. It makes movements awkward due to increased muscle tone. **Athetoid or dyskinetic cerebral palsy** is characterized by uncontrollable slow, writhing movements in the face, arms and hands. **Ataxic cerebral palsy** results in problems with balance. Individuals with more than one type are diagnosed with **mixed cerebral palsy**.

Challenging behavior is defined as culturally abnormal behavior(s) of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behavior which is likely to seriously limit or deny access to the use of ordinary community facilities. Common types of challenging behavior include self-injurious behavior (e.g., hitting, head butting, and biting), aggressive behavior (e.g., hitting others, screaming, spitting, and kicking), inappropriate sexualized behavior (e.g., public masturbation or groping), behavior directed at property (e.g., throwing objects and stealing), and stereotyped behaviors (e.g., repetitive rocking, echolalia, and elective incontinence). Challenging behavior may be caused by a number of factors including biological (e.g., pain, medication and the need for sensory stimulation), social (e.g., attention-seeking, the need for control, and lack of knowledge of community norms), environmental (e.g., physical aspects such as noise and lighting, or gaining access to preferred objects or activities), or function as a means of communication.

Childhood Disintegrative Disorder is a rare condition characterized by seemingly normal development for at least the first two years of life followed by marked regression in previously acquired skills including communication, motor functioning (at times), and loss of adaptive skills.

Cholalia is a disorder of language that results in repetitions of words or phrases previously heard. Echolalic responses can be immediate or delayed.

Congenital Rubella Syndrome (CRS) is a group of physical problems that occur in infants whose mothers are infected with the virus that causes German measles. The most critical time is the first trimester (i.e., the first three months of a pregnancy); after the fourth month, the mother's rubella infection is less likely to harm the developing fetus. Symptoms in the infant can include cloudy corneas or white appearance to pupils, deafness, developmental delay, excessive sleepiness, irritability, low birth weight, mental retardation, seizures, small head size, and a skin rash at birth. There is no specific treatment for congenital rubella.

Cornelia de Lange Syndrome (CdLS) is a syndrome of multiple congenital anomalies characterized by a distinctive facial appearance, prenatal and postnatal growth deficiency, feeding difficulties, psychomotor delay, behavioral problems, and associated malformations that mainly involve the upper extremities. Children with CdLS often suffer from gastrointestinal tract difficulties, particularly gastroesophageal reflux. CdLS can also include a number of behavior problems including self-stimulation, aggression, self-injury, or a strong preference for a structured routine. Many children with CdLS exhibit behaviors within the autism spectrum.

Developmental Disabilities (DD) are conditions that occur prior to the age of twenty two that engender significant functional impairments in independent living, self-care, receptive and expressive language, learning, and economic self-sufficiency. The term developmental disability is an umbrella term that includes mental retardation, cerebral palsy, autism, and epilepsy. Developmental disabilities can result from a variety of conditions such as autism spectrum disorder, genetic and chromosomal disorders (e.g., Down syndrome and Fragile X syndrome) epilepsy, fetal alcohol spectrum disorder, cerebral palsy, mental retardation, and learning disorders. Persons with such conditions are a heterogeneous population with varying abilities. Developmental disabilities are usually classified as severe, profound, moderate or mild, as assessed by the individual's need for supports. They affect between one and two percent of the

population in most western countries and are twice as common in males. Some researchers have found that the prevalence of mild developmental disabilities is likely to be higher in areas of poverty and deprivation and among people from certain ethnic groups.

Down Syndrome is the most common and readily identifiable chromosomal condition associated with mental retardation. It is caused by a chromosomal abnormality in which an error in cell development results in forty seven instead of the usual forty six chromosomes. This extra chromosome alters brain and body development. A diagnosis of Down syndrome can be made in accordance with results from a chromosome test administered shortly after birth. Approximately four thousand children with Down syndrome are born in the U.S. each year, or about one in every eight hundred to one thousand live births. Although parents of any age may have a child with Down syndrome, the incidence is higher for women over thirty five. Most common forms of the syndrome do not usually occur more than once in a family. There are over fifty clinical signs of Down syndrome, but all or even most of them are rare in one person. Some common characteristics include:

- Poor muscle tone
- Slanting eyes with folds of skin at the inner corners (called epicanthal folds)
- Hyperflexibility (excessive ability to extend the joints)
- Short, broad hands with a single crease across the palm on one or both hands

- Short, low-set ears
- Short neck
- Small head
- Small oral cavity
- Short, high-pitched cries in infancy
- Flat bridge of the nose
- Broad feet with short toes

Individuals with Down syndrome are usually smaller than their peers and display slower physical and intellectual development. In addition to distinct physical appearance, children with Down syndrome frequently have specific health-related problems and a lowered resistance to infection making them more prone to respiratory problems. Individuals with Down syndrome are more prone to visual problems (e.g., crossed eyes, hyperopia, or myopia) and mild to moderate hearing loss, and speech difficulty. Approximately one third of infants born with Down syndrome have heart defects, most of which are correctable. Some are born with gastrointestinal tract problems that can be surgically corrected. Some individuals may also have Atlantoaxial Instability, a misalignment of the top two vertebrae of the neck, making them more prone to injury if they participate in activities which overextend or flex the neck. Children with Down syndrome can have a tendency to become obese as they grow older. Down syndrome is associated with increased incidence of hypothyroidism that may present with symptoms of depression. It is also associated with Alzheimer's dementia, although the clinical symptoms are rarely apparent prior to forty five to fifty years of age, and as many as seventy five percent may be clinically affected by age sixty. Individuals with Down syndrome display wide variation in mental abilities, behavior, and developmental progress. The level of retardation can range from mild to severe, with the majority of persons functioning in the mild to moderate range. Research has shown that stimulation during early developmental stages improves chances for developing to the fullest potential. In addition, frequent reinforcement, consistent feedback continuing education, positive public attitudes, and a stimulating home environment have been found to promote overall development.

Epilepsy is a brain disorder in which neurons emit abnormal signals causing strange sensations, emotions, and behavior, or sometimes convulsions, muscle spasms, and loss of consciousness. Epilepsy can develop due to illness, brain damage, and abnormal brain development, all of which can lead to seizures. One seizure is not necessarily indicative of epilepsy, while two or more seizures are considered to be the result of epilepsy. EEGs and brain scans are common diagnostic tests for epilepsy. People with epilepsy are at risk for two life-threatening conditions: status epilepticus and sudden unexplained death. Seizures can be controlled with antiepiletic medications and surgical techniques for about eighty percent of people diagnosed with epilepsy,

First generation anticonvulsants are phenytoin, carbamazepine, phenobarbital, and valproate. Second generation anticonvulsants are topiramate, gabapentin, lamotrigine, tiagabine, levetiracetam, oxcarbazepine, zonisamide, ethosuximide, primidone, and pregabalin. In 1997, the FDA approved the vagus nerve stimulator for people whose seizures are not well controlled by medication.

Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT) is designed to determine potential health and/or developmental problems in children as early as possible to assure early intervention. EPSDT is a federally mandated Medicaid program and EPSDT visits, also known as well child visits, are a covered benefit for all eligible Medicaid beneficiaries under the age of twenty one. Providers must complete all testing components at the specific ages indicated on the periodicity schedule found in the [Michigan Medicaid Provider Manual](). The periodicity schedule can be found on the MDCH web site at [www.michigan.gov/mdch](). The ESPDT program is important in identifying children with existing and potential developmental disabilities so they can receive early diagnostic and treatment interventions.

Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term used to describe the range of conditions that can occur in individuals whose mothers consume alcohol during pregnancy and includes **fetal alcohol syndrome (FAS)**, **alcohol-related neurodevelopmental disorder (ARND)**, and **alcohol-related birth defects (ARBD)**. Individuals with FASD experience challenges in independent living and require assistance in managing money, obtaining medical care, shopping, meal preparation, personal hygiene, and using public transportation. In addition, employment, personal relationships, and structuring leisure time are impaired. Individuals with FASD often experience difficulties accessing financial benefits because many states base eligibility for developmental disabilities benefits on IQ score and many people with FASD have normal IQs.

Fetal Alcohol Syndrome (FAS) is characterized by growth retardation, characteristic facial features, and central nervous system neurodevelopmental abnormalities. Growth impairment may be evidenced by low birth weight for gestational age, decreasing weight over time (not due to nutritional factors alone), or disproportional weight to height. Characteristic facial features include short palpebral fissures, a thin upper lip and flattened philtrum. Children who do not meet these specific criteria may be considered for other diagnoses such as alcohol-related birth defects (which may be cardiac, renal, skeletal, ocular or auditory), or alcohol-related neurodevelopmental disorder.

Fragile X is a family of genetic conditions caused by gene changes in the FMR1 gene. Fragile X includes:

> **Fragile X Syndrome (FXS)** is the most common cause of inherited mental impairment which can range from learning disabilities to more severe cognitive or intellectual disabilities (i.e., mental retardation). FXS is the most common known cause of ASD. Symptoms also can include characteristic physical and behavioral features and delays in speech and language development.
>
> **Fragile X-Associated Tremor/Ataxia Syndrome (FXTAS)** is a condition that affects balance, tremor, and memory in some older male gene carriers.
>
> **Fragile X-Associated Primary Ovarian Insufficiency (FXPOI)** is a problem with ovarian function that can lead to infertility and early menopause in some female gene carriers.

Functional Analysis consists of an evaluation of assets, deficits, neurological and medical conditions, aberrant behaviors, and reinforcers as well as environmental antecedents and consequences of both adaptive and problematic behaviors. The involvement of mediators in natural support systems (e.g., teachers, parents, residential caregivers, employers, etc.) is taken into consideration.

Functional Assessment is based on direct observation of an individual, interviews with an individual and significant others, including family members, caregivers, support team members, and review of available information (e.g., assessment and incident reports).

Individual allocations and **personal budgets** are the amounts of funds that are under a person's/family's control and include the line item expenditure plan developed to carry out person-centered plans. The development of an individual budget is based on the unique supports that an individual may need and is a first and necessary step toward self-determination. Individual budgets must be approved for a specific amount in advance of the actual use of services based on an individual's specific needs and other available resources rather than average costs of the same amount for all participants. In other words, individualized budgets finance the specific supports that an individual needs rather than financing residential or program slots and then fitting people into those slots. Such financing allows individuals to change residences and take their support financing with them or change service providers without losing their place in the community. Thus if someone's needs change the support equation around that particular person can be readily changed. If someone wants to change service providers, or vice versa, (a not infrequent experience for people who struggle with challenging behaviors), they can move their support contract to another service provider, and retain their housing. Individual budgeting engenders fundamentally novel ways to deliver and finance services and can be challenging to implement because it involves an entirely different set of financial management skills from those required for grant-based and fee-for-services approaches.

Intermediate Care Facility for people with Mental Retardation (ICF/MR), an optional Medicaid benefit under Section 1905(d) of the Social Security Act, was created to fund institutions (I.e., four or more beds) for people with mental retardation or other related conditions. The ICF/MR Program was established in 1971 when legislation was enacted which provided for federal financial participation (FFP) for ICF/MRs as an optional Medicaid service. Congressional authorization for ICF/MR services as a state plan option under Medicaid allowed states to receive federal matching funds for institutional services that had been funded with state or local government money. To qualify for Medicaid reimbursement, ICF/MRs must be certified and comply with federal standards (referred to as Conditions of Participation, found in Federal regulations at 42 CFR Part 483, Subpart I, Sections 483.400- 483.480) in eight areas including management, consumer protections, facility staffing, active treatment services, consumer behavior and facility practices, health care services, physical environment, and dietetic services. Individuals who receive ICF/MR services must financially qualify for Medicaid assistance.

Learning Disability is defined by the National Joint Committee on Learning Disabilities (NJCLD) as a heterogeneous group of disorders manifested by significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning or mathematical abilities. These disorders are intrinsic to the individual and presumed to be due to central nervous system dysfunction. Even though a learning disability may occur concomitantly with other conditions (e.g. sensory impairment, mental retardation, social and emotional disturbance) or environmental influences (e.g. cultural differences, insufficient/inappropriate instruction, psychogenic factors) it is not the direct result of those conditions or influences.

Lesch-Nyhan syndrome (LNS), also known as Nyhan's syndrome, is a rare, inherited disorder caused by a deficiency of the hypoxanthine-guanine phosphoribosyltransferase (HGPRT) enzyme. LNS is characterized by three major features: neurologic dysfunction, cognitive and behavioral disturbances, and uric acid overproduction (hyperuricemia). Damage to the basal ganglia causes a characteristic fencing stance due to the nature of the lesion. Virtually all individuals with the syndrome are male, have delayed growth and puberty, and develop shrunken testicles or testicular atrophy. Female carriers are at an increased risk for gouty arthritis, but are usually otherwise unaffected. LNS is an X-linked recessive disease; the gene is carried by the

mother and passed on to her son so it is present at birth. Individuals with syndrome have severe mental and physical problems throughout life. The lack of HGPRT causes a build-up of uric acid in all body fluids, and leads to problems such as severe gout, poor muscle control, and moderate mental retardation, which appear during the first year of life. A striking feature of LNS is self-mutilating behaviors, characterized by lip and finger biting, which begin during the second year of life. Abnormally high uric acid levels can cause sodium urate crystals to form in the joints, kidneys, central nervous system and other tissues of the body, leading to gout-like swelling in the joints and severe kidney problems. Neurological symptoms include facial grimacing, involuntary writhing, and repetitive movements of the arms and legs (similar to those in Huntington's disease). The direct cause of the neurological abnormalities remains unknown. Because a lack of HGPRT causes the body to utilize vitamin B12 poorly, some boys may develop megaloblastic anemia. The symptoms caused by the buildup of uric acid (i.e., arthritis and renal symptoms) respond well to treatment with drugs (e.g., allopurinol) that reduce the levels of uric acid in the blood. The mental deficits and self-mutilating behavior are more challenging to treat. There is no cure, but many individuals with the syndrome live to adulthood.

Mental Retardation (MR) is not a single, isolated disorder, but rather describes a condition that affects individuals who have limited mental functioning to the extent that many aspects of life are impacted including communication, self-care, and social interaction. It is estimated that about one percent of the population is affected by mental retardation. MR is characterized by an IQ of 70 or below and at least two impairments in adaptive functioning. Cognitive testing instruments are used to assess intellectual development and diagnose mental retardation. IQ (intelligence quotient) is measured using standardized, individually administered tests (e.g., the Wechsler Intelligence Scale or the Standford-Binet). The threshold for mental retardation is typically set at 70[49]. It is generally agreed that scores of 71-75 are consistent with mental retardation in the presence of significant deficits in at least two or more adaptive skill areas (e.g., communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work). The severity of mental retardation is classified as mild (generally defined by an IQ test score of between 50–55 and 70, accompanied by deficits in adaptive behavior), moderate (IQ of 35–40 to 50–55), severe (IQ of 20–25 to 35–40), or profound (IQ below 20–25). The majority (seventy five to eighty five percent) of people with mental retardation fall into the category of mild mental retardation (MMR). People with severe mental retardation are more likely to display signs of serious conditions with neurological complications (e.g., Down's syndrome, cerebral palsy, epilepsy, hearing impairment, visual impairment, and other structural, chromosomal, or metabolic birth defects affecting the central nervous system).

Normalization, a Scandinavian paradigm that entails a commitment to creating normal conditions of life for people with intellectual disabilities, was described, promulgated, and operationalized in the United States and Canada by Wolf Wolfensberger and became the dominant philosophy by the end of the 1970's. The principle of normalization is based on the concept of **Social Role Valorization** which postulates that people who are in danger of being devalued should be helped to assume valued social roles in order to significantly increase their likelihood of being accorded respect from others as well as receipt of an equitable share of existing resources.

Pervasive Developmental Disorders (PDDs) consists of disorders arising during the first years of life which disrupt various developmental processes. PDDs are characterized by impairments in

---

[49] Normal IQ measurements on these tests generally fall between 80 and 135.

social interaction and communication skills, or the presence of stereotyped behavior, interests, and activities. It is estimated that anywhere from seven to forty eight individuals out of one thousand are diagnosed with PDD. Four times more males are diagnosed with PDD. There is an increased risk for autistic spectrum disorder among siblings of individuals with the disorder. According to research, autism has familial links with other psychiatric disorders including depression, obsessive-compulsive disorder, and motor tics. In addition, mental retardation, language disorders, and congenital deafness and blindness can also co-occur with autism. Epilepsy co-occurs in up to thirty percent of individuals with autism and can amply symptoms. There is some research suggesting that epilepsy can cause or mimic autism.

TYPES OF PERVASIVE DEVELOPMENTAL DISORDERS
● **Autistic Disorder:** Impairments in social interaction, communication, and imaginative play prior to age three years. Stereotyped behaviors, interests and activities.
● **Asperger's Disorder:** Characterized by impairments in social interactions and the presence of restricted interests and activities, with no clinically significant general delay in language, and testing in the range of average to above average intelligence.
● **Pervasive Developmental Disorder-Not Otherwise Specified** (commonly referred to as atypical autism): A diagnosis of PDD-NOS may be made when a child does not meet the criteria for a specific diagnosis, but there is a severe and pervasive impairment in specified behaviors.
● **Rett's Disorder:** A progressive disorder which has occurred only in girls. It is characterized by a period of normal development followed by a loss of previously acquired skills and the loss of purposeful use of the hands replaced with repetitive hand movements beginning around ages one to four.
● **Childhood Disintegrative Disorder:** Characterized by normal development for at least the first two years of life followed by significant loss of previously acquired skills.

Phenylketonuria (PKU) is an autosomal recessive genetic disorder characterized by a deficiency in the phenylalanine hydroxylase (PAH) enzyme which is necessary to metabolize phenylalanine to tyrosine. Deficient PAH results in an accumulation of phenylalanine which is converted into phenylpyruvate (phenylketone) and detectable in urine. PKU is found on chromosome number 12. Newborns affected by PKU usually do not show any signs of the disease at birth but, within the first few weeks of life, begin to show neurologic disturbances such as epilepsy. Children suffering from undiagnosed PKU may have an unpleasant, musty smell. Almost ninety percent of people with PKU have blond hair and blue eyes. Signs also include skeletal changes such as a small head, short stature, and flat feet. Individuals with PKU may also have eczema. Left untreated, the disorder can cause problems with brain development leading to progressive mental retardation and seizures. While there is no cure, PKU can be controlled by a diet low in phenylalanine and high in tyrosine. Phenylalanine is commonly found in protein-containing foods such as meat. Babies who are diagnosed with PKU must be placed on a special milk/formula substitute immediately. Later in life the diet is primarily vegetarian. Screening for PKU is mandated in all fifty states although methods of screening vary.

Pica is an appetite for non-nutritive substances (e.g., coal, soil, chalk, paper, etc.) or an abnormal appetite for things that may be considered foods (e.g., food ingredients such as flour, raw potatoes, and starch). Symptoms persist for more than one month at an age where eating such objects is considered developmentally inappropriate. The condition's name comes from the Latin word for the magpie, a bird which is reputed to eat almost anything. Pica is seen in all ages, particularly in pregnant women and small children, and especially children who have a developmental disability. It is the most common eating disorder in children with developmental disabilities.

Prader-Willi Syndrome (PWS) is a developmental disability that results from a complex genetic disorder and causes low muscle tone, cognitive disabilities, problem behaviors, short stature, and

a chronic feeling of hunger that can lead to fatal obesity. Children with PWS may exhibit a high pain threshold, respiratory difficulties (due, in part, to weak chest muscles), lack of vomiting, severe gastric illness, and/or body temperature abnormalities. PWS is not fatal, but can lead to health problems that may be fatal.

Rett's Disorder is a rare genetic disorder in girls[50] that causes impaired social interactions, loss of language skills, and repetitive hand movements. It is characterized by the appearance of accelerated head growth and psychomotor retardation, replacement of purposeful hand movements with stereotyped gestures (e.g., hand-wringing), poorly coordinated gait, withdrawal from social interaction, and impairments in speech and language comprehension between the ages of five months and four years. It is caused by spontaneous mutations in the MECP2 gene on the X chromosome. Prenatal testing is available for families with an affected daughter who has an identified MECP2 mutation. Since the disorder occurs spontaneously in most affected individuals, the risk for a family having a second child with the disorder is less than one percent. Genetic testing is also available for sisters of girls with Rett's syndrome and an identified MECP2 mutation to determine if they are asymptomatic carriers of the disorder. There is no cure for Rett's syndrome. Treatment focuses on the management of symptoms. Medication may be needed for breathing irregularities and motor difficulties, and to control seizures. Regular monitoring for scoliosis and potential heart abnormalities is needed. Occupational therapy is used to help children with the disorder develop skills needed for performing activities of daily living and physical therapy is used to prolong mobility. Most individuals with Rett's syndrome live well into middle age and beyond. But, because the disorder is rare, there is a paucity of information about long-term prognosis and life expectancy.

Rumination is an eating disorder in which partially digested food is regurgitated and chewed again before swallowing or spitting it out. Rumination is more common in individuals with severe and profound mental retardation than persons with mild or moderate mental retardation.

Sensory Integration is the process through which the brain organizes and interprets external stimuli such as movement, touch, smell, sight and sound. Children with autism often exhibit symptoms of Sensory Integration Dysfunction (SID) making it difficult for them to process information conveyed through the senses. Mild, moderate or severe SID deficits are manifested in increased (hypersensitivity) or decreased (hyposensitivity) to touch, sound, movement, etc. For example, hypersensitivity may lead to avoidance being touched while hyposensitivity may lead to seeking the stimulation of feeling objects and being situated in tight places.

Sensory Integration Therapy (SIT) aims to facilitate the development of the nervous system's ability to process sensory input in a more typical way in order to form coherent information upon which to act. SIT uses neurosensory and neuromotor exercises to improve the brain's ability to repair itself and improve attention, concentration, listening, comprehension, balance, coordination, and impulsivity control. The evaluation and treatment of basic sensory integrative processes of children with autism are usually performed by an occupational and/or physical therapist. A specific program is planned to provide sensory stimulation often in conjunction with purposeful muscle activities, to improve the manner in which the brain processes and organizes sensory information.

---

[50] Since males have only one X chromosome they lack a back-up copy that could compensate for the defective one, and they have no protection from the harmful effects of the disorder. Boys with such a defect die shortly after birth. However, different types of mutations in the MECP2 gene can cause mental retardation in boys.

The therapy often requires activities that consist of full body movements utilizing different types of equipment. It is believed that SIT does not teach higher-level skills, but enhances the sensory processing abilities, thus allowing the child to acquire them. Although SIT is widely used for autism and other developmental disorders and is supported by anecdotal evidence, there is as yet little research to establish it as an evidence-based treatment. While many studies have been conducted on SIT, none have been rigorous enough for it to be considered evidence-based.

Smith-Magenis Syndrome (SMS) is a rare genetic disorder characterized by a specific pattern of physical, behavioral, and developmental features that is the result of a deletion of chromosome 17 (17p11.2) which occurs from a spontaneous genetic mutation, the etiology of which is unknown, It is estimated to occur in one out of every twenty five thousand live births. The major features of SMS include mild to moderate mental retardation, delayed speech and language skills, distinctive facial features, sleep disturbances, and behavioral problems. Most people with Smith-Magenis syndrome have a broad, square-shaped face with deep-set eyes, full cheeks, and a prominent lower jaw. The middle of the face and the bridge of the nose often appear flattened. The mouth tends to turn downward with a full, outward-curving upper lip. These facial differences can be subtle during early childhood, but usually become more distinctive in later childhood and adulthood. Dental abnormalities are also common.

Disrupted sleep patterns are characteristic of Smith-Magenis syndrome, typically beginning early in life. Individuals may be very sleepy during the day, but have trouble falling asleep and awaken several times each night. People with Smith-Magenis syndrome have affectionate, engaging personalities, but most also display behavioral problems including frequent temper tantrums and outbursts, aggression, anxiety, impulsiveness, and difficulty with attention. Self-injury, including biting, hitting, head banging, and skin picking are very common. Repetitive self-hugging is a behavioral trait that may be unique to Smith-Magenis syndrome. People with this condition also compulsively lick their fingers and flip pages of books and magazines (a behavior known as "lick and flip"). Other signs and symptoms of Smith-Magenis syndrome include short stature, scoliosis, reduced sensitivity to pain and temperature, and a hoarse voice. Some people with the disorder have ear abnormalities that lead to hearing loss and/or eye abnormalities that cause myopia, and other vision problems. Cardiac and renal defects also have been reported, although these are less common.

Tics are sudden, quick recurrent, non-rhythmic motor movements or vocalizations. Tics are categorized as follows:

Simple Tics:
> Motor: eye blinking, head jerking, shoulder shrugging and facial grimacing
> Vocal: throat clearing, yelping and other noises, sniffing and tongue clicking

Complex Tics:
> Motor: Jumping, touching other people or things, smelling, twirling about and, only rarely, self-injurious actions including hitting or biting oneself
> Vocal: uttering words or phrases out of context and coprolalia (vocalizing socially unacceptable words)

Tourette's Disorder is an inherited neurological disorder that is characterized by repeated involuntary motor and vocal tics. While a diagnosis is generally made prior to age eighteen, symptoms usually appear between the ages of five and ten and start with mild, simple tics that become more frequent and increase in variety involving more body parts (e.g., trunk or legs) and disrupt activities of daily living. Sudden explosive behavioral outbursts occur in twenty five percent of individuals with the disorder, more often in children, and are usually accompanied by feelings of mounting tension and spontaneous activation. Tourette's is more common in males. Facial tics (e.g., rapid eye blinking or twitches of the mouth) are first indications of the disorder. Tics of the

limbs or involuntary sounds (e.g., throat clearing and sniffling) can also be first signs. Vocal tic activity typically involves loud grunting but can also include word shouting with obscenities (coprolalia). It is estimated that fifteen percent of persons with Tourette's suffer from this symptom. Approximately forty percent of children and adolescents with Tourette's also experience attention problems, and fifty percent are thought to meet diagnostic criteria for ADHD. Thirty percent experience academic difficulties. Twenty five to thirty percent of individuals with the disorder also experience symptoms of obsessive-compulsive disorder or other forms of anxiety. Learning problems and developmental stuttering are common. In addition social discomfort, self-consciousness, and depressed mood are commonly seen as children reach adolescence.

Tuberous Sclerosis (TSC) is a rare, multi-system, genetic disease that causes benign tumors to grow in the brain and other vital organs (e.g., kidneys, heart, eyes, lungs, and skin). A combination of symptoms may include seizures, developmental delay, behavioral problems, skin abnormalities, and lung and kidney disease. TSC is caused by mutations on either of two genes, TSC1 and TSC2, which encode for the proteins hamartin and tuberin respectively. (These proteins act as tumor growth suppressors, agents that regulate cell proliferation and differentiation.) Common symptoms in addition to benign tumors include seizures, mental retardation, behavior problems, and skin abnormalities. There is no cure for TSC, although treatment is available for a number of the symptoms. Antiepileptic drugs may be used to control seizures and medications may be prescribed for behavior problems. Intervention programs, including special education and occupational therapy, can be of benefit. Surgery, including dermabrasion and laser treatment, is used to treat skin lesions. Because TSC is a lifelong condition, regular monitoring by a physician is indicated.

Williams Syndrome (WS) is a rare genetic disorder characterized by mild to moderate mental retardation or learning difficulties, a distinctive facial appearance, and unique personality traits that blend overfriendliness and high levels of empathy with anxiety. Most individuals with WS worry excessively. The most significant medical problem associated with WS is cardiovascular disease caused by narrowed arteries. WS is also associated with elevated blood calcium levels in infancy. The disorder is most frequently caused by a random genetic mutation (deletion of a small piece of chromosome 7) rather than inheritance. However, individuals who have WS have a fifty percent chance of passing it on to their children. The characteristic facial features of WS include puffiness around the eyes, a short nose with a broad nasal tip, wide mouth, full cheeks, full lips, and a small chin. People with WS are also likely to have a long neck, sloping shoulders, short stature, limited mobility in their joints, and scoliosis. Some individuals with WS have a star-like pattern in the iris of their eyes. Infants with WS are often irritable and colicky and have feeding problems that keep them from gaining weight. Chronic abdominal pain is common in adolescents and adults with WS. The majority of individuals with WS have diabetes or pre-diabetes and mild to moderate sensorineural hearing loss (a form of deafness due to disturbed function of the auditory nerve) by age thirty. Hearing loss can start as early as late childhood. WS also is associated with a characteristic cognitive profile comprised of strengths in verbal short-term memory and language, combined with severe weakness in visuospatial construction (i.e., the skills used to copy patterns, draw, or write).The strongest language skills are typically in concrete, practical vocabulary, which, in many instances, are in the low average to average range; abstract or conceptual-relational vocabulary is much more limited. The majority of older children and adults with WS speak fluently with good grammar. More than fifty percent of children with WS have attention deficit disorders (i.e., ADD or ADHD), and about fifty percent have specific phobias (e.g., fear of loud noises). There is no cure or standard course of treatment for WS. Medical complications associated with the disorder may shorten the lifespan of some individuals with WS.

APPENDIX D: QUICK REFERENCE GUIDE

DISORDER	EVIDENCE-BASED AND PROMISING PRACTICES	UNPROVEN TREATMENTS	COMMENTS
Mental Retardation	Individual Therapy Family Therapy Social Skills Training Cognitive Therapy	Diet restrictions (e.g., vitamin and mineral supplements, yeast and gluten-free regimens)	CBT is recommended for children with a verbal IQ of at least 69
ASD/PDD	ABA (Applied Behavior Analysis) Discrete Trial Methods TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children) DIR (Developmental, Individual-Difference, Relationship-Based) Floortime Natural language methods Picture Exchange Communication System (PECS) Intensive Behavior Intervention (IBI) Risperidone for co-occurring aggression, tantrums, self injury on a short-term basis Methylphenidate for co-occurring ADHD SSRIs for repetitive behaviors, impulsivity, irritability, aggression, self-injury and anxiety Social Stories PLAY Cognitive Behavior Management Social-decision Making Assistive Technology Augmentative and Alternative Communication (AAC) Incidental Teaching Joint Action Routines (JARS) Occupational Therapy Speech Therapy CBT (for children who have a verbal IQ of at least 69)	Auditory integration training (AIT) Facilitated communication Hyperbaric oxygen Secretin Vitamin B6 and magnesium Dimethylglycine (DMG) Intravenous immunoglobulin (IVIG) AZT (zidovudine, Retrovir) Steroids Antifungal medications Detoxication; chelation Gluten Free, Casein Free Diet (GFCF) Hippotherapy Dolphin therapy Sensory Integration Therapy (SIT) Craniosacral therapy Behavioral optometry Psychoanalytic treatments RDI (Relationship Development Intervention) Insight-oriented psychotherapy Music Therapy Facilitated Communication Combined vitamin B6 and magnesium Secretin Amantadine Clomipramine Lamotrigine Vancomycin	There is no proven treatment for autism. Early intervention is critical. There is no single treatment protocol for all children with autism, but most individuals with ASD respond best to highly structured educational programs. Risperidone has no effect following discontinuation and weight should be monitored regularly Methylphenidate's adverse effects include difficulty falling asleep, appetite decrease, irritability and emotional outbursts Preliminary research suggests RDI (http://www.rdiconnect.com/) may help children with ASD, but it has not been established as an evidence-based practice. Occupational therapy can benefit a person with autism by attempting to improve the quality of life for the individual. The aim is to maintain, improve, or introduce skills that allow an individual to participate as independently as possible in meaningful life activities. Coping skills, fine motor skills, play skills, self help skills, and socialization are targeted (e.g., dressing, feeding, toilet training, grooming, social skills, fine motor and visual skills that assist in writing and scissor use, gross motor coordination to help with riding a bike or

Disorder	Evidence-Based and Promising Practices	Unproven Treatments	Comments
			walking properly, and visual perceptual skills needed for reading and writing). Occupational therapy is typically a component of collaborative efforts of medical and educational professionals, as well as parents and other family members in order to improve appropriate social, play and learning skills needed to function successfully in everyday life.
			Though no one treatment has been found to successfully improve communication, the best treatment begins early during the preschool years, is individually tailored, and involves parents along with professionals..
Tourette's Disorder	Behavior Therapy Neuroleptics	Plasma exchange (Intravenous Immunoglobulin [IVIG])	
Sleep Disorders	Extinction Graduated Extinction Melatonin (for sleep problems that do not response to behavioral interventions)		
Sex Offending Behavior	Education Social skills training Arousal control techniques Emotional self-regulation techniques' Relapse prevention techniques SSRIs, antiandrogens Rx for co-morbid conditions,		

APPENDIX E: SYSTEM VALUES ASSESSMENT

Activities, services, and supports are based on the person's dreams, interests, preferences, strengths, and capacities.	◆ The person's dreams, interests, strengths, preferences, and capacities are explicitly acknowledged and drive activities, services and supports. ◆ Services and supports are individualized and do not rely solely on pre-existing models. ◆ Supports and services have meaningful and functional outcomes selected by the person ◆ The person achieves personal goals.
The person and people important to them are included in planning and have the opportunity to exercise control and make informed decisions.	◆ The person and their advocates participate in planning and discussions where decisions are made. ◆ A diverse group of people, invited by the person, assist in planning and decision-making.
The person has meaningful choices, with decisions based on their experiences.	◆ The person has opportunities to experience alternatives prior to making choices[51]. ◆ The person makes life-defining choices related to home, work, and relationships. ◆ Opportunities for decision-making are part of the person's everyday routine. ◆ The person decides how to use his or her free time.
Natural and community supports are used when possible.	◆ The support of family members, neighbors, friends, co-workers, and others is encouraged with the person's consent. ◆ The person makes use of typical community and generic resources whenever possible.
Activities, supports, and services foster skills to achieve personal relationships, community inclusion, dignity, and respect.	◆ The person has a presence in a variety of typical community places. ◆ Segregated services and locations are minimized The person has friends, and the opportunity to form other natural community relationships. ◆ The person can access community-based housing and work if desired. ◆ The person has the opportunity to be a contributing member of the community.
Opportunities and experiences are maximized, and flexibility is enhanced within existing regulatory and funding constraints.	◆ Funding of supports and services is responsive to personal needs and desires, not the reverse. ◆ The person or advocates make decisions when funding constraints require supports be prioritized or limited. ◆ The person has appropriate control over available economic resources.
Planning is collaborative, recurring,	◆ Planning activities occur periodically and routinely; lifestyle

---

[51] People will request things that they know about and, unless they have already experienced something, will not know whether or not they like it. Many people with disabilities have never had opportunities to partake in life experiences needed to determine the manner in which they really want to live.

and involves an ongoing commitment to the person.	decisions are revisited. ◆ A group of people who know, value, and are committed to serving the person maintain involvement.
The person is satisfied with his/her activities, supports and services.	◆ The person expresses satisfaction with his/her relationships, home, and daily routine. ◆ Areas of dissatisfaction result in tangible changes in the person's life situation.

SELF-DETERMINATION: PRINCIPLES FOR EVALUATING YOUR SYSTEM			
PRINCIPLE	**INDIVIDUALS WITH DISABILITIES**	**FAMILIES**	**SYSTEM**
People have the freedom to plan their own life and to pursue the things that are important to them with the support of independent planning and support coordination	I have the freedom to plan my life and do the things important to me. I can get help from people who are not MRDD or paid workers to make my plan work.	We can receive unbiased assistance of our own choosing when we develop a plan for our child with a disability	Unbiased, competent and independent support coordination of an individual's or family's choice is always available for both planning purposes and for assistance with ongoing monitoring, evaluation and implementation.
People have the freedom to experience the same life opportunities as other people their age, connected with others in their communities.	I have the freedom to have life experiences the same as everyone else, and be a part of my community.	We can choose those opportunities typical for all children with the assistance of resources from the system	Individuals with disabilities and families are encouraged and supported to seek personal and community connections that are age appropriate with the support of our resources. There is no fixed menu.
Each person has authority over his own individual support budget.	I have the freedom to use my individual budget to help me get the things that I need. I know everything about my budget, and I decide how it is spent.	We have the freedom to control a targeted amount of resources and to exercise creativity in purchasing supports.	Once a fair and equitable amount of resources is identified individuals and families can exercise freedom and creativity in making support purchases that assist the person with a disability to lead a meaningful life.
All those involved demonstrate confirmation of the critical role people with disabilities and their families must play in making decisions in their own lives and in designing and operating the system they rely on	Everyone understands and shows that self-advocates and their families are the most important decision-makers when: 1. I make plans for my own future; and 2. Decide about how the service system will operate.	We have the authority to implement responsible planning choices for loved ones who are minors and are an integral part of all rule making and system changes. Our adult children are listened to objectively and considered as "adults" by the human service system.	We encourage and support both responsible individual and family control over resources and enter into equal partnerships with both in all system re-design issues.
People have the freedom to choose and set up the support they need to pursue the life they envision	I have the freedom to choose the people I want to help me reach my goals.	We have the authority to select all personnel and supports to further the life goals of our loved ones.	We delegate the authority for selecting both personnel and supports to individuals with disabilities and families.
People enjoy the freedom of economic independence and security, with opportunities to earn adequate income.	I have the freedom to work and make enough money so I can support myself and have a better life.	We are encouraged and supported to assist our loved ones in planning an economic future through real work at minimum wage or above and/or microenterprise development (very tiny businesses). We are supported in planning these goals while our children are minors. Our targeted amount of resources can be used at various stages to assist in developing these opportunities.	We establish policies together with individuals and families that both encourage economic futures and provide resources to make this a reality.
People take responsibility for decisions in their lives and for the support money allocated to them with the assistance of an independent fiscal intermediary	I take responsibility for decisions I make and for how I spend my individual budget, with help from someone I choose.	We exercise great responsibility for the wise use of public dollars and receive the assistance of an independent fiscal agent.	We provide for the establishment of fiscal intermediaries and jointly with individuals with disabilities and families establish guidelines and principles for the wise and cost-effective use of public dollars.

TASH (http://www.tash.org/)

Health and Safety	• The individual has a primary physician • The individual receives adequate medical and dental care • The individual receives medical tests related to issues of gender when appropriate • The individual has choice about and a trusting relationship with all health providers • The individual's medications are reviewed on a regular basis and the reasons for prescribed medications are adequately communicated and accepted by the individual. If not, an independent review is conducted and a plan for non-coercive intervention if there is an important issue of health or safety is extant. • All supports providers are freely chosen and in caring relationships with the individual • Someone who understands the communications of an individual who does not use speech or communicates in typical ways is always available and in a position to act in accordance with the person's wishes and needs. • The individual resides in safe housing in a neighborhood that is considered safe • There evidence that an individual's guardian respects their wishes • Regular review of the need for guardianship is conducted • Alternatives to guardianship are explored • Whether the individual has a do not resuscitate order • Independent legal assistance is available for the individual to challenge do not resuscitate orders and their imposition by a guardian
Living	• Individuals with disabilities live in typical and safe housing • Individuals with disabilities have truly chosen their homes • individuals who live other individuals with disabilities whether or not they also have a disability, are chosen by mutual agreement • The degree to which persons with disabilities control who comes through the front door
Community	• The numbers and kinds of community organizations, clubs, and voluntary associations individuals belong to • The amount of money and time they spend as members • The contributions they make to these groups and the use of community resources
Relationships	• The amount of time individuals spend with freely chosen friends • Individual's ability to engage in romantic activities • The degree of privacy individuals have and the mutual support they receive and extend to friends

Income	• The number of dollars individuals earn each week
	• The number of hours individuals work in jobs they have chosen that pay minimum wage or more
	• The amount of money individuals generate through self employment and the degree of freedom and responsibility they can exercise in the disposition of those dollars.
	• The degree to which an individual generates private income by:
	    · Working at a job of his/her choosing
	    · Operating a microenterprise

	• Having disposable income for private purposes and documenting the amount • Contributing to one's own long-term care costs

Transportation	• Whether individuals control their means of transportation
	• Whether individuals can decide to go somewhere and do something, including work, in a planned or spontaneous manner
	• The degree to which the person can in a planned and spontaneous way:
	   • Decide to go out
	   • Plan an evening or weekend trip
	   • Get to work on a regular basis
	   • Decide to provide transportation for a friend

Home	• The degree to which an individual lives in typical and safe housing • The degree to which an individual chooses that home • The degree to which an individual chooses with whom they live

Community	The degree to which an individual belongs in their community measured by:
	   • The number of organization affiliations
	   • Regular attendance at a place of worship if desired
	   • The amount of shopping at typical neighborhood stores
	   • The use of community and generic recreation resources
	   • Attendance at cultural, social, and political events

Relationships	The degree to which an individual is involved in reciprocal relationships measured by:
	   • The number of visits from and to friends
	   • The number of visits from and to family
	   • The number of invitations from friends
	   • Interest in and facilitation of romantic relationships

APPENDIX F: THE COMMUNITY IMPERATIVE

Human Rights:

- ◊ **All people have basic human and legal rights.**
- ◊ **These rights must not be taken away just because a person has a mental or physical disability.**
- ◊ **Included in these basic rights is the right to live in the community.**

Education and Support Services:

- ◊ **All people are valuable.**
- ◊ **All people have strengths and abilities.**
- ◊ **All people have the right to services in their lives that support these strengths and abilities.**
- ◊ **These supports are best provided in the community.**

To meet basic human rights and get the best services, *all* people, no matter what their abilities, have the right to live in the community.

Human Rights:

- ◊ **All people have fundamental moral and constitutional rights.**
- ◊ **These rights must not be abrogated merely because a person has a mental or physical disability.**
- ◊ **Among these fundamental rights is the right to community living.**

Educational Programming and Human Services:

- ◊ **All people, as human beings, are inherently valuable.**
- ◊ **All people can grow and develop.**
- ◊ **All people are entitled to conditions which foster their development.**
- ◊ **Such conditions are optimally provided in community settings.**

Therefore:

In fulfillment of fundamental human rights and in securing optimum developmental opportunities, all people, regardless of the severity of their disabilities, are entitled to community living.

(Center on Human Policy, Syracuse University)