

With a little help from my friends...  
*A series on contemporary supports to people  
with mental retardation*

## **Growing Strong**

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## PREFACE

Services and supports to people with mental retardation have undergone significant change in the last 50 years. Today people with disabilities are living longer. They and their families are asking for and expecting meaningful support to live their lives as full citizens in their own communities.

This series of five booklets provides information in a comprehensive but basic manner designed for individuals who do not know much about how supports are currently provided, but who would like to know more about the history of services and supports as well as current issues and future trends.

The following is a brief overview of the information and issues covered by each booklet:

**Speaking Up, Speaking Out (Booklet #1):** This booklet covers definitions and prevalence of mental retardation, issues in the current legal system, along with self-advocacy and self-determination.

**Growing Strong (Booklet #2):** This booklet covers issues and topics in early intervention, family supports, and the educational system.

**Real lives (Booklet #3):** This booklet covers services and supports in the areas of supported living, vocational opportunities, and supported recreation.

**I Am Who I Am (Booklet #4):** This booklet covers a variety of specialized support needs including challenging behaviors, supports to the aging, culturally competent supports, and person-centered planning as a tool for providing supports that are meaningful to the individual.

**Changing Systems (Booklet #5):** This booklet covers issues in quality assurance and funding of supports and services.

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## **A Note About Language**

Who we are is as much about how others see us as it is about our physical beings. We can eat right, exercise, and believe in ourselves all we want, but if no one ever notices it won't last for long. So what does it mean to be "a person with mental retardation?" Does it say something about a person that is meaningful and relevant? Does it tell people something about that person that is valuable, helpful, or essential?

When asked, most self-advocates with mental retardation will make it clear that the label "mentally retarded" is stigmatizing and limiting. If the label comes before the person then a large part of who that person is has already been defined.

Despite clear indications from self-advocacy groups that the words mental retardation should be "retired," support professionals and agencies that oversee support systems struggle with how to provide the necessary assistance to people who need it, without defining who is eligible (i.e., creating a label). By its very nature service provision hangs onto labels in order to know where to best put resources. The dilemma of dropping all labels and still accurately describing who can receive supports through State agencies is not solved. But there is a clear mandate from the people who receive these services and supports that people—not labels—always come first.

That part is simple. It's a commitment that when we talk, write, or otherwise communicate about people with mental retardation or any disability we never put the word "disability" before the word "person;" that when we have the chance to educate others about people-first language, we do; and that as we look at the global issues of how to support people, we remember that it's the person, not the service, that matters. It's a sign of respect. It's a sign that although not all the questions have been answered correctly, we are up to the challenge. Spread the word: "People First!"

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## **Overview**

Good support to people with mental retardation and their families spans the lifetime. It starts before a child is born by providing proper prenatal care and education to parents on how to avoid or minimize the impact of a disability. It continues with accurate, timely assessment and early intervention strategies and appropriate educational opportunities for children. And throughout, it is most successful when family members are properly educated, supported in making good choices, viewed as part of the solution rather than the problem, and respected as the key to a meaningful, life-long natural support system. This booklet provides useful information on prevention, early intervention, education and family supports.

### **Family Ties: Prevention, Early Intervention, Education and Family Supports**

Prevention, early intervention, education and family supports are areas that are both critical and complex. They bring with them a "messiness" that is not always a comfortable place for policymakers. In our current era of government reform, where government assistance is often equated with a "hand-out," the public has shown its intolerance for perpetuating long-term government-sponsored assistance. For that reason many assistance or entitlement programs such as welfare or Medicaid are currently at risk of cut backs and substantial reform. During this critical time it is important that while excess or ineffective programs are cut or reorganized that proactive, effective programs are not.

Cost and effort applied early in life in terms of prevention, early identification, and intervention, and in ways that maintain natural connections, such as family supports, for people "at risk," can have long-term benefits and decrease the need for costly supports later in life. At a time when everyone wants the "biggest bang for their buck," especially when tax dollars are being spent, those programs that are effective at preventing or decreasing the long-term effects of mental retardation and other disabilities on individuals are likely judicious investments of public funds.

## **Prevention**

Each child that comes into the world deserves to get the best out of it. They deserve to have the loving care of parents and other family members, adequate shelter and food, and opportunities to play and grow in safe, nurturing environments. Every day thousands of babies are born in the United States, and fortunately most are healthy both mentally and physically. But some children are not born healthy, and others, who are born healthy, lose abilities through environmental exposure to toxins or through environmental deprivation such as lack of stimulation, or abuse and neglect.

There are a number of factors which can increase the likelihood that a child will be born with mental retardation or other developmental disabilities. The prenatal environment can have a dramatic effect on infants and children who most likely would have been born without disabilities. For instance, Fetal Alcohol Syndrome, the leading known cause of mental retardation today, is completely preventable if pregnant women do not drink alcohol. Smoking during pregnancy greatly increases the likelihood that a baby will have a low birth weight, as does use of certain drugs (prescription or illegal), poor maternal nutrition, and extremes in maternal age. Babies with low birth weights are three times more likely to have mental retardation or other developmental disabilities.

After a child is born they may be at risk for developmental delays and mental retardation through deprived or harmful environments (e.g., lead poisoning, inadequate nourishment, lack of stimulation, etc.). Impoverished physical and social environments where children are not provided adequate nutrition or stimulation will affect their cognitive abilities. Children must be able to touch, explore, and move around their environment. Babies must be spoken to, held, and cared for in a loving manner in order to make connections with others. The risk that the environment will not be satisfactory for optimal health and well-being on the part of the child can be increased when parents or other caregivers have mental health issues, cognitive disabilities, or are overstressed or inexperienced.

Lead at certain levels is a preventable source of environmental contamination that can reduce IQ scores, and increase the likelihood that a child will exhibit aggressive behaviors or have learning disabilities. Sources of lead are prevalent in our homes and neighborhoods. Until the late 1970's many paints commonly used in homes were lead-based, fuel for cars contained lead and soldering material used on pipes to carry tap water in some homes used lead. Children most at risk are young children (under 6) who live in older homes and urban areas where lead may literally be found in almost every part of their environment from the water, to the soil in their yards and parks, to the dust in their homes. Lead contamination comes from ingesting the lead which is why small children, who tend to put everything in their mouths, are at greatest risk.

Identifying and eliminating sources of lead is critical, however a child does not exhibit symptoms of lead poisoning until irreparable damage has already been done. Many pediatricians test children for blood-levels of lead in the first year of life. For children who have elevated levels but have not experienced symptoms, immediate intervention in the environment to discontinue the exposure can prevent long-term effects. Children without adequate health care are the most likely to have undiagnosed levels of lead until damage has occurred and symptoms such as decreased cognitive abilities and behavior problems are exhibited. Education about lead poisoning is critical but funding to provide lead abatement (by professionals since this process when done incorrectly increases the lead in the environment) and for proactive testing of all children is necessary.

**Children born with disabilities are at higher risk for environmental deprivation for reasons including:**

- ◆ **The child's disability may reduce its ability to engage people socially. (e.g., smiling, cooing, eye contact, crying).**
- ◆ **Families have complex responsibilities and may become overwhelmed when a child with disabilities is born.**
- ◆ **Children are at risk in the prenatal environment due to poverty, or lack of medical benefits.**
- ◆ **Parents of children born with disabilities may go through a "mourning" period which reduces their ability to parent effectively.**

Genetics also play a role in the development of disabilities in children. Tay-Sachs disease, Klinefelter's syndrome, and Down's syndrome, are all caused by genetic abnormalities, and although not fully understood at this time, autism also appears to have a genetic component. Most of these diseases and syndromes are not clearly preventable through traditional prenatal care however, genetic counseling can help prospective parents decide if the risk is too great and decide not to have children. In addition, early detection helps the parents to mobilize necessary environmental supports for after the child is born which may reduce the range of effects caused by the disability and prevent secondary disabilities caused by lack of appropriate environments.

While not all causes for mental retardation are known or are preventable, there are many which are. As medical science becomes increasingly more sophisticated in identifying factors that may cause a child to have cognitive delays the challenge will be how to disseminate the information to potential parents and support them in the choices that will be best for the child.

This is no small challenge. For instance, recent studies have found a strong correlation between a woman's proper consumption of folic acid and the reduced incidence of neural tube defects (NTD) such as spina bifida. When a woman has sufficient amount of folic acid in her diet the rate of pregnancies where the child has NTD drops by 50-70%. But for optimal results the woman must have adequate amounts of folic acid for up to three months before conception as well as during the first trimester of pregnancy. Similarly other studies have shown that smoking or cocaine use on the part of fathers can increase the incidence of birth defects by affecting the health of his sperm.

Information like this is very valuable, but there are still a number of barriers to potential parents receiving and acting on information concerning the prevention of birth defect. For instance the majority of pregnancies are still unplanned, particularly among younger mothers. Unplanned pregnancy makes it much more difficult to use this information, since the time prior to pregnancy is lost as well as the first few critical weeks or months of the pregnancy.

Lack of adequate prenatal care is another important factor in considering prevention. This is particularly important for families, many of which come from racial/ethnic minorities, where poverty is a daily reality and access to reasonable health insurance and health practitioners can be scarce. As a dramatic example, in the United States, the rate of infant mortality of babies born to white women is comparable to those of other wealthy democratic countries where infant mortality rates are the lowest in the world. On the other hand, the rate of infant mortality of babies born to African-American women is comparable to poor countries where mortality rates are the highest in the world. Because infant mortality is highly correlated with adequacy of prenatal care it is clear that large segments of our society are missing out on necessary medical care which help to bring healthy babies into the world and keep them healthy once here.

Unplanned pregnancy may be difficult to completely prevent, however providing early and thorough prenatal care should be possible at a much higher rate than is happening now. Programs are in place to help remedy the problems associated with poverty. For instance the Supplemental Food Program for Women, Infants and Children (WIC) provides vouchers for nutritious foods to pregnant women and mothers of young children who are within certain financial guidelines. In addition these women receive nutritional counseling. The U.S. General Accounting Office has looked at studies which compare the birth weights of babies born to women who participate in WIC programs with a non-participating control group and found that the WIC participants had significantly higher birth weights.

Clearly, programs that provide access to proper nutrition and medical care can help to reduce the numbers of children born with mental retardation and other disabilities. However current programs are not aggressive enough and are not reaching the numbers of people necessary. Continued poor outcomes for certain racial/ethnic groups supports the need for programs which are comprehensive and culturally sensitive.

For instance, many cultures see pregnancy and birth as a natural process that does not require intense medical intervention. Women from some cultures have strong preferences not to undress unnecessarily in front of male doctors. Pregnant women who participate in illegal drug use may avoid medical attention if they feel at risk for incarceration or having their child removed from their care. Sensitivity on the part of practitioners can go a long way in making these women comfortable in seeking and accepting adequate prenatal care.

Women and children who live in poverty may have a number of programs which will offer help either through counseling, vouchers, or direct financial aide. However these programs usually attack the problems piecemeal, each focusing on one small part of the problem (i.e., WIC's focus on nutrition). Since it is unusual that families experience only one risk factor, consideration of more aggressive and comprehensive programs which work with families to overcome the variety of risks associated with prevention of disabilities, may be warranted. Attending to all the forms and wading through all of the

bureaucratic red tape necessary to participate in programs can be overwhelming and may discourage women from participating in all public assistance available to them. Programs with a central point of contact for a number of services and supports which are provided in culturally competent ways may have the best chance at succeeding in reducing the likelihood that children will be born with mental retardation and other disabilities.

## **Early Intervention**

When it comes to identifying and providing supports to the child at risk for mental retardation and related conditions, it can not be understated that there is no such thing as beginning too early. One 1990 study, funded by the Robert Wood Johnson Foundation, found that children with low birth weights who received comprehensive early intervention services in the first three years of life had significantly higher IQ scores (from 6-13 points higher on average) and had fewer reported behavioral problems than children who did not receive the interventions. This study is one of many which has provided statistical evidence that children's environments are critical factors in their mental, social and physical development, and that sufficiently enriched environments after birth can prevent or minimize the impact of mental retardation and related conditions later in life.

In 1986 the Federal government recognized the benefits of early intervention by authorizing what is now known as Part C (previously Part H) of the Individuals with Disabilities Education Act (IDEA). Part C supplies Federal dollars to the States for planning and implementing early intervention services for children from birth through age two. In addition, by the fifth year of implementation States had to guarantee a free and appropriate education to children age 3 -5 through the Preschool Grant Program of Part B. Part B uses the same criteria in services as the rest of IDEA such as the Least Restrictive Environment clause (LRE) and the use of Individual Education Plans (IEP) (For more about IDEA see the section of this booklet on education).

Part C authorizes financial assistance to the States for the following purposes:

- ◆ Develop and implement a statewide, comprehensive, coordinated, multi-disciplinary, interagency program of early intervention services for all infants and toddlers with disabilities and their families.
- ◆ Facilitate coordination of payments for early intervention services from various public and private Sources.
- ◆ Enhance the State's capacity to provide quality early intervention services and expand and improve existing services.

In addition Part C includes that services must be family focused, individualized, and outlined in the Individual Family Support Plan (IFSP); that the States must coordinate services across the many agencies that provide supports, through the creation of an Interagency Coordination Council, and by specifying ways to promote collaboration at the local level; and that States must engage in activities which help to locate and identify children in need of services.

Early intervention services can vary greatly depending on the needs of the child and family. Families may use just a few hours a week in services or may need very intensive services. A first step for children and families is accurate screening and assessment. Once the child's and family's needs are known, they may use any variety of necessary supports including the following:

- ◆ Access to specialist in the areas of speech therapy, physical therapy, psychology, or medical specialist.
- ◆ Respite care either in their own homes or in alternative placements.
- ◆ Assistive technology, and adaptations to their homes or vehicles.



- ◆ Training and counseling in working with the child effectively, or in providing basic medical care (e.g., giving medications, changing a catheter, etc.).
- ◆ Transportation.
- ◆ Nursing services.
- ◆ Case management or coordination of services.

In general Part C has been helpful in improving services to families with children who have special needs. Reports from the States have noted a number of achievements since the implementation of Part H, now Part C, including the following:

- ◆ The family focus of Part C has had positive outcomes by reducing family stress, empowering parents, increasing individualization, creativity, cultural sensitivity, and flexibility of supports;
- ◆ Cost benefits in terms of reduced need for special education services or out-of-home placements;
- ◆ More streamlined services;
- ◆ Increases in the number of children being identified and served;
- ◆ Expansion of services especially in the areas of home and community-based inclusive services,
- ◆ Personnel development which has increased the numbers of people qualified to provide services to families and children with early intervention needs.

Despite progress there have been a number of challenges in implementing Part C and the Preschool Grants Programs of Part B. Some of the challenges of early intervention services which remain for the majority of States are the following:

- ◆ *Continued difficulty in coordinating services.* Although progress has been made a number of services are still fragmented, duplicative, and at times over-lap with each other. Some of the reasons why coordination can be difficult include the fact that States must coordinate a large number of variables including multiple funding streams, various service providers and programs, and State regulations, laws or other requirements over-seeing these types of services. States struggle with the lack of central authority for making decisions. The process of building consensus can be very slow. States that have the most trouble are ones which lack a history of collaboration in the area of early intervention, do not have a common vision for services in this area, and which primary stakeholders do not agree or do not have the power to facilitate changes.
- ◆ *Providing adequate funding for early intervention programs.* The Federal funding through Part C is designated for coordinating and supplementing existing services, rather than creating a large number of new programs. The States are responsible for locating the necessary funding sources to cover the majority of the activities provided through Part C. In return they received a great deal of flexibility and control over how they develop and implement their plans. However as both State and Federal budgets tighten, it is difficult for States to locate and allocate funds that provide the bulk of the services. Some of the funding sources currently used by States include Medicaid, Maternal and Child Health Block Grants, and private insurance.
- ◆ *Creating a smooth transition from services provided under Part C (Birth-2) and Part B Preschool Grants Programs (ages 3-5).* States have experienced difficulties in creating a seamless system between early intervention for infants and toddlers and pre-school options. Transition planning criteria has been recently added to the language of Part C in order to help States understand this.
- ◆ *Providing access to Least Restrictive Environments in the Preschool Grant Programs.* Because many States don't offer preschool options to 3 and 4-year-olds without disabilities it has been difficult to comply with the LRE. Strategies and suggestions shared included increasing the work on collaboration between agencies such as Head Start programs, and private preschools.

Part C and the Preschool Grant Programs of Part B are still relatively new. Families and States have been providing feedback to the Federal Government as to how it can be revised and shaped to make early intervention and preschool services as effective as possible. Access to appropriate, effective, family-centered supports early in life are critical. For some children early intervention can mean that they avoid the need for services in the future. Others with more severe disabilities may continue to need supports throughout their lives. But thanks to the promise of Part C, children and their families today do not have to face the heartbreaking choices of institutionalization and social isolation. The family focus of Part C starts the process of supporting and maintaining one of the most meaningful lifelong bonds a person will have: the bonds of family.

## **ABC's, IEP's and LRE's: Education**

School: It's where children learn the ABC's and how to add 1-2-3's. But it's also where they learn about relationships and other people—how to make friends, and how teachers' expectations differ from parents'. School is where children begin to make small steps in independence, gradually learning more about themselves, the world, and others. Eventually, the hope is that around the time of graduation they are ready to take on some adult responsibilities like further education, working, raising families and participating in civic duties.

This educational promise has not always been there for all children, especially children with severe disabilities, including mental retardation and other developmental disabilities. While their brothers, sisters and neighbors left for the classroom, children with disabilities stayed behind. If they were lucky, and their parents had some money, and there was a privately run school which provided education to the children with disabilities, they may have been able to attend. But for other families the choices were to provide 24-hour a day supports to their children or to hand them over to State run institutions. These practices set the stage for years of isolation and lack of any substantial opportunity for future employment or a productive place in society.

**“For 22 years now, the IDEA has been the driving force behind the simple idea we have heard restated and symbolized here today, that every American citizen is a person of dignity and worth, having a spirit and a soul, and having the right to develop his or her full capacities. Because of IDEA, disabled children all over America have a better chance to reach that capacity. And through IDEA, we recognize our common obligation to help them make the most of their God-given potential.”**

*—Excerpt from President Bill Clinton's speech upon signing the reauthorization of the Individual's with Disabilities Education Act June 4, 1997*

This history of exclusion is still with us today. Despite good progress in bringing children with disabilities into the school environment most continue to be isolated from peers who don't have disabilities and do not attend a full range of regular education classes or integrated after school activities (e.g., sports, cheerleading, clubs, etc.). Children who reach adulthood without experiencing a variety of school experiences may find it difficult to suddenly participate as an active community member with a real job, friends, and the ability to live in their own homes. For this reason, there is an increased interest in planning and creating inclusive educational opportunities for all children with disabilities. Inclusive education means opportunities to fully participate in a range of classes and activities, to interact and make friends with peers of all abilities, and to strive toward the best possible future as an adult.

In the mid-1970's Federal legislation that mandated free and appropriate education for all children with disabilities was passed. Once Federal mandates and funding of education for children with disabilities was put in place, students and families had more options not only in education and future employment, but also to keep children in the family home, instead of placing them in institutions in order to receive basic services. But there is still more to do.

The Education for All Handicapped Children Act which was originally authorized in 1975 (now called the Individuals with Disabilities Act-IDEA) and its subsequent amendments contained in them a number of components including guidelines for the way education should be conducted for children between the ages of 5-21 with disabilities. Some of the critical components and expectations first mandated and subsequently strengthened and clarified include the following:

- ◆ The "Least Restrictive Environment" (LRE) clause which mandates that children receive education in the least restrictive setting possible.
- ◆ The establishment of the Individual Education Plan (IEP) for every student receiving special education services.
- ◆ A plan for the student to transition from the school environment to the adults world which focuses on not only employment but other aspects of adult living such as self-care, functional skills, and plans for a satisfactory adult living arrangement as well.

The IDEA also contains within it a due process provision so that conflicts between the desires of parents/students and the school system can be resolved. The procedure may include mediation, an impartial due process hearing, state-level reviews, and appeals to the court system, depending whether there is satisfaction at each level. Most of these disputes are settled through mediation or due process hearings although there have been several court cases in the country since the initiation of the IDEA.

**“It seems silly, really, that we expect adults with developmental disabilities to participate in the community and yet we segregate them throughout their school years.”**

*— researcher from Nevada*

Originally much of public education to children with disabilities was provided in segregated facilities in the community. A good first step from complete denial of education, however this segregation still left children isolated from their peers, unable to attend schools with their siblings, and with lower expectations of achievement. Eventually people asked why children couldn't attend school in their own neighborhoods. At the time it seemed impossible to many, but today the majority of neighborhood schools have special education services. Since the IDEA was first authorized, education for children with disabilities has been continually pushing the boundaries of what people have thought was possible. At each juncture there were groups of people willing to take risks and to work to overcome what were seen as insurmountable barriers.

Some barriers to bringing special education services into neighborhood schools and regular classrooms which have been consistently identified include the following:

- ◆ Lack of accessibility in buildings and transportation. Not all schools were built with children who use wheelchairs or have other mobility issues in mind.
- ◆ An assumption that special education students will not get anything out of attending regular classes because they can not keep up with the regular curriculum.
- ◆ An assumption that bringing special education students in the regular classroom will be detrimental to the other students by taking up the majority of the teachers time and limiting the curriculum that can be offered.
- ◆ Fears that regular education teachers will be unable to meet the needs of a wide variety of students with different abilities in regular classrooms.

Despite these concerns more and more school systems and classrooms have opened their doors to special education students, very often with positive results. The components of the IDEA have served to continue the necessary mandate that all children deserve to be educated fairly and to serve as guiding principles that help overcome these issues.

The LRE clause of the IDEA has been instrumental in continuing the push to full integration and inclusion for children with disabilities in educational settings. There has been, and continues to be, an evolution in how this clause is interpreted. Originally it was fulfilled by the creation of segregated schools in the community for children with significant disabilities. This option provided many children with educational opportunities for the first time, however, children who attend these "community" schools often have to travel long distances and attend different schools than their siblings and neighbors. This model of education is still in existence however it is rejected more and more by educators, school systems and families because it perpetuates the isolation of students receiving special education services.

Another way in which the LRE has been interpreted and implemented is to have self-contained special education classes in neighborhood schools and to place special education students into classrooms with regular education students whenever the class seemed appropriate for the special education student. These self-contained rooms in the larger school setting allow for more time for interaction with peers who do not have disabilities and to let children attend the same schools as their brothers, sisters and neighbors. "Mainstreaming" and "integration" are the buzzwords often used to describe this view of the LRE. Under this model students with and without disabilities typically spend very little time in the same room with each other and often even less time interacting. The classes which are most often used as mainstreaming opportunities are classes such as gym, art, and music.

The most recent interpretations of the LRE are the foundation of "inclusive" education. These education models are implemented with the presumption that all children should attend the same classrooms and be active in the school community. In addition there is an emphasis on students interacting with each other and working together, each in their own way toward learning necessary academic material.

Another provision of the IDEA calls for the creation of an Individualized Education Program (IEP) for each student with a disability. This is a plan for the student which outlines what educational goals are appropriate for the up-coming year and specifies what services will be necessary to meet these goals. The IEP is a legal written document developed by an interdisciplinary team which should include the student, the student's parent, the teacher, another person from the district who is qualified in special education, and any other person or professional that is identified by the school or parents as necessary.

The IEP can be an effective tool for planning and achieving individual goals for students when it is properly used. Unfortunately many times the IEP is written early in the year, or even the previous year in order to comply with the law, and then is filed away until the next review. Many regular education teachers who are asked to include children with disabilities in their classes do not participate in the IEP process and may not even ever see the IEP. Recent changes in the IDEA require a regular education teacher to be involved in the development of the IEP. In addition, traditional interdisciplinary planning for children with disabilities has focused on remediation and correction of perceived problems. As in other areas of services to people with disabilities, this type of planning is falling out of favor and being replaced with person-centered planning approaches which focus on and build upon student strengths, capabilities, gifts and talents.

As with any form of planning and childhood educational experience, active participation on the part of the parent can not be underestimated in creating a basis for success. IDEA has always indicated the need for parents to attend IEP meetings, however sitting in the room doesn't always mean participation. It is important for teachers, special education professionals and other school personnel to facilitate maximum parental participation by creating comfortable, open and respectful environments.

For the older student, transition services are required under the IDEA. The most recent amendments to this act require a focus on transition beginning at the age of 14 (previously 16). Transitional planning is a time where the student's future needs as an adult are considered and actions are taken to promote the student's ability to enter into the adult world prepared to work, with an appropriate place to live, and to have connections to the community that will lead to a satisfactory life style. Outside of work and self-care skills this transitional plan may include opportunities to volunteer, to develop a rich leisure life, or to continue on to post-secondary education.

While transition has traditionally been seen as taking place toward the later part of a student's education, the School-to-Work Opportunities act (STWO) which was authorized in 1994 has increased the emphasis on preparing students for work or post-secondary education even as early as kindergarten. The STWO does not apply strictly to children with disabilities but is part of greater national education reform. It includes language which targets all students and particularly emphasizes students who have traditionally had more difficult transitions into adult life due to disabilities, race, gender, or other issues. One possible outcome of the STWO is that inclusive practices and supports during and after transition may become more common and more individualized as all educators begin to focus on these issues.

**Criteria critical to effective planning identified by experienced educators:**

- ◆ **Students are included and involved in the IEP/Transition planning process.**
- ◆ **Transition planning acknowledges each student's total life experience.**
- ◆ **Agency personnel are actively involved in each student's transition process.**
- ◆ **Students receive training to increase awareness of their strengths and limitations, and to attain skills in self-advocacy.**
- ◆ **A personal transition file and action plan is developed for each student and given to them to use after high school.**
- ◆ **Transition team members are informed, creative, and committed to collaborating for student success.**
- ◆ **At age 14 adult outcomes are addressed in the IEP, and goals are developed and implemented in all documented areas.**
- ◆ **Transition goals are based on student needs.**

Across the nation nearly 40,000 students with developmental disabilities transition out of school each year. For many the transition is still less than satisfactory. Many people with mental retardation or related conditions leave school without having real jobs, or adequate places to live. Some of the reasons transition planning doesn't work include the following:

- ◆ Lack of energy, knowledge or interest on the part of the transition team to make real preparation happen.
- ◆ Lack of collaboration between all possible partners in the transition (parents, schools, adult services).
- ◆ Lack of real options in the services and supports available to adults.
- ◆ Long waiting lists for those services and supports which are available.

Yet another aspect of difficulty in transition may also have its roots in the lack of inclusive practices in education. As adult services continue to work toward the full integration of adults as a standard for supports it makes sense that the continued push for inclusive education is the place to start.

Inclusive education (where all students are expected to be an active part of the school community and participate fully in classrooms and after school activities) requires a fundamentally different approach than mainstreaming or simple integration (having students participate "when able" in regular classrooms). In order to be successful, inclusion can not be an isolated case by case situation but rather an entire philosophy that the majority of the school system supports and believes in as the right way to educate for all students.

The Department of Education's Office of Special Education (OSERS) began sponsoring systems change grants in 1987. LEARNS, one of the system's change grants from Maine has published this set of guidelines for use by school administrative units interested in fostering learning environments in which all students are encouraged to participate and achieve to high standards. They were designed after review and analysis of state and national school restructuring initiatives and reflect those values. The guidelines are aimed at stimulating systemic change at the State and local school levels that support the free, appropriate, public education of all students, in the schools and classrooms they would attend if they did not have a disability.

The following are LEARNS Guidelines for Creating Effective Inclusive Schools:

*I. Commitment to School Restructuring for All Students.* A school demonstrates its commitment to effective inclusive education through the development of policies, procedures and practices, that ensure that all students are integral members of the school community. This includes the following:

- ◆ A shared vision reflecting high expectations for all students, parents and educators.
- ◆ A climate supportive of change.
- ◆ A shared commitment to providing effective and creative learning environments for all students.
- ◆ Aligning curriculum, instruction and assessment based upon learning results developed for all students.
- ◆ People, programs and resources connecting across the system and accessible to all students.
- ◆ Professional development focusing on the support of student learning, and consistently leading to change in practice.
- ◆ Professional development incorporating strategies for all students. These include, but are not limited to: cooperative learning, conflict resolution, multi-age grouping, integrated curriculum, alternative assessment, etc.

*II. Commitment to Creating Inclusive Educational Environments.* A school demonstrates its commitment to inclusive education, through the development of policies, procedures and practices that ensure that all students are accepted and supported as contributing members of the school community. This includes the following:

- ◆ All students attend school with their brothers and sisters, friends and neighbors.
- ◆ All students attend school on the same days and during the same hours.
- ◆ All students have access to the general education curriculum and are provided with supports they require for successful participation.
- ◆ Learning opportunities within the school are student centered.
- ◆ Natural environments are used for meeting IEP goals and objectives.
- ◆ All students are encouraged to participate in after-school and extracurricular activities, transition and graduation ceremonies, and other school related events.
- ◆ Extended school year programs are designed to provide continued opportunity for participation with other students.
- ◆ All students have access to the same transportation services.
- ◆ Administrators provide leadership and support for ongoing collaboration and facilitate development of, and provide ongoing support for school based teams.

- ◆ Professional development for interdisciplinary school teams is a priority and is accessible to all school personnel.
- ◆ Commitment to community and family education and participation, are an integral part of the functioning of the school.
- ◆ "People first" language is used (e.g. student with autism vs. an autistic student).

*III. Commitment to Plan for Inclusive Education.* A school demonstrates its commitment to inclusive education by developing and implementing a plan to ensure that all students are given the necessary supports and classrooms.

- ◆ As part of total school restructuring, teams are developed and meet regularly in order to identify and assist in the provision of necessary supports, which enable all students to be participating members of the school community. Teams may be comprised of:
  - a. Teachers
  - b. Parents
  - c. Administrators
  - d. Support services staff
  - e. Friends and classmates
  - f. School board members
  - g. Community members
- ◆ A planning process which focuses on the individual student and family is used to plan the student's educational program. This process incorporates the Pupil Evaluation Team and the IEP. The process includes:
  - a. Sharing a brief history of the student.
  - b. Sharing insights about the student by describing his/her personality, strengths, likes and dislikes and other relevant evaluation information.
  - c. Based on the above information, determining what the student needs.
  - d. Categorizing these needs into educational goals.
  - e. Identifying educational goals and objectives that can be implemented in the context of the regular classroom and general education curriculum.
- ◆ A student planning team comprised of family members, regular educators, specialists, other related school staff and classmates meet regularly to share resources, plan and problem solve using a collaborative teaming process.
- ◆ The development of friendships among students is facilitated through activities that promote understanding and acceptance of diversity and recognition of the unique gifts that each students brings to the school and classroom community.

*IV. Commitment to Meeting All Students' Needs in the Regular Classroom.* A school demonstrates commitment to effective inclusive education through the development of policies, procedures and practices that enable all students to receive their educational and related services in regular classes.

- ◆ All students are in regular classes appropriate for their age.
- ◆ Classroom teachers collaborate and consult with special educators and related service professionals, based on student needs identified in the IEP.
- ◆ Regular and special education personnel and related service professionals share resources, and through a collaborative learning process to meet the individual needs of each student.
- ◆ Related services, as identified in the IEP, are available to students with disabilities in the regular classroom. They are provided directly by the specialist or through consultation.

- ◆ An array of instructional strategies that benefit all students are used in the classroom and may include:
  - a. Cooperative learning strategies
  - b. Team teaching
  - c. Integrated curriculum
  - d. Multi-level curriculum
  - e. Multi-age grouping
  - f. Positive support strategies for students with challenging behaviors
  - g. Assistive technology
- ◆ A variety of instructional options and learning supports are provided so that ALL students can access the general education curriculum.
- ◆ Transitional planning for all students for career opportunities is assured through student participation in career pathways and expected outcomes (School-to-Work Opportunities Act of 1994).

*Adapted from the "Guidelines for Inclusive Schools" (1995) For more information about the LEARNS project contact : LEARNS, Center for Community Inclusion, UAP, University of Maine, 5717 Corbett Hall, Orono, ME 04469-5717, (207)-581-1084.*

As these guidelines point out inclusive education isn't just about the student with disabilities. In order to achieve effective inclusive practices there needs to be a real sense of community at all levels of the school which believes every single student benefits from inclusive practices. By creating system-wide change to inclusive practices, instead of a making student-by-student decision about who should participate in inclusive classrooms, the inevitable debate over appropriate placement can be avoided. When a problem comes up educators focus on solving it and not on removing the student. When the entire system is working from an inclusive model it keeps the child with disabilities who has successfully been accepted into a classroom at one grade level, from the risk of returning to a segregated special education class if the next level teacher or new school doesn't agree with inclusive placement.

This holistic approach which is beyond just tolerating the presence of students who don't have traditional learning styles requires a lot of effort, especially in the area of professional development and community strengthening. When successful, there are many benefits for the entire school community.

Inclusive education is at a crossroads. Much effort has been put into proving that it can be successful and that all members of the school environment benefit. But today most children with disabilities, especially the most severely disabled, are still attending special schools or spending the majority of their day in segregated classrooms. The following are a number of barriers still in the way of the achievement of fully inclusive schools:

*1. There is no agreed upon definition of inclusion.* Data and research on "inclusive" practices, and their concurrent findings of success or failure of the practice, have been collected with various definitions being used. Some people define inclusion as regular and special education students simply being in the same room together for all or part of the day. Others define it as classrooms and schools where all students have high expectations for involvement in the school community, relationships between students are emphasized and fostered, professional development is an integral component and there are no separate facilities for special education students at all. Until there is an agreement upon the definition, research and practices will result in confusing and uneven results.



2. *Funding barriers.* Originally the IDEA was federally funded at 40%, currently it is under 10%. This lack of funding makes it more difficult for States to comply with the spirit of the IDEA. Some people believe inclusive practices will be less costly in the long run because of its emphasis on natural supports and utilization of personnel in efficient ways, however due to training and accommodations needed initially there is the need for seed money to help school systems on their way.

3. *System change grants typically have only been given in 3-5 year cycles.* Realistic time frames for this type of change is more like 7-10 years. The initial groundwork of educating and locating important stakeholders can take a year or more.

4. *Change must be internally owned by the local area.* Federal or even State mandates are followed only grudgingly and often students are set up for failure if there is not acceptance at all levels. People at all levels must have access to adequate resources and time to make the change. In addition each locality needs to be allowed to move toward inclusion in their own way.

5. *There is a great need for materials, education and training in inclusion to make it happen.* Dropping a special education student into a regular education classroom without offering sufficient preparation and training to the teacher and others is not inclusive education. Teachers need ideas for curriculum adaptation and they need time to prepare and rethink their teaching strategies.

6. *There are a number of attitudinal barriers on both sides of the issue.* Special education teachers may not want to give up "their" students. Regular education teachers may feel overwhelmed. There are a thousand reasons "why not" but previous successes have shown that anything is possible.

7. *Physical barriers, schools and transportation options need to be made fully accessible.* The lack of assistive technology may be keeping children out of inclusive classrooms. School systems may be resistant to identify these issues since they bear the primary financial responsibility for these accommodations.

Every year students with disabilities and their families are expecting more from the educational system in terms of inclusion. Fortunately when these changes have taken place the outcome has usually been positive for everyone who is involved. As more and more children are identified as "at-risk" in school due to environmental and social or economic factors, the training and experience of inclusion will give educators positive strategies for working with all types of students. In many ways the push to inclusive classrooms isn't about the student with disabilities at all, but about how society feels about making free and appropriate education available to all children.

## **Two Profiles of Successful Inclusive Education**

### **Jackie: A Case Study of an Elementary Student**

In a small elementary school (student population 300), located in a large urban city, a relatively new approach has been taken to educate a young girl who has severe disabilities. Jackie is ten years old, and has been attending her neighborhood school for the past four years. Before this, she attended a segregated special school for students who have developmental disabilities. In 1985 Jackie moved to a group home which was located in the suburbs, and was welcomed into her local elementary school.

The staff in this small elementary school were open to many suggestions from a variety of people, especially Jackie's mother and the staff in the group home. Jackie is well known for her sense of humor, and her willingness to try new things. Jackie has many therapeutic needs that had been previously addressed in a self-contained therapy room (including physical therapy, occupational therapy, speech therapy). In the new setting, support would be provided by professionals in these fields, on an ongoing basis. Jackie also uses an augmentative communication system that requires monitoring by speech therapists as well as maintenance by technicians. Jackie has cerebral palsy, which for her means that she is in a wheelchair because of spastic quadriplegia. Her smile and personality attracts many people to her, and the opportunity for developing meaningful friendships in this setting was extremely exciting for everyone who knew her.

Jackie's entry into the school was initiated with a great deal of enthusiasm by all. Several meetings were held with her mother, the school personnel, and the group home staff. The school personnel included the teachers who would be involved with Jackie directly, as well as those others who were interested in helping out, the principal, the resource teacher, and special education consultants.

During the first meeting, a facilitator assisted the group with a planning process known as the McGill Action Planning System-MAPS, whereby Jackie's life in school and the community was the theme. The first central topic was determining who Jackie is, and gathering information regarding her interests, and what her school needs might be. A delightful image of Jackie emerged: beautiful smile, attractive child, knows what she wants, is determined, is patient, loves younger children, and expresses her emotions to mention just a few. Some of her school needs were: to have friends during school and after school, to relax at certain times of the day, to continue to improve her communication skills, to attend classes following a regular grade four curriculum with modifications made in class, and to help out in a junior kindergarten class.

Based on the preliminary planning meetings, the teaching team decided to introduce Jackie to a wide variety of school opportunities. There were some hunches about certain things that Jackie might enjoy, but the first half of the year was meant to be flexible for Jackie. Given this, the following activities were highlighted for Jackie: regular grade four class, physical therapy to be done on a daily basis (in class) while students are engaged in sustained silent reading, participation in intramurals after school, Brownie meetings once a week and chorus.

All of Jackie's therapeutic needs were addressed as imbedded goals wherever possible. This allowed for generalization of skills, as well as teaching the skills in a meaningful environment for Jackie. Physical therapy goals were met through daily range of motion exercises that were incorporated into classroom routines. Also, whenever Jackie put on her coat, or participated in her personal care routine, motor skills were blended into these naturally occurring events. Opportunities for Jackie to relax out of her chair were provided to maximize Jackie's level of comfort, and was done in such a way as to include her in other activities, not to isolate her with therapeutic equipment. A bean bag chair with some support pillows and sandbags, along with a gym mat, were all the necessary equipment.

Jackie uses an augmentative communication board, which was developed for her by a speech therapist and electronics technician. It consists of a 16 picture display (4 X 4 matrix), with lights illuminating each square. An interface switch connected to the board allows Jackie to select the picture/symbol of her choice. She communicates with people by first gaining their attention (with a call switch), and then pointing to a picture. Her squares include basic vocabulary, as well as pictures of things in the classroom and photos of people. It is hoped that she can progress to a larger matrix in the future. Until then, she consistently eyepoints to objects and other pictures when she is presented with these choices. The students in the class are adept at understanding Jackie with her board and eyepointing.

In Language Arts, Jackie frequently helped to select stories that the class would read. The teacher structured the class based on a cooperative learning model, and the students frequently switched partners or groups, on a rotational basis, so that everyone had an opportunity to work with each other. Each day the teacher would select parts of the activity that could be accomplished by Jackie (direct selection most often). The students found ways of encouraging Jackie to assist them too.

In Mathematics, while the students were working with number facts and basic operations, Jackie was learning to use a calculator, as well as listening to the lesson regarding number facts. Her adapted calculator and interface switch were placed on her tray at the table with her work group. Another student would enter her responses on her work sheet for her.

The teacher had all students involved in daily classroom routines (passing papers, cleaning brushes, etc.). Jackie's responsibilities included taking the daily attendance sheet to the office, and helping the grade one class as a reading buddy.

In physical education class, Jackie helped to keep score with another student if games were being played, or she would often play modified games with her classmates. For example, in soccer, a student would push Jackie in her wheelchair around the field, and Jackie would "trap" the ball with her chair. Once again, the students often thought of their own modifications to the games.

In music and art, Jackie would be assisted by other students. Music is often filled with lessons about listening, so very little had to be done to modify these lessons. Art projects were a cooperative effort, and students assisted her sometimes with full hand-over-hand assistance. Choice-making and active participation were goals for Jackie in these classes.

A great deal of the success of Jackie's involvement is directly related to her friendships with other students. An outsider looking in on her class would be left with the impression that Jackie was one of the most popular students in the class. She always had a group of students hanging around her.

Initially the teacher asked a few students to do little things with Jackie, such as meeting her at her bus in the morning. Then the teacher would ask another student to help Jackie take the attendance to the office. Slowly, but surely, each child had an opportunity to do different things with Jackie throughout the day. The teacher spent some time teaching the students how to use Jackie's communication system with them. She also discussed with them what Jackie's disability means for Jackie and her participation (in a humanistic way that did not discourage the students). All aspects of Jackie's disability were dealt with as the questions arose. Very soon the students came to accept Jackie as a full member of their class.

In particular there were four girls who became quite close to Jackie. They were the ones who thought of the after school activities, including Brownies, sleep-overs, and other get-togethers. These students would approach the teacher and ask her for help in planning events, or just to share their ideas with her. Once the students felt comfortable contacting Jackie at home on their own, the teacher was relied upon less frequently to help plan their leisure time.

In this setting the fourth grade teacher became the central teacher in planning for Jackie's academics. The grade four curriculum was examined by this teacher, along with a resource teacher and a special education consultant. Wherever possible, the goals were met in naturally occurring classroom activities. A creative approach was taken by the teacher and the modifications were made. Regular meetings with consultants also helped the teacher to meet the objectives with Jackie's therapeutic needs.

A teaching assistant was requested at the outset to help provide support in the classroom for Jackie. This person helps with Jackie's personal care needs, and helps her with her lunch routine. The

assistant maintains a low profile within the class, and only assists Jackie when necessary (e.g. transfers from wheelchair to the beanbag chair, gathering equipment, ensuring that the interfaces are working). The teaching assistant helps the teacher with all of the students, not just with Jackie. The range of motion exercises are done by the teaching assistant as well after being taught by a physical therapist.

**“Our school has been greatly enhanced by Jackie’s presence. The school climate is more warm and inviting, and I can’t imagine our school without her.”**

— Jackie’s School Principal

Jackie's school day looks very different today than before she attended her home elementary school. She now has many friends who come over to her house to play, and she sees her classmates when she goes shopping in her neighborhood. All of this has happened because some educators, administrators, and a parent were committed to making this work for Jackie. The plan also was supported and well received by the group home staff where Jackie lives.

It is important to recognize that group home staff can play an active and important role in facilitating school friendships with their residents. These staff members made it a point to know when Jackie's friends had their birthdays, so Jackie could send them cards; they also opened the doors to Jackie's friends by hosting parties (even sleep-overs) for them; transportation issues were solved by creative planning, which enabled Jackie to go to her friend's homes, or to the movies. The teacher also helped to bridge the communication between the friends and the group home staff, until their own means of communication was solidified.

The principal of Jackie's school once said to a group of other administrators, "Our school has been greatly enhanced by Jackie's presence. The school climate is more warm and inviting, and I can't imagine our school without her."

## **Mike: A Case Study of a Senior High Student**

In a medium-sized high school (student population approximately 1200), the staff and students have welcomed a student who has a developmental disability. Mike has been attending his neighborhood high school for the past three years. Previously he attended a segregated school for students who have developmental disabilities. His family which had always had a strong presence in their local community, thought that it only made sense for Mike to attend his local school. After preliminary plans were made, that dream became a reality for Mike in the spring of 1986.

Initially Mike's parents were told by several concerned professionals that their son would not benefit from attending a regular high school program. Mike had a reputation of having a temper and being too affectionate (in high school he would undoubtedly be "all over the girls"); he also needed speech therapy. Physically Mike is very handsome, and is in good condition after many years of playing sports in local community leagues. Another major concern was that other students would tease him, which would give him an opportunity to display his temper. Mike's parents thought that what he needed most of all, was to have proper role models, and to develop his friendships with people his own age who did not have a disability.

Because of their dissatisfaction with their school board's response to their request for integration, the parents decided to send Mike to a parochial high school in their own neighborhood which did accept all students, regardless of disability.

With the help of an outside facilitator, several meetings were held in Mike's home, and in his new school, to figure out what Mike's school day would look like (using MAPS-McGill Action Planning System).

Mike and his parents always attended these meetings. The school personnel who attended these meetings included the principal, the resource teacher, some interested teachers, and a school board consultant (special education). All of the people were committed to having Mike succeed in his new school environment.

The first meeting was focused on the question of: "Who is Mike?", and finding out what his talents and needs were. Mike's parents led the discussion by sharing their vision of Mike's future, which includes having a good job, and living on his own in an apartment. Some of Mike's strengths were: responsibility, good self esteem, leadership, and following instructions. A few need areas were also discussed such as: controlling his temper; learning not to tease inappropriately; being too affectionate; learning not to interrupt others, and learning how to ride a bus on his own. A list of descriptors helped the group to determine how Mike's program would take shape.

The team and Mike decided that he needed to do the following things at school: participate in intramurals, improve reading skills, have a locker, attend industrial arts classes, develop writing skills, work with computers, attend religion class, attend physical education, improve money handling skills, join the drama class, and attend a literature class.

This school is divided into two semesters and each day contains four periods that are approximately 75 minutes long. Homeroom period is 30 minutes in length. Mike's current grade ten curriculum includes the following courses:

<u>Semester One</u>	<u>Semester Two</u>
Keyboarding	Literature
Homeroom	Homeroom
Drama	Religion
Lunch	Lunch
Physical Education	Physical Education
Vocational Education	Vocational Education

In keyboarding Mike learned to use a standard keyboard for typing, as well as specific computer skills on a Macintosh computer. He followed the teacher's instructions for the class, and when he required additional help, a teacher's assistant or a classmate would provide him with that help. During homeroom class the students receive the morning announcements, attend assemblies, take attendance, and complete work that has been assigned to them. At this time Mike received additional help with math skills (using a calculator, writing checks), and language skills (reading and writing, and filling out application forms), with the help of a teacher's assistant.

In physical education, drama, and religion, the curriculum did not need to be modified to any great extent. Mike participated in group work in all of these classes, and he wrote tests that all the other students wrote. The only difference was that Mike was given additional time to complete the tests, and on occasion he was tested orally.

The Literature course gave Mike an opportunity to hear rich language, and to improve his own diction. The teacher employed a cooperative learning style which enabled Mike to participate in group work and projects to the fullest extent. The speech and language pathologist met with the teachers to discuss Mike's goals for speech development. These speech goals were embedded skills in all of his classes, and were monitored by the consultant.

Through vocational education at school, Mike has had the chance to work in various places: for the Mayor's office, delivering inter-office mail and photocopying; McDonalds, where he held various duties; local grocery store, stocking shelves and packing groceries; and working at a local elementary school with the custodial staff. Each job provided Mike with a variety of experiences, and he is now hoping to work for another small business. Each job typically lasted for the entire semester, with the option of continuing the placement if desired.

One of Mike's parent's concerns was that Mike had very few friends in his neighborhood and that as a consequence he was often lonely. Mike wanted to make new friends in the high school. To this end some teachers approached a couple of students who expressed an interest in Mike. Being fairly gregarious fellows, they thought that it would be fun to have Mike around their group. One student said that at first he wasn't too sure how nice he "had to be" towards Mike. He quickly reported back to his teachers that, "I don't have to treat him any differently than the other guys. He's just like one of the guys now." As was previously mentioned, Mike has a fondness for members of the opposite sex. The girls weren't sure if they should tolerate Mike's advances. Finally, one girl was heard saying, "For heaven's sake Mike, you just can't do that here! A handshake would be a fine way to greet me, but not a kiss!"

Mike has a job at the local grocery store during the week and on the weekends. He got his job partly through his work during a school placement for cooperative education, and also because the store manager valued his work and effort. Through his earnings at the store, Mike saved up enough money to go on a school trip to Washington, D.C., and to buy several other items for himself.

Now that he has more friends, and pocket money from his job, Mike often goes to movies with his friends, school dances, as well as sporting events. His parents commented that, "the phone is always ringing for Mike now." And his speech has improved dramatically, even to the point where he has picked up several slang expressions!

**Mike's school day looks markedly different today compared to three years ago...his self-confidence has soared; he has meaningful friendships; he takes the bus on his own; he has a real, paying job and he has dreams for the future.**

The school administration felt that Mike might need help in addition to the help he would receive from his teachers and peers. Therefore a full-time teacher's assistant (TA) was hired to work under the guidance of the senior resource teacher. The resource teacher acted as a coordinator for Mike's IEP, planning meetings, and helped to modify the curriculum content along with input from the specific teacher for those courses. The teachers met on a regular basis to ensure that Mike's goals were being met. Meetings took place during school hours, when teachers had planning and evaluation time.

The teacher assistant's role was to help Mike make connections with other students. He felt that it was very important to give Mike an opportunity to learn things on his own, without the constant "shadowing" of an assistant. The assistant was always in the background, helping the teacher with other tasks and students. This was also true during vocational education; the assistant merely accompanied Mike until such a time that Mike felt he could do it on his own. The TA was also responsible for helping Mike organize his homework and assignments, and to meet with the teachers on a regular basis to discuss Mike's progress (along with the resource teacher). Tests were written during class time as usual, but if Mike needed additional time, the TA would assist him with the test in the resource room.

Mike's school day looks markedly different today compared to three years ago. He has been given a chance to develop in ways that were unimaginable to many people. His self-confidence has soared; he has meaningful friendships; he takes the bus on his own; he has a real, paying job and he has dreams for the future. During another planning meeting with his teachers and parents, Mike said that he wants independence, to continue to work, to have an apartment with some friends, and to be happy. Judging by the way things are today, he will realize his dreams.

What can we learn from Mike's story? The first thing is that his parents had a dream for Mike's education that was quite different from the practice at the time. With help from some interested teachers, and the support of a principal, their ideas became a reality. This high school has a strong commitment to providing an education to anyone who wishes to attend, regardless of disability. This philosophy is clearly stated, and is endorsed by the administration and faculty.

We can also see how with some creative planning, flexibility, and determination, curricula can be adapted to meet the needs of all students, regardless of disability. Traditional math classes can be adapted so that a student can work on modified skills. Not everyone is a star athlete, but some students can keep score for other teams, or participate cooperatively. Virtually any goal can be met through curricular adaptations, along with the desire to make these changes.

Finally, friendships were the most significant improvement in Mike's life. Many students have said that their school's spirit and climate has been enhanced with Mike's presence. Indeed one student said that it was a privilege to have known Mike. According to Mike, there's no point in being in the community if no one knows that you are there.

*Profiles by Janet Duncan, adapted from "Resources on Inclusive Education" Kathy Hulgin (Ed) (1993), Research and Training Center on Community Integration: Syracuse University, NY.*

## **Family Supports**

Outside of formal education, preschool, and early intervention programs families with a member who has mental retardation may need a variety of other supports in order to balance the needs of the entire family with those of the individual who has a disability. What is family support? It means different things to different people. For some it means government-funded programs that pay for services which enable children to remain at home. For others it means networks of family members who come together, learn from one another and provide support to one another. And yet, for others it means families advocating for the rights of their children. Whatever the individual definition, there are common themes which emerge about family supports:

- Families want to keep their children at home and in their local communities.
- Families want more control over determining the types of services and supports they receive.
- Families want services to be tailored to the individual needs, preferences, values, culture and abilities of their family members.
- Families want services and supports to be simple and flexible.

Since the 1980's an increasing number of States have been offering an array of services to families and people with disabilities. These programs make use of structured services and supports, as well as informal or natural supports from friends, neighbors, extended family or others in the community. The focal issue of family support programs is to provide "whatever it takes" to families of people with disabilities so they can live as much like other families as possible. Providing useful family supports can involve any number or types of services and supports. These supports might be aimed not only at the person with the disability but at other family members as well.

The goals of most family support programs are: 1) to keep families together until the person with a disability chooses to live independently, 2) to enhance a family's ability to meet the many needs of their family member with a disability, 3) to improve quality of supports to families while minimizing the need and cost of out-of-home placement, 4) to allow families to participate in integrated leisure, recreational and social activities, and 5) to make a positive difference in the life of the person with a disability as well as the lives of all family members.

The Human Services Research Institute (HSRI), a leader in research and technical assistance on family supports, completed a survey of State administrators in 1995 regarding States efforts in developing and implementing family support programs specifically for families with members who have developmental disabilities. Below is a summary of what they found.

- In 1995, all but one State (Mississippi) reported the presence of some type of formal family support program in their State.
- Over half of the identified family support programs were mandated by State legislation.
- Most States reported increases in the number of families receiving family support services within their programs since the time the programs began, with 23 States indicating a growth of 10-25% and 15 States indicating a growth of over 25%.
- State budget allocations for family support programs vary across States. Overall spending for family support programs amounts to less than 3% of total State developmental disability budgets and is very small when compared to State expenditures for out-of-home placements (Agosta & Melda, 1995).

**Family supports might include:**

- **Diagnosis and treatment**
- **Therapeutic services**
- **Medical/dental services**
- **Home health care**
- **Recreational opportunities**
- **Special clothing**
- **Special diets**
- **Transportation**
- **Peer support**
- **Advocacy**
- **Adaptive equipment**
- **Housing adaptations**
- **Adequate health insurance**
- **Information/referral**
- **Service coordination**
- **Respite services**
- **Family counseling**
- **Parent/sibling education**
- **Day care financial assistance**
- **Financial planning**
- **Support groups**
- **Advocacy**
- **Housing/vehicle modification**

However, on a national level family support expenditures and the numbers of families receiving family supports continues to increase as more and more States make a commitment to helping families which have children with disabilities. For example, nationally between 1988 and 1996 family support expenditures increased from \$157.9 million in 1988 to \$518 million in 1996, and the number of families increased from 168,300 in 1988 to 275,000 in 1996 (Braddock, Hemp, Parish & Westrich, 1998).

- Family needs often cut across multiple public sectors (e.g. education, transportation, welfare, human services). Effective, cohesive responses to family needs requires State agencies to collaborate, yet collaboration is not common across the States.
- The primary source of revenue for family support programs is State dollars. However, many States offer respite care, case management/coordination support and home and community services through their Home and Community Based Services waiver programs. This waiver also can be used to expand Medicaid eligibility to children with disabilities and their families. Families may also receive flexible support through the Federal Supplemental Security Income (SSI) program. Low income children with disabilities are eligible to receive cash payments adjusted to family income level, as well as possible State supplementation in 27 States (Agosta and Melda, 1995).



Family support programs typically promote inclusion by helping families avoid out-of-home placements, and by supporting community connections. However, these programs vary across and within States. Areas of variability include: access, available services and supports, and the role of families in determining and directing services and supports.

*Access.* Beyond eligibility, decisions must be made concerning how some families are chosen over others to gain access to family support services. Family support programs in States vary in this regard. Some States provide access to anyone who applies, others use a "first come first serve" approach, others use a lottery and yet others use an assessment of family needs to determine those with the most critical need.

*Services and supports.* Generally States efforts to provide family supports are comprehensive and respond to individual family needs. Respite care is available in every State that offers family support programs. Other examples of services and supports made available through these programs include: service coordination, information and referral, specialized therapies, recreation supports, home or vehicle modifications, adaptive equipment, money for medical expenses or to offset household expenses.

*Services, cash assistance and vouchers.* Many States offer cash assistance and vouchers to families. These services provide the opportunity for families to receive cash grants or subsidies to spend as they choose (or within some pre-determined parameters) or to purchase various supports from participating providers.

*Local or State family councils.* Numerous States have established various family/consumer councils at State and local levels to guide or direct policy decisions. Nineteen States have both State and local councils, 14 have only State councils and 7 have only local councils.

*Support and networking for families.* This type of family support is sometimes provided by State and local funded programs, but is more often provided by voluntary, non-profit organizations such as the Arc and other family focused grassroots organizations. The opportunity for family members to learn from one another, share stories, share strategies and to build momentum for change is invaluable.

As supports to families have continued to grow and we have learned more about their importance and value, we have also learned about what makes these programs effective. Quality family support programs should:

- *Focus on the entire family.* Services should not just focus on the person with the disability but should focus on the entire family (e.g. parents, siblings, aunts, uncles, grandparents). Family means different things to different people and therefore, listening to how the individual and those around them define family is critical.

**The guiding principles of the Atlanta Alliance on Developmental Disabilities Family Support Program include:**

- **Approaches need to be personalized and people need to be served on their own turf.**
- **Services need to be flexible—available when, where, and how it makes sense for those requesting support.**
- **Decision-making should be decentralized, and made with staff closest to the family.**
- **Services need to be to the entire family, not just the person with a disability.**
- **Staff should be selected for their qualities and characteristics, not just their credentials.**
- **The relationship between the support staff and the family is critical. All involved need time and support to get to really know one another.**

—Adapted from *IMPACT: Feature Issue on Supporting Diversity Vol. 9(#)* Summer 1996.

- *Change as the family's needs, roles and ages change.* What a family needs today may not be what they need tomorrow or the next day. As the life circumstances change for people with mental retardation and developmental disabilities and their families so should their services and supports.
- *Encourage families to express their own needs and decide how their needs will be met.* Families are not often used to "professionals" asking them what they need. More often than not they have never been asked what they need or how best to meet their needs. In this case, because they know their own situation best, families are the experts, and services and supports to families need to welcome and invite them to define their own needs and how they can best be met.
- *Treat people with disabilities and their families with dignity by respecting their individual choices and preferences.* For too long families have been viewed by "professionals" as barriers or burdens. Good family support services value, recognize and give the power to families as the experts and directors of services and supports.
- *Respect cultural, economic, social and spiritual differences.* All people and all families are unique and have their own circumstances strengths, capacities and needs. Family support services must recognize, value and honor these differences.
- *Encourage families to use natural supports and generic community resources.* The system of services that has been developed to meet the needs of people with mental retardation has evolved into one which primarily offers specialized supports. Families need to have opportunities to remain connected to their own communities of choice. Developing effective supports to families means that they are afforded the opportunity to utilize their own identified resources and supports within their own families and communities.
- *Provide supports and services that are easy to find and easy to use.* Families need access and as little hassle as possible. Current services and supports often come with multiple layers of red tape, regulations and barriers. Effective services and supports to families make every effort to eliminate these obstacles.

*Portions of this section adapted from: Human Services Research Institute National Survey on Family Support: Research Brief, 1995).*

## **Conclusion**

The child born today is coming into a different world than the generations before. Today there are a variety of programs, positive interventions, and supports available to facilitate the positive participation of children with disabilities in the life of their communities and families. As the field of developmental disabilities continues to change and respond to the needs of people with developmental disabilities and their families, it will be ever important to focus on families, schools, communities, and providing necessary supports to keep people with disabilities and their families connected to one another and to their communities. Continued efforts to coordinate existing services, to increase their flexibility and accessibility, and to tap into local capacity to support all members of their communities will help children with developmental disabilities and their families grow strong.

## Resources

*Andreas: Outcomes of Inclusion.* (1991). This videotape is a discussion among teachers, administrators, classmates, and employers concerning the importance of inclusion in the school and in the general community for Andreas, a high school student. Center for Developmental Disabilities, 499C Waterman Building, University of Vermont, Burlington, VT 05405. telephone: (802) 656-4031. Cost: \$19.00

*Celebrating Family Strengths: Preschool Curriculum Guide.* (1994). Lessons assist early childhood educators and providers of early intervention services in encouraging children to develop a strong positive view of themselves and their families. PACER Center, Inc., 4826 Chicago Ave. S., Minneapolis, MN 55417-1098 (612) 827-2966 9612)827-7770 (TTY).

*Emerging Issues in Family Support.* This American Association on Mental Retardation monograph on family supports provides overview information on the family supports movement, State efforts in developing and providing family support programs, several case studies and reviews of evaluations of family support programs. To obtain a copy contact the American Association on Mental Retardation.

*National Information Center for Children and Youth with Disabilities (NICHCY).* NICHCY provides free information to assist parents, educators, caregivers, advocates and others in helping children and youth with disabilities become participating members of the community. NICHCY P.O. Box 1492, Washington, D.C. 20013-1492 (703) 893-6061 (local) (800) 999-5599 toll free, (703) 893-8614 (TDD).

*National Survey on Family Support: Research Brief.* This brief summarizes the results of a 1995 national survey of State administrators concerning the present status of family support programs in the United States. To obtain a copy contact The Human Services Research Institute, 525 Glen Creek Road (230), Salem, OR 97304; 503/362-5682 or 503/362-7729 fax.

*Resource manual on curriculum and adaptations.* (1991). A manual developed through a national network of 50 full inclusion sites. Examples of curriculum development and adaptation included. For information contact Dotty Kelly, California Research Institute, San Francisco State University, (415) 338-2959.

*Serving Children with Special Needs in Your Child Care Facility.* (1996). This manual is designed to assist child care providers with information on including children with disabilities in their programs. Contact : Dianne Apter, Early Childhood Direction Center, 805 S. Crouse Avenue, Syracuse, NY 13244.

*The March of Dimes Birth Defects Foundation.* This foundation seeks to improve the health of babies by preventing birth defects and infant mortality through community services, advocacy, research, and education. Visit their home page at <http://www.modimes.org>. National Office: 1275 Mamaroneck Avenue, White Plains, NY 10605 (914) 428-7100.

*The National Organization on Fetal Alcohol Syndrome (NOFAS).* This referral organization seeks to educate people about the leading known cause of mental birth defects: Fetal Alcohol Syndrome. Visit their website at <http://www.nofas.org/> or contact them at: National Organization on Fetal Alcohol Syndrome, 1819 H Street, NW, Suite 750, Washington, DC 20006 (202)785-4585 or (800) 66-NOFAS.

*Transition to Adult Life for Individuals with Disabilities.* (1992). This book is a compendium for resources including books, journal and magazine articles, video tapes and training curriculum. Available at the Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455, 612/ 624-4512.

*Whatever It Takes! Excellence in Family Support: When Families Experience a Disability.* A book filled with creative ideas to make the most of family support dollars and help families who experience disability flourish in their communities. Spotlights 49 outstanding family support programs in 22 states. Available through: Training Resource Network, PO Box 439, St. Augustine, FL 32085. 904/823-9800; 904/823-3554 fax.

Check out this educational resources website: <http://www.lrp.com/Education/special.htm> for a list of books, brochures, pamphlets, video and audio tapes on trends, legal compliance, inclusive education and other education related topics. A brief description of items and ordering information is included.

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## Glossary

**Access:** Getting services easily enough so the person is encouraged to do so rather than give up and go away.

**Action Plan:** One of many terms being used for creating a plan for people receiving services that is based on their abilities, strengths and personal desires or goals. These plans are created by support teams or circles of support (the people who know the person best and who the person would like to have participate in planning), and professionals who are only invited at the request of the rest of the support team. Action plans are more and more being used to replace previous deficit based planning (see IEP/IPP/IHP/ISP).

**Advocate:** A person who advocates on behalf of individuals with developmental disabilities.

**Arc National:** A national advocacy group for people with mental retardation. There are also many State and local Arc chapters throughout the United States.

**Autism:** A severe disorder in which the person affected may have difficulty in both verbal and non-verbal communication, and may relate to others or events in unexpected ways such as appearing disinterested, aloof, or unable to concentrate. Autism occurs in five out of every 10,000 births and is four times more likely to occur in boys than in girls. People with autism may exhibit repetitive behaviors such as rocking, banging their heads against objects, touching, or hand flapping.

**Case management or care coordination:** A system in which a single professional is responsible for ensuring that a recipient obtains the full range of services required.

**Cerebral Palsy:** A central motor deficit that results from injury to the brain which can occur prenatally, perinatally or postnatally.

**Community integration:** A concept that reflects the practice of sharing in community life, involving at least these four aspects: (a) physical integration where the individual actually lives in the community, (b) cultural integration where the individual exhibits locally valued lifestyles and roles, (c) integration where the individual enjoys reciprocal relationships with others in the community, and (d) self-determination (see definition of this term below).

**Consumer:** A term often used to describe a person with a developmental disability who receives some type of services from a government or private agency. A consumer of services. This term is used in place of client to put the emphasis on the person as someone who uses services rather than someone who has a problem which needs professional help.

**Culturally competent supports:** Supports which go beyond simply an awareness that there are different cultural perspectives to having a number of sophisticated methods for respecting and infusing preferred cultural preferences into each person's individual supports.

**Demographics:** Percentages and real numbers that are useful in describing populations and understanding trends. For example, the percentage of people with disabilities between the ages of 25-40 who are employed full-time compared to the percentage of people without disabilities between the ages of 25-40 who are employed full-time.

**Dominate culture:** In multicultural societies, the cultural practices which are the basis for judging actions and establishing public traditions. Usually the dominate culture is so much a part of the societies' perspective that it is "invisible." Behaviors which are contrary to the perspective of the dominate culture are usually considered inappropriate or wrong, even when they are not harmful.

**Down's Syndrome:** A genetic disorder which results in several characteristics including: a shortened stature, mental retardation, small nose, upward slanting eyes, short stubby fingers, poor muscle tone and frequently heart problems.

**Epilepsy:** A disorder which affects about 1% of the population and which seizures are a primary symptom.

**Family support:** Describes service programs for families who provide support at home for children, and sometimes adults, with developmental disabilities. Within a family "centered" or "driven" context, the programs make use of structured services, natural supports, and often cash assistance to: (a) make it possible for families to keep their family member at home, (b) assure that the person with disabilities receives needed services at home, (c) enhance the capacity of families to provide supports at home, and (d) realize some cost savings related to promoting care at home over out-of-home options.

**Functional skills:** The skills a person needs to do the ordinary tasks of day to day life. Functional skills may be an ability to read, open a door without assistance, or cook a meal.

**Generic:** As in generic community resources. Public resources available to all people regardless of ability such as parks, swimming classes at the local YMCA, or professionals like doctors/dentists.

**Group home:** A typical home in the community which has one or more people with disabilities living in it and receiving services. These homes can range in size from 2 people to 15 people and can be publicly or privately owned and operated.

**Home and Community Based Services:** A variety of services which are funded through the Federal Medicaid Home and Community Based Waiver program. HCBS unlike ICF/MR funding is a less regulated and more flexible pot of money which can help fund services provided in a number of settings including small agency run group homes, family homes, and a person's own home or apartment.

**IEP/IPP/IHP/ISP:** Individual Educational/Program/Habilitation/Service Plan. Individualized plans for a person receiving services which includes goals to be achieved in an upcoming time frame (usually 1 year). Traditionally these plans have been developed by teams of professionals with some input from family members and the individual receiving services. Goals focus on improving in areas where a person had a weakness.

**In-home services:** Services provided in a person's home.

**Institution:** Large public or private residential program in which 16 or more people with mental retardation and other developmental disabilities live. Institutions are most often part of State-run hospitals and usually comply with the Intermediate Care Facility (ICF/MR) standards set by the Federal government. Institutions were once the only place where people with mental retardation could receive residential supports, they are now the place of last resort for residential placement.

**Integrated:** A setting where people of all abilities and backgrounds work, live, or play together.

**Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR):** The first Federal program targeted to monitor residential services to people with mental retardation. The size of ICFs/MR range from 6 people living in a community home to several hundred living in a large congregate setting (including units in state institutions). These programs require 24 hour supervision of the people who live in them.

**I.Q.: Intelligence quotient.** The numerical measure of a person's intelligence, often used in definitions of mental retardation.

**Least Restrictive Environment:** a clause in IDEA which mandates that children receive education in the least restrictive settings possible.

**Long term services and supports:** Supervision or assistance given to a person with disabilities to help the individual complete daily living activities (e.g., eating, dressing, bathing, communicating, keeping a job, taking prescribed medications), learn new skills, maintain a general sense of safety and well-being, or otherwise pursue a normal daily life rhythm. Such assistance typically excludes medical interventions due to injury or illness.

**Natural supports:** Supports which naturally occur in all people's lives. Some examples include, a friend who helps paint your house, a neighbor who picks up your mail when you are out of town, a coworker who picks up your paycheck when you are sick, the family member who introduces you to a potential new employer.

**Outcome:** The benefit of services or supports.

**Paraprofessionals:** Another name for direct support worker most frequently used to describe people in direct service roles employed in educational settings.

**Participant:** People who are direct or indirect recipients of developmental disabilities services. In participant-driven service systems these individuals may play a strong role in directing policies and practices related to the delivery of services.

**Person-centered planning:** A planning process which looks at the person's strengths, needs and personal goals as a basis for service delivery. There are formalized forms of person centered planning such as Essential Lifestyle Planning, MAPS, or Personal Futures planning, as well as informal ways of gathering information and listening to a person to see what they consider important in relationship to services and supports.

**Personal assistance:** One person assisting another with tasks individuals normally would perform for themselves if they did not have a disability.

**Segregated:** An environment where only people with a certain label or defining characteristic work, live, or play.

**Self-advocate:** A person with a developmental disability who is active in standing up and speaking out for the rights of all people with developmental disabilities.

**Self-determination:** To act as the principal causal instrument in one's life and to make choices and decisions regarding one's chosen lifestyle independent of undue influence or interference from others.

**Semi-independent Living Services (SLS):** A program for people with mental retardation who have low support needs and live for the most part independently with a few hours of services each week from paid staff.

**Sheltered work:** A work setting in which only people with mental retardation and other disabilities work.

**Supported employment:** Describes services to help individuals with disabilities to find and keep a paid job in a regular community business (not counting employment in sheltered workshops or similar service environments). Paid staff can: (a) work with the individual to determine the type of job preferred, (b) find appropriate employment, (c) work with the employer to modify the job, apply assistive technology, or otherwise assure that the individual can perform the job, (d) provide support to the individual on the job or to his or her coworkers, and (e) monitor quality and provide support as needed.

**Supported living:** A residential service model which is based on the provision of only those supports which the person needs- tailoring services to meet individual needs.



## Common Acronyms

The field of services to people with mental retardation and other related developmental disabilities uses literally hundreds of acronyms. While they can be useful for brevity, common courtesy requires that assumptions are not made while speaking, presenting, or writing. A term should always be defined the first time it is used and more frequently if the information is intended for people who are not professionals in the field. The following are just a few of some of the most common acronyms used:

**AAMR** - American Association on Mental Retardation (formerly Mental Deficiency)  
**AAUAP** - The American Association of University Affiliated Programs for Persons with Developmental Disabilities  
**ADA** - Americans with Disabilities Act  
**ADD** - Administration on Developmental Disabilities (Washington, DC)  
**AFDC** - Aid to Families with Dependent Children  
**ARC** - Association for Retarded Citizens  
**ASO** - Administrative Service Organization  
**BIA** - Bureau of Indian Affairs  
**CAP** - Community Action Program, or Client Assistance Program  
**CEC** - Council for Exceptional Children  
**COBRA** - Consolidated Omnibus Budget Reconciliation Act  
**COLA** - Cost of Living Allowances  
**CP** - Cerebral Palsy  
**CSLA** - Community Supported Living Arrangement  
**DAC** - Developmental Achievement Center  
**DD** - Developmental Disabilities  
**DHHS** - Department of Health and Human Services (Washington, DC)  
**DHS** - Department of Human Services  
**DRS** - Division for Rehabilitative Services (federal level); Division for Rehabilitation Services (state level)  
**DSP/W** - Direct Support Professional or Direct Service (or Support) Worker  
**E/BD** - Emotional/Behavior Disorders  
**ECFE** - Early Childhood Family Education  
**ED** - Emotionally Disturbed  
**EEOC** - Equal Employment Opportunity Commission  
**ELP** - Essential Lifestyle Plan  
**EMH/R** - Educable Mentally Handicapped or Educable Mentally Retarded  
**EPS** - Early and Periodic Screening  
**FAPE** - Free Appropriate Public Education  
**FAS** - Fetal Alcohol Syndrome  
**FERPA** - Family Education Rights and Privacy Act  
**FY** - Fiscal/Budget Year  
**GAO** - General Accounting Office  
**HCBS** - Home and Community Based Services  
**HCFA** - (Federal) Health Care Financing Administration  
**HCPA** - Handicapped Children's Protection Act  
**HMO** - Health Maintenance Organization  
**ICAP** - Instrument for Clients and Agency Planning  
**ICF/MR or ICFs/MR** - Intermediate Care Facility or Facilities for Persons with Mental Retardation  
**IDEA** - Individuals with Disabilities Education Act  
**IEP/IFSP/IHP/IJP/IPP/ISP/ITP** - Individual Education Plan/Individualized Family Service Plan/Individualized Habilitation Plan/ Individual Justice Plan/Individual Program Plan/Individual Service Plan/Individual Transition Plan  
**IQ** - Intelligence Quotient

**LEA** - Local Education Agency  
**LRE** - Least Restrictive Environment  
**LTC** - Long Term Care  
**MA** - Medical Assistance  
**MH** - Mental Health or Mentally Handicapped  
**MI** - Mental Illness  
**MR/RC**- Mental Retardation and Related Conditions  
**NASDSE** - National Association of State Directors of Special Education  
**NASDDD** - National Association of State Directors of Developmental Disabilities  
**NIDRR** - National Institute on Disability and Rehabilitation Research  
**OASDI** - Old-Age, Survivors and Disability Insurance (also RSDI)  
**OSERS** – Office of Special Education and Rehabilitation Services  
**OT** - Occupational Therapist  
**P&A** - Protection and Advocacy (System)  
**PASS** - Plan for Achieving Self-Support, Social Security Administration, or Program Analysis of Service Systems  
**PCA** - Personal Care Attendant  
**PCEPD** - President's Committee on Employment of People with Disabilities (formerly PCEH)  
**PCMR** - President's Committee on Mental Retardation  
**PCP**- Person-Centered Planning  
**PFP** - Personal Futures Planning  
**PKU** - Phenylketonuria  
**PL** - Public Law  
**PT** - Physical Therapist  
**QA** - Quality Assurance, or QE - Quality Enhancement  
**QMRP** - Qualified Mental Retardation Professional  
**RFP** - Request for Proposal  
**RRTC** - Rehabilitation Research and Training Center  
**RSA** - Rehabilitation Services Administration  
**SABE**- Self-Advocates Being Empowered  
**SE** - Special Education or, Supported Employment  
**SILS** - Semi-Independent Living Services  
**SLA** - Supported Living Arrangements  
**SLF/SLS** - Supervised Living Facilities/ Supervised Living Services  
**SNF** - Skilled Nursing Facility  
**SSA** - Social Security Administration  
**SSDI** - Social Security Disability Insurance  
**SSI** - Supplemental Security Income  
**STWO**- School-to-Work Opportunities Act  
**TASH** - The Association for Persons with Severe Handicaps  
**TDD** - Telecommunications Devices for the Deaf  
**VR** - Vocational Rehabilitation  
**WAC** - Work Activity Center

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