BOOK 3

THE PARENT/PROFESSIONAL PARTNERSHIP:

THE PARTNERSHIP:

HOW TO MAKE IT WORK
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National Association for Retarded Citizens  
NARC Research and Demonstration Institute

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Preface

Many attempts have been made to define what mental retardation is, but the most widely accepted definition today is that of the American Association on Mental Deficiency (AAMD). It was adopted by the Organization in 1973, and it states:

"Mental retardation refers to significant sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period."

If some of these terms are unfamiliar to you, they can be explained as follows:

SUB-AVERAGE GENERAL INTELLECTUAL FUNCTIONING: Falling below 97% of the population on standardized tests of global intelligence (tests which attempt to measure vocabulary, comprehension, memory, reasoning, judgement and visual-motor functions).

ADAPTIVE BEHAVIOR: The ability to adapt to and control one's environment, usually defined in terms of maturation, learning and social skills.

DEVELOPMENTAL PERIOD: The period from conception to about 16 years of age.

Since there are varying degrees of mental retardation, experts have tried to classify them into several different levels. One system of classification divides the degrees of mental retardation into three classes: educable, trainable and sub-trainable. This system of classification has been used in the field of education for some time. However, there are some negative aspects to it. When a person is classified "sub-trainable," the label implies that this individual may be so retarded that he can't learn. This is a misconception because everyone has the capacity to learn. Some just learn more quickly than others.

Another classification system that is more widely accepted and does not have negative connotations is the following:

Mild: Mildly retarded individuals make up about 89 percent of all mentally retarded people. With proper education and training, they can function independently in society with only occasional assistance in social, financial and legal matters.

Moderate: Moderately retarded individuals represent about 6 percent of all mentally retarded people. Their
mental handicap is usually detected by the time they reach school age. With special education and training these people can usually learn to live semi-independently in the community in group homes or supervised apartments. Some may be able to compete in the labor market, while others will be more successful in sheltered employment. 

**Severe:** Only about 3-1/2 percent of all mentally retarded persons are severely retarded. These people are capable of learning how to take care of their daily needs like eating, dressing, bathing, toileting, grooming, and personal hygiene. With special training, most of them can work productively in supervised settings. Some are residents in public and private institutions and others live at home or in community-based residences.

**Profound:** Profoundly retarded individuals constitute only about 1-1/2 percent of all mentally retarded people. Most of these people are capable of learning self-help skills when given highly specialized training. The earlier this training is introduced in the lives of these people, the more successful their development will be. Profoundly retarded individuals are sometimes capable of doing work in a sheltered environment. They live in institutions, at home or in supervised group-home settings.

Severely and profoundly retarded children are for the first time beginning to enroll in public schools across the country. Research has proven that these children, with proper instruction and support, are capable of learning skills and knowledge. Now they are finally going to have the opportunity to receive the help they need to develop to their full potentials. At least they may begin receiving it, if their parents, teachers and friends are prepared to work together to give it. Severely and profoundly retarded children cannot be expected to progress, if they only receive instruction from the school. Training must be carried into the home environment as well. Cooperative partnerships need to be formed between parents and professionals in order to educate severely handicapped students.

The Parent/Professional Partnership, a series of three books, was written for parents, professionals and friends who are involved in educating severely and profoundly retarded children. Hopefully, by reading the information included in this series, they can learn what they need to know to form more cooperative working relationships.

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**The Parent/Professional Partnership: How To Make It Work**

A quality public education for every severely and profoundly retarded individual is no longer a hopeless dream; it is a very feasible possibility. Necessary technology and teaching techniques have been tested and proven to be effective. Laws have been passed that declare it is every child's right to receive a free public schooling. Now the future of this long sought dream rests on the shoulders of the parents and teachers. If they can cultivate close working relationships, severely and profoundly retarded children may finally have the opportunity to develop to their full potentials.

Unfortunately, this kind of relationship may not be easy to establish. Many years of conflict between professionals and parents have generated ill feelings and misunderstandings, some of which still linger. The one thing that may provide common ground for these two groups is their shared concern for the welfare of the child. If a relationship can begin to grow from this, much can be accomplished.

**Professional Mishandling of Parents**

Professionals have been partially responsible for creating barriers between themselves and parents of retarded children. Many of these barriers have been the result of professionals mishandling parents.

**Professional ignorance**

Many professionals in the medical and behavioral sciences still have very little knowledge of mental retardation. Rather than admit their ignorance, they give parents misleading information. Sometimes they may not even recognize mental retardation in a child.

**Professional hopelessness**

Some medically oriented professionals see mental retardation as an "incurable disease." Therefore, anyone who is mentally retarded is a hopeless case. Parents often sense this defeatist attitude and either adopt it or resent the person who holds it.

**Referral ad infinitum**

It is well known that some parents "shop around" in the hope of finding answers to their questions that are satisfying to them. However, in many cases, professionals have referred parents to other experts. These referrals may be made because the professional doesn't wish to be the one to tell the parents the bad news. Or it might be that the professional doesn't feel he has the expertise to discuss mental retardation with the parents. Unnecessary referrals lead parents on wild goose chases and frustrate their efforts to find help for their child.

**Veil of secrecy**

Parents are too familiar with the veil of secrecy many professionals try to place over information about a child. Most parents want to know about any important information concerning their youngster, no matter how threatening or uncomfortable the professional may think it would be for them to hear.

**Deaf ear syndrome**

Too many times, professionals have been guilty of disregarding information or questions parents have about their child.

*The materials in this booklet are based primarily upon several publications by Dr. Philip Roos, Executive Director of NARC.*
Parent Mishandling of Professionals

Professional omniscience

Many professionals are guilty of trying to impress parents with their great knowledge. They often use terminology that is difficult for a layman to understand, although the concepts may be very simple. They have excluded parents and their children from decision-making processes, assuming that only professionals have the wisdom to make final decisions about other people's destinies.

Parents as patients

Parents are considered prime candidates for psychotherapy by many professionals. Instead of receiving information about their child, parents may be offered counseling to help them accept mental retardation and relieve themselves of the depression caused by it. This counseling is unrealistic because it is impossible for parents to accept mental retardation without some sorrow and resentment. In fact, these responses are really quite normal.

As in any human relationship, there are always two sides to a story. Parents have also been guilty of mishandling professionals.

Shopping around

Parents have been guilty of "shopping around" for a professional who will give them the answers they want to hear. This is a waste of energy and time for both parents and professionals. Once parents have received several similar opinions from experts on a certain question they should cease asking about it. They should then expend their energy on trying to find the best possible services for their child.

Unfair expectations

Some parents place professionals on a pedestal — expecting them to have all the answers and to take on the responsibility of making all the difficult decisions concerning their child. This is unfair, for no one person is able to know all there is to know, and should
not be expected to. In fact, it is dangerous for parents to assume that professionals are omniscient in their field. It is always good to obtain several opinions about a problem before trying to resolve it. Since parents are the legal guardians of their child, they should assume the responsibility of obtaining recommendations from professionals and then making their own decisions about what is best for the child.

**Dishonesty**

Sometimes parents are not honest with themselves or professionals about their feelings. It may be difficult for a parent to admit to a professional that he does not really want to or is not capable of taking on another responsibility (working with a child at home, going through parent training, participating in multidisciplinary team meetings, etc.) that demands more of his time and energy. Parents are not traditionally supposed to feel this way, although many do. However, if the professional does not understand a parent’s limited amount of resources, he cannot give a workable recommendation to the parent.

**Unwillingness to listen**

Some parents feel their authority or integrity is threatened by professional advice. They adopt the attitude that "no one is going to tell me about my kid. I know what’s best for him." This attitude prevents parents from taking advantage of a professional’s expertise.

**Unreasonable demands**

In some cases, parents tend to demand unreasonable amounts of attention and time from professionals. Parents may harrass a professional for information that he cannot give them. In their frustration with inadequate programs, they may attack a professional who is powerless to remedy the situation.

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**Parental Reactions to Mental Retardation**

The reactions parents have about having a mentally retarded child can often interfere with constructive parent/professional relationships. These reactions may also prevent the parents from being able to deal effectively with their child. Therefore, these attitudes are important to identify and understand.

**Disillusionment**

Everyone grows up thinking that their child will be a healthy, happy person — who might be a physician, lawyer, or maybe even President. Many of us hope to realize our own dreams through our children. Parents of a mentally retarded youngster are not able to realize their dreams or expectations in this way.

**Aloneness**

Intimacy is something that everyone needs. Yet, it is impossible for our parents, mate, and friends to fulfill this need totally. So many hope to find it with their children. A retarded child may not be able to respond to his parents in the way they want him to because of his inability to communicate or understand. Therefore, his parents may feel more alone because they cannot have the intimacy they need.
Vulnerability

As we grow up, we find that we have little control over the world. We are extremely vulnerable creatures; easy prey to illness, injury and failure. To have a mentally retarded child reminds a parent that even his most precious dreams and possessions can be mutilated, and he can do nothing about it.

Inequity

In a country that is founded on the premise of "...justice for all," children are raised to believe that fairness and justice will always prevail. However, a parent who gives birth to a retarded child wonders at the unjust treatment he has received. The natural reaction is to ask "why me?" He begins to believe that either he has sinned in some way, or that there is no such thing as justice in this world.

Insignificance

In adulthood, an individual eventually realizes that the world does not revolve around him. In spite of this realization, most people still try to achieve greatness or at least meaning in their lives. Having a mentally retarded child may thwart one of a parent's few opportunities to find meaning in an important and significant role in life — being a parent.

Past Orientation

When an individual dwells on the past and avoids thinking about the future, society views him as being an unstable person who can't face reality. Someone who thinks about the future tends to be considered as a mature person with a healthy view about life. Generally, parents anticipate their child's future with optimism. Parents of a mentally retarded child, on the other hand, tend to view their child's future as a source of anxiety and hopelessness. They don't see a very fulfilling life ahead for him. So the future holds very little for them, and they turn their attentions to the past when things were better — an unhealthy attitude in society's eyes.

Loss of immortality

Many individuals think of themselves as "living on" through their children and their children's children. This symbolic form of immortality is potentially threatened by a retarded child, especially when he is the only child.
Constructive Parent/Professional Interactions

Despite professional and parental mishandling, parent reactions toward mental retardation, and negative stereotypes, parents and professionals have shifted from being adversaries to partners.

Parents as Members of Multidisciplinary Teams

Parents are becoming active participants in multidisciplinary teams, instead of being passive recipients of the decisions professionals make. This change is not only a result of the efforts of voluntary organizations like NARC, but it is also the consequence of the following:

• Research has proven that a mother's teaching approaches with her children can have a positive impact on their learning. Mothers are important teachers.
• Curricula, training materials and audiovisual aids for teaching parents how to work with their children are now available.
• The Education For All Handicapped Children Act mandates that parents be involved in decision making concerned with the education of their handicapped children.

Parents as Decision Makers

Parents of mentally retarded individuals are interested in making decisions in two types of situations. They want to be involved in decisions affecting their own child, and they want to participate in decisions that affect mentally retarded people in general.

Parents are interested in being involved in the selection of their child's educational goals and objectives. They are legally responsible for their youngster during his first eighteen years and rightfully should have a voice in determining what he learns. One role of professionals should be to provide parents the information they need to make informed decisions. Once this information has been given, the parents, teachers and other support personnel can jointly establish the goals for a child's educational program. When the goals have been set, it should be up to the professionals to select the specific methods and approaches for achieving them. However, some parents may even want to have some input as to what approaches should be used. In these cases, the professionals would describe the different alternatives — with their pros and cons — and their recommendations as to which choice is most appropriate for the student.

The right of parents to make decisions about their own child’s education is becoming widely recognized by many organizations and state and federal governments. For instance, national accreditation standards, federal court mandates, and federal guidelines already have provisions for parent participation in decision making processes. National organizations also reflect this stance in policy statements. For example, NARC states in its 1971 Policy Statements on Education of Mentally Retarded Children that: "There shall be competent, voluntary and individual informed consent which is knowledgeable and autonomous and given by the individual, his parent or guardian without coercion or duress . . ." The American Association on Mental Deficiency (AAMD) advocates a similar position in regard to individual program plans in residential institutions.

Parents as Social Change Agents

Parents have become very active advocates for the rights of mentally retarded individuals. The roles of organizations like NARC have shifted over the years. They are beginning to evolve from being entities that provide services directly to mentally retarded individuals (operating schools, recreational programs, etc.) to ones that advocate that society must provide these services.

Parent groups are increasingly joining other organizations to achieve their goals. Some of these coalitions include professional groups like AAMD, Council for Exceptional Children (CEC), the American Orthopsychiatry Association, and many others.

Another area in which parent groups act as effective social agents is in placing key members on state and national education advisory boards, task forces, and advisory committees. NARC has been an instigator in establishing major entities designed to serve as national advocacy and monitoring bodies. The National Center for Law and the Handicapped and the Accreditation Council for Services for Mentally Retarded and other Developmentally Disabled Persons are just a few examples. ARC representatives serve on these groups’ governing bodies along with administrators and professionals.
Parents have often been joined by professionals in litigation that was meant to improve conditions for mentally retarded individuals. To date this litigation has centered around issues related to the right to education and the right to treatment. Parents have been relatively successful in these endeavors.

When confrontations between parents and professionals occur in legal matters, they are usually a result of bad timing rather than conflicts in basic goals or philosophy. Administrators usually admit that services are lacking, but they argue that budget, poor facilities, lack of staff and time prevent them from responding quickly to parent demands. These arguments are no longer acceptable to many parents.

Formal training programs have been developed to help parents become effective citizen watchdogs and advocates for mentally retarded individuals. NARC has developed several parent training packages that serve this purpose.

Through citizen advocacy, parents have encouraged other citizens to be social change agents for mentally retarded individuals. Citizen advocacy programs match a mature, enthusiastic citizen with normal intelligence (the advocate) with a mentally retarded person (the protege). Ideally the citizen advocate will be a friend to the mentally retarded person, guiding him in practical daily living and emotional crisis, and obtaining needed services for him.

Although parent/professional relationships have improved in recent years, there are still some potential problem areas. They can be troublesome when parents and professionals are not aware of their existence.

Differing Values

Ruth and Michael Burnstein had placed their severely retarded son, David, in a state institution for the mentally retarded when he was five years old. They had been told this was the best thing to do by their family, friends and professionals in the field. Years passed by; they visited their son when they could. It was always a sad experience, but they were faithful.

It had been eleven years since David had entered the institution. A letter arrived at their home. Ruth read it first. She couldn't believe it. Her heart started pounding against her rib cage. David was ready to come home. The evaluation team at the institution felt he was prepared for a home-community lifestyle. They wanted the parents to take him back home.

Ruth couldn't understand her feelings. She knew she should be happy that David was able to come home. But all she felt was anxiety and yes — even a slight tinge of dread. She and Michael were comfortable in their life together. They had their careers, commitments in the community, and they were older. What would they do with David — a sixteen year old, severely retarded young man — a stranger?

Michael and Ruth panicked. They called the institution that evening to see if there had been some mistake. Was the evaluation team certain that its decision was in David's best interest? Wouldn't he be lost in the community? Surely, it would be better for him to be around others that were more like him. The institution's official was a young man and didn't seem very sympathetic with their concerns. He even seemed to be angered by their questions. As far as he was concerned, David should come home.
Although educational programs for severely and profoundly retarded students are based on values, most parents and educators never discuss them. However, when their values are incompatible, problems can arise, especially in the area of setting learning objectives and lifelong goals.

The question of "whom does the program serve?" may seem easy to answer — the mentally retarded child. However, this is not really the case. The program provides jobs for the professional, respite for the parents, etc. It is not uncommon that the needs of parents and their children do not coincide. This was evident in the Burnsteins' story.

Even when the question of "whom does the program serve?" has been clearly answered in favor of the child, other values held by the educator and parents may be incompatible. Here are a few objectives that these two parties have been known to disagree with:

- Helping a retarded person develop so that he functions as close to his potential as possible.
- Providing the retarded child an environment that is as normal as possible.
- Helping the retarded person achieve the highest possible level of contentment and happiness.
- Helping a retarded person obtain as much economic independence as he can.
- Teaching the retarded person behaviors that make him more normal in the eyes of society.

Differing Objectives and Priorities

It was nearing the end of the 2nd semester of school. Judy's parents were scheduled to meet with her teacher, Mr. Roberts, at 3:00 p.m. Mr. Roberts was looking forward to this appointment. He felt he had some very good news to report. Judy was finally learning to differentiate the primary colors. He had been working with her on this for some time.

Three o'clock arrived. "Mr. Roberts, it's real nice that Judy knows red from blue. It's not that we don't care. It's just that it doesn't seem very important when you see her dripping food down her chin and blouse at dinner — or when she screams bloody murder in the department store because she can't have a toy. Can't you work with her on some of these things, instead of red, blue, green?"

Even when parents and educators have compatible values, they may differ on which learning objectives and lifelong goals have priority over others. Professionals sometimes tend to stress abstract and academic goals, while parents are more interested in the child's achieving more practical objectives and immediate problems.
Differing Temporal Orientations

Mrs. Clark began the planning meeting with Julie's parents by asking them if there were any learning objectives listed in the plans that they disagreed with.

"Yes," said Mr. Ross, "We don't like those items you've listed concerned with sex education."

"May I ask why, sir?"

Mr. Ross shifted in his chair, "We are facing more immediate problems with Julie right now."

Mrs. Ross interjected, "Quite frankly, we aren't convinced that she ever really needs to have a lot of knowledge about sex. She will live with us most of her life, and we don't think there will be any occasions when someone would try to take advantage of her. I mean, after all, she's severely retarded, Mrs. Clark. We doubt that she will ever even date, much less get married."

Mrs. Clark really couldn't understand the Ross' viewpoint. Julie was fourteen years old and developing into a very attractive young woman. Older boys at school were already noticing her in the hallways. Besides, Julie was progressing well enough in school to be able to eventually live in a semi-sheltered environment in her adult years. Why were her parents being so shortsighted?

Since educators tend to be future-oriented, and parents are threatened by what they fear is in store for their child, misunderstandings can occur in this area. Long range goals may hold little attraction for parents, which a professional may find frustrating.

Competition

"I don't know why you're having so much trouble with Billy at school, Ms. Dickens. I've had him toilet trained at home for some time now," boasted Mrs. Jennings.

Mr. Jennings began to feel a little uncomfortable. He knew that Lillia had worked very hard with Billy at home and with some success. He usually had three accidents a day. So why was she coming on so strong with the teacher?

"Well, I can't understand it either, Mrs. Jennings. For Billy to be doing so well at home and yet be only partially successful at school is puzzling, to say the least. Are you sure that he isn't having a few accidents now and then? He has about one a day at school."

Mrs. Jennings replied confidently, "He is doing fine at home."

Mr. Jennings was really disturbed now. Billy wasn't doing as well at home as he was in school, if what Ms. Dickens said was true. So, why was Lillia implying that he was? Why was she being so defensive?

It is not uncommon for parents and professionals to feel — often unconsciously — competitive toward each other in educating retarded children. It is threatening for a parent to have a stranger be able to handle his child better than he can in certain situations. It is also hard for a professional to admit that parents might be more successful in teaching a child than he is.
How to Overcome Barriers

"In working with people there is no escaping the fact that differences exist among us ... Consequently, we must learn how to recognize and manage our differences if we hope to be successful. . . Our differences result naturally from our individuality. Each of us brings to an encounter with others our own experiences, our way of perceiving the world and other people, and our own expectations and assumptions. The important thing to recognize is that differences are natural, should be expected, and are a source of creativity as well as potential disruption of our relationships." (Organization Development Workshop Trainers Manual, NARC, 1967)

Avoiding coming to grips with conflict. Many people find the easiest way to deal with conflict is to deny that it exists. This type of approach is characterized by "looking the other way." Another similar approach is for people to maintain neutrality and refuse to state an opinion on any issues that they consider to be controversial. While these persons may believe that this approach doesn't get anyone mad at them, they should also realize that conflict is not solved in this manner. Instead it continues to grow in a "cancerous" fashion.

Smoothing over the conflict. A second negative approach to managing conflict is an attempt to smooth over any disagreement. Here the individual attempts to maintain a harmonious atmosphere at all cost. There is an attempt to cajole people into agreement by presenting a "rosy" picture of a given solution, emphasizing the positive implication. Humor may also be interjected to give a feeling of friendli-
ness. These tactics may serve to keep the conflict below the surface, but they do not solve problems.

**Suppressing disagreements.** Another ineffective approach to managing conflict is for one of the parties involved in the conflict to simply suppress any opposition to his point of view. This approach is easily adopted by persons who are in a position of authority. Others may, however, employ this tactic by assuming an authoritative role and attempting to "outshout" and "bully" the opposition. Similarly, these individuals may ridicule the ideas and personalities of others who disagree with them. This type of conflict management may result in a temporary end to the open conflict, but the basic differences remain and will likely reappear in the future.

**Splitting the difference.** This fourth approach centers around compromise. Each party is expected to "give a little to get a little." While the result may not be the most positive, both parties have gotten at least a portion of what they wanted. While the compromise approach is often viewed as a positive way of solving problems, its goal is not to seek the best possible solution but rather an acceptable one. The result is often a compromise solution that is mediocre in nature and leaves each party only partially satisfied with and committed to the decision which has been reached.

**Directly confronting conflict.** A more effective way to approach conflict is through a direct confrontation of the problem. Disagreements are brought out into the open and examined and evaluated by those persons directly involved. Candid discussion aimed at identifying and resolving the underlying cause of the disagreement is encouraged. Some may resist this approach because of a fear that feelings may be hurt or that discussion of this type will weaken the position of the person in authority. A person holding this attitude loses sight of the true goal of education — to serve the mentally retarded person rather than to cater to the insecurities of either parents or educators.

In an effort to make important decisions about the lives of mentally retarded students, parents and educators will surely encounter situations in which disagreements and conflicts will arise regarding what constitutes the best approach, the most important learning objective, the most appropriate educational setting, etc. If an attempt is made to avoid, smooth over or suppress these conflicts or to seek compromise solutions, it is likely that little will be achieved. If, on the other hand, conflict is openly confronted and an honest effort is made to resolve the underlying differences, a more relevant and appropriate education for the mentally retarded child can be achieved.
Recommendations for Productive Parent/Professional Partnerships

Many of the potential problem areas that have been described can be worked through by parents and professionals. There are some things that both parties can do to ensure that they can establish a cooperative and constructive partnership.

Parents should be included in any decision-making body that determines educational programming for their child. They should not only be included, but should also be considered equal participating members of the team. Professionals should treat parental questions and information with respect, even though they may disagree with them.

Professionals should accept parents as they are and resist the temptation to criticize parental attitudes which conflict with their own. Otherwise, parents may become intimidated and will not fully express themselves. They may also tend to feel guilty or worthless, which will not help them develop constructive attitudes toward their retarded children.

Professionals should reveal any relevant information to parents, so they can make intelligent, informed decisions. They should have access to the same information that the professional has access to, including test findings, written reports, etc.

While professionals usually have the major responsibility in deciding what teaching techniques to use in an educational program, parents should have authority to select the goals and objectives. Professionals should advise the parents of the various alternatives and give them recommendations as to which goals and objectives they think are best for the child. If professionals do not agree with parents on the selection of a program for a child, they should use formal appeal procedures (discussed in Book II).

Professional jargon should be kept to a minimum when parents and educators try to communicate to one another. Reports should be presented to parents in everyday language. When technical concepts are inescapable, they should be explained to the parents in terms that they can understand.

Being the parent of a mentally retarded child is no easy task. Parents need support and encouragement from professionals. They also need to know that professionals recognize that they are facing difficult problems. Professionals need to reinforce a parent’s efforts by giving him positive reinforcement when he is making progress with his child.
In Closing

When parents and professionals establish cooperative, working partnerships much can be accomplished. These constructive relationships need to be formed so that parents and educators can begin to achieve these very important objectives for severely and profoundly retarded children:

• All mentally retarded children should be provided a public education.

• Education should begin as early in life as possible, so that severely handicapped children can develop to their full potentials.

• Continuing education should be available to retarded adults throughout their lifetimes, whenever they need it.

• Educational programs for severely and profoundly retarded children should be based on child development research. They should also focus on practical skills that will help the students learn to be more independent individuals.

• Severely and profoundly retarded students should be taught in the "least restrictive environment" possible.

• Parents should be involved in decision-making that concerns their child's educational program.

• Every student should have an individual educational plan and program designed especially for his needs. In addition, every student living in a residential institution should have an individual program plan as well. Both types of programming should be reviewed periodically and modified when needed.

• Each student should be given every opportunity to make his own decisions and shape his own destiny.

References
