

## **ADVOCACY:** **HOW TO SPEAK FOR THOSE WHO CANNOT**

Advocacy equals action that results in change. It is not always enough that we have found the best local program, housing, vocational services, or school for our child. Situations sometimes arise that call for action.

It could be said that advocacy is the art of being part diplomat and part detective. It requires the development of skills we all possess and a willingness to remain levelheaded in the face of bureaucratic runaround and rigid guidelines. It is easy to become confused and mistake complaining for advocacy. The difference lies in the process.

Advocacy is composed of (6) steps:

1. Identifying and defining problems;
2. Brainstorming (creative problem solving involving two or more people);
3. Evaluating and choosing alternatives;
4. Communicating intentions;
5. Taking action; and
6. Assessing the outcome of the action.

Any problem that cannot be solved by the simple communication of stating your or your child's preferences may become an advocacy issue. As an example, let us imagine that once a week your child starts acting out, is uncooperative, aggressive, perhaps cries, and refuses to eat. You notice the pattern almost at once and call the school to see if they have noticed the change. You learn that on the same day you see this behavior, the children have swimming class as part of physical education. You had neglected to tell the school of the fear your child has about pools. Now that they know he is afraid, the school schedules a different activity for your child during physical education. The problem is solved. This is not true advocacy. If the school had insisted that your child, "get used to the pool and overcome his/her fear", and you felt this was ethically inappropriate, you would have an advocacy situation on your hands. Advocacy exists when resistance to change appears.

**To understand advocacy, we must define the six- (6) steps mentioned above.**

**Defining the problem:** In our example above, the initial problem may seem to be the child's behavior or their fear of swimming. This is only true if the school discontinues putting the child in swim class. If the school insists on continuing to put the child in swimming, the problem stops being the child's issues and becomes the "system's" problem. So, in our example the problem can be defined as: School program does not allow flexibility for personal preference.

**Brainstorming:** This process means contacting people directly and indirectly involved with the problem and having them all come up with solutions to the problem. In this case, our group might include parents of children in the school, family members, and a teacher who sympathizes with our difficulty and a social worker from the school department. If these people can be brought together

for a meeting, you will see the rapid development of a pool of ideas. If you must, contact each one individually, review the other's ideas and generate more. The process will be slower but just as effective as a meeting. Let us say the following list of ideas is generated:

1. Remove the child from the school.
2. Let the situation remain the same (maybe the child will adjust).
3. Offer school alternatives for activities during swim time.
4. Threaten the school with legal action.
5. Begin a desensitization program to help the child overcome her/his fear of pools.
6. Keep the child home on swim days.
7. Have a parent attend swim class with the child.
8. Implement a comprehensive behavior program utilizing imagery and reinforcers for attending swim class.

**Evaluating and choosing alternatives:** Some choices may be too radical to consider, while others may not be cost effective. The ideal is to find solutions that will address the issue and can be effectively implemented. In our example, both teachers and family could assist if solutions 5, 7 and 8 were used. These solutions would lead to maximum involvement and have the potential to address the child's fear and the larger issue of school cooperation.

**Communicating intentions:** This can be as simple as a phone call to all parties involved or as complex as a written proposal to the same. You will need to meet with the highest level necessary to implement your plan. In other words, if the State Committee on Human Rights must authorize the program, it will be important to invite the Director of Special Education and the principal of the school. If your plan can be implemented with the authorization of only those directly involved, then those are the individuals that need to be present. Putting your message across in a calm, rational way may be the most significant part of your presentation. Loud voices and anger will sabotage the best-laid plans.

**Taking action:** Once everyone understands his or her roles in the plan, the process of implementation can begin. Some of the design work developed in stages 2 through 4 may need re-working. Changes are acceptable as long as the goal does not become lost in the process.

**Assessing the outcome:** Periodic review of the plan and progress is a necessary part of this process. If the plan has achieved its goal then the program can be partially or fully dissolved. The child will be the most significant indicator in this process.

The example we chose was relatively simple compared to some you may encounter. Most schools attempt to be sensitive to your concerns and opening the lines of communication will, usually, achieve satisfaction. It is most often state or federal agencies that present the most rigid guidelines and may force advocacy to the level of the courtroom or an arbitration setting.

If you truly think your child is receiving inappropriate services and his/her needs continue to not be addressed, you may need to take action. Individuals with disabilities often find it difficult to speak for themselves and you may need to be their "voice" to ensure their desires are heard.

**RESPITE CARE**  
**FOR THE TIMES WHEN YOU NEED TO GET AWAY**

**The Groden Center provides respite by trained professionals for qualified families of their students in order that the families may have relief from providing constant care.**

**Some Basics**

The RI Department of Developmental Disabilities and The Department of Human Services contract with the agency Training Thru Placement (TTP) to provide respite services to some of the families of individuals with developmental and behavioral disorders in the state. Because of its experience and expertise in servicing individuals with autism, the Groden Center is sub-contracted by TTP to serve as the respite care coordinator for individuals with autism and/or behavioral disorders in Rhode Island.

Respite care provides parents with the opportunity to meet planned and emergency situations or to take a well-deserved break. It may also prevent stressful situations from becoming crises. The services are typically provided on a temporary, as needed basis, however respite may also be part of a regular schedule of care.

Respite care services can be arranged in or away from the family's home. The length of care can be several hours, overnight or even longer. Families with Title XIX waiver status are allocated ninety (90) hours of respite service for each six- (6) month period. Because of a limited number of providers, however, services for a particular day or time (example: vacation week) are usually available on a first come, first serve basis.

**Who Are the Providers**

Respite care providers are carefully trained and screened before providing services. Groden Center Staff must have worked at the school a minimum of three (3) months and all staff must have completed respite care training. Documentation of the provider's familiarity with the client and/or relevant behavioral techniques is made before assigning a provider to a client. Parents may also refer friends, other relatives, or neighbors to the Groden Center so that they may become Respite Providers.

**How It Works**

Respite services are currently available to individuals who have received a Medicaid Title 19 Waiver Authorization through their social worker at the Department of Developmental Disabilities. Currently DHS is not accepting referrals for a wait list, and no new authorizations have been granted. However, families needing respite are encouraged to contact DHS. Unfortunately the waiting list for waiver status is long. The process can be difficult but worth the effort. You will need to disclose personal information as well as wait a long time for the authorization to be granted.

## **Nonwaiver Help**

Occasionally, the state will make Emergency Funds for respite services available. This is typically referred to as “non-waiver respite”. You should contact the Department of Human Services to inquire about this option. In addition, your local CASSP may be able to allocate limited, short-term respite funding. If an emergency arises, The Groden Center has a special fund to pay for limited respite services as well. Once you have secured a funding source, contact the Respite Supervisor at the Groden Center to arrange for services.

Your school will have information and emergency release forms which you will need to fill out. You will not be able to receive respite services until these forms are on file.

Please do not overlook respite! It could give both you and your child the break you need.

## FINANCIAL ASSISTANCE

### HOW TO APPLY FOR SSI AND MEDICAL ASSISTANCE

Although it may seem as though you are on your own at times, there are programs designed to provide children and adults with financial assistance and services. Certain criteria, listed below must be met in order to be eligible for these services. Whenever in doubt, contact the involved agency or your social worker for advice.

#### **Supplemental Security Income**

SSI is a program that gives money and services to people who are over the age of sixty-five (65) and to people who are blind or disabled including dissolved children under the age of eighteen (18).

A developmental disability is a severe handicap resulting from autism, cerebral palsy, epilepsy, mental retardation or similar problems that require the same treatment or services. Criteria includes onset prior to the age of eighteen (18), that the disability continue for an unknown period of time (generally a lifetime) and that the disability impedes the performance of everyday tasks.

You can apply for SSI at your local Social Security Office. It is listed in the phone book under Social Security Administration, or U.S. Government – Social Security Administration. When applying you will need to bring your child's birth certificate, pay stub, rent receipts and bankbooks. If your child is under the age of eighteen (18), your income will be looked at in determining eligibility for SSI. You will also need written proof from a doctor or another professional familiar with your child that can state that your child has a disability. Different information will be necessary dependent upon the disability as outlined below.

If your child is mentally retarded, you should take a letter from a psychologist or psychiatrist documenting what your child can and cannot do. The letter should state how he/she acts in comparison to his/her age group, whether he/she can feed and dress himself/herself, whether he/she is toilet trained, etc. Also, any reports documenting I.Q. scores are important to take with you.

If your child has seizures, you should take reports from his/her neurologist, the results of the last EEG, how much and what kind of medication controls the seizures. You should also have documentation of what happens to your child before, during and after the seizures, how often they occur and whether he/she faints.

If your child has autism, you will need all of the information indicated above for mental retardation. Also, any information regarding your child's level of speech and communication, degree of interest in age appropriate activities and ability to understand those around him/her. You will need documentation from a psychologist or psychiatrist indicating characteristics of your child's disability, such as keeping to himself/herself, lack of eye contact, not liking to be touched, not playing with toys or not playing with them in the usual way, a need for sameness, self stimulatory behavior(s), self abuse, aggression, etc.

After you have given the Social Security Office all of your information, it will be sent to their medical agency to decide if your child qualifies for SSI. It may take up to three (3) months for the decision to be made. In the event that you are notified that your child is not eligible and you feel he or she should be, IMMEDIATELY call the office to inquire about filing an appeal. Upon re-examination, the Social Security Office often reverses their decisions. While the process of filing for SSI can be complicated, the end result justifies the work.

If you qualify for SSI, you automatically qualify for Medical Assistance (Medicaid). If a family/child does not qualify for SSI, they may still qualify for Medicaid, as the asset/income requirements are less restrictive. In addition, through legislation, Medicaid is available for individuals with disabilities based solely on their diagnosis. Medicaid pays for all services obtained through outpatient clinics at hospitals (excepting obesity nutrition and pain clinics). It also covers all types of evaluations and therapy including psychological, psychiatric and behavior therapy. Payment is at the "reasonable", customary charge and the treatment must be "justified", or medically necessary. Further information may be found in the section on Insurance Needs and by contacting the Medicaid Office.

## **INSURANCE NEEDS**

### **PREPARING FOR MEDICAL COSTS**

Children with special needs may require a wider scope of health care and a greater depth of benefits than their non-disabled peers. It is important for parents to determine whether their private or public insurance carriers offer the services or benefits their child may require.

There are a number of considerations that should be made when deciding upon a health insurance policy. The major factors that should be considered are: the family's future need for medical care; financial resources to meet this need for care; and access to appropriate medical care. When looking at private policies, pay particular attention to the enrollment requirements (example: Are there limits such as pre-existing conditions, waiting periods or dependent age cut-offs?), costs (example: Are premiums, annual deductibles, co-insurance, co-payments, costs of benefits not included in the plan and amount of catastrophic protection offered?), covered benefits (example: What Limits are placed and how flexible is the plan?) and participating insurance providers (example: Do current primary physicians participate in the plan under consideration? Are the plan's doctors and facilities available for emergency, after hours and weekend care?) in the insurance plan you choose.

Private insurance policies offer either a group policy or a non-group policy. Most families obtain their insurance through their employer under a group policy and are liable for only a portion of the premium costs. Other families may have non-group policies, which they purchase directly from an insurance agency. These families must pay the full cost of the premium and often the benefits are not as generous as those in a group policy. Generally, if you have a choice, group policies are preferable to non-group policies.

The three major types of private health insurance that families have to choose from are traditional plans (Blue Cross and Blue Shield), health maintenance organizations (HMOs) and preferred provider organizations (PPOs). Each of these has their own advantages and disadvantages that should be carefully weighed before committing to a plan.

In a traditional indemnity plan (BCBS), the physician receives a specific fee for each service. Usually the patient pays at the time of treatment and waits to be reimbursed from the insurance company unless the physician or hospital agrees otherwise. The patient is made to pay a deductible and then is liable for a portion of the health care costs after this has been met, usually up to a set amount, then the insurer covers the full amount. There is typically a greater choice in the selection of physicians, hospitals and other health providers.

Health and Maintenance Organizations (HMOs) are characterized by a fixed premium cost, no matter how few or how many services are used. There are typically no or minimal deductibles, co-payments or co-insurance's except for certain services (example: mental health treatment). Choice of providers is limited to those health care professionals who belong to the plan unless specifically exempted.

Preferred Provider Organizations (PPOs) provide a fixed, discounted rate which is set by a group of physicians or hospitals contracting to a health insurer or employer for the care they provide.

In addition to paying premiums and deductibles, you will be liable for a portion of the health care costs. There is a choice available as far as providers, however fiscal incentives are offered to those who choose preferred providers.

The most common form of public insurance used by children with special health needs is medical assistance or Medicaid. Not all health providers accept Medicaid, therefore, as with any insurance policy, it is important to ask before beginning services with a new provider. The bill is sent to Medicaid and the patient does not pay for services. Medicaid, although essentially a federally funded, nationwide plan, is run by the individual states. The states determine not only eligibility but have the option to add to the covered services or impose certain restrictions. A list of the services covered should be obtained from the state Medicaid Office.

If your child receives SSI, he or she will automatically receive Medicaid. If you wish to seek only Medicaid for yourself or your family, it can be applied for at your local human services department (call 401-464-3361 for the phone number). Forms that will be required to determine eligibility include: proof of residency such as birth certificate; driver's license; social security card; or any other identification for each member requesting medical assistance. If a child is under the age of eighteen (18) or for family eligibility, bring documentation such as bank statements and check stubs showing family's monthly income. Food stamps and SSI money do not count, however, monies received through Social Security, unemployment benefits and pensions are included. Also, bring documentation of family assets and resources although they generally exclude one house, one car and nominal savings (less than \$1,000.00). A recent tax statement should also be submitted. They will question the size of your family; therefore, birth certificates and social security numbers will have to be provided for each family member. Other questions they may ask include pregnancy, marital and employment status.

For Further information and worksheets to compare costs of insurance plans, the booklet, Understanding Your Health Insurance Options: A Guide For Families Who Have Children With Special Health Care Needs, may be obtained through the Groden Center Family Services Library or by calling (202) 244-1801.

## **WILLS, TRUSTS AND DESIGNATED GUARDIANS** **WHEN YOU ARE THINKING ABOUT THE FUTURE**

No one enjoys planning for the day they will no longer be here to watch over their child but it is the only means we have to secure the continued protection and support we give our children today.

The purpose of this chapter is to give you a basic idea of the elements involved in creating a will. It will provide a framework for consulting with experts as well as give you some ideas of what is involved in this process.

A will is your means of designating who will receive your personal real property after you are gone. In order for your will to be valid, you must be over the age of eighteen (18), have mental competence and be acting voluntarily. Moreover, the will should also be signed in front of a notary public.

It is a good idea to have your will professionally prepared. A lawyer can bring clarity and ensure compliance with state regulations. It is essential that you go prepared with lists of assets, property, monies, securities, bonds, etc. and to whom they will be distributed.

The individual who executes or carries out the orders of the will is referred to as the administrator or executor. They shall ensure that debts and taxes are paid, leaving the remainder of your estate free to be passed on to your family.

Issues you might cover are:

Specific legacies	Payment of taxes
General legacies	Payment of debts
Outright gifts	Residuary legacies
Funeral arrangements	Disinheritance
Bonding of fiduciaries	Power of executors
Common disaster and survivorship	
Appointment of guardianship of minor children and those declared incompetent	

It is important to remember that a will is primarily a tool for the disposition of your property. If you have specific requests regarding the care of your child with disabilities, you should write a Letter of Intent and Letter of Instruction. These documents are not open to public inspection and will help guide your executor in making future decisions regarding your child. These letters are not legally binding and an executor may not be sued for non-compliance. This is another of the many reasons why care must be taken in choosing an executor.

Your legal advisor will clarify any questions and help you create a sound document. Do not be afraid to ask questions. Have examples and a rough draft of your Letters of Intent/Instruction available for review. These documents will only be as good as the effort you put into them.

## **Trust Funds**

Trust funds can add a measure of security to your child's future by providing for luxury items like new furnishings, dinner out, recreational activities and other special items. Unfortunately, a trust may be plundered by state agencies in a legal process called Spend Down. The income from trusts may also effect your child's state supported benefits. It is important to follow your state's regulations and the guidelines that follow.

The purpose of a trust is to leave funds to a person who needs assistance in managing funds. There is no rule as to the size of a trust fund, although you will find that larger banks will not willingly handle under fifty thousand (\$50,000.00) dollars. Local or smaller banks are sometimes more cooperative. A small trust of ten thousand (\$10,000.00) dollars could generate eight hundred (\$800.00) dollars to one thousand two hundred (\$1,200.00) dollars annually. A trust can be set up while you are still alive so that you may add to it or secure funds now or it may be created from funds generated from a life insurance policy, the sale of real property after your demise or any other source you receive monies from. There is always a fee for managing a trust fund and you should discuss this with your bank before committing funds.

For more information and guidance regarding wills and trusts, you should seek legal counsel. Discuss all of the options and ideas with your lawyer and he/she will help you design the best fund for you child.

If you would like more information, examples and explanations prior to meeting with a lawyer, we suggest consulting the text Disability and the Family, A Guide to Decision for Adulthood, written by Turnbull, Turnbull, Bronicki, Summers and Roeder-Gordon, and published by Paul Brookes Publishing Company. This book is available through the Groden Center Family Service Library.

## **RESIDENTIAL CARE** **LIVING OUTSIDE OF THE FAMILY UNIT**

The reasons for choosing a living situation outside the family unit are as varied as the children/adults who need the option available. Why and how your family reaches this decision may affect funding availability, however, the important factors are that your child is placed into the proper setting and you are comfortable with the living arrangement.

The most common approach to this discussion begins with “brainstorming”. Sit down with family members, social workers, treatment teachers and anyone else who can provide solid information about your child’s needs and abilities. You will be your own best source in this process but the act of speaking with others will help you define and outline your goals.

The following is a partial list of questions you might consider in your search for a placement.

1. What level of supervision is needed?
2. What is the staff to client ratio?
3. Will this be a relatively stable placement?
4. If your child must move out at twenty-one (21) years old, what methods of transition are employed?
5. Does your child like a lot of activity around or does he or she prefer quiet?
6. Does your child need easy access to bus lines, cabs, and car pools or will transportation be provided (this is very important if your child is over twenty-one (21) and will be working)?
7. How does your child reach decisions? Are they made for him/her, does he/she participate or does he/she choose options independently?

These are only a very few examples of questions you will need to address when reviewing residential options for your child. For further areas of concern and more complete questionnaire profiles, we recommend the text Disability and the Family, A Guide to Decision for Adulthood, written by Turnbull.

The following is a list with a brief description of residential options. This does not mean that the other options could not be utilized, it means that you would have to do all the research involved in how the placement is run and devise a means or source of funding. Most of the models discussed target the over-twenty-one (21) population. An asterisk (\*) will indicate those options best suited to children under twenty-one.

## **Independent Living**

This format can be as formal or informal as your child's needs. Most independent arrangements are funded through a variety of resources, including SSI, parental contributions and wages from the working "child" (now referred to as an adult). Two types of independent living are apartment living and joint ownership. Apartment living would be similar to what you see with most college students today. The exact amount of supervision can range from full coverage (living space provided to a staff person(s) who is available twenty-four (24) hours a day), to minimal supervision (help with budgets or interpersonal issues). Any amount of supervision can be negotiated if the resources are available. Joint ownership would originate with a core of parents providing the initial resources to purchase a home and negotiate with the state for funding for services other than housing. The concept is similar to condominium ownership where each adult contributes a specific amount to upkeep and bills due, with each individual owning a percentage of the total value of the property. This can be complicated if legal documentation is not carefully drawn-up. It is best negotiated in a lawyer's office. Board and care Residences also come under this heading, which is any environment that provides a room and adequate meals as well as minimal supervision. Rest homes often meet these criteria.

## **Supported Living**

Supported living arrangements are non-custodial in nature. The state usually provides a stipend and the adult with disabilities provides a share of wages or their SSI income as rent. This model may be constructed with a family as the host or an individual with a large enough apartment or home they may want to share.

## **Professional Family Living Arrangements (PFLA) at the Groden Center**

Professional Family Living Arrangements provide short- to long-term placement for children, outside their homes, between the ages of three- (3) and twenty-one (21). The children generally display challenging behaviors, have developmental disabilities, and are in need of an alternative residential placement. PFLA providers are individuals or couples who can implement home and community-based daily living skills and behavioral programs. Providers receive a salary and stipend, training in their homes, weekly respite and support from the Groden Center professional staff. The whole team composed of the provider, Groden Center staff, child and biological family work toward reunification with the biological family.

## **Intermediate Care Facilities**

This model is commonly used by individuals who are Medicaid eligible and in need of special services. There are traditionally three (3) levels utilized but variations exist even within these models. **Nursing Homes** are commonly utilized for their ability to provide around the clock supervision and medical accessibility. This would only be appropriate for the truly medically involved adult. \***Group Homes** of many varieties are also an option. These typically have twenty-four (24) hours coverage and one (1) to four (4) or one (1) to three (3) staff ratios are common. These facilities are usually appropriate for the more behaviorally involved, however funding is often difficult to secure. The third model utilizes **Home Health Aids** and is commonly used to help avoid

placement in one of the two previous settings. Once again, this is funded through the Medicaid program.

### **Group Homes and the Groden Center**

The Groden Center is fortunate to have access to four (4) group homes for adolescents. Only one (1) of the adolescent homes is owned by the state (DCFY). Every group home is run by Groden Center personnel and managed in accordance with the Center's philosophy as well as state regulations.

In order for a child to be placed in a Center group home, a referral must be made. The usual referral sources are school districts, the Department for Children, Youth and Families (DCYF) or an out of state agency equivalent to DCYF. Occasionally, a parent will refer his or her own child. The referral process is fairly complex.

Documentation in the form of evaluations must be forwarded to the Center where they receive an initial review by the Admissions Coordinator and the Director of Residential Services. Examples of documents needed would be a current copy of the child's IEP, psychological evaluation, social history, speech/language, various educational and vocational (if the child is 14 or older) evaluations as well as other assessments if deemed necessary. If after reviewing the file they feel the child may be appropriate, then the group home managers and classroom supervisors are brought into the screening process. It is essential to remember that many factors come into play when residency is discussed. Foremost is the availability of housing. If all of the group homes are filled, then a placement may be a long time in coming. The Admissions team must also consider the actual "fit" of the client to the available placement.

Placement is based on whether or not the Groden Center feels it can provide a safe, nurturing and educational environment for that specific individual.

### **Words of Warning and Caution**

Remember that this is not an easy or quick process. The initial decision is personal and often fraught with emotions. The process can be long and tedious as well as personally intrusive. Do not wait for a crisis. Planning for your child's residential lifestyle will take time and patience. A well thought out plan with funding sources identified, options reviewed, and goals outlined will provide you and your child with long term satisfaction.

*For more detailed information, we recommend the text Disability and the Family, located in the Groden Center Family Services Library.*

## **TRANSITION PLANNING** **WHEN YOUR CHILD TURNS 14**

Arranging for adult services can be a trying time for parents, since at age 21 there is a termination of mandated educational services which have been a central part of your child's development. The State of Rhode Island, like many other states has suffered severe budget cuts. While it is difficult to accept, these cuts can interfere with the availability of adult services. Parents must advocate for their child's need for services. Advocacy can be frustrating and time consuming, however the end result, quality service, justifies the means. Advanced planning can help prevent your child from being left without services when he or she becomes an adult under special education law (at age 21).

The Individuals with Disabilities Education Act (IDEA), defines "Transition Services." This category is an addition to each child's IEP. In accordance with this law, a transition plan will be initiated at the age of 14 and will be followed and modified through the termination of services at age 21. The Groden Center has a form for this, which will become part of your child's IEP. Specific areas include educational needs, leisure, employment, independent or supported living arrangements, vocational training, financial, family and community involvement.

The key players in transition planning are the school department, Department of Developmental Disabilities (DDD), Office of Rehabilitative Services (ORS), Department of Children, Youth and Families (DCYF), (if involved), the parents and the student, if appropriate. All the involved parties share in the responsibility of developing and following the tasks identified in the plan. One of the most important factors in successful transitions is parent involvement. You know your child best and you are the most powerful spokesperson.

***What follows are some of the changes made in IDEA to be aware of in planning for your child.***

In IDEA, "transition services" are defined as "a coordinated set of activities for a student, designed within an outcome-oriented process, which promotes movement from school to post-school activities, including post-secondary education, integrated employment (including supported employment), adult services, independent living or community experience. The coordinated set of activities shall be based on the individual's needs, taking into account the student's preferences and interests and shall include instruction, community experiences, the development of employment and other post-school adult living objectives and, when appropriate, acquisition of daily living skills and functional vocational evaluation."

The IDEA adds the requirement that a child's IEP include "a statement of the needed transition services for the student beginning no later than age 14 and annually thereafter. In the case where the participating agency, other than the educational agency, fails to provide services agreed upon, the educational agency shall reconvene the IEP team to identify alternative strategies to meet the transition objectives".

***The following contains a list of issues, which should be addressed when planning a smooth transition into adulthood. Any questions/ concerns regarding transitions can be addressed to the Groden Center Transition Coordinator for clarification.***

While the law mandates that transition plans commence when your child turns 14, it is not until your child is age 19 that formal transition planning will actually begin. Prior to the age of 19, it is crucial that your child's strengths, weaknesses, interests and abilities be identified. When your child becomes 19, the school department will write letters of referral to adult services agencies which will provide adult programming (over age 21) for your child.

After the letters of referral have been sent to adult service funding agencies (such as Department of Developmental Disabilities or Office of Rehabilitation Services) by your child's school department, it is highly recommended that parents take an active role in the transition process. Your child will be assigned to a case manager from DDD. It is important for you to get to know this person, as the case manager is the one who will refer your child to adult service programs. All programs are different. It is important the case manager becomes familiar with your child to ensure that a match can be made between your child and the adult service agency that will best support his/her needs. When appropriate, visit some possible adult programs with your child. Do not settle for just a description of each program. Visiting a prospective program more than once before agreeing to it is also an important step in the process. If your DDD case manager cannot recommend a program you are comfortable with, you can call RI Disability Law at (401) 831-3150 to assist you in advocacy.

A separate issue, which causes considerable concern for parents, is the decision of whether or not to pursue legal guardianship of their adult child with developmental disabilities. Guardianship enables one person to act for another. If you do not believe that your child is able to handle his/her own personal affairs, can provide for their own safety, or can manage their own physical health, then your child most likely requires some form of guardianship. The law now states that all guardianships must be limited, which enables your child to retain some of his/her own legal rights as an adult. For more information on guardianship, refer to the chapter in this manual entitled "Guardianship".

If your child is over 18 and not receiving SSI, he/she should be eligible now, unless otherwise determined by Probate Court. Your own income is no longer considered part of the formula determining your child's benefit eligibility. In addition, your child would receive Medicaid benefits with the SSI.

## GUARDIANSHIP WHEN YOUR CHILD TURNS 18

Upon turning the age of eighteen (18), every person, regardless of disability or IQ, is considered an adult and competent to make all personal and financial decisions.

Parents, including those with children who have special needs, no longer have the legal guardianship of their children after they turn eighteen (18) years old. Establishing guardianship is a legal process that must be decided in the Probate Court. There are several different types of guardianship that can be obtained. Some parents of children who attend the center eventually choose to pursue some form of guardianship but it is an individual decision and may or may not be right for your child. As a parent, you must look at your child's level of competency and decide in which areas, if any, she or he might need a substitute to give consent.

All adult persons are considered competent to exercise judgment in financial, medical, legal and personal decisions such as making contracts unless otherwise determined. Establishing guardianship essentially states that the person is unable to manage his or her own affairs. It limits the legal rights of the "ward" because the court determines that he or she is unable to act on or decide matters concerning his or her property or person. The guardian assumes responsibility for these decisions.

There are different forms of guardianship that an individual can seek in Rhode Island. A "*guardian of the person*" is responsible for the personal health and safety of the ward. A "*guardian of the estate*" is responsible for managing the ward's financial assets. A "*full guardianship*" would make the responsible individual a "*guardian of the person and estate*".

Individuals are also entitled to seek a form of "*limited guardianship*". Under this type of guardianship, a court can limit the scope of the guardian's powers and duties so that the ward is assisted only in those areas that he or she truly lacks in ability to make judgments. For example, the court may permit a guardian to make decisions regarding surgical procedures and allow the ward to obtain routine medical care. The ward is considered to have partial competency and able to maintain his or her own legal rights in selected areas.

Responsibilities of a guardian differ depending on the type of guardianship sought. In a limited guardianship, the duties and responsibilities of the guardian are clearly specified by the court. A guardian, who is responsible only for an individual person, must provide for her or his health, welfare and education, if appropriate. You would not have to file an annual accounting of your activities with the Probate Court.

An individual, who is guardian of a child's estate or is a full guardian, will be charged with managing the estate "frugally and without waste". Within thirty (30) days of being appointed your child's guardian, you must file a complete inventory and appraisal of the real and personal property of his/her estate. Any debts that your child owes would be paid at this time. You will be required to make an annual accounting as required by law, under oath, detailing the management and disposition of the estate.

To start the guardianship process, contact the Probate Court of the city or town where your child resides. If unsure where the court is, contact the city or town hall. The probate clerk should have the necessary forms to start the guardianship procedure. Fees vary, but there will be a nominal fee to file the petition, which may be waived according to income. Notice of the filed petition must be given to the ward and to the general public by notification in the newspaper.

After the proper notice has been given, a hearing date will be set. The burden of proof is on the person seeking guardianship to prove the child is not competent to make his/her own decisions. Oral or written testimony by a physician should be submitted, including child's history, physical examination by doctor, diagnosis, how diagnosis was arrived at, and the physician's opinion as to whether the disability would interfere with the ward's ability to manage his/her estate or provide for his/her personal health and safety.

Nothing in the law requires you to be represented by an attorney. As a parent of a developmentally disabled child, you may want to seek the assistance of an attorney in the event that difficulties arise in obtaining guardianship of your child.

This information is only to help give you direction in the complex issue of guardianship and should not be considered complete. Additional written materials to help you decide if your child needs guardianship can be obtained through the Groden Center Family Services Library, or by contacting the Groden Center Transition Coordinator, or Rhode Island Legal Services.

**ADULT SERVICES**  
**WHEN YOUR CHILD TURNS 21**

When your child turns twenty-one (21), your local school system is no longer responsible for the funding of education or any other resources. The following is a list of various human service organizations that you may need to utilize when your child turns twenty-one (21) years old.

**Social Security Administration**

Provides income for individuals and their families as partial replacement of earnings lost due to age, disability or death. Administers SSI programs for persons over sixty-five (65) and blind or disabled individuals under sixty-five (65).

Address: Pawtucket District Office  
55 Broad Street  
Pawtucket, RI 02860  
(401) 724-9611  
(401) 772-1213

**Rhode Island Department of Human Services  
Economic and Social Services**

Provides financial, medical and social services to families and individuals whose income is inadequate to meet basic living needs. Includes Aid to Families with Dependent Children, General Public Assistance, Medical Assistance, Food Stamps, medical and social services to SSI recipients and Title XIX Waiver for eligible children with disabilities.

Address: 600 New London Avenue  
Cranston, RI 02920  
(401) 462-3361

**State Services for the Blind and Visually Impaired**

Services to visually impaired residents of the State including vocational rehabilitation, social services, talking books and Independent Living Program.

Address: 275 Westminster Street  
Providence, RI 02903  
(401) 222-2382

**Office of Rehabilitative Services**

Counseling, evaluation, medical treatment, training and educational assistance towards a vocational goal for disabled individuals.

Address: 40 Fountain Street  
Providence, RI 02903  
(401) 421-7005

## **Rhode Island Department of Employment Security**

Job service employment for the general public including testing, screening and placement referral, special assistance for veterans, youth, older workers and handicapped. Contains a job bank of available positions.

Programs and Apprenticeship Information: (401) 222-3564

## **Vocational Resources Inc.**

Provides vocational/educational/social programming for special needs students sixteen (16) years of age or older. Also provides vocational evaluations. Social activity groups, speech and language therapy is provided.

Address: 100 Houghton Street  
Providence, RI 02904  
(401) 861-2080

## **Training Thru Placement**

A continuum of rehabilitative programs for handicapped adults over age eighteen (18). Includes job placement, a sheltered workshop and continued socialization (leisure time).

Address: 20 Marblehead Avenue  
North Providence, RI 02911  
(401) 353-0220

## **Rhode Island Department of Mental Health, Retardation and Hospitals Services (MHRH/DDD)**

Address: Howard Avenue  
Building 54  
Simpson Hall  
Cranston, RI 02920  
(401) 464-3421

\*ICF/MR funded group homes and apartments, supervised on a twenty-four (24) hour basis and offer a variety of developmental and rehabilitation services at home and in day treatment programs.

\*Supervised apartment programs offering support services in a more limited basis to higher functioning clients who are able to live more independently in their own apartments.

\*Family Living Arrangement in which families share their home and provides opportunities for growth and development within a family atmosphere.

\*In Home Support Services for qualified individuals who would require ICF/MR level of care and who are at risk of needing placement. Services can include:

\*Adult Rehabilitation Programs, Case Management, Devices to adapt the home environment, Homemaker Services, Personal assistance devices, respite and transportation

### **Special Olympics of RI**

Conducts, promotes and sponsors athletic activities, exercise and fitness programs for special needs individuals age eight (8) and over.

Address: 33 College Hill Road  
Building 31  
Warwick, RI 02886  
(401) 823-7411

### **Very Special Arts of Rhode Island**

Introduces disabled people to a broad spectrum of art experiences. Provides grants for projects that bring Rhode Island artists together with disabled children and adults. Sponsors art festivals, which give disabled individuals a chance to experience various art forms and exhibit their work.

Address: 500 Prospect Street  
Pawtucket, RI 02860  
(401) 725-0247

### **Rhode Island Association ARC**

Promotes knowledge and general understanding of the special needs populations and advocates for the needs of people with mental retardation and other disabilities. Services include educational programs, vocational evaluation and training, leisure and family activities.

Address: 99 Bald Hill Road  
Cranston, RI 02920  
(401) 463-9191