Supportive Decision-Making: An Alternative to Guardianship

Individuals with disabilities have access to the full array of rights that all other members of society enjoy. They have the right to self-determination.

Supported decision-making is a way to promote and encourage self-determination in the legal decision-making context. By working with individuals with disabilities to determine what additional information and support they might need, families and loved ones can help them achieve a greater measure of self-determination in their lives.

What Exactly is Supported Decision-Making?

Supported decision-making is a formal term for something that comes naturally to many of us – when you were 18, did you talk over major life decisions with your parents and other trusted adults before you made them? This is an example of informal supported decision-making.

Supported decision-making can be used in any context where a person with a disability may need to make a legally significant decision; for example, about health care, income or benefits, or banking. In the education context, supported decision-making arises after a student turns 18, which is when they reach the age of majority and their educational rights transfer to them. (The Individuals with Disabilities Education Act (IDEA) requires that schools prepare students for this eventuality, for information about how this works in the District of Columbia, see http://osse.dc.gov/page/transfer-rights.)

Supported decision-making is a way for families to help children learn to make good decisions and learn to ask for help from others when needed. However, like any other skill, it takes practice and young people must practice that skill to get better at it.

My child is about to turn 18 – what do I do?

After your child turns 18, ask him or her to sign a release of information form, so you can still get information and records from the school. Next, help your child send a letter to the school that says he/she wants you to be invited to all Individualized Education Programs (IEP) meetings. Help your child get ready for meetings ahead of time by sharing all the advocacy skills you have learned as a parent; review the IEP and any other documents that might be discussed at the meeting. You and your child can write down questions to ask at the meeting. At the meeting it is important that your child feel comfortable talking and expressing their point of view. AJE offers trainings just for youth on leading and participating in their IEP meetings.

Besides a release of information form, you and your child might want to talk about an educational power of attorney. An educational power of attorney is a simple document and many legal service agencies can help you and your child draft an one. Your adult child can allow you to make his/her educational decisions, or allow you to share that decision-making power with them. Another advantage of the power of attorney is that it is revocable; it allows your child to change his or her mind and cancel the power of attorney at any time without going to court. To sign a power of attorney, your child is not required to first know about all of their rights under the IDEA. What is important is that your child knows that a power of attorney gives you (or whomever they select) the right to make or help make some of his/her decisions.

What about Guardianship?

Guardianship is a much more involved and complicated process and requires going to court. This limits the person’s right to self-determination, and their decision making ability has been taken away by a judge and given to someone else. This is a very serious decision. A guardian for an incapacitated person still must include the person in the decision making process, and has many other responsibilities, including submitting a report to the court twice year, and coming to court for hearings, if the judge orders it.

Good Decision-making is a Learned Skilled

Just like learning to ride a bicycle, it is ok if your student’s decision-making is a little “wobbly” at first. Eventually both you and your child will become more comfortable, just like when they learned how to ride their first bike.
The Family’s Role in the Early Intervention Process

Families play a key role in the early intervention process. Families are valued members of the team throughout the entire early intervention process from the initial contact with the family service coordinator—to the development of the Individualized Family Service Plan (IFSP).

Initial Contact/First Visit, and Initial Family Assessment

Families share their concerns related to their child’s development, provide the multi-disciplinary team with information regarding their current family routines and schedule, and identify what interventions are working well at home.

Evaluation and Assessment Process

Families participate with their child during the evaluation and assessment process; communicating whether their child’s functioning during the evaluation and assessment process is typical.

IFSP Development

Families are active participants in the IFSP meeting. They add information regarding their child’s skills to supplement the information gained through the evaluation and assessment. They also identify their priorities for their child’s goals, as well as collaborate with the other team members on strategies for strengthening skill development.

Throughout the early intervention process parents assist with:

- Deciding what early intervention services their child and family needs assistance with;
- The outcomes of early interventions that are important for their child and family; and
- When, where and how their child will receive the early intervention services.

Families know their child best and they understand their child’s needs, including knowing what is beneficial for their child. During the early intervention process families have the most information about their child’s growth and development and their input is essential in ensuring their child is provided with the early interventions that will best meet their needs.

Tips for Parents to Prepare Youth for Transition from School to Adulthood

Successful and meaningful transition services result from careful planning. Planning is driven by a young person’s dreams, desires, and abilities. Transition planning helps them to develop the skills they need to succeed in their post-secondary career. As you and your child plan for the future, consider these tips for a successful transition.

- **Develop self-determination and self-advocacy skills.**
  All young people need a strong sense of their strengths, abilities, interests, and values. If students have a disability, they should also know how it might affect them at work, in the community, and in their educational pursuits. Youth should also be able to explain how their disability impact’s them to others.

- **Expand social and community support networks.**
  As children with disabilities become adults, they may need support from a variety of sources. You should start developing social and community support networks for your youth.

- **Build a resume.**
  Many young people struggle to find work experiences that help them be competitive in the job market. By participating in a variety of community activities, young adults can develop employment and social skills while building a resume, increasing their network of potential employers.

- **Learn “soft” employment skills.**
  In addition to the work skills people need for their jobs, they also need “soft skills.” Soft skills include things such as: being able to accept direction, returning from breaks on time, dealing with conflict, having the confidence to decide and engage in appropriate personal communication.

- **Practice “money management” skills.**
  Children must learn how to save, spend, donate, and budget their money. Parents can begin by opening a savings account and taking their child to the bank regularly to deposit part of his or her allowance or earnings, so he/she becomes familiar with financial institutions.

- **Connect with adult service providers.**
  Upon graduation from high school, special education services end. This means that the Individualized Education Program (IEP) team will no longer coordinate disability-related services that your child may need. Adult services will be provided by different agencies, each with its own application process and eligibility standards.

- **Plan for health care needs.**
  Young adults with disabilities must manage their own health care, prescription drug use, and insurance concerns. Parents can help youth take on more responsibility as they get older by encouraging them to make their own medical appointments, speak directly with their doctor, and take their prescription drugs as directed.

- **Visit postsecondary training and education programs.**
  Visiting a college or training program can help your child visualize the future.

- **Prepare for change.**
  Helping your child plan for the future can lead to success, as long as you are flexible. Plans will change no matter how carefully they are developed.

*Adapted from the Pacer Center, Inc.*
Supporting Youth with Mental Health Needs

Supporting youth with mental health needs can be a complex process. Youth with mental health concerns need assistance accessing services within the school, work, and the community.

School-Based Support
Because of the episodic nature of mental health, youth with mental health needs require educational environments that are flexible, stable and provide opportunities to learn and grow. These youth may need additional educational supports and services such as:

- Comprehensive transition plans (including school-based behavior intervention plans) linked across systems, without stigmatizing language, that identify goals, objectives, strategies, supports, and outcomes that address individual mental health needs in education;
- Appropriate, culturally sensitive, behavioral and medical health interventions and supports;
- Academically challenging educational programs that engage youth in learning;
- Opportunities to develop self-awareness of behavioral triggers and reasonable accommodations in educational settings; and coordinated support to address social-emotional transition needs from a highly qualified, multi-disciplinary support team, which includes health, mental health, child welfare, case managers, and supports from family, friends, and others helping to support the young person.

Career Preparation & Work-Based Learning Experiences
Because some youth with mental health needs may feel their employment choices are limited, they need connections to a full range of youth employment programs and services such as:

- Opportunities to gain and practice their soft skills in workplace settings;
- Positive behavioral supports in work settings;
- Connections to successful peer role models with mental health needs;
- Knowledge of effective methods of stress management to cope with the pressures of the workplace;
- Knowledge of and access to a full range of workplace supports and accommodations such as supported employment, customized employment, and job coaches; and connections to programs and services (e.g., One-Stop Career Centers, Vocational Rehabilitation, Community Rehabilitation Programs) for career exploration provided in a non-stigmatizing environment.

Youth Development & Leadership
Some youth with mental health needs may be susceptible to peer pressure, experiment with antisocial behaviors or illegal substances as a manifestation of their disability and/or expression of independence. To facilitate positive youth development and leadership, these youth need:

- Meaningful opportunities to develop, monitor, and self-direct their own treatment, recovery plans, and services;
- Opportunities to learn healthy behaviors regarding substance use and avoidance, suicide prevention and safe sexual practices;
- Exposure to positive youth development such as nutrition, exercise, and recreation;
- An understanding of how disability disclosure can be used in a positive way;
- An understanding of mental health treatment options including medication management, outpatient and community-based services and supports;
- Continuous access to and an understanding of the requirements and procedures involved in obtaining mental health services;
- Strategies for addressing the negative stigma and discrimination associated with mental health needs; and
- Opportunities to give back and improve the lives of others through community service.

Connecting Activities
Some youth with mental health needs may require additional access to information, programs, services, and activities that are critical to a successful transition. These youth may need:

- An understanding of how to create and maintain informal personal support networks;
- Access to safe, affordable, permanent housing;
- Access to flexible financial aid options for postsecondary education;
- Policies and service practices that provide a safety net for fluctuations in a youth’s mental health status;
- Case managers who connect and collaborate across systems; and
- Service providers who are well-trained, empathetic, and take a holistic approach to service delivery.

Family Involvement & Supports
Youth with mental health needs also need parents, families, and/or other caring adults who:

- Understand the episodic nature of mental illness;
- Offer emotional support;
- Know how to recognize and address key warning signs of suicide, the co-occurring relationship between substance abuse and mental health, and other risky behaviors;
- Monitor youth behavior and anticipate crises;
- Understand how individualized plans across systems can support the achievement of educational and employment goals;
- Access supports and professionals to help navigate systems of care;
- Access supports and resources for youth with mental health needs, including emergency contacts; and
- Extend supported decision-making past the age of majority, if appropriate.

Adapted from http://www.ncwd-youth.info/guideposts/mental-health.
Camp Funward Bound
Camp Funward Bound is the camping experience for adults, ages 21 years and over, with special needs. Participants will enjoy a variety of activities that include shopping, fishing, arts and crafts, swimming, hiking, tennis and more!

Location(s):
- Theodore Hagans Cultural Center

Discovery Inclusion (formerly known as Let’s Play Together)
Discovery Inclusion is a camping opportunity for youth with disabilities, ages 6–10 years old. With the assistance of an Inclusion Camp Counselor, youth with disabilities can enroll in an inclusive camping or sport experience with youth without disabilities. All children will experience a variety of fun-filled activities including sports, aquatics, trips, arts and crafts and much more.

Location(s):
- Lamont Recreation Center
- Sherwood Recreation Center
- Turkey Thicket Recreation Center

Let's Play Together: Little Explorers
Let’s Play Together Inclusion Camp is a camping opportunity for youth with disabilities, ages 3–5 years old. With the assistance of an Inclusion Camp Counselor, youth with disabilities can enroll in an inclusive camping or sport experience with youth without disabilities. All children will experience a variety of fun-filled activities including sports, aquatics, trips, arts and crafts and much more.

Location(s):
- Rosedale Recreation Center
- Therapeutic Recreation Center

Therapeutic Recreation (TR)
Camps are offered to both District and Non-District residents with or without disabilities. Campers must complete an assessment at the TR Center (3030 G Street, SE) before registering for a TR camp. If you require further assistance or have any questions, please call the TR Center directly at (202) 698-1794.

An assessment by staff must be completed prior to registration. During the assessment, a recreation therapist will determine the skill level of the participant and assist in selecting the best camping program to meet the applicant’s needs.

Session Dates
- Session 1: June 20 – July 1, 2016
- Session 2: July 5 – July 15, 2016
- Session 3: July 18 – July 29, 2016
- Session 4: August 1 – August 12, 2016

Camp Adventure
Camp Adventure is an inclusion-based camp program designed for youth ages 6–16 years old. The program offers a variety of experiences that include swimming, ice skating, arts and crafts, group activities, environmental activities, water tubing, trips to theme parks and much more.

Location(s):