

FAMILY SUPPORT AND SELF-DETERMINATION Connections to a Life in the Community



Massachusetts Alliance for 21st Century Disability Policy (MA21)

The mission of the Massachusetts Alliance for 21st Century Disability Policy is to advance full community participation for individuals with disabilities.

FAMILY SUPPORT AND SELF-DETERMINATION

Connections to a Life in the Community

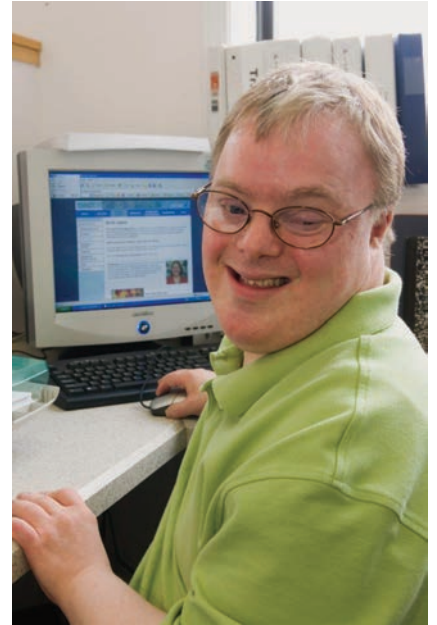
When individuals cross the bridge into parenthood their identity changes to "a family." If the child born has a disability, the parent may feel that he or she is on a different bridge than other parents. It's important to help parents understand early on that they are crossing the same bridge as everyone else. The right support can lead to full, meaningful lives and avoid a destination of isolation or dissatisfaction.

Viewed in this context, family support services are a package of essential tools families use to assist their children with disabilities to become as independent as possible⁽ⁱ⁾. Family support practices can help each child (and family) reach their valued goals. By becoming strong advocates, teachers and leaders, parents can affect positive change among school teachers, extended family members, neighbors and community members. The most important impact parents can have is upon their children: ensuring children, including those with disabilities, develop a strong sense of confidence, their highest abilities and self-determination.

Self-Determination

"Self-determination" is the freedom to make one's own choices. It is a right of every individual, regardless of ability. Self-determination begins in our childhood years. We all want to make choices in our daily lives, whether choosing friends, our work or other activities. A disability does not eliminate the right to or the need for self-determination. This must be understood and accepted by our communities, but it starts first with parents and from there outward to extended family, neighbors, school, the community and society at large.

Why is "self-determination" and maximizing one's ability to self-direct so important? Research has shown that young people with disabilities develop new skills regardless of the impairments which limit functioning. For example, "choice making" can be taught to children and adults with moderate and severe disabilities. Further, children with learning disabilities, mild intellectual impairments and other disabilities benefit from being taught self-advocacy⁽ⁱⁱ⁾. "Self-determination" can be advanced for all with disabilities including those with significant intellectual impairments⁽ⁱⁱⁱ⁾.



Meet Bengt Nirje

As early as 1972, Bengt Nirje made the call to self-determination for all. One of the early thinkers of the "normalization" movement,^(iv) Nirje realized that acting from the perspective of the individual with the disability was essential in assisting all with disabilities to enter the mainstream of community life.^(v) More than forty years later, we have failed to ensure that this principle is realized throughout the world of supports.

Best Practice: Individualized Family Support

How can Family Support contribute to creating a real and meaningful life for an individual with a disability? The way that family support services are provided can increase the family's capacity to create a nurturing environment for their child to exercise choice making and self-determination.

1. Family Support should be available immediately after a diagnosis of disability is made, ongoing as needed and during transition periods.
2. Supports need to be readily accessible: families should not have to spend valuable time looking for family support.
3. Early matches with mentors are key; mentors can provide emotional support, a context to view this new experience (often unexpected), and glimpse into the future when relevant.
4. Parents can be coached in how to readily address questions or unexpected reactions or behavior from extended family or neighbors.
5. Staff training should be such that they can:
 - recognize differences in parental awareness, acceptance and understanding
 - have knowledge of cultural differences, and addressing language barriers

Reaching parents early is good practice not only because supports can be provided during key developmental years. It also:

- Allows for the development of habits in leadership and advocacy that will be needed throughout a family member's life
 - Looking for resources and information when needed
 - Asking tough questions when needed
 - Becoming teachers or obtaining the help of others
- Strengthens confidence and self-esteem
- Increases the probability that extended family and neighbors will show respect toward family members with disabilities and include them in family events or community activities.



In addition, protocols or processes are necessary to assure that medical providers and other professionals know how to facilitate follow-up for families. Meanwhile, families need to learn the skills to navigate the systems of care that interface with their child.

Meet Jolene, George and Aaron

Jolene and George's first baby was an infant with Down syndrome. While unexpected, Jolene readily accepted her infant. Due to her experiences she was very knowledgeable about disabilities and helped her husband adapt to their new reality. They joined a local group, talked to family and received literature from family members that they took advantage of. Within the first year of her son Aaron's birth, Jolene advocated with his early intervention program manager about therapies that her son was not receiving (e.g., swallowing and other functions.) Through reading and consultation, she knew that there were some essential tasks that Aaron could master through early intervention which would increase his independence over time and healthy development.

Meet Michael, Neva and Maxine

Michael and Neva had a bumpier ride early on. Their daughter, Maxine, was born with an unclear developmental delay. At age 18 months they noticed communication delays and less responsiveness to their interaction. The pediatrician did not refer them to any specialists, despite repeated visits, until Maxine was 22 months old. A specialist immediately referred them to an early intervention program. The director assigned a staff person almost immediately, explaining that there would be a delay in obtaining therapies but they would work to get services started. Neva reached out to some groups and finally found a developmental disabilities support group where a parent encouraged her to appeal the delay. She didn't even realize that was possible. She and Michael checked with others and began to advocate, realizing key months were passing.

Best Practice: Family Support Plan as a Roadmap

1. Formal assessments are critical to set the foundation for supports and the development of self-determination. In Massachusetts, Early Intervention programs develop individual plans for families as well as the infants and toddlers they serve. This approach abruptly ends at age three as toddlers graduate to "pre-school" or public school. It should continue at each stage: preschool, grade school, teen years and transition to adulthood.
2. A family support plan that addresses basic needs and sets objectives for a child, teen or adult's development lays the foundation for higher level goals of building self-esteem and achieving self-determination. It facilitates more positive long term outcomes for all family members.



3. At a minimum, a Family Support plan should include:

- Person-centered planning to address the child’s developmental, social and self-determination objectives
 - Parent/Family need for training: parenting gaps & goals, understanding “the system”
- Guidance to address perceived or real barriers faced by parents:
 - lack of information on disability
 - financial barriers
 - loneliness or isolation
 - emotional concerns
- Advocacy and Leadership



Other Aspects of Family Support Plans

- Plans change as circumstances change
 - Plans are individualized to implement a vision of the person in the context of his or her community.
 - The supports, services and activities that the individual is involved in will evolve as he/she ages.
 - All supports and services will stem directly from the needs, desires, and visions of primarily the individual and secondarily the family. Individualized family support tailors services and supports to the individual and the family.
 - Program staff should consider how to integrate individuals into the community on an ongoing basis rather than relying on self-contained programs that may only occupy the person’s time
 - Flexible funding is available to implement the plan
4. Advocacy and Leadership skills are integral components of the plan, often addressed through advice or one-time training sessions. But as noted above, training parents early can result in large gains for the child with a disability including his/her ability to exercise self-determination. Some examples of best practices here include:

- Parents learn about and demonstrate obtaining the community services they want
- Parents are able to approach their child’s school, youth groups in a church, temple or other community groups to address accommodations and other concerns
- Parents educate and obtain supports to help siblings’ growing awareness, acceptance and advocacy
- Parents and the family help others on the road to acceptance and awareness
- Parents join groups to raise awareness and further opportunities for all

Systemic Challenges

On a system-wide level, disability and education policies need to consider how to merge the individual lives into their communities. Rather than conceptualizing programs that exist in a self-contained vacuum and are aimed at occupying an individual's time, program decision-makers should be constantly considering how to integrate individuals into their communities. A “Program” can make services cost-efficient through group strategies. But when the objective becomes filling space in a program versus fitting the program to the individual, we lose sight of our original goal.

An ongoing and formidable challenge is the lack of funding to provide appropriate family support services to those in need. Family support is an effective way to substantially reduce expenditures of taxpayer money by avoiding costly residential care for the family member with disabilities. Yet families often face limitations in therapies or financial barriers for implementing plans for support (if plans are developed in the first place). Parents cannot develop advocacy or leadership skills if they face daily barriers in family economic self-sufficiency, caregiving or their child's education.

Another systemic obstacle is respecting those with disabilities enough (regardless of the severity of impairment) to recognize they are worthy of being treated as individuals. Obtaining adequate funding is and will always be a challenge. However with the level of funding available, it is important to prioritize that a set portion should be allocated toward addressing individualized solutions rather than general programs.

Meet Janet and Ben

Janet is 24 years old and works in a day program setting. Her father, Ben, reached out to an agency because she doesn't have enough activities after work. She also misses connecting with friends she used to know when in high school. Ben works two jobs and her mother cleans houses to make ends meet, so they hope that something can be arranged. The Family Support coordinator shared a brochure of activities. There were two that Janet chose, an evening social night that runs for eight weeks and an 18-week Saturday morning exercise and outing program. Ben asked if some of the fees could be waived. After two weeks he learned that the fee for the Saturday program could be cut in half. Janet is enjoying these new activities.

Meet John and Alice

John is 28 years old. He and his mother, Alice, reached out to the family support provider to help him find social recreational activities. In the discussion, Alice noted that there were community activities that John enjoyed and asked for assistance in both guidance and connecting them, including possibly helping with transportation or funding. The Family Support staff person handed John and Alice the agency's brochure of a series of activities. She noted that they didn't have the resources to help with John's specific goals. When the family inquired further, there were no referrals or other resources to share with them. John tried a recreation outing but didn't enjoy it. They have not accessed anything else. Alice is trying to develop their own option for John but it's hard to do it on their own. But she's not giving up. She and John will advocate to build new pathways for support.

Today and Tomorrow

The value of family support coupled with self-determination needs to be acknowledged by policymakers, provider staff, educators and other stakeholders:

1. Self-Determination is a reality, whether or not it's recognized: individuals and families make choices every day.
2. Starting from an early age, everyone should be given the opportunity to make choices.
3. Community connections are valuable in and of themselves. They also serve as learning opportunities for choice-making, e.g., identifying individual strengths or possibilities for long term participation in community/ neighborhoods/ schools/ other environments.
4. The loneliness that many with disabilities experience in large part reflects "isolation from community."
5. Students who have been taught self-determination experience better outcomes in employment and independence.
6. Family support programs and staff can advance best practices for individualized support.
7. Funding is critical and should be allocated to actualize best practice recommendations.

Our system of supports can and should help families in their journeys. Parents, and perhaps other family members, need to be leaders to ensure the best possible impact upon their family. They need the tools and support to appreciate that their child, regardless of disability, can attain valued goals.

- This is a publication of the Massachusetts Alliance for Twenty-First Century Disability Policy (MA21) which includes The Arc of Massachusetts, Massachusetts Families Organizing for Change, Massachusetts Developmental Disabilities Council, Massachusetts Advocates Standing Strong, Advocates for Autism of Massachusetts, Disability Law Center, Massachusetts Down Syndrome Congress, The Federation for Children with Special Needs, The Massachusetts Sibling Support Network. For more information email arcmass@arcmass.org or 781-891-6270.

This product and related activities funded through the Massachusetts Developmental Disabilities Council, U.S. Department of Health and Human Services, Administration on Intellectual and Developmental Disabilities, Federal Award No. 93.630.

Edited by Leo Sarkissian, Dianne Huggon, Evelyn Haussein, Susan Nadworny and O. Sophie Johansson with guidance and input from the Steering Committee at MA21 Alliance.

Footnotes

ⁱ Family Support is defined as a comprehensive and coordinated set of strategies that are designed to ensure that families who are assisting family members with intellectual disabilities/developmental disabilities (ID/DD) have access to person-centered and family-centered resources, supports, services, and other assistance. These strategies are directed to the family unit, but ultimately benefit the individual with ID/DD. -- Building a National Agenda for Supporting Families with an Individual with Developmental or Intellectual Disabilities. Located online at <http://familysupportagenda.org/FSNA/familysupport/whatis.aspx>

ⁱⁱ Abstract of “Effects of Interventions to Promote Self-Determination for Individuals with Disabilities”, Algozzine, B., Browder, D., Karvonen, M., Test, D.W., & Wood, W.M., Review of Educational Research, 2001, 71(2), 219-277. Located online at <http://nichcy.org/research/summaries/abstract38>

ⁱⁱⁱ “Self-Determination for Individuals With Significant Cognitive Disabilities and Their Families,” Ann Turnbull and Rud Turnbull, JASH, 2001, Vol. 26, No. 1, 56-62, (The Association for Persons with Severe Handicaps.) Located online at www.fcsn.org/pti/topics/transition/tools/self_determination_cognitive_disabilities.pdf.

^{iv} Michael Wehmeyer’s article “Self-Determination and Individuals With Significant Disabilities: Examining Meanings and Misinterpretations” notes Nirje’s call and also identifies misinterpretations in what Self-determination is. Published first in JASH, now RPSD (Research and Practice for Persons with Severe Disabilities) 1998, Vol. 23, No. 1, 5-16. Located online at http://kuscholarworks.ku.edu/dspace/bitstream/1808/6229/1/SD4A_Self-Determination%20and%20Individuals.pdf

^v The normalization principle means making available to all people with disabilities patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society. Bengt Nirje, The Basis and Logic of the Normalization Principle, Sixth International Congress of IASSMD, Toronto, 1982. Located online at www.psawa.com