

NATIONAL GATEWAY

TO SELF-DETERMINATION



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Research to Practice in
Self-Determination

Issue 4:
Family Focus on
Self-Determination

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Research to Practice in Self-Determination Series

Introduction

People who are self-determined make things happen in their own lives. They know what they want and how to get it. They choose and set goals, then work to reach them. They advocate on their own behalf, and are involved in solving problems and making decisions about their lives.

The purpose of this series, Research to Practice in Self-Determination, is to describe key issues in the field of developmental disabilities that can be enhanced by considering efforts to promote self-determination. Each issue is prepared with a social-ecological framework in mind. This framework calls for strategies for intervention and support to take into account both the capacities of the person and the demands of the environment. Interventions to promote self-determination should focus on enhancing personal capacity, improving opportunity, and modifying the environment. A series of seven issues will be produced, each focusing on a specific topic: self-advocacy, health, employment, community services, aging,

family support, and siblings. The format for these issues will include definitions, a brief review of the literature, promising practices, applied examples, and targeted recommendations for scaling-up efforts. This series is intended for use by people with developmental disabilities, family members, professionals, state and federal agencies, and academic programs. By collaborating with and enabling each of these entities, the goal of full inclusion for people with developmental disabilities can be realized.



Vera and her adopted daughter, MyaGrace, share family time with Mya's three brothers and dad, Marco.

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 A National Gateway
to Self-Determination

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Focusing on the Role of Families to Support Self-Determination

Susan Palmer and Sheli Reynolds

Families are the core unit in our society, serving as a source of support for each member. For individuals with disabilities, the role of family is unique and often central in the support and care provided across the lifespan. Family members play key roles in identifying and securing opportunities for one another to meaningfully participate

Families naturally support self-determined practices.

in their community, beginning at a very young age and often continuing into adulthood. Families also play a significant supporting role as people within their family unit progress in their journey toward self-determination.

The National Gateway to Self-Determination project, funded by Grant No. 90-DD-0659 from the Administration on Intellectual and Developmental Disabilities, is amassing resources and providing information regarding self-determination for individuals with intellectual and developmental disabilities. The aim of this Research to Practice on Self-Determination—Focus on Families issue is to provide insight into what parents and siblings can do to support self-determination for individuals with disabilities.

Understanding Families

For most families, the members serve as the foundation for the development of culture, experiences, resources, emotional closeness, unconditional love,

membership, and, most importantly, a lifetime commitment (Turnbull, Turnbull, Erwin, Soodak, & Shogen, 2011). For individuals with disabilities, the additional types of support that are sometimes needed to live successfully in the community require families to assume and maintain unique and sometimes crucial roles that begin in childhood and last throughout the lifespan. This is especially true now as individuals with disabilities are growing up as peers, neighbors, and colleagues in their communities and family homes.

Parents often lead in fulfilling these roles; however, the significant role of other family members throughout the lifespan has become more recognized. Turnbull et al. (2011) highlights the role of families in supporting eight major life areas: affection, self-esteem, daily care, spiritual, economic, socialization, recreation, and education. Additionally, in families with members with disabilities, other members often manage and advocate formal supports and services by serving

as the gatekeeper, negotiator, monitor of quality, and sometimes the complainant (Bigby & Fyffe, 2012). Bigby, Webbers, and Bowers (2012) found that adult siblings influence formal care, support inclusion, occupy formal next-of-kin roles, and assist with plans for the future.

Families, once limited by definition to the parents or those blood-related living in a household, are now defined as a group of people with common ancestry, purpose or conviction that considers themselves to be related and is committed to adapting and accommodating to the experiences and changes of individual members throughout their lives (Hecht & Reynolds, 2012). The definition, as it relates to disability, is inclusive of parents with and without disabilities themselves, siblings, aunts and uncles, grandparents, step-parents, nieces and nephews, and others considered to be family, such as a neighbor or friend. This definition includes members living in the same home or within the community; people can be close to their own family members or less connected, depending on



Families pose for a photo at a parent support group meeting at the Mattie Rhodes Center in Kansas City, MO.



a wide range factors. But no matter what the situation is, the influence of the context of family for self-determination is critical.

Focusing on Families

Our understanding and response to the needs of families with members with disabilities has evolved over the last century. Families, once believed to be the cause of their child's disability, evolved into the role of administering informal therapy and interventions developed by professionals to their children at home. Now, in both policy and practice, the family unit is recognized as a system of strengths that can accommodate and adapt to life situations across the lifespan, forming partnerships with professionals and directing services and supports.

According to the recent *Building a National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities* report, the goal of family supports within the context

A person with a disability exists within the context of the family environment and families influence outcomes for self-determination.

of the disability service system is to maximize families' capacity, strengths, and unique abilities so they can best support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members (Hetch & Reynolds, 2012). Families play a crucial role in creating opportunities, environments, and expectations in supporting their family members with disabilities to have

the lives with the outcomes and the quality of life that they want to achieve.

Self-Determination and the Role of Family

The role of the family across the lifespan is especially important given the significant shift in the focus of formal supports for people with intellectual and developmental disabilities (I/DD). In the past decade the number of people with I/DD receiving support while living with family members has grown 3.3 times more rapidly than the number of persons receiving non-family based support. Between 2000 and 2009 the percentage of people living with a family member while receiving waiver funded services through Medicaid Home and Community Based Services for people with disabilities grew by 217%, from 74,939 to 237,920 (Lakin, Larson, Salmi, & Webster, 2010). In fact, of the 1.3 million people with intellectual and/or developmental disabilities receiving publicly funded support services in 2009, 599,152 (58%) lived with a family member (Lakin, et al., 2010).

Although the importance of families supporting self-determination for their members is often emphasized, few articles in the professional literature exclusively address family perspectives regarding self-determination. To begin filling this gap, the National Gateway to Self-Determination has focused on the role of families in fostering and supporting the self-determination of their family members with disabilities. Using the social-ecological theory of self-determination, conceptualized by Abery and Stancliffe (2003), the National Gateway project recognizes the importance of person-environment fit for the promotion of self-determination. This Family Focus on Self-Determination issue recognizes that a person with a disability exists within the context of the family environment and that families influence outcomes for self-determination. The issue also recognizes that self-determination emerges within the culture of the family, while understanding that the larger culture and surroundings in which people live also have impacts. In addition, when environments are supportive, individuals build social capital within their communities over time, thus making individuals with

disabilities welcome participants in various settings. Families play a large role in supporting an individual with disabilities as they gain social capital in their community and beyond.

The National Gateway to Self-Determination project also draws on the theoretical framework developed by Michael Wehmeyer that defines self-determination as the volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life (Wehmeyer, et al., 2007). A person's self-determination varies on any given day and time according to the environment (persons, places, things) and specific within-person abilities. When behavior is self-determined the person is: a) acting autonomously with a minimum of support; b) acting in a self-regulated manner, with personal control over one's actions; c) initiating and responding to events in a psychologically empowered way; and d) acting in a self-realizing manner, understanding the effects of one's actions on others and the environment in which one lives.

Self-determination and independence are related principles, but an individual does not need to be considered wholly independent of family culture and values in order to be self-determined. Within some cultures and in many families, it is important to embrace a collective perspective, with everyone in the family working to meet family needs rather than independent objectives. An individual can still be self-determined within family guidelines, making choices and decisions that benefit and enhance collective family outcomes while continuing to make choices that advance his or her individual goals.

It is not new or innovative to consider families when focusing on self-determination for individuals with disabilities. In many cases, families naturally support self-determined practices. But sometimes, when a person with a disability presents more than the usual challenges, additional planning and support are needed to encourage a self-determined life. This Family Focus on Self-Determination publication shares the experiences of siblings, parents, grandparents, and other family members who serve in supporting roles for individuals with disabilities across the



country. Their voices illuminate a variety of ideas and effective practices regarding the role families play in supporting self-determination for individuals with intellectual and developmental disabilities.

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Building a Foundation for Self-Determination in the Early Years of Life

Susan Palmer and Jean Ann Summers

Structuring a child’s immediate environment in early life can support self-determination in later years. Young children cannot be fully self-determined as they need guidance and support from their parents and other adults to make critical decisions and solve problems. Nevertheless, children can practice age-appropriate skills that equip them for later self-determination. For example, infants choose toys or show preferences for specific people or settings. Families provide additional opportunities for children to practice elements of self-determination during childhood years, since building such experiences supports child engagement in activities and learning. Preschoolers can begin to make choices about what to eat for snacks, what shirt to wear, or what book to look over. In addition to knowing how to make choices, self-determination requires a young adult to control himself or herself to enable rational problem solving. Therefore, another foundation for self-determination is self-regulation. Children learn self-regulation of behavior and bodily functions during their early years. Finally, children need to be able to engage with materials and people in their environment long enough to be able to make choices and self-regulate themselves. We consider these three early childhood skills—choice-making, self-regulation, and engagement—to be the foundations of later self-determination. Families and the practitioners who interact with children and families have the opportunity to support later self-determination and to prevent learned helplessness, as they can influence aspects of choice making, simple problem solving, and self-regulation by adjusting the environment (people, places, things) to match a child’s special needs or situations.

Many families naturally support later self-determination throughout early childhood within their family system and identified culture. The kinds of supports families provide for later self-determination in childhood may vary by their cultural beliefs, practices, and preferences. Some families emphasize developing autonomy as a means to an independent adulthood. Others believe in the primacy of the family or the collective and emphasize developing skills to enable their child to function successfully in their culture. Accordingly, some families may emphasize developing self-regulation more than choice-making, while other families may create safe zones where children can practice making independent choices. We have learned that all cultures value some levels of independence. Professionals can support a level of independence specified by families for their children as they grow up to become adolescents and young adults.

A recent project at the Beach Center at the University of Kansas has investigated how families and practitioners can collaborate to support these foundations for self-determination in children ages 3 to five with disabilities or at-risk for delay. The Foundations project has worked with 16 preschool programs in six states to develop and test an intervention for parents and teachers to work together on goals to develop one or more of the foundational skills for children. We asked each participating teacher or other professional to identify a family of a child in her classroom to be part of our project. The parent and teacher met with a member of our research team. Together and over the course of several meetings, they followed the steps of the Foundations intervention. First, they used a routines inventory to learn about challenging events or situations in both classroom and home

and to select a home- and classroom-based goal for the child. Second, they selected one or more strategies to address the goal both at home and at school. Third, they used a small video camera provided by the project to demonstrate how the strategy worked and to share what was happening at home and school. Fourth, they discussed their results and decided on a next step. Over a timeframe of six to eight weeks, the parents and professionals were able to address at least one, and, for many, two goals for the child. Beyond helping the child learn Foundations skills, the project had a secondary outcome of encouraging improved family-professional partnerships. The research team's hope is that families will begin the long road to advocacy for their son or daughter during the preschool years, as this project encourages, and increase advocacy skills over the years as their son or daughter becomes an adult.

Many of the short-term goals the partners selected during our intervention trials related to familiar routines throughout a young child's day – getting dressed at home and arrival at school, transitioning between activities at home and school, snack time and meal time, and other parallel activities. Adults focused on adjusting the young child's environment to support increased self-regulation, improved access to choices, or engagement in typical activities to improve learning. For example, one family set a goal to use a picture board to help a young boy with autism to initiate toy choice and engagement. This child had the same goal at school, with visual prompts and peer support to encourage engagement. Both goals were successful and the child displayed more functional behavior.

At the conclusion of two rounds of setting short-term goals to support a young child's needs, one parent said, "I found out that bed time does not have to be such a big challenge every night." Another parent mentioned, "I learned so much! The biggest thing was the amount that can be accomplished when goals are set. Tools are available that support the goals and when there's a structure to support teamwork." Another family shared that the project "helped me identify his learning style, and incorporate visual supports into his room and play area to help him complete his tasks at home. I feel as if I have been able to get to know my

son better through a different approach." Teachers said, "A small change in how we do things can make a huge difference," and, "I learned that daily practice, using the same language, consistent use of strategies is very effective." Goals at home and school were primarily successful. Further, we learned that the short term and focused "project" nature of the Foundations intervention encouraged parents and teachers to work together on a more equal footing. Also, parents and teachers both learned more about what was happening at home and school and gained greater insight into each other's perspectives. Altogether, the project set the stage for families and teachers to collaborate effectively to adjust the environments of young children. In this manner, adults can promote the foundations that

support the roots of self-determination for children during early childhood.

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Mother and son spend quality time reading together.



10 steps to Independence: Promoting Self-Determination in the Home

Michael L. Wehmeyer, Sharon Davis, and Susan B. Palmer

The road leading to a successful transition from childhood to adulthood begins much earlier than the teenage years. It starts when children learn about themselves, their strengths and weaknesses, and, in doing so, begin to value themselves. It ends when, as adults, these same children can take control over choices and decisions which impact their lives and take responsibility for their actions. This is called self-determination.

For children with intellectual and developmental disabilities, families and teachers may need to take extra responsibility to be sure that this process occurs. Children learn many of the attitudes and abilities leading to self-determination by watching their families. Here are 10 ways that families can play a critical role in teaching their son or daughter to be self-determined:

1. Walk the tightrope between protection and independence. Allow your son or daughter to explore his or her world. This may mean biting your lip and watching from the kitchen window when your child first meets the neighbor's kids, instead of running out to supervise. While there are obvious limits to this, all parents have to "let go" and this is never easy.
2. Children need to learn that what they say or do is important and can have an influence on others. This involves allowing risk-taking and exploration. Encourage your child to ask questions and express opinions. Involvement in family discussions and decision-making sessions is one way of providing this opportunity to learn.
3. Self-worth and self-confidence are critical factors in the development of self-determination. Model your own sense of positive self-esteem to your child. Tell your child that he is important by spending time with him. Again, involve him in family activities and in family decisions.
4. Don't run away from your child's questions about differences related to her disability. That doesn't mean, however, to focus on the negative side of the condition. Stress that everyone is individual, encourage your child's unique abilities and help him or her accept unavoidable limitations.
5. Recognize the process of reaching goals, don't just emphasize outcomes. Children need to learn to work toward goals. For older children, encourage skills like organization and goal-setting by modeling these behaviors. Make lists or hang a marker board in the laundry room which shows the daily schedule for each family member. Talk about the steps you are going to use to complete a task and involve them in tasks leading to family goals, such as planning for a vacation.
6. Schedule opportunities for interactions with children of different ages and backgrounds. This could be in day care centers, schools, churches and in the neighborhood. Start early in finding chances for your son or daughter to participate in activities that help all children realize that everyone is unique.
7. Set realistic but ambitious expectations. The adage that our goals should extend just beyond our reach is true here. Take an active role in your child's educational experience. Be familiar with his or her reading ability and identify books that provide enough challenge to move to the next reading level. Be sure you don't just force activities which lead to frustration, but don't assume that all of the progress should occur at school.
8. Allow your child to take responsibility for his own actions... successes and failures! Provide valid reasons for doing things, instead of simply saying, "Because I said so!" Providing explanations provides the opportunity for the child to make an activity his or her own.
9. Don't leave choice-making opportunities to chance. Take every opportunity to allow your child to make choices; what she wears, what is served for dinner, or where the family goes for vacation. And, although this is not always practical or possible, make sure that these choice opportunities are meaningful. For example, for most children choosing between broccoli and cauliflower is not a choice! Also, when offering choices, make sure that the child's decision is honored.
10. Provide honest, positive feedback. Focus on the behavior or task that needs to be changed. Don't make your child feel like a failure. For example, if your son or daughter attempts to complete a school activity, say a math sheet, but is unable to do so, phrase the feedback so that he or she knows that the failure was specific to the worksheet and not to him or her. We all learn from our mistakes, but only if they are structured so that they do not lead us to believe that the problem is within us.

There is no more important environment in which the child with intellectual disabilities learns to become self-determined than the home. A child who learns from his or her parents that he or she has worth will become a self-determined adult. By being allowed the opportunities to make choices and decisions, to explore and take calculated risks and to learn from experiences of success and failure, your child will develop the abilities and attitudes necessary to reach his or her potential.

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Family Focus on Self-Determination

Erik Carter

The words of families can be the best and most effective supports for other families, especially with regard to self-determination for individuals with identified disabilities. A research team from the University of Wisconsin-Madison and Vanderbilt University - led by Erik Carter, Katie Weir, Molly Cooney, Martha Walter, and Colleen Moss surveyed on the premise that parents are the first and best experts on their children. The team published a summary of the family wisdom collected as part of their project. In order to provide easy access to this advice for families and others looking for practical suggestions and strategies to promote self-determination, this report, *Fostering Self-Determination Among Children and Youth with Disabilities – Ideas from Parents for Parents*, has been made available on-line at the Waisman Center (<http://www.waisman.wisc.edu/naturalsupports/pdfs/FosteringSelfDetermination.pdf>). This report has been summarized below, but please take time to look at all the ideas on self-determination from the surveyed parents.

While the questions in the survey had a limited range of options, an open-ended component invited families for helping children with disabilities develop key such as decision making, problem solving, goal setting, self-advocacy, self-management, and choice skills – as they grow into self-determined adults. Families also suggested strategies for encouraging self-regulation and leadership to support children in becoming more self-determined over time. The opening article in this series provides a general explanation, but we now provide brief explanations of the elements of self-determination.

Choice making is showing a preference among two or more things, ideas, or an array of items by designating one favored option. Young children use choice-making early in life and continue to indicate preferences during the lifespan. Families can help their children learn choice-making by setting up opportunities

throughout the day (when time permits) for children to experience choice. Parents can discuss how they make selections or model the choice making process for their children. Some children may need visuals or alternative communication to be able to make choices but family encouragement and narration of choice making helps children learn and enjoy the process. It is important to continue to practice and experience choice-making and the other elements of self-determination listed below throughout the years.

Decision making is the basis for other higher-level elements of self-determination such as problem solving, goal setting, and self-management. In order to make a decision one must consider possible solutions to determine how each outcome will affect oneself and others. Family members can model effective decision making, share details about relevant decisions made, and write or draw details of the process for children and youth.

Problem solving involves identifying effective solutions to challenging issues, situations, and dilemmas which may occur once or be ongoing. Young children need help to identify problems and evaluate and carry out strategies to work through problems. The content and complexity of problems will change over time for children and youth, but families can model this skill as well as teach problem solving directly while involving their children in the process. Other family-generated suggestions for problem solving included using media and books to illustrate the process while offering them help when necessary, writing out problems and solutions so that they are visible, and beginning to help children and youth to identify the relative importance of problems they encounter in their environment.

Goal setting involves identifying an objective and steps needed to reach a successful outcome. Families remind us that setting very short-term goals, perhaps for a day or week, is a good way to encourage this process. Again,

visuals and narration of the process are helpful, as is encouraging the realization that some goals are much too large to be accomplished without a lot of things happening in the meantime – such as a career choice or going to college. Making a plan for vacation or what to do in the coming year is one way to demonstrate goal setting in action.

Self-direction and self-management of activities encourages children and youth to become self-sufficient over time. These skills can be promoted to the degree that families think is important, but all students, including those with disabilities often need to experience more self-direction in their lives in at least some of their activities. Some children are more self-aware than others, but teaching children strategies to be able to self-calm and self-manage with some consistency, such as through expectations regarding chores and being ready for school on time, as well as through consistent consequences can be helpful. Parents mention that children often need prompts or warnings ahead of time for changes in schedule or circumstances.



Families enjoy time together.



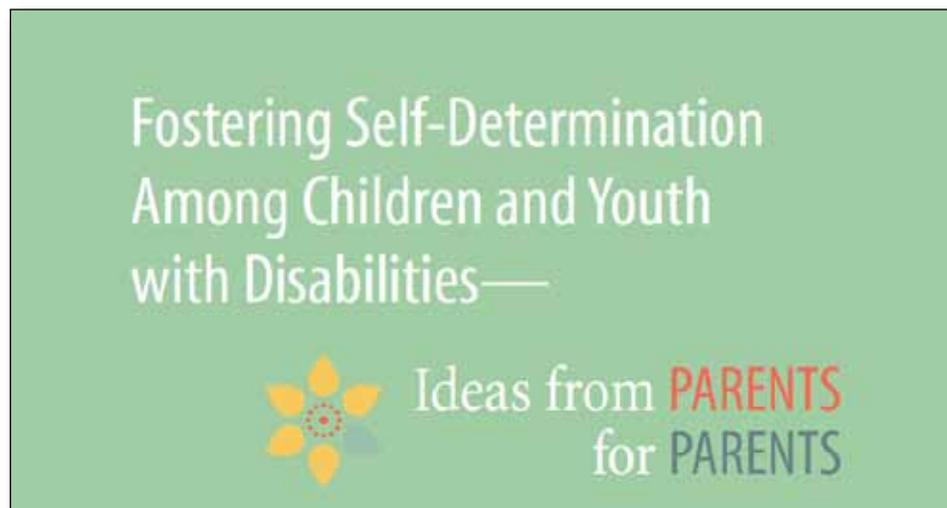
The families also provide suggestions for **fostering responsibility** and encouraging **independence** within family limits for children and youth. It is important for children to have some chores to do at home and to learn that homework is a responsibility but they can ask for help. Families also encourage education about emergency procedures and about safety, in general. One family mentions supporting child's independence by proving support in the background and avoiding overprotection, when the situation is less critical or the child or youth has already experienced the setting.

Self-awareness is the process of knowing one's strengths and limitations over the course of one's life. These characteristics change over time and children at different ages need different supports to learn about themselves. Learning about everyone's different abilities and gifts from a young age can help children to be more tolerant when they are older. Everyone should have the opportunity to try out different activities and be guided to learn new things. Youth can share their abilities with others and learn about the skills and abilities of members of the community. One family suggests that teaching children with disabilities that they are accountable for tasks, even though it might be more difficult for them to accomplish specific tasks, is an effective strategy. Parents can build skills at home by providing challenges and helping children find ways to accomplish difficult tasks.

Becoming a **self-advocate** involves effectively communicating what you need and knowing how to start obtaining it. One can, of course, advocate for oneself and also for others. Young children can be encouraged to talk about their wants, needs, and feelings. Youth can begin to make plans for the future with supports, as needed, to encourage mature choices and decisions. Families can help their family members to be better communicators by holding family meetings and discussions and by providing alternative methods of communication as well as remembering that wait time is needed to allow children and some youth to form and express their thoughts. Families tell us that encouraging participation and building social capital (networking and encouraging connections) supports children and youth

to be more self-determined. Connecting with peers with and without disabilities supports children and youth to be a part of their community. Children with autism or communication limitations may benefit from joining and participating in a social skills group. Youth can volunteer in the school or community to build skills.

and communicating with teachers in order to help them to meet special needs. Parents are usually one of the best sources of information for teachers and teachers often have strategies to share with families. Families in the study strongly suggest attending all Individualized Education Program (IEP) meetings



The advice from parents concludes with suggestions that **parents be role models** for their children. A family member could model daily living skills such as hand washing or cleaning up after oneself at home and elsewhere. Asking for help when needed, following tasks to completion, being persistent, and taking manageable risks can be modeled by family members when appropriate. But, above all, family members suggest that celebrating progress whether small or large, talking to children and youth rather than yelling, and having high but reasonable expectations are all important. Parents can set limits for behavior while remaining supportive and continuing to reassure children of their strengths and abilities. An effective way of helping children understand what to expect is to establish a fair and consistent system of family expectations and consequences. Children can be praised for success or reminded of what the expectations are and what types of support are available to meet these.

Families suggest that partnering with schools is very important, since children and youth spend considerable time there working on both academic and social skills. Parents of children with disabilities must spend additional time coordinating

and sharing the process with their child, in order to help them understand the purpose of receiving specialized instruction. Of course, children can also build advocacy and leadership skills by attending meeting themselves.

If you want to consider even more strategies to encourage self-determination for your children during the school years, you can read the full document *Fostering Self-Determination Among Children and Youth with Disabilities – Ideas from Parents for Parents* at <http://www.waisman.wisc.edu/naturalsupports/pdfs/FosteringSelfDetermination.pdf>. You can also ask other families for ideas and suggestions to encourage the development of self-determination during the school years. Family wisdom provided in the voices of other families that you might know or have yet to meet in your community is an important resource for you and your child with a disability.

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Brothers and Sisters of People with Disabilities - Supporting Self-Determination through Employment

John Kramer

Employment is an important issue to many people with disabilities. The impact of employment - or lack thereof - for people with disabilities affects not only feelings of self-worth and self-determination, but also the entire family. For example, consider John, a person with a disability, when he relays,

If I was working full time I could open a 401k I could put money away for a time that's another possibility. If I could put money away I could. Plus I'd have dental insurance and medical insurance for me too. Right now I don't have any dental insurance or [eye] insurance. Right now I gotta talk to Nicole later on about helping me get a new pair of glasses because my eyes have changes and I don't have money for them.

John articulated the reality of many siblings with disabilities in this study when he said,

If I had all those things, I wouldn't have to rely on my sisters.

The difficult and important issues of chronic under-employment and unemployment across the lifespan are becoming increasingly acute for individuals with disabilities. Finding meaningful and/or gainful employment has long been cited as an established pathway to self-determination and empowerment. People with intellectual and developmental disabilities (I/DD) are living longer than ever before, making adult siblings of people with I/DD key components of the future generation of family support. This increased lifespan also extends opportunities for community participation, social interaction, and employment. Since adult siblings have a vested interest in maximizing the independence of their brother or sister with I/DD, they may be



Sibling Support: Patrice, Maggie, and Katie.

a natural support to their sibling in the area of employment. A current research study is examining how adult siblings of people with I/DD support their brothers and sisters in finding and maintaining competitive employment. Brothers and sisters are in a unique position to provide different kinds of support to people with disabilities across the lifespan.

This support changes over a lifetime for everyone, but decisions made about employment earlier in life can impact what happens later on. In John's story, he viewed his need for support as a direct outcome of being underemployed and not being able to be gainfully employed. A lifetime of struggling to find work and employment can make it difficult to provide for oneself, causing people to rely more on their family members.

Siblings of people with disabilities pick up on this issue, recognizing the importance of employment, and mobilizing their own capital and connections to create employment opportunities for their siblings with I/DD. One sibling, Kim, recalled her brother's

connection with the community in getting their sister Michelle a job. She said,

So my brother [who does not have a disability] says, "I'll work on the job side of it." He hits the pavement. He knows a few people in town [be] cause he's lived there for six or seven years by now... We don't even know that there's agencies available. I start making calls about housing kinds of things. My brother starts pounding the street of local merchants. He actually gets a bite from the local grocery store that's willing to give [Michelle] a try.

Siblings can offer a perspective and level of support that may not be available from parents.



While her brother without a disability used existing connections to create the opportunity, Kim had to find a way to sustain the opportunity for Michelle. She found out about a policy that would enable her to be paid for providing support to Michelle. She continued,

I had called [a local rehabilitation agency] to find out how the whole job coach thing worked and found out that you could get a job coach or you could get the wage subsidy for “x” amount of hours. Like, “Okay, I’ll be willing to be her job coach if we get the wage subsidy,” ‘cause that gives a little sugar cube to the employer, take a chance. It’s not really gonna cost you anything for “x” number of months. The T family in Western Springs...were willing to give a chance in a job that probably is more advanced than what she even has today... I went in and job coached with her. She’s still with the T-Family Grocery Stores since 1993.

This passage suggests that siblings played a key role in Michelle’s successful community employment. A few factors contributed. One was her brother’s ability to use his social capital to create an opportunity for employment. A second was the support Kim was willing to provide. Third, a state policy provided funding for Kim to be Michelle’s job coach.

The level of support for employment might be different when someone is getting their support from their parents. Continuing with John, for example, he

The impact of employment—or lack thereof—for people with disabilities affects not only feelings of self-worth and self-determination, but also the entire family.

did not have employment opportunities in the community when he lived with his mother. He recalled, “... I never really worked for anybody...I never really knew what it was like to have somebody telling me what to do...” According to John, he did not know how to talk to bosses or potential employers because his early opportunities to build experience and employment connections were limited when he lived with his mother, hence limiting his opportunities to build

connections in the community through the workplace. This changed when John’s mother passed away. After his mother died, his sisters used their connections to secure an employment opportunity in which he could be successful. John said, in reference to Nicole, “because when I lived [with her]...she found me odd jobs and I made some cash.” Nicole used her social capital within her community to get her brother connected to employment.

Brothers and sisters of people with disabilities can support self-determination in a variety of ways, but the area of employment is especially important, as siblings can offer a perspective and level of support that may not be available from parents.

John Kramer, PhD, is at the Institute for Community Inclusion at the University of Massachusetts at Boston working on systems change and employment issues for people with disabilities. John worked with others to found the Sibling Leadership Network, Massachusetts Sibling Support Network, and Supporting Illinois Brothers and Sisters.

Things to consider

- Family members can have diverse perspectives on employment. Sometimes parents may not see employment as a viable option, while brothers and sisters may see it as a possibility.
- Employment impacts many aspects of self-determination. If someone is employed, they have an opportunity to earn money and are more likely to be economically self-sufficient.
- Siblings have access to their own networks, which could be used to connect people with disabilities to work. It would be beneficial for siblings to explore connections they have to different work opportunities and to assess if they might be a possibility for their siblings with a disability.
- Siblings can connect their brothers and sisters with an agency that is responsive to their siblings’ goals and listens to his/her allies. Supporting self-determination can be more difficult if the sibling’s agency does not include family members regularly and effectively.

Self-Determined Transitions are Challenging: The Perspectives of Two Families

Susan Palmer

Transition to life beyond high school can be a real challenge for many students with disabilities and their families. Such challenges are more easily overcome when multiple support systems are available: an aware and helpful family a school at which the teachers know that *ability* is part of the word *disability* and are supportive of students who have them; and external therapy support, if needed. However, in some cases, it is difficult to find what works for each and every individual within the available services in the community and state in which you live, either due to the severity of disability or other circumstances that limit opportunities. This article shares information from two families whose children have been associated with the Thompson Center for Autism and Neurodevelopmental Disorders in Columbia, Missouri. Erik is still in school and navigating transition services, while Gary is an adult whose family is helping him achieve a self-determined life.



Erik, age 17.

Erik's Family

Erik, age 17, has been assisted in multiple ways over a period of more than 4 years at the Thompson Center. As he recently told the audience at the annual Thompson Foundation for Autism *It's in the Cards, 2012 Dinner Gala and Auction*, "Kids like me with autism don't know they are not normal but I have learned I can't read body language or facial expressions. For me it is hard work to learn about them and body cues." He gave a great speech at the event in front of over 400 people and enjoyed speaking to the crowd.

According to Erik's mother, Erik was not diagnosed on the autism spectrum until he was 13 when they moved from New Jersey to Missouri. He was born prematurely, weighing only 2 pounds, but after he was discharged from the Neonatal ICU, he was a happy baby and enjoyed his family of mom, dad, and two older brothers. Early in his school life, Erik was diagnosed with ADD without hyperactivity and was given an Individualized Education Program (IEP) and various accommodations to be able to manage school work. But it was only when the family moved to Columbia and Erik, then in 7th grade, was evaluated at the Thompson Center, that Asperger's Syndrome was determined to better describe Erik's struggles with peers and others in his world. The Thompson Center went beyond diagnosis and provided Erik's parents with information, care, and access to available programs to help Erik evolve into the personable teenager he is today. Erik benefits from services at the Thompson Center that support social skills, sessions with a therapist to work on issues he might have, and occasional sessions with a psychiatrist for prescription medicines. He has attended day-long trainings with his peers and is scheduled to attend a one-week course for life skills

Through self-determination and the enlightened support of his family, teachers, and therapists, the future appears bright for Erik who is in high school.

later this year. Erik's mother describes him as easy-going and likeable, and the therapists at the Thompson Center call to see if he is available to attend new classes and share information with others with autism who are less interactive.

At Erik's high school, where all of his classes are in regular education settings, his teachers are aware of and adhere to his IEP. This supportive school environment allows Erik, and other students with similar problems, to spend a bit of time each day with a special education teacher during Educational Lab, study time that every student has, and lunch. Sherry says that the option of a sequestered lunchtime supports interaction with others who have the same social needs. The special room offers camaraderie, social skills support, and a safe haven for kids who don't fit in as well, while also offering psychological help if they are having issues with other students in the general population.

This summer, Erik is learning to drive at the request of his parents. His brothers do not live close by and Sherry has stressed to him that to get to any college classes or job, Erik needs to be able to drive himself around as his parents will not be available regularly. Erik now has his driver's permit and is taking driving lessons. His parents consider this to be a critical step in his transition to adult life, not only for the practical reasons of transportation in



a community with very little public transportation, but also because of the required attention to the environment and maturity of judgment and behavior that driving requires. Plans for his transition to adulthood are underway. His ultimate goal is to get a special education degree “to

Families are often caught up in the ‘moment’ when their children are 14, 15, 16...but they need to be thinking five years ahead all the time and preparing for that time.

teach special education kids like himself”. Part of Erik’s transition plan for next year is to work for several hours each week at the Title 1 Preschool class that is part of the high school. The preschool will provide exposure to working with children who are younger than he is, something that will challenge him but still support his long-term career goal of becoming a teacher. Erik’s plan is to start attending a junior college shortly after completing high school this coming year, rather than enrolling immediately as a full-time student at the University of Missouri. This plan allows time to adjust to the demands of college and to ease into life in general, which would be more complex at the larger university than at the junior college.

Erik successfully traveled independently by air this summer to visit his brother in Washington, DC. Sherry expressed pride in Erik’s accomplishments – entering his senior year of high school, learning to drive, traveling independently, and making plans for the future. It is clear that Erik’s family supports him with high expectations, but they also treat him as normally as possible, despite his diagnosis label on the autism spectrum. Their belief is that if you have a disability, you can recognize what needs to be worked on and move forward to become a productive part of society at the level you are able.

Through self-determination and the enlightened support of his family, teachers, and therapists, the future

appears bright for Erik. Erik’s family has graciously shared their wisdom in order to help other families make appropriate and practical transition plans a reality for their children, too. They interact often and share ideas with the families of Erik’s friends at school. The families collectively figure out strategies and opportunities for success throughout the year, providing family-to-family advice and sounding boards for one another. Knowing your own family, having support from the school and outside therapists, and crafting a transition plan that fits your child and the situation within your community are all parts of a self-determined transition.

Gary’s Family

A parent with a son who is twenty-nine years of age and has transitioned beyond school has different wisdom to offer families, especially families whose children experience more significant disabilities. Gary, who is nonverbal with significant cognitive delays, was identified with Down syndrome, has the additional challenges of autism, and has experienced celiac disease during the last five years of his life. Celiac disease, a serious ailment of unknown cause that can occur at any age, damages the lining of the intestines and is the body’s autoimmune reaction to eating gluten or wheat-based foods. For Gary, the onset of this disease affected his young adulthood and impacted his transition adversely. However, due to this onset, Gary was finally able to move from the waiting list and receive the Home and Community-Base (HCBS) waiver. Gary’s mother Donna is philosophic about the additional support of the waiver – just having Down syndrome and autism and being non-verbal did not immediately assure needed supports. Donna is one of the project development specialists working for the Thompson Center for Autism and Neurodevelopmental Disorders as a family resource specialist, making this family somewhat more aware of potential supports and of how to navigate the “system” than many others. However, the uniqueness of Gary’s situation has challenged his family to be even more creative and to understand that the somewhat typical way that services are provided to adults with significant disabilities does not fit Gary’s needs.

Gary was born in Iowa, and there, his family bonded with a number of other parents whose children had Down syndrome to become a cohesive group of early advocates for inclusive services in the public schools. Gary’s parents were active in the parent advocacy organization, now called The Arc, and felt that building social capital for Gary within public education was a better path than sending him to a segregated school for children with various disabilities from birth to 21 years within their Iowa community. Throughout preschool and elementary grades, Gary’s family was able to collaborate with individuals within the school system, coordinators and some teachers who were willing to work with Gary in their classes, to ensure that Gary learned in the same classrooms as his non-disabled peers. This created a foundation of self-determination for Gary. Although individuals with significant disabilities such as Gary have fewer choices, need more assistance with decisions, and may need constant supports, Gary has been able to make his wants and needs known throughout the years through various behaviors and reactions to situations. His family nurtures his ability to make choices and honors his opinions.

When the family moved to Missouri during Gary’s middle school enrollment, his educational placement changed to partial inclusion, followed by a self-contained classroom in high school with integration at lunch, pep rallies, and all-school events. These inclusive opportunities were actually less than optimal for someone with autism and sensory sensitivities because they represented the loudest and most chaotic opportunities to be a part of the school community. Donna mentions, “Looking back on this, I wish I had been smarter about thinking those things through to make inclusion more successful”.

Despite Donna’s regrets regarding inclusion in high school, Gary had multiple positive experiences in community-based transition services and was on his way to having opportunities that would hopefully become more permanent later on. Gary’s mother shares that “families are often caught up in the ‘moment’ when their children are 14, 15, 16...but they need to be thinking five years ahead all the time and preparing



for that time. Most adult services are segregated or restricted; so often families are tired by that time and take the course of least resistance”. This mother sees the transition years as being a discovery process that can provide a “ray of hope” for the future, but families need to keep thinking ahead. Professionally, Donna is the consummate family advocate who listens well to “whatever young parents tell [her] they need”. Declaring, “I’ll support them in their choices, even if they don’t match my own.” Even though the schools are coming up with innovative options for children with autism such as having Autism Navigators and specific autism facilitators to help children of all ages manage within the same setting as their non-labeled peers, there may be a demand for autism-only classrooms or putting children with autism in one group.

Gary spends 5 days every week for 6 hours each day with support from a local residential services organization. One community support person accompanies Gary and another man who is blind on forays to the food bank, the Ronald McDonald House, and other organizations where they volunteer and interact with people in the community. Gary uses signs and has a recorded community system to express his wants and needs, but like many other people with significant challenges, these measures are often ineffective. For example, when Gary is with the other man and noise levels exceed what Gary

tolerates, his sign for quiet or stop has no effect on his friend who cannot see.

At home, Gary enjoys his solitude, but his favorite activity is to take a ride in the car. He loves to go anywhere just to be going. He and his father are kindred spirits and spend time doing activities together on a daily basis when time permits. Gary’s family members have become an integral part of his activity of choice more or less by default, due to the level of support required to meet Gary’s needs.

Now that Gary’s celiac disease is resolving with his special diet, his family is moving toward obtaining self-directed supports in the state of Missouri. Gary’s family will work with him to set up his week and his world using this option of matching supports very specifically to Gary. They are looking into establishing a business for Gary to provide him with something that he would prefer to do and a way to contribute to the larger community while building social capital. Donna says, “It isn’t about making money as much as it is a quality of life issue for Gary. If he makes a small amount of profit a week but is happy doing it, then so am I!”

The pain and discomfort that Gary experienced in the past due to the celiac disease is something Gary remembers and this experience continues to make it difficult to encourage Gary to ingest food or to develop the habit of drinking the proper amount of fluid. “It is something I never dreamed that we would be dealing with,” Donna says. “It has been hard; we

started out with one dream and that dream continues to alter each year. I still fully believe in self-determination, choice and full inclusion in the mainstream of life. It’s the dignity of choice that makes life rich and satisfying for all people. Gary’s path has not been straight and we can’t see what lies around the curves ahead but to quote my father-in-law’s wisdom: “That all goes with it. Five years ahead and counting!”

Families are the ultimate support for self-determination at all ages. Parents can share high expectations for their children’s lives with professionals, and when necessary, help others to understand what is best for their adolescent and adult children. Families can work together with their members with disabilities supporting them to lead self-determined lives, within the constraints of budgets and abilities and taking advantage of existing or future opportunities.

Susan Palmer, PhD, KUCDD and Beach Center on Disability, University of Kansas, Lawrence, KS. Susan is a research professor working on funded projects related to self-determination for individuals, families, and teachers to support self-determination for people with disabilities.

MU Thompson Center provides resources for transitioning to adulthood

The Thompson Center for Autism and Neurodevelopmental Disorders at the University of Missouri has developed two resources to assist individuals and families as they prepare for the transition from adolescence into adulthood.

The first of these resources is an on-line training module that provides an overview of the transition process and addresses five life skill areas. Community Living, Health and Safety, Education and Training, Employment and Adult Services are all discussed in the online module. Participation in this module is free but registration is required. To learn more visit: <http://thompsoncenter.missouri.edu/training/modules.php>

The five life skill areas addressed in the training module are also found on the *Roadmap to the Future: Transitioning to Adulthood with ASD* website. The website, <http://asdtransition.missouri.edu>, also provides numerous resources for transition planning and videos of individuals telling about their own experiences.





Family Supports, Self-Determination, and Safety

Jana Peterson-Besse, with Mia Peterson

Our family has always prioritized self-determination. My sister, Mia, is a self-advocate, and she has goals, preferences, and dreams. The rest of the family has worked hard to support her in setting goals and taking steps to realize those goals, making choices about her life, and living independently. Mia often tells the story of the first time she advocated for her goals.

I was in a junior high reading class with all boys and I didn't like it one bit! Those boys didn't care much about learning to be better readers and writers. I wanted out of that class so bad. But my teacher did not listen to me and said, "I can't let you out of this class because your schedule has been put into the computer since the school year started. I cannot change the classes that have already been put into the computer."

I became very mad and frustrated with her. Since I did not know how to speak up for myself I had to let her know what my feelings were in my gut, so I wrote a letter instead. I said in that letter, "I really want out of this class and to start taking classes that I want to take. So take that and put it into that computer of yours." Guess what happened, I got her attention and she began to understand what I really wanted.

An important addition to that story is that the teacher called our parents to let them know that Mia had 'acted out.' They listened, but they were also quietly cheering to each other. They were working to help Mia overcome roadblocks to her educational goals, and they knew that Mia asserting herself was an important part of her path to self-determination.

Mia has accomplished so much and is pursuing many of her dreams. She moved out of state to pursue a career with a self-advocacy organization and continued to live hundreds of miles from her parents and siblings for eight years. She lives in her own apartment and has a

personal business. She has traveled quite extensively, both independently, related to work as a self-advocate, and on trips with her boyfriend. Many people see all of this and think that self-determination comes easy for Mia, and that supporting her self-determination must be easy for her family. Mia is the first one to say that self-determination takes a lot of work for her. It also takes a lot of work for her family to be the best supports we can be. We know there are times we struggle—when we are too bossy or critical, or when we speak for Mia, or when we make decisions for Mia rather than with Mia, or when we gather at her apartment and then proceed to take the place over. (Mia likes to be positive about her family, so to her credit, she did not say negative things during interviews for this story, although I know she has plenty of stories to tell!) Most of the time, though, we genuinely do our best to provide positive and appropriate support.

Independent Living and Safety

As family members in support roles we often struggle in the balance between independent living and safety. We know this is a common struggle for other families, too. We have concerns that arise about the safety of where Mia lives, the trustworthiness of people she meets, and the safety of getting from place to place. It is important to note that concerns about safety are not unique to Mia. I get cautions from our parents about safety issues, too.

When we talked about self-determination for this article, Mia told me that one of the most important aspects of living her self-determined life is to have her own apartment and live independently. She has an apartment in Des Moines that she loves. She can walk to the grocery store where she works, the drug store, several restaurants, her church, and a gym where she recently started working out. Her neighborhood also has good bus access, which helps

Mia is the first one to say that self-determination takes a lot of work for her. It also takes a lot of work for her family to be the best supports we can be.

her be even more independent. Mia says, "I like knowing who people are who work at stores in my neighborhood. It's one way to feel connected. I like having good places to eat. It's easy to walk to my store where I work. It's nice because it's easy to get to, to work there. It's also good because I can do shopping there. I can also get to church as well. It's right in the same neighborhood, close by. When things are right in your neighborhood like that, it helps you know where you are and to not get lost. I like being able to know where I am, to know my surroundings, and to get there by myself."

Our parents actually located the building, and they were thrilled that Mia liked the building and the neighborhood. For them, the most important aspect was safety. Her building is locked, with a secured entrance. Of course, living in a safe building in a relatively walkable neighborhood is expensive, and so this decision has had the consequence of requiring family financial support. At times, some people have questioned whether it is appropriate for Mia to have rent that is too high for her to afford independently and for our parents to help her to live in this building. For our parents, though, the safety of this building is what makes them feel secure about Mia living so independently.

Therefore, this is the compromise that makes it work for everyone. In other words, when our parents worked with Mia to find an apartment that also met their needs—even if it decreased her financial self-sufficiency—it helped Mia maintain independence in the ways that are important to her. Luckily, this is not a point of conflict for our family because Mia agrees that safety is important. She said, “I feel pretty safe with where I am. I am getting to know my neighbors. I am still getting to know them because I keep getting new neighbors. I think the locked doors are a good idea so no one can just get in. That is a big safety issue. Only the people who live in the building are allowed to get in. We just don’t let anyone in who we may not know.”

Mia also said that the support of her family has helped her learn a lot about safety related to trusting people she does not know, which has been a hard but important lesson related to living independently. She said, “Most of the time, part of being independent is part of knowing my own safety, and knowing who to talk to and who not to talk to. I remember that I made a mistake with this once. I think that was one of the biggest lessons I have had to learn. Being able to talk about it with family really helped me



Mia Peterson (center) enjoys spending time with her family, (from left to right) father Mike, sister Jana, sister Missy, and mother Carol.

out a lot - even though sometimes I didn’t want to hear it at first. [When I lived at my old apartment], there was a person who would not leave me alone, and I could not

do it myself. At first I thought I was able to myself. I needed family to work with me.”

New technologies are helping self-advocates gain independence and improve safety around community living. When asked about safety and independence, Mia immediately described her cell phone as a very important tool. She said, “I take my phone with me everywhere I go now because I know safety is really important. If I’m in a rut and I don’t know where I am, it is good to have my phone with me for safety reasons. If I’m lost, I call Dad. If for some reason I can’t get ahold of Dad, I would call someone else in my family who might be able to help me.”

The Role of Siblings

I asked Mia if there were ways that her sisters provide supports that are different from her parents, and she said that sometimes she just prefers to hear sibling opinions. She said, “It’s important to me, talking with siblings, and enjoying the time we all have together. It’s like personal time with one another. Sometimes it feels good to talk to my sisters, rather than Mom and Dad all the time. Depending on the issue, sometimes my sisters have different opinions, and it is good to hear it from my sister’s point of view. They sometimes are less strict with what they think. Sometimes

I also talk to my brother-in-law and get his point of view. Sometimes it just feels good to talk to somebody to help me brainstorm, to help me feel confident in knowing where to go or where I want to be. It feels good to have someone who can take my call and talk to me when I am in a crunch. I also call my sisters when

I’m frustrated with Mom and Dad. With Mom and Dad, sometimes it can be overwhelming. Sometimes it can get to be a little too much to hear, and that bothers me. Some things are

hard to hear sometimes. Sometimes I would rather hear it from my sisters.”

Regarding safety, as siblings we sometimes struggle with our role. All three siblings (Mia, our other sister Missy, and I) want to be confidants for each other and not betray each other’s trust, but it is difficult when we have a safety concern. There have been times when Missy and I have shared things without Mia’s permission and regretted it, and there have been times when we have not shared concerns and regretted that, too. I generally try to work with Mia to decide if others should be involved if there is a concern. I want Mia to know that I am a trustworthy person with whom she can share things so that she will tell me what is on her mind. I believe that maintaining confidence helps me to better support her, and also to better contribute to her safety and well-being, because it means that she wants to keep talking to me. As Mia said in the previous paragraph, sometimes she still does not like to hear what I have to say, but sometimes she would rather get a sibling perspective, anyway.

Final Thoughts

I asked Mia if she had any other thoughts about her family supporting her self-determination. She said, “My family is my support by communicating together, by talking. Like nothing about me without me. Even though I have my own thoughts and ideas, sometimes it’s good to hear about others in the family. We all have our conversations. We talk about it, and then we end up doing our own thing. We brainstorm. I think, hmmm, that sounds like a really good idea; I should just do that because I communicated that with my family. We as a family communicate, and then I decide what I’m going to do.”

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Mia Peterson lives in Des Moines, Iowa and owns a Self-Advocacy business called Aiming High. She writes and gives speeches about self-advocacy and her life story. To learn more about Aiming High, follow the Aiming High page on Facebook.



Self-Determination Tools for Families: Resources from The National Gateway to Self-Determination

Jana Peterson-Besse

Families can promote self-determination for their family members with developmental disabilities in many ways. Often, families are aware that they can promote self-determination through encouraging choice-making and statement of preferences. Self-determination can also be promoted by encouraging goal setting, self-advocacy, independent living, and personal responsibility. In addition, families can provide supports or assist in locating supports that will help choices and goals be realized. They can also offer different opportunities for life experiences, which may help an individual to more thoroughly identify his or her preferences.

Many families want to support self-determination but are uncertain how to do so. A goal of the National Gateway to Self-Determination project is to provide information about resources that can be used to promote self-determination of individuals with developmental disabilities. These resources are compiled in a Resource Guide, available on the National Gateway to Self-Determination website www.aucd.org/NGSD. For each product listed in the Resource Guide, there is either a direct link to the web-accessible materials or information about how to locate or order the resource. As the variety of resources indicates, there are many ways to promote self-determination. The organization of the materials assists in directing families to the resources that will fulfill their needs. For example, resources that focus on youth with disabilities would be appropriate for parents of children with disabilities, while other resources focus on adults and could be useful for siblings as well as parents of adults with disabilities. Tools that focus on issues related to aging or end-of-life planning may be especially relevant to siblings who are supporting an aging brother or sister.

To use the on-line Resource Guide, first access the website at www.aucd.org/NGSD. Materials can be selected by entering a keyword and by indicating a specific target audience, such as parents or siblings; an age group, with options ranging from birth-4 to 65+; life areas, such as relations or health and safety; product type; and more. Individuals can select multiple options and categories to narrow a search or leave categories unchecked to return a greater variety. Below, we will highlight a number of materials from the Resource Guide that may provide useful information to families. Some of these tools were designed primarily to promote self-determination but also address the role of families. Other tools were designed primarily to support families but also adhere to self-determination philosophy. All tools included here can be purchased or downloaded directly by family members without additional training.

Presence in the Resource Guide does not imply endorsement by the National Gateway on Self-Determination Project. The intent is to provide detailed information so individuals can find the materials they need.

Self-Determination Resources for use by families

These resources emphasize development of self-determination as outcomes.

I'm Determined

The I'm Determined project, a state directed project funded by the Virginia Department of Education, focuses on providing direct instruction, models, and opportunities to practice skills associated with self-determined behavior beginning at the elementary level and continuing

through the student's educational career. The self-determined student knows how to set and achieve goals and has a greater understanding of personal strengths and how to get support for areas of need. This on-line tool has separate sets of tools directed at parents, educators, and youth with disabilities. The website includes a variety of resources, including instructional modules, videos, and activity templates for download.

URL: www.imdetermined.org/

Self-Determined Learning Model

This tool is intended for parents of young school-aged children with disabilities. This guide enables parents and teachers to help children become more self-determined individuals. With the support of parents and teachers, children will learn how to problem solve, set and achieve goals, and make decisions at school and at home.

URL: http://www.beachcenter.org/resource_library/beach_resource_detail_page.aspx?intResourceID=2505&Type=book&JScript=1

The Preference Indicators

The Preference Indicators are a series of guides that assist in gathering information about an individual's preferences in seven domains. They have the potential to unfold the interests, abilities, and preferences of the individual in a positive manner and are designed for individuals across the lifespan.

URL: <http://www.ou.edu/content/education/centers-and-partnerships/zarrow/preference-indicators.html>

Thinking Ahead: My Way, My Choice, My Life at the End

The Coalition for Compassionate Care of California developed the "Thinking



Ahead Workbook” and DVD by working with self-advocates who wanted to ensure end-of-life wishes were respected. The pictorial and plain language workbook and DVD help people with developmental disabilities to make choices, find support, create plans, and act through the “Think-Plan-Do” organization of each section. The materials were specifically designed to be used by people with developmental disabilities with minimal support. Parents and siblings wishing to engage in end-of-life planning with their family member may find this tool useful to facilitate full participation by their family member in the process.

URL: www.coalitionccc.org/thinking-ahead.php

Resources Specific to Siblings

Thicker than Water: Essays by Adult Siblings of People with Disabilities

Thicker than Water: Essays by Adult Siblings of People with Disabilities edited by Don Meyer, contains over thirty essays by adults who reflect about how having a sibling with special needs has greatly impacted their lives in both good and maybe not so good ways. This book gives great insight into the lives of these individuals through their blessings and struggles that are told through honest written snapshots of life. If you have a brother or sister with a disability, *Thicker than Water*, can give you support and show you that you are not alone. Even if you do not have a sibling with special needs, this book can help you better understand what other people you may know are going through. This

book is available from a number of booksellers including Woodbine House.

URL: http://www.woodbinehouse.com/main.asp_Q_product_id_E_978-1-890627-91-1_A_.asp

Family Support Resources emphasizing self-determination

These resources focus on life planning and future planning for families, utilizing person-centered planning and preferences and emphasizing choice.

A Good Life

This book, a future planning guide by Al Etmanski, includes information on wills and estate planning, supported decision-making, circle of support development, and alternatives to legal guardianship. It looks “beyond contemporary social and rehabilitation services and programs to support our family members.” The book is intended to be utilized by families, persons with a disability, and service providers for future planning. It is available from a number of booksellers, including Amazon.

URL: <http://www.amazon.com/A-Good-Life-Al-Etmanski/dp/0968046215>

Guardianship: Understanding Your Options & Alternatives

This guide by Elizabeth Moran is intended to guide families through the process of determining what the most appropriate and least restrictive options and alternatives are to plenary or full guardianship. It addresses common concerns, misperceptions, and myths and provides guidance for addressing the potential needs of people with

developmental disabilities for support and/or protection. While this guide offers general information, it is not intended as legal advice. The information provided is based on Missouri law at the date of publication as well as the experiences and knowledge of individuals who have researched and/or provided input during its development. The guide is intended for families of transition-aged youth and adults was developed and produced in collaboration with People First of Missouri.

URL: http://moddrc.org/fast_fact.php?disID=184

Life Planning for Adult with Developmental Disability

This book is a comprehensive guide to resources that parents or other family members can use to support an adult child or other individual with developmental disabilities for whom they provide care. The author, Judith Greenbaum, begins by providing information on how to assess the quality of life of an adult with a disability. She also offers a number of suggestions for increasing quality of life. The book then focuses on long term planning. Worksheets are included to help families develop their specific plans.

URL: http://books.google.com/books/about/Life_Planning_for_Adults_With_Developmen.html?id=FCW7btEJmGUC

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If you have created a resource or curriculum designed to promote self-determination, please nominate it for inclusion in the Resource Guide.

Go to www.aucd.org/NGSD/template/topic.cfm and click the “Nominate Resource” link.



A Blueprint for Building Social Capital

Susan Palmer and Rud Turnbull



Chip Brookes (Kate's partner), Rud, Jay (age 40), Ann, Kate, Rahul Khare (Amy's husband), and Amy, 2007.

Jay (JT) Turnbull lived an enviable life, according to his family, colleagues, and fellow members of his community. Rud Turnbull, Jay's father, wrote, "The enviable life that Jay had, and that other families and individuals affected by disability should have, results from human policy, its effective implementation, and partnerships among professionals, families, and community members," (Turnbull, 2011; p. 336). Jay died very suddenly in 2009 at the age of 41, but he lives on in the hearts and minds of his family, friends, coworkers, and the community. Jay showed us what social capital really means, and his family was a moving force in providing the supports and opportunities to experience a good quality of life within a Midwestern community.

In his recent book, Rud Turnbull shares the energies and efforts needed to support Jay, a man with multiple disability labels of intellectual disability, autism, and bipolar disease.

So many years, so many forms, so much data – it is impossible for Ann (Jay's mother) and me to do it all alone. Nor do we try. We enlist "reliable allies". They include his many annually rotating job coaches – people who taught him how to work more effectively

and independently. Also joining Jay's circle of support were his housemates. Still other people entered the circle – music therapists, speech-language therapists, members of fraternities who participated in the Natural Ties program, and our friends and colleagues. (Turnbull, 2011, p. 79-80).

Rud also mentions that physicians, a psychiatrist, psychologists, yoga instructor, massage therapist, and most important of all, Jay's sisters, Amy and Kate, were part of the team. Jay had a job, a home of his own, and the support of many individuals

Family participation in developing social capital for their sibling or child helps connect individuals with disabilities to existing groups and social structures.

in the community – he experienced social capital. According to Gotto and others (2010) social capital is a set of relationships and social structures based on trust and reciprocity. Family participation in the lives of their family member who are initially developing social capital is very important, and is especially critical in connecting individuals with disabilities to existing groups and social structure within smaller communities and the larger world. Social capital is a construct that emerges over time – it is not established in a day, a year, or even a decade. There is no blueprint on how to handle each and every situation that arises in the lives of people with disabilities. However, families can learn through trial and error what works for their family members.

When the Turnbull family trusted "the system" for help with housing and employment, the system's inability to respond effectively to Jay's extreme behaviors defeated that option. In addition, Kate, Jay's youngest sister, asked why they would wish Jay to live in a place that was not very nice and that Jay did not like. Through a series of steps, Jay lived away from his family in first one and then another home of his own with 24-hour support through selected, dedicated housemates, with financial underpinning from his earnings, family, and Social Security programs. Jay also was a part of the workplace and community and developed his "Cheers" connections – favorite restaurants, colleagues at work, church friends, fraternity brothers who befriended him, his housemates, and many others.

The success of every one of his relationships is not as important as his success in maintaining some dependable connections with people outside of his family who genuinely cared for him and supported his welfare. His circle of friends was wide and continued to develop throughout his life, sometimes because of his parents and their connections in the community and at the university, but often just because Jay

was a good person, who also happened to experience the effects of disability.

Of course, Jay's life was limited in some ways – he could recognize a few sight words and some initial letters in a name, and he had difficulties with rapid cycling bipolar disorder and “challenging behavior.” He needed ‘24/7’ support at work, home, and in the community, and he got it, often because he reciprocated with other people. Jay was a terrific friend who loved music, was a regular at various restaurants and music venues – places that were his ‘Cheers’ connections, where everyone knew him and attended to his preferences and needs. Going along on Jay’s ‘uptown walk’ after a dinner on the main street in downtown Lawrence was a good way to see how Jay’s social capital in the community was solid. Many people greeted him and Jay would say hello and mention their name, introduce anyone walking with him, and give special friends his ‘JT handshake’ that he had learned during his fraternity house days.

“Jay was a person in and of himself, independent of who his parents were or whether he had a disability” according to Michael Wehmeyer (2011). Jay worked for twenty years and contributed to the mission of his employment unit, while engaging his coworkers through his subtle

mannerisms, his love of the next holiday, and his thoughts on favorite foods.

The best description of Jay in action within the family and community however, is from his siblings, who helped Jay build his social capital and live an enviable life. Amy, the older of his two sisters, is a community organizer and scholar of low-income housing, now a doctoral student at the University of Chicago. “My brother taught me so much about having reliable allies. I learned that lesson long before ‘social capital’ was a phrase in the academic world, beginning in the early 1980s. He wanted to be loved, which is a deeper way of describing social capital, and he was, because he was a loving man.”

His sister, Kate, an actress in New York and Los Angeles, wrote in her eulogy, “Jay was embraced by the Lawrence community in a way I know my parents did not dream of when they first moved here in 1980. But how could we (in the community) not embrace him? ... He was the best of the best. He knew no judgment, no race, no class, no sexual orientation - none of the things that we mortals see in one another, that we size up about each other.” It may well be that Jay’s ability to have “social capital” came as much, if not more, from him, from his refusal to judge and thus separate himself from others, and from his wanting to belong and thus his ability to invite others to belong to him.

“We gave Jay away to our community,” says Rud and Ann, “and, in taking that leap of faith, we found that the community took him in. He needed it, but, truth be told, the community

“My brother taught me so much about having reliable allies... [to build social capital].”

needed him. Social capital—that glue—comes from the acknowledgment of mutual need.” For a full description of Jay’s life, read Rud’s memoir about him, *The Exceptional Life of Jay Turnbull: Disability and Dignity in America, 1967-2009* available at Amazon.com.

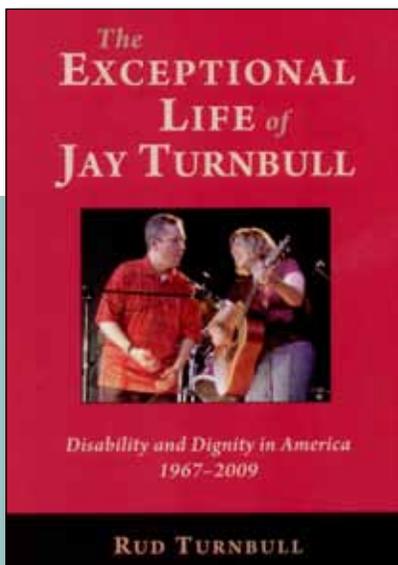
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The Exceptional Life of Jay Turnbull: Disability and Dignity in America 1967-2009 by Rud Turnbull is available from Amazon.com. This moving and honest memoir chronicles the challenges faced and inspiration provided by a son with disabilities from the perspective of a loving father who wanted the best for him. JT, whose self-determination was impacted by the severity of his disabilities and the system of care typical for individuals with challenging behavior and limitations in cognitive ability, overcame these challenges to lead an exceptional life. Professor Turnbull’s description of hopes, dreams, and the reality of what it took to encourage JT’s successes provides both a tribute and a roadmap to families who experience the same or similar life events.



The Family Role in Promoting Self-Determination in Relationships and Sexuality

Linda Sandman

Relationships help give meaning to our lives. They provide a context for helping us understand who we are and how we fit into this world. Our families, naturally, are our first primary relationships. Much has been written about the impact of family relationships on the identity formation of people with disabilities (Linton 1998, Jahoda & Markova 2004). But there is a noticeable lack of information about how family relationships can help shape and support the understanding of one's own sexuality for the person with a disability. Family attitudes and perceptions about sexuality and disability have been explored in multiple articles and studies (Pownall & Jahoda 2011, Swango-Wilson 2008, Stokes & Kaur 2005, Pender & Hingsburger 1991). This article will strive to further the dialogue about how family relationships can play a role in supporting self-determination for the person with a disability.

Parental concerns can range from feelings of uncertainty about how to approach the topic of sexuality with their child with a disability to fear that their child will be sexually exploited or abused. Equally compelling is the concern that their child/adult will engage in some public sexual behavior that could lead to arrest and/or legal problems, i.e., disrobing in public, public masturbation, touching others inappropriately. Yet, as Hingsburger (1995) described, too often parents and caregivers respond to these concerns by creating a "prison of protection" that is designed to protect the person with a disability from society, from relationships, from sexual information and from decision-making. Ultimately, it can lead to more vulnerability for the person with a disability. One exciting development in the literature on sexuality and people with disabilities

is the increasing presence of the voices and opinions of people with disabilities advocating for themselves. Self-advocates have spoken up about their desire to have relationships – from friendships to intimate partners and marriage.

Self-advocates say that "being sexual is for all of us." Too often though, self-advocates feel that they don't get the chance to get into a relationship or get the support they need. (The Riot!, Issue 23, p. 1)

They want sexuality education and opportunities to date. When a relationship becomes physically intimate, they want safe places where they can express their love and caring in private. (Hollomotz and The Speakup Committee, 2008). Self-advocates have helped define a new term called sexual self-advocacy. This means people with disabilities taking control of their own sexuality by making their own decisions and speaking up for themselves and others about sexuality. (SDC fact sheet on Sexual Self-Advocacy).

In Illinois, self-advocates have described sexual self-advocacy to mean:

- Finding someone you can trust to talk about sexuality
- Getting educated about sexuality!
- Understanding there are many different types of relationships
- Learning how to be in a relationship
- Learning how to find help if you have been abused
- Learning about choice and respect in relationships

(SDC fact sheet on Sexual Self-Advocacy)

Yet, self-advocates worry that their families will not be supportive of their efforts to choose to be in intimate relationships. (Healy, et al 2009)

One way to help families support the self-determination goals for the person with a disability with regard to sexuality

Self-advocates have spoken up about their desire to have relationships – from friendships to intimate partners and marriage.

is to remember the broader goal of a fully inclusive community life. Families are keenly aware of the challenges that face the person with a disability. Their hopes for the future include a desire for fulfilling relationships, regardless of age or ability level of their child. (Nichols & Blakely-Smith 2010). A well-done person-centered plan can help the person with a disability identify his or her goals regarding friendships, dating, and intimacy. Being open to conversations about the desires and dreams of the person with a disability can be a positive first step. The family's values and beliefs can provide a foundation and context for this discussion.

Family support for the person with a disability's desire to obtain information about sexuality education can make a significant impact in his or her life. Communicating to provider agencies and community organizations that sexual health and opportunities for age-appropriate social interactions need to be expanded and supported is another important step families can take. While offering support to the person with a disability, it is important for families to maintain a sense of appropriate

Family support for the person with a disability's desire to obtain information about sexuality education can make a significant impact in his or her life.

boundaries. There are occasions when out of a desire to help, a parent may overstep a boundary and inadvertently "take over" the planning and participation in social, recreational and even intimate activities. It is equally, if not more, important to listen to the person with a disability and let his or her choices guide the process.

Another key resource families can make use of is the relationship of the sibling to the person with a disability. Siblings are in a unique position to observe and understand how the person with a disability interacts in the community and what barriers the community presents to the person with a disability. Many siblings are aware of the negative reactions to their brother or sister at school, in the neighborhood or in the community at large. They may act protectively and advocate for their sibling. Sibling relationships are enduring and often have more elements of egalitarianism than found in the relationship with parents. Siblings may have the advantage in understanding more about the person with a disability's desire for romantic and intimate relationships. They can provide support and help advocate for better opportunities for socialization, recreation and community living. At the same time, it is important to be aware that sibling rivalry can be a factor influencing the relationships between brothers and sisters. This can be a relatively normal and healthy aspect of family relationships. However, there can be times when a person with a disability may feel jealous or "left behind" watching his or her sibling date, marry and have children, feeling that these life events are unattainable.

It can take some effort for the person with a disability to feel comfortable expressing his or her goals and dreams regarding relationships and sexuality. The family can model openness and acceptance. Many families have come up with creative solutions to encourage the person with a disability to identify goals, including the use of scrapbooks, PhotoVoice, future planning and the person-centered planning tools, such as PATH and MAPS. Relationships give meaning to our lives. The family can play a central role in supporting and modeling healthy relationships. Sexuality is a natural part of everyone's life. The importance of friendships and romantic and intimate relationships for the person with a disability should be guided by the goals and aspirations of the person with a disability, with family members playing a key supporting role.

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Siblings are in a unique position to observe and understand how the person with a disability interacts in the community and what barriers the community presents to the person with a disability.



The Sibling Leadership Network: Promoting Self-Determination through Sibling Advocacy

Katie Arnold

Siblings are uniquely positioned in the family to support their brothers and sisters with disabilities to lead self-determined lives. The sibling relationship is the longest relationship of most people's lives and the peer nature of their relationship makes them well suited to help create an environment of support that allows their brothers and sisters with disabilities to live the lives they want. Siblings can promote choice-making and opportunities for their brothers and sister with disabilities. The sibling story of Nora and Marty highlights the ways siblings can do this.

After the death of their mother, Nora's brother Marty moved in with her family for a year and a half. During that time, Nora played a key role in helping him navigate the disability service system to get the supports he needed. The sibling pair attended the *Future is Now* training and began talking about and planning for the future. At first, Nora thought about her role with Marty as stepping into her mother's shoes and acting like a parental figure to her brother. She assumed that she knew what was best for Marty. However, as they worked through the *Future is Now* training (Factor et al., 2010; Heller & Caldwell, 2006) she realized that Marty had his own ideas about what he wanted for his life. And, some of his ideas were a little scary to her. He wanted to live on his own, have a girlfriend, and make decisions about his life.

Nora's idea about her role as a sibling has changed over time and she has learned how to advocate *with* her brother with disabilities. She has supported Marty to advocate for himself and become more independent. Marty now lives on his own with support, has a job in the community, and volunteers. Marty found love and has developed a strong relationship with his girlfriend. Marty has even taken the

advocacy skills he has learned and applied them to help his girlfriend.

From her own sibling experience, Nora identified a need for siblings of people with disabilities to have way a place where they could go to receive information and support. She helped create Supporting Illinois Brothers and Sisters (SIBS), the Illinois state sibling chapter of the national Sibling Leadership Network. It was an organization she wished had been around to help her get the information and support she needed to provide support, in turn, to Marty. Nora has served as the Treasurer of SIBS since 2007.

Marty joined the Self-Advocacy Council of Northern Illinois, which helped him connect with other people in his area and strengthen his self-advocacy skills. About a year ago, Marty called Nora to share his exciting news that he had just been elected Treasurer of his self-advocacy group. She was surprised and excited, saying "it must run in the family" as they are now both the Treasurers of their respective advocacy organizations.

As a sibling pair, Marty and Nora serve on the Consumer Advisory Committee of the Illinois University Center of Excellence in Developmental Disabilities (UCEDD). At the meetings they have distinct voices and share their own personal perspectives. They often sit in different places around the table at meetings, though they occasionally help each other remember facts or dates related to experiences or ideas they share. Their support is mutual.

While Nora and Marty's relationship is not perfect, they continue to learn and



The Sibling Leadership Network in action.

grow together. Their interactions evolved from one of parental authority to one of mutual support in which Marty's self-determination – through pursuit of personal interests, independent

living, self-sufficiency, and important personal relationships – has been enhanced throughout the years.

About The Sibling Leadership Network

Founded in 2007, the Sibling Leadership Network (SLN) is a national nonprofit dedicated to providing siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families. Siblings of people with disabilities have traditionally been overlooked by parents, professionals, and policymakers, yet the sibling perspective brings value to strengthen family support. The SLN provides information and training to siblings throughout the lifespan, as the needs of young siblings change as the family ages.

The SLN Board of Directors consists of volunteers from across the country, including representatives from Self Advocates Becoming Empowered, the Sibling Support Project, and the state sibling chapters. In April, the SLN hired its first, part-time Executive Director to help build and grow the organization's capacity. The SLN and the Sibling Support Project co-host an internet based forum for adult siblings to connect online and provide peer support called SibNet. The SLN network consists of over 1700 leaders



of sibling groups, organizations, and individuals, including state chapters and national partners. Currently, there are 13 state chapters of the SLN (AL, DC, GA, IL, MA, MI, NH, NY, OH, PA, TN, UT & WI) and additional chapters are being nurtured throughout the country. Chapters are the grassroots of the organization and maintain more personal contact with people, ensuring that they obtain the information and support they need. National partners include Self Advocates Becoming Empowered, The Sibling Support Project, and The Arc. The SLN is a member of the National Self-Determination Alliance and Autism NOW's National Partners Council. The SLN and state sibling chapters host and promote Sibshops for young siblings as well as Sibshop facilitator training in order to build the capacity to run Sibshops across the country. The SLN holds national sibling conferences, leadership meetings, and webinars to educate siblings, family members, professionals, and policymakers.



The SLN believes that individuals with developmental disabilities share the same rights as all members of society, including the right to the opportunity to grow and be productive members of their communities. The SLN believes in promoting these rights and is committed to advocating for policies and services that meet their needs. Policy and advocacy activities are major components of the SLN. The group advocates for federal policies that advance opportunities for full community inclusion and participation of people with disabilities through appropriate long-term services and supports.

The Sibling Leadership Network (SLN) encourages siblings to support their brothers and sisters with disabilities to lead self-determined lives. Siblings of people with disabilities are an untapped constituency for policy advocacy that can increase the power in the disability advocacy movement. If the majority of the over 54 million people with disabilities in the United States has at least one sibling, the number of potential advocates grows

exponentially. A great deal of potential exists for siblings to work and advocate together for important issues to improve the lives of their entire families. The Sibling Leadership Network believes that all citizens have the right to vote, including people with disabilities. Our organization has created a voting position statement as well as a voting video to share with our network and encourage siblings to support their brothers and sisters with disabilities in the voting process. For example, siblings can help their brothers and sisters with disabilities get registered to vote, get educated about the candidates, and get to the polls. As a sponsor of the non-partisan National Forum on Disability Issues being held on September 28th in Columbus, Ohio, the Sibling Leadership Network is helping our network get information about the presidential candidates' visions of policy that affect people with disabilities. Our state chapters will hold watch parties around the country where the National Forum will be streamed live over the internet. We plan to partner with various organizations to hold these state and local gatherings and bring the disability community together with allies in order to educate themselves and make an informed decision for the upcoming election.

For more information visit:
www.siblingleadership.org.

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Katie Arnold, MS, is the Executive Director of the Sibling Leadership Network (SLN), a national nonprofit organization dedicated to providing siblings of individuals with disabilities necessary information, support, and tools to advocate with their brothers and sisters. Katie also works on community education, aging and developmental disabilities, and health-related projects at the University of Illinois at Chicago, serving on the Council on Quality and Leadership and AUCD's Family Support Special Interest Group.

The future is now: A future planning training curriculum for families and their adult relatives with developmental disabilities (2010 updated version)

Factor, A., DeBrine, E., Caldwell, J., Arnold, K., Kramer, J., Nelis, T., & Heller, T.

This evidence-based curriculum equips families and their adult relative with a disability with the communication skills and information to jointly plan for the future. Participants learn how to overcome the emotional and systematic barriers to planning with the support of peer mentors who have



made plans. They prepare a letter of intent that lays out their dreams for the future and identifies the steps required to transform this dream into a reality. This state-of-the-art approach to future planning was developed, implemented and evaluated by the Rehabilitation Research and Training Center on Aging with Developmental Disabilities at the University of Illinois at Chicago.

It is an excellent resource for agencies, family organizations and advocacy groups.

Softcover Curriculum and CD-ROM: \$70.00+Shipping

Training can be provided to groups of families or a train-the-trainer for professionals.

Visit www.rttcadd.org or contact Alan Factor at afactor@uic.edu or (312) 413-1510



Thinking Ahead for Healthcare Advance Directives

Tia Nelis and Stacy Yusim

Self-determination means that you know what you want and are in charge of your life. You are telling people the things that you want to make choices about, and you're directing the things that you want in your life. Part of having a self-determined life is making both easy and hard choices and decisions.

It's important for everyone to have an advance directive. Advance directives are for when a person needs health care but can't make a decision because he or she is sick, in the hospital, or has had an accident. It tells the doctor and others what you want when you are not able to tell them. Also, others will know what

people who they want or trust, or you can also help your son or daughter to complete the advanced directive on their own. There are many different support forms for advance directives that help everyone to understand how to fill it out. Some forms have pictures and easy to understand words. For example, the State of California Department of Developmental Services published "Thinking Ahead: My Way, My Choice, My Life at the End." This tool consists of a workbook with pictures and a video, created by California advocates with developmental disabilities from three regional centers. It is available for free at www.dds.ca.gov/ConsumerCorner/ThinkingAhead.

Family members should know that an individual has the right to choose their health agent. A health agent can be a family member or a friend, someone the person is close to and trusts to make health decisions for them. This health agent can be changed at any time if needed, but if you change health agents, you need to make sure you give out the new advance directive to the people that need to have it.

Advance directives also let you choose treatment preferences. This part lets you choose how you want to be treated if you have a terminal illness and/or you cannot communicate. Treatment preferences only become effective if you can't communicate your wishes. When the person is not too sick to make decisions, they can still change their mind about how they want to be treated.

Advance directives can be used in medical situations other than end of life decisions. For example, when your son or daughter wants someone to support them during a doctor's appointment, they may use it to ask the doctor if that person can be present with them in case they don't understand what the doctor is saying or what they need to do or medications they may need to take.

You need to check with your state on how to make your advance directives



Tia Nelis advocates for herself and others nationwide.

legal. You don't have to have an attorney write up your advance directives, unless you want one. I hope more people with and without disabilities will make sure they have their advance directives done ahead of time, so others will know what choices and decisions are important to them, even when they are not able to communicate. An advance directive is an important part of self-determination and directing what you want in life.

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An advance directive helps you be in charge of your life.

you want before an emergency happens. Stress can be high during an emergency, so it important to make a plan ahead of time. An advance directive helps you be in charge of your life. Everyone needs to follow the decisions you make in your advance directive, even if you can't tell them at the time what you want.

It is also important for all of your family members to know about the advance directive and participate in the decisions so everyone will be prepared and know what you want during medical emergencies. As you and your family members are working on the advance directive, make sure you include the person who the advance directive is for. So if it's for your son or daughter, or brother or sister, with a disability, it's important to include them in the discussions and the decisions about what they would want. If they need support to do the advance directive, make sure they choose the



Scaling Up Self-Determination through Family Support

Sheli Reynolds, Jane St. John, and George Gotto

One of the key priorities of the National Gateway to Self-Determination initiative funded by the Administration on Intellectual and Developmental Disabilities is to scale-up self-determination activities by moving from “promising practices” to a large-scale adoption of the practice across states and service systems (Bacon, et al., 2011). In other words, self-determination activities should be adopted throughout our systems of support and principles of self-determination should be infused into existing practices and drive innovation in services for individuals with disabilities. One example of scaling up is the development and further adaptation and varied use of the *Self-Determined Learning Model of Instruction (SDLMI)*, (Wehmeyer, Palmer, Mithaug, Agran, & Martin, 2000) which has been shown to have an impact on student attainment of academic and transition goals and to enhance self-determination. The SDLMI successfully moved through the four phases of scaling up: (1) emergence, (2) demonstrating capacity, (3) elaboration, and (4) system adoption. To this point, self-determination as a set of volitional actions has been scaled-up most effectively among students with developmental

disabilities in high school settings and transition to adulthood (Wehmeyer, 2007). The next step is to expand the scaling-up activities regarding self-determination beyond the educational arena into other environments that provide opportunities for fostering self-determination, such as early childhood, the formal disability service system, vocational rehabilitation, and even the family home.

We propose that one of the most effective ways to scale-up activities focused on self-determination is to identify strategies that support and build the capacity of families to promote self-determination and build these principles into daily routines and expectations early in childhood and throughout the lifespan. As highlighted in the introduction article, families play an integral role in the process by creating environments and opportunities that lead to self-determination, integration, independence and productivity starting early in the child's life and continuing into adulthood. Historically, however, families with members with intellectual and developmental disabilities are less likely to receive supports for creating a vision for their loved one or the tools to navigate and support opportunities for life in the community. When families do seek supports, they often find the design of traditional services is to respond to a crisis. Families often face the reality of having to wait until a crisis occurs to get needed supports or accepting supports they may not want or are not well-designed for their family member's needs.

The Missouri Family-to-Family Disability and Health Information Center, housed within the University Center on Excellence in Developmental Disabilities at the University of Missouri-Kansas City, Institute for Human Development, is scaling up self-determination practices by infusing the theory and concepts of self-determination into the existing

family support training and information tools at the center. Specifically, this group has infused the concept of self-determination into their *Charting Your Life Course* tool guide that helps families realize that even when children are very young and as they age and grow into adulthood, their experiences and environment can continually shape how they will live their life in the future.

Historically, families and professionals alike may not start thinking about teaching or instilling self-determination until a person with a disability reaches the age of transition from school to adulthood, or even later. This makes perfect sense since families are very much involved in the day-to-day nurturing and care of members, especially for individuals within their family who have disabilities. This ongoing support takes an enormous amount of energy but could very well include elements of self-determination as part of the life course journey from the very beginning. Families naturally include

Siblings of people with disabilities have traditionally been overlooked by parents, professionals, and policymakers, yet the sibling perspective brings value to strengthen family support.



their members in ongoing activities within the family home, but sometimes supporting a child with a disability makes



it harder to infuse self-determination into daily life without conscious planning and implementation of accommodations and adaptations to build on child strengths masked by obvious limitations. Children can start building capacity to be self-determined from birth by having opportunities to make choices, to learn about new places and things, develop skills, and learn responsibility. Individuals and families, as well as professionals who provide support, need tools to guide them to consider self-determined practices to help them along the way to achieving full and meaningful, self-determined lives.

Charting the Life Course tool was originally created to help guide individuals and families who experience disability or special healthcare needs as they consider the various life experiences, choices and opportunities at each stage of life. It was developed over a 2-year period through a series of meetings with the Missouri Family to Family Stakeholders group which includes representatives from over 35 different organizations, with 75% of the members identifying as a self-advocate or a family leader.

The guide is organized to help families in the current stage of their life journey, but also to encourage an eye to the future, and recognize that experiences and

environments now can shape and affect how the rest of their life unfolds. The tool is written and formatted utilizing visual icons that represent two major areas; life categories and life stages. Life categories are the different aspects and experiences of life that we all consider as we age and grow, such as daily life, community living, health and wellness. Everyone (whether with a disability or not) has to figure out: what they are going to do during the day—go to school, volunteer, get a job; where they are going to live; how they are going to stay healthy and safe; and so on. The life stages represent different ages and stages of life from pre-natal/birth through aging/end of life. At the intersection of each life stage and life category is a set of questions for families to ask or think about in order to plot a course toward a meaningful life now and in the future.

Scaling Up Self-Determination into the Tool

For the second edition, the Missouri Family to Family staff worked closely with the National Gateway to Self-Determination project to further infuse and highlight the concept of self-determination into the tool. For example, questions specifically focusing on self-determination across the lifespan were

Families play an integral role in the process by creating environments and opportunities that lead to self-determination, integration, independence and productivity starting early in the child's life and continuing into adulthood.

based on an article, *Self-Determination: A Life-Span Perspective* written by Susan B. Palmer. Throughout the guide some questions have a star to highlight ways to foster self-determination throughout the entire life course. Finally, after the concepts were incorporated into the tool, staff from National Gateway to Self-Determination and the Self-Advocates Becoming Empowered Self-Determination work group reviewed and provided additional feedback on the tool.

Additionally, the questions were rewritten to reflect a “first-person” perspective across the lifespan to represent the viewpoint of the person with a disability and the on-going transformation to an adult who is self-determined, autonomous, and independent. For the questions in infancy and early childhood stages, the person with a disability asks questions about what the family or others around them are doing to *support them* or *helping them* learn to do. As the child ages into transition and adulthood, the person begins to ask questions about *what they themselves are doing or should be doing*. This illustrates how during earlier years young children are more dependent on the parent or family unit. In transition and adult years, the family, while still involved and an important part of the person's life, takes on different roles as the person with a disability assumes a larger role in making their own choices and decisions about how they live their life.

Table 2. Life Course Legend

Life Categories	Life Stages
 Daily Life What a person does as part of everyday life— school, employment, volunteering, communication, routines, life skills.	 Prenatal/Infancy Before or at birth, or when child is an infant, wondering if hitting developmental milestones
 Community Living Where and how someone lives— housing and living options, community access, transportation, home adaptations and modifications.	 Early Childhood Preschool age; getting a diagnosis
 Social & Spirituality Building relationships friendships and relationships, leisure activities, personal networks, faith community.	 School Age Everyday life during school years
 Healthy Living Managing and accessing health care and staying well— medical, mental health, behavior, developmental, wellness, and nutrition.	 Transition Transitioning from school to adult life
 Services & Supports Services and supports for individuals and families— both funded (systems) and natural supports; personal/family financial.	 Adulthood Living life as an adult and as the family of an adult
 Safety & Security Staying safe and secure— emergencies, well-being, guardianship options, legal rights and issues.	 Aging Aging and preparing for end of life (parent/family/individual)
 Advocacy & Family Support Support for families/individuals— peer support, self-advocacy.	 Promotes self-determination

Examples of Scaling-Up Self-Determination into Practice

To continue to scale-up the guide into practice, the Missouri Family to Family partners with the different state systems, such as the Division of Developmental Disabilities, Missouri's disability service system, First Steps (Part C Early Childhood) and the Bureau of Special Health Care Needs. The guide which also includes ideas for utilizing it with self-advocates and families, is provided to support coordinators, teachers, early childhood educators, and family leaders. Specifically, Family Support Coordinators work one-to-one with families, as well as using the tool to guide group discussions. During professional development training, the guide serves as the focus for adult learning conversations.

One Family Support Coordinator utilized the tool during a training session to families and Special Educators on the topic of transition. During the training, small groups identified and discussed a topic and a life stage of their chose. For one group, the focus was on socialization

Self-determination should be infused into existing practices and drive innovation in services for individuals with disabilities.

with the specific question, "is my child learning social skills to help make friends and maintain friendships?" Several weeks after the training, a Special Education teacher explained how one family brought up that question during their daughters IEP. As a result, a goal focusing on this topic has been included in her plan for the upcoming school year.

Another Family Support Coordinator facilitated a conversation during a Disability Support Group meeting for families in her local community. Again,

each attendee identified a question in the guide that they wanted to discuss. A week after the meeting, an African American father with a daughter in preschool contacted the facilitator to let her know that he had really thought a lot about the meeting and the questions discussed. He explained that this was the first time that he realized that if he wanted to achieve the quality of life for his daughter that he wanted; he was going to have to develop relationships with people that cared about his daughter and put expectations in place now to make that a reality for when she was an adult. He said the guide helped him recognize a future for his daughter while providing concrete areas to be focusing on now in early childhood that will affect adulthood.

By infusing self-determination concepts into the tool and scaling-up the utilization of the tool into practice, professionals, self-advocates and families are better equipped to interact within structures and systems that can support self-determined lives. This not only increases individual understanding of self-determination but also creates opportunities for fostering self-determination in environments beyond the educational system.

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Self-Advocates on the Role of Families and Self-Determination

Laura Walker Jackson

In June 2012, a group of leaders in the self-advocacy movement met to discuss the ways in which families, including parents and siblings, have presented both supports and challenges while building their dream through self-determination. A parent and two siblings joined the discussion and provided their perspectives as well. The following highlights and suggestions may help families and siblings to better understand the positive role families can play in supporting the growth of an individual to ensure a self-determined life.

Families of individuals with disabilities understand more today about the abilities and strengths of people with disabilities, but it is important to remember the societal changes that have occurred and consider the possible differences among generations.

- Older family members are used to what society taught them about disabilities. We can still educate them on how they interact with people with disabilities and treat their own family members with disabilities
- Older self-advocates had to fight much harder to be heard and have their families understand their right to self-determination.
- Youth are growing up with many more opportunities for self-determination and are often educated among people without disabilities in school.
- Youth with disabilities today are much more able to use their choice-making and abilities to go to college and get jobs in the community.
- “Families made assumptions and decisions for the person even more so in the past when the person did not want/need it.”

Many families are the unseen supporters of self-advocates.

Families can be a great support for people with disabilities with the right information and education about self-determination.

- It helps to encourage your family and siblings to participate in your activities as a self-advocate.
- If you understand disability rights and disability history, educate your family and siblings. Invite family to participate in your self-advocacy activities
- There are so many resources available to families and siblings now on self-advocacy and self-determination.



Siblings Bryon and Gayla Murray discuss their experiences with advisor, Vicki Turnage, and self-advocate, Vicky Wray, at a SABE board meeting.



“My family over the years has helped me to be independent and self-reliant, and to live in a home of my own,” says Brad Linnenkamp, Self-Advocate.

Share them with your family members of all ages. Parent groups and sibling groups are all over the country, both online and in person.

- Teach your family and siblings about People First and Respectful language.
- Families and siblings need to know the history of struggling for self-determination. They need to know what others have had to go through in order to get where they are today.
- When treated as an equal sibling within a family, the individual with a disability is more likely to succeed and make their own decisions.
- “It helped to be included in all family activities as equal to my siblings - even chores and punishment.”
- “If your family believes in you, then they are going to support you in the things that you do. They will see the things that you do as great things.”
- “How society explains people’s disabilities to parents is a major factor. They see behaviors rather than the person.”

It is important to recognize certain realities of family support after parents can no longer participate.

- Don’t expect all your family members to want to participate in your goals or your future - it’s their life too.
- Some family members, such as adult siblings, might not want to be a part of your support once your parents are gone.
- If both you and your sibling want and have agreed on a sibling system of support, be sure to prepare siblings, especially if they are not that close, about what changes will occur in your support needs before they happen.
- The amount of support needed depends on the disability. For example, support needs would vary between medical supports and everyday living supports. Some family members aren’t comfortable with physical care responsibilities.
- Even though we have made a lot of progress as a society, we are sometimes still looked at as weak by family members.
- Some family members are naturally geared toward certain kinds of support, not necessarily wanting to be a caretaker. For example, they can be a connector rather than a doer.
- “Help your family member recognize that support goes both ways. People with disability take care of family members, too.”
- “Hidden disabilities are difficult to get supports for, especially when someone is not seen as having a disability, even in the family.”

People with disabilities can and should live in environments that afford as many opportunities as possible to experience life in a self-determined manner. Advocacy

Help your family member recognize that support goes both ways. People with a disability take care of family members, too.

and self-advocacy are important parts of self-determined abilities. The self-advocacy movement has helped to increase the voice, opinions, visibility, and leadership of individuals with disabilities in local or community, state, and national issues and legislation. While much of the movement depends on individuals with disabilities, many families are the unseen supporters of self-advocates. Although we often think of self-advocacy as a singular activity, it occurs through the collaborative effort of other self-advocates, self-advocacy groups, and individuals, such as family members or friends.

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The self-advocacy movement has helped to increase the voice, opinions, visibility, and leadership of individuals with disabilities in local, state, and national issues and legislation.



A Sibling's Perspective on Supporting Self-Determination

Kate Fialkowski

I am a sibling of a powerful man named David. I consider David powerful because his life is a testament to the world of possibility for all individuals. Through him, I, and others, have learned to celebrate each person's uniqueness and capacity to contribute and add value to society. You should know David has achieved the complete antithesis of what was expected of him when he was born in 1962. Not only was it assumed that David would do nothing and amount to nothing but -- and this is really hard to write -- some of the greatest minds and professionals of the day thought that individuals with Developmental Disabilities (formerly labeled with the term mental retardation) were societal detractors.

David is two years my senior. He and I are the youngest of 11 children. As a family of thirteen people, our small row house in Philadelphia ran like a manufacturing production line. Each person understood the constraints of one bathroom. Our compensating strategies included anticipating needs and habitually finishing each other's tasks if in proximity. We were forced to work closely together to ensure the tasks of the day could be completed, even simple things like making sure supper got on the table and the kids got off to school.

When David and I were still in elementary school, everyone else had cleared out of the house; they'd grown up, moved out, and moved on with their own lives. Meanwhile, our lives at home continued together and even intertwined in a number of ways. As a small child my job was to anticipate what David would need. Was he hungry? Thirsty? David and I were always in the same school -- from my very first day. After David was "mainstreamed" (included in the public school system as a result of our parents fighting for the "right to education"), it was my job to check in on him in the school room. Was he okay? Was he safe?

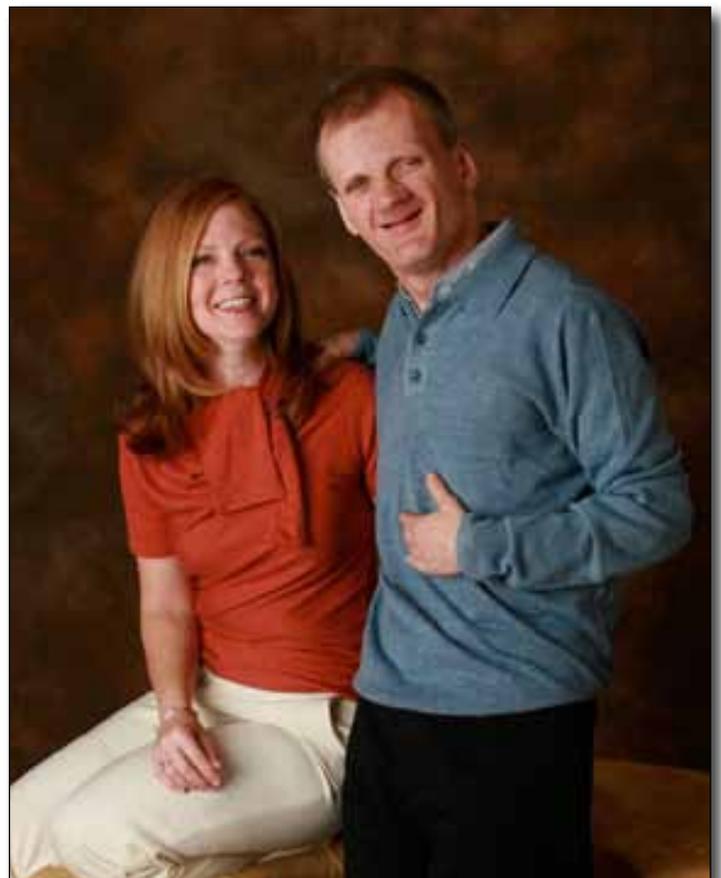
These were valid questions as the right to education preceded expertise in education for individuals with developmental disabilities. I would often find David alone in a corner, strapped to a chair. It broke my heart to see him tethered. Being the "watcher" was so ingrained that when my parents died, this role continued.

When my parents died, I have to be honest and tell you that I wasn't thinking about "self-determination for David." I was consumed with watching, anticipating, and ensuring David's basic needs: Was he eating? Was he well? Was he safe? I was consumed by these things because they seemed to be missing. After our mom died, David's weight dropped. We had an incident when he was rushed to the emergency room with a large gash from his forehead to the back of his head. I was terrified that something would happen on my "watch."

I have often woken up in the middle of the night asking myself one of two questions: what will happen to David if I die first? What will happen to me if David dies first? These two questions can be all consuming. My "caring *for* David" might never have progressed to "caring *about* David" except little by little, moments of awakening came to me. I started noticing David's daily life. Here are a few samples of his reality and how I see my role supporting his self-determination:

There is a prevailing assumption of incompetence

I see that David--capable of walking, albeit slowly--is often not walking. He has a walker and more often than not, people sit David on the walker to move him about more quickly. I watch as David--capable of taking off his coat and hat--is regularly dressed and undressed by others, without his participation. David--who can tell you when he is thirsty--is given drinks when it's convenient, or when others think about it. Surrounding David there is such a pervasive assumption of incompetence that David doesn't have to initiate a single thing. In fact, sometimes his initiating is seen as inconvenient and is often discouraged. As a by-product, David learns helplessness in almost every aspect of his life.



Kate and David - a family portrait.

My job as a sibling is to present opportunities for him to experience competence, autonomy, and relatedness through which he can grow, risk, conquer, express, select, exist.

What is my job in promoting self-determination? Presume Competence.

Simply put, my job is to remind people as often as I can that “David can do it.” My job is to help people change their minds and assume competence. When this happens, David blossoms. Before, David would not walk anywhere unless someone else initiated it. But he now gets up and walks across his living room to his bedroom completely unaided, without his walker and without leaning on anyone, and he goes when he wants to. At home when he wants something to eat, he walks to the dining room table. When he wants something to drink, he taps his chin with his hand. Yes, David can do it.

I won’t exaggerate. Sometimes after all those years of growing up together, I am the one at fault. I am the one anticipating and compensating. Luckily I have friends who are self-advocates and when I do it, they are quick to speak up and say “Kate, um, maybe David can do it!”

There is a pervasive structure of interdependence

I bought David a membership to a garden and one day I met him there. A staff worker took me aside to tell me how the world worked. She was quite blunt when she said to me, “Don’t you understand that when David comes here everybody else suffers? When David has the van no one else can go out?” Ah, I had to wake up to the fact that David was part of a system. His housemates. His staff. His day program. They were all intertwined. They were to move together as one entity, one system. I was supposed to concede to the interconnectedness. I

was being told to acquiesce to the fact that David had to relinquish his autonomy.

What is my job in promoting self-determination? Demand autonomy -- for everyone. Sometimes we call it “person centeredness” but it really is about autonomy. David’s life should be his own unique life. He should be able to do things he wants and he should be able to make choices. I know I’m not there every minute of the day to ensure this happens. So I see that my role as a sibling is to provide options for David and others. Through financial means I provide memberships, tickets, and events -- concrete things that David and others get to experience and through the experience of doing them, have the opportunity to express their interest, excitement, enthusiasm, or disinterest. David is expressive. He is emphatic when he does not like something and he is equally demonstrative when he does like something. My job is not to keep David quiet but to encourage opportunities where he gets to express himself.

I can admit that this is not perfect. Unique, isolated events work occasionally. But when David loves something--baseball, swimming, etc--they do happen recurrently but sometimes not consistently. It is a work in progress.

There continues to be prevalent isolation

Despite our best efforts, individuals with developmental disabilities still often live outside the community even if their house is in the middle of the community. My brother lives inside his house, not really inside his community. As for our family, after our parents died, the hub at the center of our family was gone and we all drifted apart. Within the family and the neighborhood, there is a distance that surrounds my brother and it is its own barrier that is hard to overcome. David became invisible. Unknown. If David is invisible and unknown, how can he have relationships? How can he find belonging with individuals who are not paid to be with him? Of all the issues, this is the one that I worry most about. This is the one I fear makes him truly vulnerable.

What is my job in promoting self-determination? Be a “reference.” When someone needs a job, we will be the person that “refers” them. Relationships are referential. Social media has presented

a new means by which our family was re-introduced to David. I set up a Facebook page for David so that others in the family could see what happens in David’s life. We occasionally post pictures of David in his travels. Much to my surprise (why was I surprised?) our nieces and nephews reached out to David immediately. They posted pictures of themselves with David over the years. More “references!” Then other people “friended” David, people who had previously worked with him or supported him. I was surprised that he had his own “friends” and they weren’t mine! David went from invisible to existing overnight. And more importantly, all of these “references” have helped “personalize” David. David does have his own life, his own interests, and his own relationships.

David celebrated his 50th birthday this year. Fifty family members were there to celebrate. In large part this happened because the wall of isolation had been thawed by social media. People felt comfortable to come to the event.

In conclusion

Supporting my brother’s self-determination is hard. Through the process I have learned so much about humanity and dignity. I can’t stop myself now. Little by little we have achieved occasional positive forward progress, which fuels hope. My job as his sibling is to present opportunities for David to experience competence, autonomy, and relatedness through which he can grow, risk, conquer, express, select, exist. My hope for David in the future is that his environment becomes more supportive--not in terms of providing more to him but in terms of expecting more from him, and honestly, we have to expect more from each other. As we know, if David’s environment becomes more supportive he will be even more welcomed as a participant in society. I know for a fact that when this happens, our lives, as well as David’s, will be changed.

Kate Fialkowski is the Executive Director at The Arc of Maryland, Maryland’s largest grassroots statewide advocacy organization. Kate served as Joseph P. Kennedy Jr. Public Policy Fellow at the Administration on Intellectual and Developmental Disabilities (AIDD) and lives near Annapolis, Maryland.



A Parent's Perspective on Making Choices, Behavior Challenges, and Self-Determination

George Gotto

Self-Determination is important at different life stages for individuals with intellectual and developmental disabilities. When people finish formal schooling and move into adult services, it is critical to navigate through the array of services and figure out what is working or not. Individuals with behavior needs present even greater challenges when we consider self-determination. For example, typical services are often set up to meet the needs of people as a group. However, individuals who present needs outside of what is normally expected are often less satisfied with “business as usual”. The following is a brief interview we conducted with Debra Wohlers, the Director of the Adair County Missouri, Senate Bill 40 Board on Developmental Disability.

George: Tell me about your experience as a parent and how you became interested in self-determination.

Deb: I’m the parent of a twenty-eight year old daughter with disabilities. It was a matter of survival. My daughter has intellectual disability and some pretty challenging behaviors. We had pretty much reached the end of our rope as far as traditional supports go for her. It was a matter of self-preservation that I really learned about self-determination and self-directed supports since Jessica

had been in individualized supported living (ISL) for about six years and things were going from bad to worse.

George: What else changed to support self-determination for your daughter?

Deb: About that time, the state started looking at transition into a variety of services to meet people’s needs. Kyla Eversman, now State Director of Self-Determination, happened to visit our office on Jessica’s meeting day and shared about self-determination and choices, there I am the protective parent going, “I don’t think so!” It’s always been more about restriction and more supervision for my daughter, not giving her more choices. We were at the point where I was about ready to try anything and we supported self-determination in Jessica’s life.

George: What can parents do to support self-determination? What did you do?

Deb: I sat down with Jessica and asked her what she wanted in her life. Jessica started talking about the things that she wanted when she finally was convinced that somebody was listening. We used self-directed supports and started building those things into her life according to what Jessica wanted, instead of what everybody else thought was best for her. That made me a firm believer that self-determination is something that everybody’s entitled to, and that we should do our best to support any person to have the highest degree of self-determination possible in their lives.

George: What were some of the decisions Jessica made about her life?

Deb: Jessica didn’t want to live in individualized supported living anymore with the roommates and staff that she didn’t like. We found a home for her to live affordably by herself, close to us in her old neighborhood where she grew up. She wanted to choose the people that worked with her – a big step in the right direction. It was kind of a no brainer that you pick the people that she gets along

with and that understand her to support her. Jessica’s been so much happier since she was able to do that, even though it means that she has less spending money that she would have otherwise.

George: What else has changed?

Deb: Jessica thought she wanted a dog, but that didn’t work out. She’s had a cat for almost a year and has been very happy. Jessica has also recently chosen a different plan to work. Previously she was in a supported work program in another town which involved riding the bus daily. Jessica did repetitive work surrounded by other folks that she didn’t particularly get along with very well but managed to keep that job for a number of years, even though she didn’t really enjoy it. She’s always wanted to work at the college near our home. We went to vocational rehabilitation and Jessica told them, “I want to work on campus.” They looked at some different possibilities and she’s now a dishwasher at one of the dorms, and doing very well and is much happier than she was before.

Self-Determination is about more than choices, but choices are a very good place to start for many people who have fewer options in their lives. Having opportunities and options is very important for everyone, but especially individuals with intellectual and developmental disabilities. Any individual can exercise self-determination, but some people with more limited abilities might need more help. Families can be a part of their children’s lives and support self-determination, much like Deb Wohlers has done. A critical focus for families is to notice when things are not working for their family member, help to address some options to make things different, and ask questions and listen very carefully in order to support self-determined lives for all.

George Gotto, PhD, UMKC Institute for Human Development UCEDD, Kansas City, MO. George is the Director of Community Services.



Jessica and Coco enjoy time at home.

A National Gateway to Self-Determination

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The National Gateway on Self-Determination

To establish a sustainable,
evidence-based training
system that enhances self-
determination training programs
that lead to quality of life
outcomes for individuals with
developmental disabilities
throughout the lifespan.



COMING IN THE NEXT ISSUE:

Self-Determination and Aging
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