



Speaking out about services in South Dakota

People Leading Accessible Networks of Support

Listen
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Dale and Arlene Delker



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Trish Dorn

Foreword

The primary goal of the People Leading Accessible Networks of Support (PLANS) Family Support 360 Project is to implement local programs that will assist families and communities in supporting individuals with developmental disabilities. The model will provide an opportunity for people to have choice and control regarding which services and supports they need, where the services are provided, and who will provide them. In order to assure that needs of individuals with developmental disabilities and their families were understood and incorporated in the model, a series of public forums were held in August 2004.

The forums were supported by the Department of Human Services, Division of Developmental Disabilities; South Dakota Council on Developmental Disabilities; PLANS Family Support 360 Project; and Sioux Vocational Services. The purpose of the public forums was to listen to individuals with developmental disabilities and family members who are currently receiving Family Support services or Home and Community Based Waiver services (HCBS) and to identify how people can be better served in the environment they want for their services. Each forum was preceded by guardianship training for interested individuals.

To successfully advertise the forums, flyers were mailed to current recipients of Family Support services and HCBS. Approximately 200 individuals, family members and staff members attended the forums throughout the week. Interviewers had the opportunity to meet one-on-one with 80 people to listen to their ideas. In addition, surveys were mailed to those who could not attend, and approximately 125 completed surveys were returned. A number of themes were identified in the interviews and surveys, and the individual stories in this brochure represent some of those themes.

The success of the public forums was due in large part to the efforts of the PLANS Family Support 360 Project Statewide Advisory Workgroup. Members of this workgroup represent individuals with developmental disabilities, family members, state agencies, service providers and community organizations.



PLANS Statewide Advisory Workgroup

Community Involvement

The last few decades have seen incredible strides in community integration and collaboration. While people feel respected by staff and community members, true community inclusion unfortunately continues to elude many people with developmental disabilities. People live in the community and are consumers of community services and supports but are not necessarily part of or involved in the community. True inclusion means actual involvement in the community. Danny describes in his own words his involvement in the community in the following section.

Danny



“I’ve been receiving services at an Adjustment Training Center (ATC) since 1985. I recently moved into my own apartment on the east side of Sioux Falls and have two roommates. Right now I work at the ATC workshop stringing pulleys but I would like to get a job working with computers somewhere in the community. I volunteer at a lot of different places in Sioux Falls, but my favorite is being an athletic trainer assistant at O’Gorman High School for the football and basketball teams. Another place that I volunteer at is Children’s Care Hospital and School, where I work in the classroom and help students. I’m also on the statewide advisory workgroup for the PLANS Family Support 360 Project. I’m a real sports fan, so I attend as many SkyForce and Canaries games as my schedule allows, and I’d also like to attend a Vikings game some time in the near future. I really enjoy helping others and volunteering whenever I can. I like being involved in the community and I don’t feel that I’m limited in doing the things I enjoy. Being involved and helping others is very important to me.”

Housing

According to the National Core Indicators survey performed in 2002, South Dakota is just below the national average for people with developmental disabilities choosing where they live. People want to choose where they live. They may not want to live in a group home; they want to choose to live in an apartment or in their own home. Agencies have been creative to facilitate this change by giving individuals more housing options. However, there are still instances where people remain on waiting lists for extended periods of time and many forum attendees expressed a desire to make more options available. In the following section, Sarah’s parents discuss their experiences in helping Sarah find a place to live.

Sarah

At an early age, Sarah was diagnosed with developmental disabilities. In high school, she was able to try out different jobs at an adjustment training center (ATC) which made the transition from high school to a work environment a little easier. She has been served by the ATC full-time since she reached the age of 21. We have been happy, for the most part, with our services. However, we had some frustrations with the lack of housing opportunities for Sarah. When Sarah was in high school



(Sarah continued)

we put her on a housing list, at the time we were told that it would be a couple of years for placement. Two years later, we checked into when her placement might be and to our great surprise we were told that it might be a five year wait or more!! Our understanding at the time was that when we were ready for Sarah to have a place, it would be available. We know that state and federal funding play a large part in housing availability and that the resources are spread thin.

For parents this issue is a double-edged sword. On one hand, we feel like we are the only ones who know Sarah and her needs. On the other, we know that it's best for her to have a place of her own. We want to find the right place for Sarah, and we continue to feel that she deserves the dignity to choose what is right for her. Sarah was given a chance to move into a group home and we chose not to place her there because of her strong feelings against it. Sarah wanted to live in a small setting with a few people. Her dream was to live with her best friend, Renae. We continue to hear the importance of 'choices' for our young adults, thus giving them responsibility to help them grow, but for a length of time we didn't see Sarah's 'choice' being considered in this situation.

An option came up in a small setting but only one opening was available for Sarah or Renae. It was hard for us, but we held Sarah back and Renae took the vacancy. We were glad Renae found a place, but then Sarah was back on what seemed like a never-ending waiting list. We felt like we hadn't been given adequate explanation for why Sarah and Renae couldn't be roommates.

Then, the call we had been waiting for came towards the middle of January 2005, as Sarah was advised that she could move into the group home that was her first choice! Although we had been talking to Sarah about moving, when the time came to move, she was not so sure. But knowing her like we do, we knew that there would not be a perfect time for her to leave. The adjustment went well with a few exceptions of not wanting to go back after being at home with Mom and Dad. We were all adjusting pretty well and then came another opportunity for Sarah to move in with her best friend, Renae. To her, there was no choice but to move in with her friend. Renae was living with two other young women in a residential neighborhood that was staffed 24/7! The reality of it was a little harder than she thought and we have had more than one moment of her emotions going wild. We are thankful for the staff and all the brainstorming different ways to help her adjust. The new chapter is just beginning!

We are hoping that with an active group of parents holding regular informed meetings and keeping in contact with the ATC, that we will be able to assure anyone who wants a placement will have one in the future. The new trend is for four to five people to have a home with full-time support until such time they choose limited support. This is a great idea for most young adults, but we understand what a challenge this brings in that it requires more housing options and staff at a time when it is hard to keep quality staff and housing is limited. We understand that resources are thin, but we hope that they can be managed in a way to maximize the benefits for the clients. We feel that these young adults deserve every opportunity to choose what is right for them. We hope that adequate housing can be found for others in the future, where they can also have space to live and grow.”

Faith Based Organizations

Faith-Based Organizations have given some individuals the ability to share their talents with others, to be involved in the community, and best of all, the opportunity to establish natural supports. Joann and Pat describe, in their own words, their respective experiences with faith-based organizations.

Joann



“I have been a member of West Center Street Baptist Church in Madison for many years. I attend church services every Sunday and Bible Study every Wednesday evening.

I also participate in fellowship activities such as potluck suppers and ‘Moms & Mentors,’ where I volunteer to baby-sit during the meetings. In the past I was a group leader for ‘Share & Care’ which was held on a weekly basis. I continue to be involved in one of the Serving Circles, which serves funerals and provides food for other church activities. Our congregation is very close-knit and I have been invited to many baby and bridal showers, where I give one of my hand-embroidered linens as a gift.

I also make baby afghans in pink and blue for every new baby in our congregation, for which I am compensated through the church.

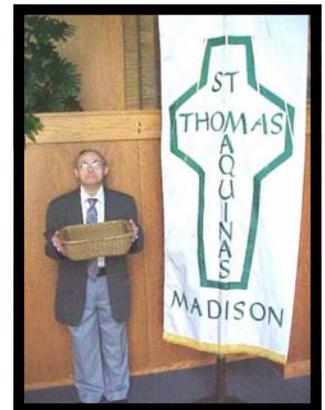
Being included and involved in my church greatly enhances my life. I feel very blessed to have such a great supportive ‘church family’.”

Pat

“I have been a member of St. Thomas Catholic Church in Madison for over 15 years. I attend church services every Sunday.

I contribute to my parish community by being a regular weekly usher for the second Sunday service. My usher duties include greeting people, assisting with the collection basket, directing communion participants, handing out church bulletins after the service has ended and ensuring that the hymnals/pew areas are in order.

I am also a 3rd Degree Knight in the Knights of Columbus organization. I attend monthly meetings and participate in as many community/parish projects as I can. I enjoy the company of my fellow Knights and my goal is to become a 4th Degree Knight soon.”



Employment Opportunities

As people receive education, experience and exposure, they feel more confident in making informed choices. Alan wanted to be his own boss and he knew that transportation was a barrier for many people with disabilities in Madison. Allan learned about the different work incentives offered through the Social Security Administration and decided a Plan for Achieving Self Support (PASS) would help him achieve his employment goals. Allan is now self-employed as a taxi driver and is able to provide transportation to many people who otherwise didn't have the service available to them. In the section below, Allan describes starting his own business.

Allan



“I first thought about starting a taxi business in January 2003. I liked the idea because I loved driving around in my pickup with friends. It took about six months to talk with my family, write a business plan, get approval from the Madison City Commission and get a PASS Plan approved by Social Security. I received assistance to accomplish each of these tasks. It felt like it took a lot longer than six months!

I officially opened the business on July 14, 2003. At first, I was available 24 hours a day, seven days a week to help discover when the most people needed rides. As time passed, I reduced my regular hours Monday through Friday 7:30 a.m. to 10:00 p.m. I was not getting enough sleep when I was trying to provide rides 24-7. I do still provide rides during other hours as I am able.

I have considered adding a partner who could operate the business for the late night runs and on weekends. My income did reduce when I quit the extra hours, but I was simply not able to provide a good service for that many hours a week.

I moved from my parent's home into my own apartment in February 2004 and I love my independence. With assistance, I do all of my own banking and bill paying. I receive a few other supports for independent living that I have specifically chosen. I am not afraid to speak my mind and tell staff what I do and do not want them to do.

I would encourage other people to start their own business, but just not another taxi business in Madison! I am always willing to talk to people about my business and how it got started. I have been invited to be a speaker at several events and I am always happy to do that. Being self-employed allows me to be in control of when I work. I make more money now than at any hourly wage job I have ever had and most of the time I love what I am doing.”

Seamless Services

Families who have loved ones with disabilities have a lot of red tape to go through, if they even know how to find the red tape. As one family member stated, "We don't know what we don't know!" We heard from families that would like to have one person to contact to help them access resources and programs, as well as the need for a continuum of services, regardless of age. The needs are many for the Delker family, who have five children with disabilities, which they describe below in their own words.

Delker Family



Tommy, 23

“One of the biggest problems we have is getting respite care. We are allowed some hours from the state and from Family Support. However, finding respite providers is very difficult because of Tommy’s age and our children who are tube fed. Also, it is very scary to providers when you mention you have four or five young adults and children with special needs.

The hours that are given to us are much appreciated but more time is needed. We would also like to see some type of recruitment for providers in this area and perhaps training for the most difficult needs.



Dimitri, 7



Anthony, 9

Family Support has been a godsend in providing diapers, wipes and other necessary items. The respite care is needed and appreciated. It has lifted a lot of the financial burden for us as the children get older and the costs soar. If we as parents get in a financial crisis it can cause stress on the family.

One of the things we need to stress is just because the children turn 18 a lot of the programs are unavailable, but the needs are still there, and will always be there. We need to look more at the needs and not focus so much on the age. We all need to work together to have programs that will help families who have children with special needs to keep them in their home and not be institutionalized.

Our children with special needs have needs just as normal children do and most of the time it is more costly. We do appreciate the programs that are offered to our children but the needs are much greater. We would like to invite anyone to come visit our family and get to know our special needs children the way we know and love them.”



Linda, 18



Lizzy, 21

Support

There are a variety of supports for families with young children. Family Support is one program that is designed to help families get what they need to stay together. It is often conveyed in the phrase "whatever it takes." The purpose is a family-centered and family directed, culturally competent, community-focused system for all South Dakota families who have children with disabilities living in their home. This program has offered a lot of relief for families in a variety of ways. Allison's parents discuss their experiences with the Family Support Program below.

Allison



“Allison is three years old and loves to play the computer, be read to, swing, and swim in addition to other three year old activities. She has cerebral palsy which impacts her ability to move and to communicate, and also has resulted in significant health challenges. Having cerebral palsy does not limit Allison’s ability to experience and enjoy life and be involved with her family.

South Dakota offers a variety of programs and services which have been important in meeting Allison’s special health care, access and quality of life needs. She has benefited from in-home nursing care provided via the Disabled Children’s Program of SD. Knowledge, recommendations and techniques of therapeutic, educational and medical professionals have helped our family cope with her challenges and have improved Allison’s health and ability to interact. Health care and quality of life needs, specialized positioning and mobility equipment, assistive technology, and augmentative devices through outpatient opportunities have further developed Allison’s skill levels and ability to experience life as an integral part of our family. The Statewide Family Support Program has also been helpful in providing financial assistance for specialized toys, equipment and services (music therapy) that are not covered by our health insurance or medical assistance.

However, one difficulty we’ve experienced is just knowing what resources and programs are out there that can be helpful and available to Allison. Much of what we have accessed, we have learned about on our own or from other people who have a family member with special needs. While we have had case managers for Allison when she was hospitalized and when she participated in her Early Intervention Program, the resources we were provided were specific to that individual episode in her life and did not transfer on when the illness or therapy services ended.

Consistent case management should be established early on for all identified persons with special health care, physical or cognitive needs set up early on (at the time of diagnosis or initial difficulty) and carried on throughout the person’s lifetime. This would be a great asset for South Dakotans and their families who have special needs. Professional guidance for negotiating the services and opportunities available can be so important in assuring our loved ones’ highest quality of life and easing stress on families. Recently, Allison was accepted into the local Family Support Program. A family support coordinator assists our family by identifying and accessing natural and formalized services to meet Allison’s needs. Along with purchasing ‘whatever it takes’ to meet her needs.”

Choice

In the past, decisions regarding individuals with disabilities have often been made by others, such as professionals, families and policymakers. These decisions were based on assumptions about what is in the best interest of the person with a disability.

We now recognize that all people have the right to express their preferences and exercise choice in all aspects of their lives. Families and professionals should work toward the development of real opportunities for choice for people with disabilities. Art's perspective on Choice is presented in his own words:

Art



“Not having a choice makes you think you done something wrong. If I make the choice and it's wrong, well, it's my fault, but it's my choice....its my right. I call my own meetings. The staff used to say; ‘Art your meeting is coming up. You gotta show up for your meeting.’ They told me when it was going to be, where it was going to be who was gonna be there and they talked all through my meeting. Then they'd say, ‘sign this paper’ bam that was it! Lot of the things they talked about, I didn't know about but I just started saying ‘now wait,

what do you guys mean about this and that’ and I learned. Now I call my own meetings. I decide when it's going to be, where it's going to be and what we're going to talk about. No surprises that way. Where I live, where I work and what I do after work, that's my choice. Man, it's kinda hard to run your own meeting and your own life but you just gotta do it.”

Natural Supports

Many students and their parents experience difficulties when transitioning to the adult system. One of the things that make it difficult is the lack of a primary resource person. The people who have been involved with the student and who know their needs, are no longer involved in the person's life because they turned age 22. The complexity of the adult system, knowing who to contact, what services are available and eligibility requirements are examples of other issues that families go through in the transition, as Kelly's mother illustrates in the following section.

Kelly

“I would like the opportunity to introduce you to my daughter, Kelly. Kelly is a twenty four year old woman with a delightful personality. She is loved dearly by her family and is respected by those she is in contact with in her community. Successful inclusion came about because of the efforts of many people who have been a support to her since birth. Her father and I were of the mind set when she was born that she would not grow up to live in a Down syndrome community, so our vision was always to keep her in the most natural environment with her peers, including those without disabilities.



(Kelly continued)

Because of Family Support, she was able to attend dances, plays and other extracurricular activities with the rest of her high school friends. After high school she attended the Sioux Falls Community Campus and continued to develop her work and social skills in the community. The appropriate role modeling that she had during those years helped her be the person she is today. The challenge we ran into was when Kelly transitioned into the adult service system. No one in the adult system knew her and could help us develop plans that were appropriate for here life. At that point it was like starting all over with no one we knew or who knew her, no natural supports. I believe supports are as individual as the person receiving them. People with disabilities need to be heard when it comes to what kind of supports they need to live their life to the fullest as an adult in their local community. Having Family Support services in the adult delivery system would allow that to happen with consistency.

Today Kelly works part-time at Burger King. She goes to Sioux Valley Wellness Center two times a week with a supported living coordinator from an Adjustment Training Center. She helps me lector in our church. She has gone to Southeast Technical Institute to continue working on her math and reading skills. She is involved with the Friends Program, that provides opportunities in the community for social activities. As a member of Toastmasters, she is learning to speak in public and become her own advocate. She is presently taking computer classes. Her goal is to go to New York and see West Side Story on Broadway. She has some big dreams and some that are not even thought of yet, but isn't that true of all of us!"

Dreams Do Come True

"Dream the impossible dream." Many people with disabilities and their families thought it was impossible to dream, but dreams come in all sizes. During the forums, we heard from one gentleman from Watertown whose dream is "to go to Sioux Falls." Another gentleman from Sioux Falls has a dream "to go to a Vikings game." Another person's dream is "to be Spiderman." Everyone has the right to dream, even if it seems impossible. Here Harold and Shawna tell in their own words how their dreams came true:

Harold and Shawna

"Harold works part-time for a food service business and lives in his own apartment, and Shawna works at a small bench assembly and lives in an apartment with a roommate.

We met in Madison. We were engaged on September 6, 2004 and were married on April 9, 2005. We were both very busy making preparations for the wedding. Our families were extremely supportive. They booked the church, bought the dress, reserved the reception hall and hired the DJ.



This had been a dream for both of us for some time. We each wanted to meet that 'special person' and get married. Our dream came true!"

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