

## **Objectives and Need for Assistance**

### Background Information

North Dakota (ND) initiated a community-based family support system in answer to consumer demands for system change in 1983 after the Association of Retarded Citizens of ND won a Federal class action lawsuit against the state. The institutional population was reduced from 1,134 in 1985 to 150 in 2000. During this time period, the economy thrived and various community programs developed through Federal, state and local initiatives were enacted. Community based services improved the lives of persons with developmental disabilities (DD); however, individualized family support services were considered to be optional under ND state law and remained challenging to secure.

Initial services and supports (e.g. care, employment, information and training) were designed to meet the needs of individuals with DD while addressing the needs of families was postponed. As deinstitutionalization continued, families asked for more individualized resources and supports designed to keep children at home and be flexible in meeting the needs of the entire family. The state of ND responded with an array of services, programs and resources (infant development, special health clinics, respite care and reimbursement for excess child care costs. As funding opportunities expanded, information and referral services, educational training programs, and behavior intervention also became available. Non-profit organizations developed other unique services through a parent training and information center, independent living centers, a family-to-family support network and wrap-around support for families with children who have emotional and behavioral challenges. In spite of this infrastructure, many families in ND remained overwhelmed by challenges associated with extraordinary demands in parenting children with disabilities, including DD.

In 2001, the Administration on Developmental Disabilities (ADD) funded a collaborative project developed by the North Dakota Center for Persons with Disabilities (NDCPD), state agencies serving children and families and non-profit family support organizations. The ND Family Support Project (NDFSP), identified and addressed several unmet needs through activities designed to align/coordinate effort and enhance family support.

Identifying the real accomplishments of this effort is both humbling and exhilarating. Foremost, families and partners involved in the project have repeatedly stated that the insights gained through collaboration into the needs and contributions of families and service organizations although difficult to measure, are invaluable. Additional accomplishments of the project include: Obtaining family insight into what it takes to bring ND families to a training event through focus group research, teaching over 70 families to exercise Leadership in Accessing Systems and Systems Change, providing over 400 families with just-in time information about ND's family support services, providing partners with technical assistance and resources in reaching diverse families, providing over 200 families with resources designed to assist them in self-managing supports and developing a strategic plan and new initiatives to achieve outcomes identified by families and partners as critical to enhancing family support.

Although multiple project goals and objectives have been realized, underlying needs and barriers remain stubbornly resistant to change. A thoughtful review of data and circumstances in ND suggests that the pieces are in place to begin the next steps in bringing families and partners together, providing them with the information and opportunities to participate in data-driven decision making, giving them new tools to access and manage supports and implementing a strategic plan to fully realize project outcomes and enhance family support in ND.

## Problem Definition and Need

Families are well-informed. *Empowered families find the information they need to help them meet the requirements of the person with a disability and the needs of the family.* An array of services including emotional support, informational resources, training opportunities, and assistance programs are available in ND for families of persons with disabilities including DD. A survey of ND family support organizations and agency web sites conducted in April 2001 revealed that although 80% of Caucasian families use the Internet to obtain information (GAO 2000) few ND families (9.5%) could find information related to targeted topics (Haarstad, 2001). Half of the successful attempts found only *related* information (a book on child care rather than access to a care provider).

The NDFSP created an informational website called Families Need To Know or n2k ([www.familyn2k.info](http://www.familyn2k.info)) which allowed families to find information on a variety of supports and services that are available in ND. Over 432 families have visited this site to obtain information. At least half of that number reached the website since March of 2003 in response to recent wide-spread dissemination activities. Project staff also created an online newsletter; entitled Leadership, which initially provided over 300 ND families with an easy-to-understand review of policy issues that were pertinent during the 2003 legislative session. Later, based on feedback from the FSAC, this document became a vehicle for updating families and partners on project accomplishments. Project staff have received multiple requests to publish various technical assistance resources and informational articles on the n2k website (Balsdon, 2003) and to continue publication of the Leadership newsletter (Wilcox, Nelson, & Feist, 2003). Inclusion of new resources and policies briefs will increase family/provider access to information and technical assistance beyond the life of the grant. ***Family support organizations need to provide***

***timely information on policy and resources to empower families and providers to access services and support.***

*Families acquire skills.* *Empowered families grow in their use of best-practice information to care for, nurture, teach and prepare their children with special needs for adult life..*

Family support and educational organizations in ND attempt to provide families and professionals with information about best-practice in parenting, education and family support. Support agencies are required often by law (e.g. IDEA, No Child Left Behind) to provide families with best-practice information. Based on consumer and professional demand, the preference to provide information in a face-to face format remains strong, regardless of research data that suggests participants have difficulty generalizing what they learn in a conference to daily circumstances (Askvig, 98). The isolation that both families and professionals experience in rural communities may contribute to this phenomenon.

Numerous barriers impact the ability of family support organizations to address training issues. Although planning meetings provide some opportunity to exchange information, they are unlikely to provide either families or professionals with the comprehensive training they desire. Conferences are typically held by single support organizations (e.g. Pathfinder Family Center, the Arc, Upper Valley, Federation of Families, ND Council for Exceptional Children). Turn-out for statewide conferences remains low in spite of family interest in new strategies that would assist them in teaching and caring for their children with special needs. Stipends have been identified by some partners as the single, most important incentive for ND family members to disrupt routines and attend conferences (Erickson, 2001). Distance, while creating the desire to connect also creates a travel barrier for both families and professionals. Conferences, while open to both families and professionals are often attended by a majority of one group or the other

(Haarstad, 2003). Feedback from partners indicate that small conferences hosted by single organizations do not constitute an effective use of resources given the current low attendance. The workload involved prevents single organizations from attempting to expand their efforts. Finally presenters may be unaware of adult learning strategies for sharing information and supporting follow-up after a conference.

Focus group research, conducted by NDFSP partners in 2002 indicated that major planning revisions to conference design and format would be needed to increase family participation. Changes need to focus not only on timing, location, cost and content but on creating an environment for planning and implementation that leads both families and support organizations to take ownership in the conference and enjoy the proceedings enough to disrupt their lives (Offut, 2003). Members of the ND FSAC are determined to view these circumstances as an opportunity. They have challenged the NDFSP project to assist them in aligning resources, bringing families and professionals together, addressing multiple training needs, finding common ground in potential content and create a sustainable and meaningful face-to-face learning experience that will allow multiple participants to realize important outcomes related to their respective missions to build capacity and enhance relationships. Specifically, the FSAC has asked for a protocol that partner organizations can use to organize and sustain a meaningful and well attended conference. ***ND families and support partners need to collaborate in effective use of resources to address training needs.***

Diverse families access support *Empowered families who come from diverse backgrounds obtain support services that are individualized to meet their unique requirements.* The partners believe that ND's family support systems could be more effective in meeting the needs of

families who are members of three under-served groups who struggle with challenges related to poverty.

*Refugee families.* Fargo, an urban community with more than 60,000 people, hosts a national refugee assistance center that supports new American families and families who are temporarily in the US. Over 52 separate languages are spoken by students entering the Fargo public school system (Tronsgaard, 2000). A number of children from these families have disabilities. Language and cultural barriers often limit refugee families' access to support organizations. The NDFSP made initial contact with families and cultural diversity specialists during the last funding cycle. Many of these families are struggling to meet basic needs and information about support options for New American families raising children with special needs often does not reach this population (Gunaratne, 2003). The NDFSP and one of its partner agencies (Family Voices) recently met with families and ethnic leaders (i.e. Bosnian, Iranian, Kurdish, Haitian, Indonesian), from the Fargo area with initial information about family support resources. The NDFSP is developing an outline for family support organizations that are challenged to reach out to this underserved group. Ongoing efforts to reach and collaborate with this unique population continue. Representation from this population and the leaders who support them on the FSAC will be critical in taking the next steps to reach and welcome refugee families. ***Family support providers need to provide refugee families with individualized, culturally appropriate support.***

*Native American families.* Thirteen percent of all North Dakotans are Native Americans and about 68% (Census, 2000) of that group live on one of ND's five reservations. Families who reside on reservations may not obtain needed supports. Educators and health service employees have little training in supporting families of people with disabilities (Belgarde, 2003, Klimpel,

2001). Remote location, cultural differences, limited presence of service providers in reservation communities and negative experiences associated with poverty keep these families from connecting with ND family support organizations. The NDFSP recently published a technical assistance manual for support providers entitled Supporting American Indian Families with Children Who Have Special Needs. Family support partners will be using this resource to reach out to families living in or near reservations and assist American Indian educators and early intervention providers in building family support networks. ***Family support providers need to respect cultural differences to help Native American families access supports and services.***

*Families headed by parents with Intellectual Disabilities (ID).* Families headed by parents who have ID are one of ND's under served groups. ND's family support organizations have not traditionally offered individualized training and support to families in this group. When parents with ID *are* offered services and/or training, it usually does not meet their needs (Lee, 2001). For example, adult training programs assume that trainees are adept readers and information processors. Parents with ID often lack these prerequisite skills and abilities. In addition, many of these multi-system families experience chaos in attempting to parent and sustain employment and subsequently rely on government benefits as a sole source of income. Balancing services from multiple agencies makes the inclusion of family support an additional challenge for parents with ID.

The NDFSP developed a comprehensive training curriculum for family support providers that has received national recognition. The NDFSP is actively supporting the development of new models and initiatives to reach this unique population by encouraging existing support networks to train staff and conduct regional needs assessments through its strategic plan. ***Family support providers need to be effective in supporting parents who have ID.***

Families access and manage support services. *Empowered families successfully secure and coordinate appropriate professional and generic supports and services.* Families must recognize and find appropriate supports, determine their eligibility for service, and find a mechanism for payment. Since no single service meets the requirements of all families, *empowered* families must expedite the delivery of targeted supports to meet their needs. A growing number of ND families want to manage their own support services (Balsdon, 2001). Families needing in-home support can have a significant role in recruiting, hiring, supervising and training staff through state funded programs (Family Subsidy), or work closely with ND family support providers through Federally funded programs (Family Support Services). Recruiting, hiring and supervising in-home care providers requires knowledge of laws related to payroll and taxes that many ND families may not have.

The NDFSP developed a technical assistance manual entitled *Managing Supports at Home (MSH)*, which provided step-by-step instructions for meeting tax and employer responsibilities in managing dollars through ND's Family Subsidy (FS) program. The FS program provides eligible families with an administrative allocation through which families may be reimbursed for excess child care costs and disability related supplies and services (e.g. therapy and specialized equipment). Although MSH was well received by service providers and described as helpful for families (Lee, 2003) the requirements outlined are challenging to implement, leading the manual to receive an informal nick-name among providers of "the scary book." Also, economic changes in the form of a 14 million dollar Medicaid shortfall left the wholly state funded FS program vulnerable during the 2003 legislative session. Families who have struggled with the challenges of hiring caregivers under ND's FS program have asked for

easier-to-implement options that still provide the opportunities for choice and control enjoyed through the FS program.

The North Dakota Department of Human Services (NDDHS) has responded by applying for an Independence Plus Waiver (IPLUS) to increase options for family choice and control. Unlike ND's current Home and Community Based Waiver (HCBW), IPLUS will allow families to recruit and hire staff as independent contractors. Families would gain the advantages of training in person centered planning and the assistance of a fiscal agent and budget, which would remove the burden of paying for services and then being reimbursed. Several components of the MSH could be used to provide families with important information about the legal responsibilities of recruitment and hiring. Many ND families are unfamiliar with the programs and services that provide this level of control and choice. Often ND families regard Medicaid programs as intended only for low-income families and believe that accessing services will prevent resources from reaching families challenged by poverty. Families report a stigma associated with needing services through this project (Balsdon, 2003). This reluctance to participate creates special training challenges. In addition, families who have applied for Medicaid sometimes find the process cumbersome and have encountered different barriers in each county. Finally, staff from several ND non-profit organizations are also unfamiliar with new waiver templates and Federally funded programs for families of children with special needs (Haarstad, 2003).

The NDDHS has asked the NDFSP to develop new parent training and information resources on IPLUS for families and service providers in a variety of formats. Training resources for IPLUS are not likely to be developed by ND's Parent Training and Information Center (Pathfinders), which concentrates solely on information related to the Individuals with Disabilities Education Act (IDEA). Information for families will be helpful to partner agencies

that may be unable to research the details of waiver services in a timely manner. ***ND families need to access information about person centered planning and self-determination options soon to be supports available in ND, within a Just-in-Time format for inexperienced users. Family support organizations need to be expert at coordinating services to help families obtain and manage effective support services.***

Families have information on policy issues. *Empowered families are aware of policy issues that impact their children and lives and knowledgeable about how to access systems and work for system change.* Families are often preoccupied with the specific needs of their children with disabilities and their immediate family. Training usually focus on overcoming barriers, understanding disabilities and achieving outcomes such as health care or a free and appropriate public education. As families gradually become aware of Federal, state or local policies that impact the services and supports available in their communities they have difficulty extending beyond the day to day realities of caring and planning for their children to learn about complex policies. ND has several resources to help families obtain information about policy issues.

The Dakota Center on Independent Living (DCIL) conducts annual training on Partners in Policy Making, which provides families with an intensive 8 week course on studying and understanding policies. The Protection and Advocacy Project also provides “Common Ground” training, which helps families learn to use a problem solving approach with policymakers and focus on the individual needs of their child to resolve conflicts. The ND Family-to-family network (F2F) developed training for families on accessing services (i.e. human service, health, education, recreation and finance). These partners contributed materials or techniques from the curricula previously described and collaborated with staff from the NDFSP to develop new training entitled Leadership in Accessing Systems and System Change to focus with families on

family support policies. This effort was successful in reaching a small number of families (70) using a train-the trainer model but the section on System Change has proven difficult for families to use as a whole in training other families and too challenging for self-study. Trainees were able to support continued local training for only a single effort before the project funding ended. The three separate curriculum continue to be requested by families and support providers (Jacobson, Smith, & Offutt 2003). Partners have identified the need to provide families with a more systemic way to learn about family support policies and a variety of options for obtaining information on policy issues. The Leadership newsletter along with the other three curricula described above, are viewed by the FSAC members as a more effective system for providing ND families with information on policy issues until the LASSC can be revised. ***Family support organizations need to align and coordinate training to provide families with a variety of informational resources on family support policies.***

Families are active in policy development. *Empowered families provide decision makers with critical information that clarifies expectations for comprehensive and timely improvement of policies and procedures.* In 2003, the ND Department of Human Services published several proposed policy changes for review and comment. Copies of these policies were distributed to persons with disabilities, family members, and service providers throughout the state. Not a single family member attended hearings during the public comment period regarding decisions to require all families wishing to receive infant development services to apply for Medicaid. (Balsdon, 2003). This is distressing because ND families eagerly spoke with policymakers during the Leadership training conducted by the NDFSP and have historically prompted change and demanded appropriate services. The crisis that diminished ND's institutions has ended and ND families seem less willing to demand systems change.

Changes in the economy and lifestyle of North Dakotans may be associated with families' apparent disinterest. The literature suggests today's families confront a number of extraordinary demands in parenting and caring for children with disabilities (HRSI, 1995). These issues often overwhelm families, leaving them with little time or energy for system change. The distances that families must travel to participate in training activities and the unavailability of respite or child care services, may also act as further barriers to family involvement. Focus groups conducted by the NDFSP in the summer of 2002 indicated that families would disrupt their schedules or routines to attend training events or conferences if adequate financial and child care support were provided and the events offered opportunities for the whole family. A single topic hearing is not sufficiently supported or designed to draw families to participate.

Another reason for the lack of family feedback may be that ND policies are usually written in comprehensive, difficult-to-understand legal language. Complex formats discourage participation in policy-related dialog and change is less likely (Balsdon, 2001). ND families have shown that they will respond to a round table discussion format in which policymakers are available to facilitate or contribute to discussion (Haarstad, 2003) and the conversation focuses on issues of day-to-day relevance (e.g. child care, in-home support, education, infant development, social development, transition or employment).

ND agency professionals can advocate for systems change; but their primary area of responsibility is the administration of budgets, policies and coordination services. They are expressly prohibited from engaging in legislative lobbying and as employees of the executive branch of ND government they represent the Governor's position on budget and legislation. Significant systems change must be associated with a strong grassroots movement for family support.

Several ND families have sponsored unsuccessful legislation to effect system change and informal interviews with members of those families suggest a concern over lawmakers' familiarity with family support issues. They reported that their recent efforts to acquaint legislators with the critical issues in family support have not been particularly effective (Brennan, 2001; Haarstad, 2001). Although the ARC of ND, the ND Partners in Policymaking, and Protection and Advocacy of ND have lead efforts to involve families in systems change, few family attempts to use existing systems change mechanisms have been successful. Those that were required families to commit substantial amounts of time away from home to secure changes in law or policy.

Policies are made based on a variety of factors including *technological* (e.g. increased survival of children with complex medical needs), *economical* (e.g. a funding shortfall or declining population) *social* (e.g. awareness of harm caused by institutionalization) and *consumer demand* (e.g. families request flexible respite care services). Policy makers acquire and track data on which decisions are often based. Families are seldom familiar with Federal or state family support policies. They are often unaware of data that support or refute policy decisions and impact the supports and services on which their family depends, leading to system change in which family support is no longer viewed as optional but essential. Ongoing system change mechanisms seldom provide the kind of focused discussion that families know and prefer nor do they provide families with information on outcome indicators, which would allow families to participate in data-driven decision making as an informed partner. The NDFSP developed a strategic plan to enhance family support which outlines specific outcomes that families recognize and approve (see Appendix A) An effort to compile and analyze data related to these outcomes and inform families of the results is critical to realizing effective system change needed to

enhance family support. *Systems change to enhance family support in ND must be realized by an active partnership between informed families, support providers, and policymakers and led by data-driven decision making in which all parties participate.*

### Goals and Objectives

The ND Center for Persons with Disabilities (NDCPD) will continue the ND Family Support Project (NDFSP) to fully realize a statewide system of family supports that are planned, designed, implemented, and evaluated by families of children and youth with developmental disabilities. Supports will enhance the capacity of families to exercise full participation, choice and control in decisions relating to family support. To realize these outcomes, NDFSP will coordinate project activities to achieve the following goals.

#### **Goal 1: Develop a single statewide plan to enhance family support.**

Objective 1.1 - Assure that the FSAC maintains continuity beyond the project period.

Objective 1.2 - Produce a prioritized version of ND's existing strategic plan.

Objective 1.3 - Develop a data base of core indicators to measure outcomes

Objective 1.4 - Disseminate data collection results; make recommendations as a strategic plan.

Objective 1.5 - Develop an ongoing system for communication and strategic planning.

#### **Goal 2: Involve families as active partners in shaping policies for family support.**

Objective 2.1 - Develop a prototype for hosting annual family support conferences.

Objective 2.2 - Develop a system of obtaining family input on policy issues.

#### **Goal 3: Improve the capacity of families to access/self manage support.**

Objective 3.1 - Develop materials for teaching families to self direct family support.

Objective 3.2 - Update NDFSP's n2k Internet site to include new policy resources.