Supporting Families of Children with Disabilities: What's Missing?

Katherine Selber
Mary Tijerina & Cathryn HeymanTexas State University, San Marcos
&
Virginia Rondero Hernandez
California State University, Fresno

Abstract: This article presents findings from a web-based survey in which advocates and primary caregivers of children with disabilities were asked to indicate their level of satisfaction with various services and service providers, and their perceptions about how closely these services centered on family needs. A total of 68 valid responses to this pilot survey were obtained from subscribers of electronic mailing groups. The survey included questions about accessibility and affordability of services, satisfaction with services, degree of family involvement allowed by service providers, and information relating to the family-centered principles of treating and educating children with different types of disabilities. Eighty percent (80%) of respondents described a frustrating and invalidating process for acquiring services. However, once families were in the health care, educational, and social services systems, they reported finding the services received helpful. Implications for disability and health care policy derived from this research are offered.

Key Words: children with disabilities, family-centered, disability policy

According to the U.S. Department of Health and Human Services (2002a; 2002c), more than 50 million Americans or almost 20% of the total population have some type of developmental, physical, or mental disability that hinders their independence or prevents them from making a full contribution to work, education, family, or community life. In addition, an estimated $300 billion is spent annually on care for Americans with disabilities (U.S. Dept. of Health and Human Services, 2002b).

The economic effects of living with a disability are substantial, and especially difficult for families who often do not have the financial resources to meet these costs. The literature estimates that 68% of U.S. households with children with disabilities have annual incomes of less than $25,000, indicating a substantial economic hardship (National Council on Disability, 2000). Health care policies that limit insurance coverage for certain conditions and establish income ceilings for accessing coverage exacerbate the financial burdens for families of children with disabilities. Some studies report as few as 11% of children with disabilities are insured, 6% are without a usual source of medical care, and 18% report being dissatisfied with their source of care (Newacheck et al., 1998).

Besides the financial strain, parents living with a child with a disability may experience wide-ranging physical demands and may be at-risk for increased health problems themselves (Ritchie et al., 2000.) The effects of disabilities are far reaching, and if inadequately addressed, they result in increased physical, social, and financial suffering for children with disabilities and their families (Selber, Rondero-Hernandez, & Tijerina, 2005).

This article examines the development and piloting of a web-based survey to capture the experiences and perspectives of family caregivers and advocates of children with disabilities

about services they acquired for their children. A basic assumption of this study was that families of children with disabilities often perceive service needs differently than service providers. As a result, families' perceptions of what works and does not work are important to an understanding of how services may be improved. The article also provides information about the study results and implications for practice and policy in the field of disabilities.

Background of the Project

A four-year federal grant was awarded to the state level health authority in Texas, located in the southwestern region of the U.S., to build statewide capacity for serving children with disabilities and their families. The grant formed part of the U.S. Centers for Disease Control and Prevention's (CDC) nationwide effort to help states better understand, prevent, and serve children and adults with disabilities and their families. Midcourse through the grant, the state health authority negotiated a contract with a local school of social work at a state-supported university in Texas to provide technical assistance for moving the state towards a family-centered model of care. There were multiple methodologies employed during the overall project and throughout the course of the two-year partnership, including secondary analysis of data, focus groups, stakeholder surveys, key informant interviews, and content analysis of strategic plans. The focus of this article includes one aspect of the project's scope of activities--the piloting of a survey to learn more about families' perceptions of the family-centered nature of the service system in order to assess its potential as a strategy for enhancing services among children with disabilities.

The Family-Centered Strategy

Family-centered care represents a consumer-oriented model of care that treats an individual with disabilities and their family with respect and dignity (Johnson, 1999). The concept appears in the literature of family-centered planning (FCP) and supports the development of service delivery systems that are responsive to family needs, linking this to enhanced quality of life (Patterson, Garwick, Bennett, & Blum, 1997). According to this model, families are viewed as the experts and are expected to participate equally with care providers regarding their children's needs and treatment (D'Antuono, 1998; Simeonsson, 1994; Simeonsson, Bailey, Huntington, & Brandon, 1991). One of the core values of this model is the importance of respecting the family's values, environment, culture, resources, needs, and strengths and viewing such characteristics as assets for the design of patient care and treatment (Allen & Petr, 1998; D'Antuono, 1998; Trivette, Dunst, & Hamby, 1996). In addition, family-centered models view the family as the primary context for promoting health, and place the family at the center of service design and delivery activities (Dunst, Trivette, & Hamby, 1996). Hostler (1994) found the two key elements of a family-centered planning model included meaningful participation by families in decision-making processes and an institutional culture flexible enough to respond to the ongoing collaboration between families and health care providers. Thus, adopting a family-centered planning model requires a substantial cultural change for many health, educational, and social service providers (Bailey, Buysse, Edmonson, & Smith, 1992; Johnson, 1999). The model also requires that family members be highly active in service settings when making decisions that concern their children. Leaders in education, health, and human service organizations who are committed to FCP principles must also find ways to

involve children with special needs and their families in such program and policy issues as planning new facilities, revising care policies, educating and evaluating staff members, and evaluating service systems (Johnson, 1999).

Although there are dissenting opinions about the value and implementation of family-centered care (Dunst, Johanson, Trivette, & Hamby, 1991; Powell, 1996), research on family-centered models has gained momentum in a variety of areas over the last decade, including work with families of children with chronic illness, developmental disabilities, early childhood intervention programs, rehabilitation programs, and mental health systems of care (Bailey et al., 1998; Patterson et al., 1997). Discussion about family-centered care is also linked with discussions about improving the quality of life for people with disabilities such as enhancing a sense of personal control over life decisions, heightened consumer satisfaction with services, and a sense of client well-being (Bailey et al., 1998; Gibson, 1995; King, Rosenbaum, & King, 1997; Selber et al., 2005; Trivette, Dunst, Boyd & Hamby, 1996). This theoretical framework was used to guide the overall project's research efforts to enhance the promotion of statewide services for families of children with disabilities.

Method

The Family-Centered Services (FCS) pilot survey was developed for two purposes. First, it was envisioned as a way to "triangulate" or bring in a third perspective to the ongoing research project's examination of state services for families of children with disabilities. Triangulation is a qualitative research strategy that seeks to pursue other sources of knowledge to confirm, disaffirm, and co-validate findings discovered through other methodologies about the same subject matter (Denzin & Lincoln, 1998). In this case, the survey complemented and informed content analysis and focus group methodologies that were being used by the authors to build knowledge about family-centered care for families of children with disabilities. They also examined if family-centered principles were evident in diverse service agency structures. The pilot survey, therefore, was developed to augment the research activities of the overall project, as well as to explore and extend current knowledge reported in the literature about accessibility and affordability of services, degree of involvement allowed by service providers, and consumer satisfaction with services for children with different types of disabilities. Although literature indicates that other factors are of importance in providing support to these families, such as informal support systems, this study examines only families' perceptions of formal systems of care (Streeter & Franklin, 1992).

Data from two statewide focus groups completed with families and providers revealed perceptions of existing state service systems in Texas, desired improvements for the system, and illuminated understanding about the prevalence and experience of secondary conditions. The domains selected in the pilot survey were designed to further test and develop these initial observations and findings as well as examine areas highlighted in the literature as important to families (Trivette, Dunst, & Hamby, 1996; Bailey et al., 1992). The survey captured data on the utilization, structure, and family-centered nature of services, training of staff in those services, financial impact of their child's illness, and their communities' readiness to serve their children's needs. The survey sought to address several questions including:

1. What do families experience when seeking services?
2. How much do families participate in the on-going treatment of their child?

3. Do families believe they have a voice in agency policies and procedures?
4. Are families accepted and understood in their communities?[1]

A web-based methodology was used to help ensure that the instrument was accessible, easy to use, understandable, and visually appealing (Bailey, 2000; Gaddis, 1998; Leaver, 2000; Murphy, Lee, Turbiville, Turnbull, & Summers, 1991; Murphy, Lee, Turnbull and Turbiville, 1995; Schonlau, Fricker, & Elliott, 2001). Use of on-line surveys is currently considered an innovative strategy for conducting survey research and is gaining popularity in the social science research community (Grahn & Swenson, 1998). Time and budget constraints also led researchers to conclude that distributing the survey via the internet would be an efficient way of accessing a pool of individuals knowledgeable about disabilities in a relatively short period of time with minimal cost. This conclusion was supported by the literature that has portrayed web-based surveys as the ideal "universal medium" for collecting and disseminating mass amounts of information quickly and inexpensively through various operating system platforms and across geographic distances (Flowers, Bray, & Algozzine, 1999).

Snowball and convenience sampling strategies were utilized to recruit potential participants for the study. The first set of participants was identified by membership on listservs devoted to developmental disabilities, special health care needs of children, and advocacy for people with disabilities. Among the listserv members were primary caregivers of one or more children with developmental disabilities, professionals, and family members interested in issues related to developmental disabilities. Also included were policy-makers and community advocates for people with developmental disabilities in the state.

The websites and listservs were chosen through several strategies. First, service providers, advocates, and family members who had completed the focus groups in the larger research project were contacted to see if they would agree to participate as respondents and to forward to the research team names of other people who might be interested in participating in the study. Next, websites in Texas were identified for associations and agencies that served families of children with disabilities in order to reach a wide sample of service providers and families as potential respondents. The websites provided staff names and email addresses for public access and the listservs provided permission to distribute materials noteworthy for their audiences. The research staff accessed these sites for distribution of the invitation to respond to the pilot survey. Examples of websites and listservs that were utilized for selecting potential respondents included: American Medical Association specialty groups in the Texas area; Texas State Social Work Licensure listserv; Texas Department of Health internal listserv; Texas Office for Prevention of Developmental Disabilities; the Texas Mental Health and Mental Retardation Authority; Advisory Board members of local and state level agencies and projects that serve families of children with disabilities, and Texas State University Schools of Education and Social Work. In addition, staff from non-profit advocacy groups such as Advocacy Inc. and the Texas Council on Developmental Disabilities were also used to promote the survey.

Permission from the University's Institutional Review Board for protection of human subjects included assurances that the research team would protect confidentiality by not requesting the respondents provide personal identifying information. In addition, no "cookies" were dropped on the respondent's computer to ensure anonymity. All data collected were kept on a separate computer that was password protected in the project's office.

Notice of the survey was announced in a general electronic email invitation sent to the identified participants and announced on listservs. The electronic email invitation explained the

purpose of the survey and provided the link to access the survey if the potential respondent decided to voluntarily participate. Another means of accessing the survey was through a link posted on the research team's University website which included the same information as in the email invitations. The website announcement reviewed the purpose of the pilot survey and the request to participate including the link which carried the respondent to the on-line survey. The invitation reached approximately 430 potential participants and could be accessed on-line for 17 days. It carried a special request that service providers pass the survey along to their consumers, increasing the potential number of families who received the pilot survey instrument.

An email address listed on the invitation allowed respondents or potential respondents to contact the researchers for questions. The project staff received several positive inquiries about the survey from both family members and service providers. One service provider wrote to request hard copies of the instrument so that she could use it with her families to evaluate her agency's services.

The university's web page posted an electronic invitation throughout the survey period. In addition to explaining the purpose of the survey, the invitation stated that participation was voluntary, and that anonymity was guaranteed. A link to the survey was located at the end of the invitation to attract people who found the site using search engines.

Results

The FCS pilot survey consisted of 24 closed and open-ended questions intended to measure the perceptions and demographics of family members of children with special health care needs. Sixty-eight (68) individuals completed the pilot survey, which represented a 15% return rate. The response rates of internet-based, convenience sample surveys typically vary from 6-75 % (Bauman & Airey, 2000; Schonlau et al., 2001). Although the 15% response rate in the existing study limits the generalizability of the findings, there are some preliminary insights that are worthy of examination.

Participants were predominantly college-educated, white, non-Hispanic, mothers of children with disabilities who were married and between the ages of 30 to 50 years.

Insert Table 1 Demographics of Respondents

The majority of children with disabilities (48%, N=32) referred to by the caregivers in the survey were between 5 and 11 years of age. The primary disabilities reported by respondents were Asperger/autism (28%), Down syndrome/mental retardation (14.7%), and cerebral palsy (11.7%). A portion of respondents also reported emotional disorders (23.5%). Forty respondents (58%, N=40) reported that their child (or children) had multiple diagnoses, while two respondents reported they had not received a conclusive diagnosis at the time of the survey. Specific secondary diagnoses included: diabetes, Attention Deficit Hyperactivity Disorder (ADHD), bipolar disorder, major depression cardiovascular, respiratory and intestinal disorders; and sensory disorders such as hearing impairment and loss of vision.

Insert Table 2, Primary Diagnosis of Children of Respondents

A Likert scale allowed respondents to rank their responses on certain questions according to five levels of agreement: strongly agree, agree, neutral, disagree, or strongly disagree.

Discussion is limited to the most outstanding topics related to family-centered care. These topics include service acquisition and costs, family participation in planning, family influence in agency policies and procedures, community acceptance and understanding, and a general commentary about the survey instrument and experiences of families who care for a child with a disability.

Service Acquisition and Costs

The three services that were most used by the caregivers included educational services (76.5%, N= 52), medical services (69.1%, N=47), supportive services (48.5%, N= 33), and mental health services (42.6%, N= 29). Almost two-thirds (63.3%, N= 43) of the respondents disagreed with the proposition that acquiring services and resources was an easy task to accomplish, whereas one-fifth of the respondents agreed with this proposition, and the remaining were neutral (17.6%, N= 12).

Also, 80.9% (N= 55) stated that information about services was not readily available to them. However, when they did get information, respondents answered that it most often came from other parents (77.9%, N= 53), advocacy groups (75%, N=51), physicians (57.4%, N=39) and program staff (48.8% N= 33).

The majority of responses (55.2%, N=37) indicated that families had difficulties getting health insurance to cover their children's medical conditions, whereas only about a quarter of the respondents (25.3%, N=17) disagreed with this statement. The majority of responses (65.0%, N=47) indicated that caregivers generally had difficulties finding affordable services for their child, while about 11.8% (N=8) reported having trouble finding services they could afford. On the subject of out-of-pocket costs for treatment, approximately 46% (N=31) of respondents perceived these costs as extremely high, while about 54% of respondents found out-of-pocket costs of treatment either manageable or not a problem to pay. When asked what types of out-of-pocket expenses they had to pay, respondents described them to be either co-payments (65.6%, N=40) or costs associated with the purchase of medications (57.4%, N=35).

Family Participation in Planning

Respondents' perceptions were mixed when it came to their role in contributing to the assessment, intervention, and treatment of their child. Of the 68 respondents, 42.6% (N= 29) agreed they were perceived by professionals as contributing partners in the treatment processes, while 26.4% (N= 18) disagreed with this statement, and almost one-third of respondents (30.9%, N=21) took a neutral stance on this issue. In addition, 60.3%, (N=41) agreed their families were considered part of the team when it came to the development of individual education plans (IEP), individual family service plans (IFSP), or admission, review and discharge meetings (ARDs). However, 33.9% (N=23) of respondents did not perceive they were treated as team members or were neutral on this statement.

Family Influence in Agency Policies and Procedures

Of the respondents completing the survey, 70.1% (N=47) disagreed or were neutral when asked if they perceived that agencies typically try to involve their families in evaluating and modifying agency policies and procedures. A little more than one-quarter (28.4%) agreed with this statement.

Community Acceptance and Understanding

When surveyed about how readily their communities accepted or understood their children's condition, 66.2% (N=45) disagreed that such a situation existed in their communities. Responses were more neutral (19.1%, N-13) in relationship to this statement, than in agreement (14.7%, N=10). Almost all respondents (98.5%, N=67) agreed that their communities could benefit from more training for staff who work with children with special needs.

General Commentary

An open-ended question was presented to participants soliciting suggestions or comments concerning the content of the survey. Thirty-five (35) of the 68 participants completed the item. Approximately one-third (31.4%) offered specific suggestions related to the survey. But 60% of the respondents wrote specifically about their personal experiences in accessing the help they needed, turning this section of the survey into a forum of discussion about the challenges, frustrations, or sorrow they have confronted in their lives as parents and caregivers of children with disabilities.

These qualitative responses were analyzed and organized into four specific content areas: 1) barriers to services; 2) barriers to education; 3) economic and/or insurance resource barriers, and 4) general comments. The three most commonly reported barriers experienced by families who completed the pilot survey were barriers related to acquiring services (48.5 %), economic and/or insurance resource barriers (31.4%), and barriers related to the education of their child (28.5%). Some of the responses were particularly descriptive of the depths of struggle that parents experience when they confront these barriers. When describing barriers to accessing services, one parent painted a gloomy picture of daily life: "Need help. In constant crisis. Can't find a meds doctor… Can't get a referral for a neurologist recommended by medical doctor, need long-term care—can't afford it—health maintenance organization won't help…" Discussions related to economic and/or insurance resources elicited this response: "…The only way I have been able to ensure my child's health care needs are met, is to go on public assistance (which I hate!)." In addition one respondent said, "We have Supplemental Security Income (SSI) and live poor to get the medical care he needs." When grappling to describe barriers in the educational arena, one parent contributed, "We've had some outrageous things happen and don't feel that due process is an option as we are in a very small school district and fear that our children will suffer if we proceed with a complaint." A general comment about the experience of caring for a child with great service needs was summed up in this statement: "This has cost me my career, my marriage of 28 years, the patience and understanding of family and friends, and my child's entire social and emotional well-being."

This snapshot of the comments offered in this portion of the survey lend an intimate insight into what it is like when one's needs and the needs of one's child or family go unaddressed. Although some respondents expressed appreciation for what help they did receive, it was acknowledged that it came at a great cost—for some financial ruin and for others the destruction of the family unit. Based on the comments of survey participants, it appears that the demands of caring for a child with a disability are compounded by social and economic hardships and exacerbated much more when services are not configured to surround and support the needs of the family unit.

Discussion

The FCS on-line pilot survey was a beginning attempt to describe perceptions and experiences of family members of children with disabilities regarding the quality and family-centered nature of services. Although the response rate (15%) was limited, it fell within the range of 6 to 75 percent response rates reported for electronic surveys (Bauman & Airey, 2000; Schonlau et. al, 2001). Generalizability to other populations of families with children with disabilities is not possible. Although the study generated a small sample size (N=68) it proved useful in exploring some of the main ideas and findings produced by the overall research project to date. The information reported cannot be considered representative of all families with children with disabilities, but the perceptions and experiences conveyed by respondents do serve to inform readers about parents' understandings and experiences of acquiring services for their children, and the extent to which some families struggle to get the services they need. The responses also serve to inform professionals about consumer perceptions of the quality of treatment that families sometimes receive from them and the communities in which they live.

Affordability of services was a formidable barrier to service. The majority of respondents had difficulties finding affordable services for their children with disabilities. In addition, the majority of respondents indicated they had trouble finding health insurance and paying for medication costs. Families also reported out-of-pocket expenses as a contributing factor to difficulty in acquiring needed health care services. While services may be affordable for some, a large number of responses indicated that out-of-pocket costs act as a barrier to care. The literature reports that across the nation parents of children with disabilities identify insurance and its costs as one of the most difficult issues facing them in their attempts to care for their children with disabilities (National Council on Disabilities, 2000). Also, Fujiura, Roccoforte, and Braddock (1994) described an inverse relationship between the amount of out-of-pocket expenses and annual income for families supporting an adult member with mental retardation. These findings heighten the need for further study about how to help alleviate families from some of the economic burden they bear when caring for children with disabilities, even if they qualify for health insurance or public programs. Such policy changes might also influence the families' decisions to care for their children in the community and help families stay together instead of disintegrating, an event that often brings further pain and financial difficulties. Since family-centered principles advocate accessibility as an important element of service delivery, it is to be expected that the issue of affordability will be an important aspect of services from a family's perception of quality.

Responses also demonstrated that some families did not know how to qualify for services or programs. This may imply a need for increased communication between providers and consumers about existing health, social, and educational services and resources. In addition, since respondents indicated that they received the most helpful information from other families, policies that support mentoring programs and other forms of support between families of the newly diagnosed and those already familiar with service systems should be encouraged.

The majority of survey participants indicated that they encountered difficulties in acquiring services they needed. As one respondent conveyed, "We fought long and hard for proper diagnosis and services …After literally abandoning him on the steps of a hospital, they finally [admitted] him." Another respondent added, "When I was seeking the services I now receive, I felt as though I was alone and no one cared if we stayed together as a family." These

statements suggest that service systems should be more responsive to the needs of families, and less contentious when brokering services. The literature demonstrates that if services are not made accessible in a timely manner and are not individualized for the needs of clients, both characteristics of family-centered services, children and families may be placed at-risk for developing secondary conditions and an overall worsening of the child's condition (Streissguth, 1997a; 1997b; Streissguth, Barr, H., Kogan, J., & Bookstein, 1996). Secondary conditions such as depression, social isolation, relationship difficulties, and behavioral conduct disorders seriously affect children and their family members, further complicating the primary condition. These secondary conditions also increase the need for additional services, bringing added obstacles, and new rounds of emotional and financial burdens (Frey, Szalda-Petree, Traci, & Seekins 2001; McCarthy & Stough, 1999; Rondero, 2001; Selber, 2001; Streisguth, 1997a). Research indicates that additional factors such as assistance from informal networks of support like other family members and friends are added resources that often can help families mitigate such difficulties with the formal provision of services (Streeter & Franklin, 1992). However, this topic was not explored in the present study but should be a future topic of research to understand exactly how informal networks might help alleviate the obstacles that formal systems of care often manifest for these families.

Although most respondents thought they were perceived as "part of the team" when it came to developing educational and service plans for their children, there was mixed agreement about whether professionals perceived families as important and contributing partners in assessment and intervention activities. Special education law may have institutionalized the role of parents in developing educational plans, but the notion of viewing parents as "experts" about their children still seems to fall short of the ideal proposed by researchers in family-centered care (Arango, 1999; D'Antuono, 1998; Simeonsson, et al., 1991). A sense of being "left out" was also detected in survey responses related to family participation and planning. More than half of the survey respondents reported they had no influence in shaping agency policies and procedures. McCarthy and Stough (1999) found that quality of life is highly dependent on self-determination and is only achievable when families of individuals with severe, chronic disabilities have access and input into essential services. Thus, family input, an essential element of family-centered care seemed lacking according to these respondent families.

Conclusions

Data from numerous studies, and special initiatives cited in this article suggest that for many children, having a disability infers social and economic hardship for themselves and their families. In addition, the demands of the child's chronic condition often overwhelm a family (Selber, et al., 2005). There are numerous challenges that face these families beyond access to formal service provision, which was the focus of this pilot study. Such issues as emotional and relationship difficulties and community isolation are equally important topics for further research. However, there was little deviation in the commentary of recommendations and needs stated by respondents in this study, regardless of the child's disability or condition. Their voices tell us that their circumstances are worsened much more when services do not reflect family-centered characteristics such as being supportive, accessible, flexible, comprehensive and centered around the needs of families. Although this study was only focused on formal service provision and not informal supports that can be of vital help for these families, future studies on the role of family members, friends, and community members might add to the understanding of

their lives and how other informal supports might mitigate inadequacies in formal systems of care.

In general, professionals in health, educational, and social service systems utilize a disease and deficiency perspective, as opposed to a family-centered one. The former perspective clashes with a child-centered and family-centered perspective, especially when parents view their children's condition in a more positive and optimistic light. The devaluing of these types of parental perspectives was exquisitely described during focus group research facilitated by the same authors (Rondero, 2001). Comments voiced by parents and advocates during these sessions also described their perceptions of the inadequate treatment children and their families receive from medical, educational, social service agencies, and the community at large. In general, this treatment was ascribed to several factors:

- Systematic use of a disease and deficiency perspective for treating persons with developmental disabilities and their families, emphasizing deficits more than assets;
- Inadequate professional preparation of medical, educational and social service personnel to address the psychosocial needs of individuals with developmental disabilities and their families;
- The absence of a continuum of services that is comprehensive, and supports the development and lifelong needs of children with special health care needs and their families, and
- Inadequate governmental support at federal, state, and local levels that enforce accountability in the provision of services to children with special health care needs and their families (Rondero, 2001; Selber, 2001).

These factors also speak to commentary gathered by the FCS pilot survey. Although the survey has limited generalizability, the study contributes to the discussion on the perceptions of families about the importance of characteristics of family-centered services for children with disabilities and their families. Such issues as access, quality of input into service decisions, timeliness of services, and the priority of service affordability and ease of access are some of the factors that speak to the family-centered nature of services and the quality of services that this study highlights. The study also serves to inform the profession about the daily challenges confronted by these families that go beyond the family-centered nature of services and reflect additional dimensions of quality of service provision. Hopefully, these results and their discussion will advance development of intervention strategies designed to reduce the abundance of burden these families carry on behalf of their children. The voices of families of children with disabilities continue to tell us of the importance of being family-centered in all of the community's service systems.

Dr. Katherine Selber is an Associate Professor and Dr. Mary Tijerina is an Assistant Professor in the School of Social Work at Texas State University-San Marcos.

Dr. Virginia Rondero Hernandez is an Assistant Professor at California State University, Fresno.

Ms. Cathryn Heyman, M.A. was a graduate research assistant at Texas State University-San Marcos at the time of this study.

Correspondence concerning this article should be addressed to: Dr. Katherine Selber, Associate Professor, School of Social Work, Texas State University San Marcos, 601 University Dr., San Marcos, Texas 78666, e-mail to ks15@txstate.edu.

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Table 1
Demographics of Respondents

	Respondents	
	n	%
Relationship to child:		
Mother	56	82
Father	5	7
Other (grandparent, foster, adopted)	7	11
Age of Respondent:		
29 and under	5	7
30 – 49	48	71
50 and above	15	23
Education:		
High School	7	11
Some College, Vocational, Technical	23	34
Bachelors Degree	24	35
Masters, Ph.D., M.D.	14	20
Race or Ethnicity:		
Native American	1	1
Asian	3	4

Black	5	8
Hispanic	6	9
White	50	74
Other	1	1
Declined to answer	2	3
Marital Status:		
Domestic Partnership	2	3
Married	54	79
Separated/Divorced	8	12
Single	4	6
Widowed	0	0

Table 2

Primary Diagnoses of Children of Respondents

	Responses
Anxiety	2
ADHD/ADD	6
Bi-polar Disorder	8
Depression/Cyclothymia	1
Obsessive Compulsive Disorder	3
Oppositionally Defiant/Conduct Disorder	3
Post Traumatic Stress Disorder	1
Asperger Syndrome	4
Autism	15
Blind	2
Cancer	1
Cerebral Palsy	8
Deaf	1
Down Syndrome/Mental Retardation	8
Epilepsy/Seizure Disorder	4
Fetal Alcohol Effects/Syndrome	7
Pervasive Developmental Disorder	9
Traumatic Brain Injury	3
Other	8
Diagnosis Unknown	2

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[1] A copy of the survey instrument used in this study can be obtained from the first author of the study.