

November 2011

Connecting the Dots: Families and Children with Special Needs in a Rural Community

Saundra Starks

Western Kentucky University, saundra.starks@wku.edu

Dana J. Sullivan

Western Kentucky University, dana.sullivan@wku.edu

Vella Mae Travis

Western Kentucky University, vellamae.travis@wku.edu

Follow this and additional works at: <https://digitalcommons.library.tmc.edu/jfs>

Recommended Citation

Starks, Saundra; Sullivan, Dana J.; and Travis, Vella Mae (2011) "Connecting the Dots: Families and Children with Special Needs in a Rural Community," *Journal of Family Strengths*: Vol. 11: Iss. 1, Article 10.

DOI: <https://doi.org/10.58464/2168-670X.1015>

Available at: <https://digitalcommons.library.tmc.edu/jfs/vol11/iss1/10>

The *Journal of Family Strengths* is brought to you for free and open access by CHILDREN AT RISK at DigitalCommons@The Texas Medical Center. It has a "cc by-nc-nd" Creative Commons license" (Attribution Non-Commercial No Derivatives) For more information, please contact digitalcommons@exch.library.tmc.edu

Over the past 20 years, there has been a rise in diagnoses of autism spectrum disorders as well as other developmental disorders and delays (Autism Speaks, n.d.). While low-birth weight babies are more likely to survive due to advanced medical care and technology, these babies are also more likely to have delays and disabilities (Carpenter, 2000). Autism is the fastest growing developmental disability and has an incidence rate of 1 in 110 births (formally 1 in 150 until 2009 and 1 in 10,000 in the early 1990's). For males, the rate is 1 in 70 births, unsurprising since boys are four times more likely than girls to be diagnosed with the disorder. The number of children with autism is more than the numbers of children with AIDS, cancer, and diabetes combined (Autism Speaks, n.d.). According to the 2010 *Kentucky KIDS COUNT Data Book*, the number of children in a south-central Kentucky Area Development District receiving social security income due to disability in 2000 totaled 1,183, whereas in 2008 when the count was updated, the number jumped to 1,512 (Kentucky Youth Advocates, 2010).

It takes a village to address these increasing social phenomena of the rise in numbers of families with special needs children. Whether these children have autism spectrum disorders, pervasive developmental disorders, or any myriad number of other limiting physical, psychological, social, or emotional issues, the habilitative response has to be collaborative and well integrated. This village must include, but not be limited to, the families, the professionals in the special needs community, the students/interns in training, and the agencies and facilities that provide the services. So what would the creation of such a village look like in a rural southern community with both a university and a community committed to having such services? What theories would support and ground such an initiative? What system of inquiry would be used to explore the needs and the gaps in services? What results would come from such an initiative?

The following discussion answers the above questions and presents not only the theoretical models but also the process of developing a special needs forum that applied training, support, and research to issues of families and children with special needs in a rural community. The exploration of these needs and gaps within the rural community is critical since rural communities in general are often considered communities in transition (Ginsberg, 2005) and can lag behind urban areas in terms of resource development and social service delivery.

The strengths perspective and systems model are integral components of all social work education and practice (Zastrow, 2002) and

are critical to service development and delivery. The strengths perspective provides an orientation that

emphasizes the client's resources, capabilities, support systems and motivation to meet challenges and overcome adversity. . . . It emphasizes the client's assets that can be used to achieve and maintain individual and social well-being. (Barker, 2003, p. 420)

In order to connect the dots for services for the special needs community, the village would need a clear understanding of how all the elements work together. Systems theories inform us about the interrelatedness and interconnectedness of people, issues, and elements. Any discussion of, or planning for, a response to major biopsychosocial issues should ethically include an understanding of systems theory. Thus begins the process in a village that includes a small force of individuals connected by their commitment to address the issues of families with special needs.

Functioning as a Clinical Education Complex (CEC) connected to a university in rural south-central Kentucky, this village proceeded to move beyond services as usual. The CEC is comprised of six programs that provide services in the areas of 1) acquired brain injury, 2) communication disorders, 3) early childhood education/intervention, 4) family counseling, 5) family resources, and 6) autism support. These programs work together collaboratively to provide services to individuals, families, and professionals in this rural community. Research and multidisciplinary training complement the service delivery and are critical to the mission of a CEC in an academic setting.

The Family Resource Program (FRP) of the CEC is a service/resource program staffed with social work faculty, students, and community volunteers. Comprehensive family needs assessments are provided to families to evaluate their needs and connect them to services within the CEC as well as community, state, and national resources. Support networks are encouraged and fostered through the services of the FRP. Education and support are also available to families who have a child newly diagnosed with autism or any other developmental disorders. Professional staff and interns are available to meet with family members and significant others to provide information, resource material, screening services, case management, counseling, and referrals.

As an integral part of a university community, the FRP strives to proactively empower individuals and caregivers. While building bridges between individuals and needed services within the community, the FRP enhances the community's knowledge and awareness of individual and family needs. The services at the FRP are offered to individuals and families referred from other programs within the CEC, from the community

agencies and programs, and from area schools; they are also available to anyone seeking resource assistance in the region.

Overall, the FRP's goals are to provide resource information and referrals to individuals and families in need of services, to identify individual strengths and assess individual needs, to assist families in connecting with needed resources in the community, especially families who have children with special needs, and to encourage and promote community partnerships in service delivery.

Historical Perspective

In 2010, the Family Resource Program (FRP), in collaboration with the other five CEC programs, developed a forum to target professionals in the community as well as parents and caregivers of children with special needs. The first forum was titled "Special Needs Family Summit" and was presented to the community in May 2010. This event was modeled after "The Family Café," an annual conference for individuals and families with special needs in Florida. The annual statewide conference of Florida's special needs community provides information on resources and services available to the special needs community, while also involving the families in the programs, agendas, and entertainment of the conference (The Family Café, n.d.).

"The Family Café" annual conference's mission is "to provide individuals with disabilities and their families with an opportunity for collaboration, advocacy, friendship, and empowerment by serving as a facilitator of communication, a space for dialogue, and a source of information" (The Family Café, n.d.) This conference, reportedly the largest of its kind in the country, has impacted over 40,000 individuals through "education, training, and networking," providing families and individuals with the opportunity to collaborate with professionals and other families (The Family Café, n.d.)

The state of Florida has a unique history of responding to the needs of children with special needs since 1994 (Stoutimore, Williams, Neff, & Foster, 2008). Several initiatives, which included placing behavioral analysts in child welfare programs as well as in-home placements for parent coaching and training, were implemented. Collaboration was a key element in the success of the programs developed. A training curriculum of behavioral management skills and tools was utilized for caregivers.

Using the Florida conference or "Family Café" as a model, the FRP proceeded with the assistance of a committee comprised of other CEC program directors, interns, parent volunteers, and faculty to develop the first Summit. Sessions were provided on the following: "Feeding

Disorders,” “Common Psychiatric Disorders in Children,” “Waiver Services,” “Applied Behavioral Analysis,” and “Play-based Parenting Strategies,” along with a psycho-drama and panel presentation on “How to be an Effective Advocate as a Parent with a Child with Special Needs in the Public School System.” Area health-care providers and other professionals were given the opportunity to earn continuing education credits through this forum.

Like the Florida conference, the Summit provided similar information and activities, although on a much smaller scale. One difference in the two forums was the research component. The Special Needs Family Summit provided an opportune time for data collection around the issues of resource availability, accessibility, and gaps in services as well as an assessment of needs directly from the stakeholders or those most impacted. This very unique Summit was the first of its kind in the area and was repeated the following year (2011) as the “Special Needs Summit.”

The 2011 Summit expanded on the original with an increase in continuing education offerings and opportunities for education and activities. The Summit concluded with a panel of college-aged students, all with a diagnosis on the autism spectrum. These students contributed their personal reflections of opportunities experienced through the service delivery programs of the CEC, in particular the mentoring and tutoring offered through the autism program.

The success of both of the Summits will be discussed further in the results and discussion sections of this article. The results from both not only provided answers to the research questions but also were consistent with the current literature on families and children with special needs.

Literature Review

A review of the literature on the issues faced by families of children with special needs produces several common themes. Parents of children with special needs tend to 1) experience chronic stress in caring for their child with special needs, 2) be more prone to feelings of social isolation, 3) experience financial difficulties in caring for their child, 4) be likely to experience frustration in trying to locate and access services, and 5) experience frequent anxiety and worry over their child’s future or life span issues (Abery, 2006; Aitken et al., 2009; Autism Speaks, n.d.; Barr, 2010; Benson & Karlof, 2009; Freedman & Boyer, 2000; Sloper, 1999). For the scope of this article, families are defined in a broad context that includes biological parents, adoptive parents, grandparents, extended family members, siblings, and fictive kin. The term “parents” refers to individuals

in the parenting or caregiving role for the child with special needs. The terms “parents” and “families” will be used interchangeably due to the primary relationships between the children and those individuals in the parenting or caregiving role.

Stress

Several studies indicate the connection between a child’s disability or health condition with parental stress and mental health issues such as depression. Parents of children with special needs are more likely to experience stress than parents of children who are considered to be typically developing (Abery, 2006; Benson & Karlof, 2009; Sloper, 1999). Having a child with a disability has a ripple effect on the family across several domains.

Specifically, studies have shown that parents of children with ASD (autism spectrum disorders) are at greater risk for mental health issues, including depression, than parents of children with disabilities other than autism. According to Benson and Karlof (2009), the symptoms and behaviors of children with ASD, which are often pervasive and chronic, may disrupt family roles and activities in multiple ways such as finances, employment, and social interaction. This in turn may lead to parental depression and other issues. In their study of parents of children with ASD, Benson and Karlof (2009) found that having a child with ASD can lead to considerable “psychological distress” (p. 358), including comparatively higher levels of depressed mood and anger.

For families who have children with special needs, higher levels of parental stress could contribute to higher parental divorce rates; however, it is difficult to draw conclusions due to the existence of contradictory studies. Differing divorce rates for families who have children with special needs seem to be related to the type and severity of disability. For example, in families where a child has autism, divorce rates appear to be higher. In studies of families with an infant who has a health condition or health risk, the family is more likely to experience parental divorce and parental separation, and the family is more likely to have a stay-at-home mother, in addition to a father with reduced work hours. In these same families, the mother is more likely to rely on public assistance (Reichman, Corman, & Noonan, 2008), probably due to the family’s loss of income.

However, one study by the Vanderbilt Kennedy Center found that the divorce rate is actually lower than the national average for families who have a child with Down Syndrome (Barr, 2010). Regardless of the actual divorce rates for families of children with special needs, there is a general consensus that these families need extra support due to the

higher levels of stress experienced, especially in families where a child presents challenging behaviors (Osborne & Reed, 2009), including sleeping problems (Williams, Sears, & Allard, 2004).

For parents of children with special needs, finding appropriate and affordable child care can add to family stress (Reichman et al., 2008). Perhaps because locating affordable and quality child care is difficult, many parents of children with special needs choose to remain at home to care for their child or one or both parents reduce their work hours in order to provide care at home (Reichman et al., 2008). Concern about how their child would be treated by caregivers outside the family could also contribute to parents' decisions to care for their child at home. For some families, their child's challenging behaviors result in one parent remaining at home to care for the child.

Social Isolation

Parents of children with special needs tend to have lower rates of social participation than parents without a child with a disability (Reichman et al., 2008), which may contribute to parental depression. In general, parents of children with special needs are more prone to social isolation than their peers who do not have children with special needs (Autism Speaks, n.d.; Abery, 2006). In a preliminary study by the organization Autism Speaks and the Kennedy Krieger Institute (2011), extremely challenging behaviors resulted in social isolation for the whole family, due to the family remaining home in order to stick to routines and avoid challenging behaviors in public, as well as the public's response to their child's behaviors.

Financial Difficulties

Financial issues and work issues are significant stressors for families of children with special needs (Aitken et al., 2009; Bachman & Comeau, 2010; Kogan et al., 2008; Lindley & Mark, 2010; Porterfield & McBride, 2007). Several factors contribute to special needs families experiencing financial difficulties; these factors include the cost of treatments and therapies, cost of child care, loss of income due to parents' not being able to work or work full-time, the time needed to receive appropriate therapies and treatments, and the costs of money and time to transport children to and from appointments (Parish & Cloud, 2006).

Not having adequate income means that families will not be able to access or purchase services and resources that their children need. Families with children who have special needs tend to have lower incomes compared to other families; this exacerbates the process of obtaining needed services and treatments (Bachman & Comeau, 2010). Since

children with special needs are more likely to be living in poverty than children in general, financial worries greatly contribute to family stress (Bachman & Comeau, 2010; Porterfield & McBride, 2007). In rural areas with high poverty rates, higher levels of stress produced by financial strains may be experienced.

Contributing to financial difficulties is the lack of access to and affordability of adequate insurance coverage (Bumbalo, Ustinich, Ramcharran, & Schwalberg, 2005; Freedman & Boyer, 2000). Of those with insurance, many have found that insurance does not cover needed interventions such as physical therapy, speech-language services, occupational therapy, applied behavior analysis, case management, and parent support (Kennedy Krieger Institute, 2011).

Locating and Accessing Services

In order to make informed decisions about their children's care, parents need information about available resources and programs (Freedman & Boyer, 2000). However, information about their child's condition or diagnosis, available services, available financial resources, material supports, and respite is often missing (Sloper, 1999). In one study by Davis et al. (2010), families reported that they did not feel supported by services that they accessed. Another study found that lower-income families frequently hold negative perceptions about existing community resources (Silverstein, Lamberto, DePeau, & Grossman, 2008). Without effective case managers who can connect families with services and resources across several agencies, the family may be forced to "piecemeal" services and thus experience higher levels of stress and frustration (Freedman & Boyer, 2000).

Special needs families often require interventions and services from multiple agencies, such as health-care, social services, education, federal, and state agencies; this leads to contact with numerous service providers (Abery, 2006; Ello & Donovan, 2005; Sloper, 1999). Having several agencies or programs involved with the family without a "key" or single point of contact leads to fragmentation of services and lack of coordination of care (Sloper, 1999). In addition, the families who receive the least services may be those in greatest need, including single-parent families, lower-income families, and large families (Sloper, 1999). Families need help in navigating the complex system of services (Freedman & Boyer, 2000).

In one study, parents often perceived that programs or agencies involved in their children's care did not communicate with each other, duplicated paperwork and procedures, and provided contradictory

information. Thus, they identified a need for agencies to communicate and collaborate, as well as the need for a single point of entry for services (Freedman & Boyer, 2000).

Life Span Issues

A major concern for parents of children with special needs is worry over what will happen to the children after the parents die. Easter Seals, along with the Autism Society of America, conducted the *Living with Autism* study, in which 1,652 parents of children with autism and 917 parents of typically developing children were surveyed regarding their daily lives, relationships, employment, finances, healthcare, independence, and so forth. This study found that close to 80% of parents with autism reported that they are extremely concerned or very concerned about their child's ability to be independent as an adult, in stark contrast to only 32% of parents with typically developing children. In comparison to parents of children who are typically developing, much smaller percentages of parents felt their child with autism would be able to make life decisions, befriend others in the community, take part in recreational/leisure activities, or have a life partner or spouse (Easter Seals, 2008).

Strengths

In spite of the increased demands and increased stress on families of children with special needs, many families not only cope with the additional demands and stress but find ways to thrive. In families of children with developmental disabilities, parents often find ways to cope with caregiving demands, build strong marriages, and raise children without disabilities who appear to be well adjusted (Abery, 2006). As mentioned earlier, in families with a child who has Down Syndrome, the parental divorce rate was actually lower than the national average (Barr, 2010).

Some positive benefits to the family have been identified in families with a child who has an intellectual disability. Though having a child with an intellectual disability is not stress-free, it can be very rewarding and enriching. Family members may have positive experiences which contribute to an overall appreciation of life. For siblings of children with an intellectual disability, several positive outcomes included "increased empathy, love, sense of social justice, advocacy for those in need, protection-nurturance, loyalty, implicit understandings and acceptance of difference" (Dykens, 2005, p. 361).

Several factors have been identified as contributing to families' success in raising a child with a disability, including the meanings that

family members attribute to their situational demands and capacity to meet those demands, the resources used by or available to the family, and the coping behaviors used by family members to balance demands and resources (Abery, 2006). Programs such as those examined in this study aid families in navigating the needed services and resources as they strive to maintain and promote the well-being of their children and entire family.

Resource Centers for Families with Special Needs

Across the United States, there are several resource centers serving families of children with special needs. The Southwest Autism Research & Resource Center (SARRC), located in Phoenix, Arizona, carries out its mission to “advance research and provide a lifetime of support for individuals with autism and their families” (Southwest Autism Research & Resource Center, n.d.). SARRC provides services and support to children and families with autism, while conducting research and providing trainings for and presentations to family members and professionals in the special needs community (Southwest Autism Research & Resource Center, n.d.).

Another center that serves professionals in the autism community as well as families of children with autism is the University of Louisville Autism Center at Kosair Charities, located in Louisville, Kentucky. The center combines different departments in the university to provide evaluations, treatment, and interventions for children while providing training and information to parents, caregivers, and professionals. The goal is to provide children, caregivers, and professionals a single place where they can obtain information, treatment, and referrals (University of Louisville, n.d.).

In Austin, Texas, the Johnson Center for Child and Health Development provides diagnostic services, health-care services, behavioral therapy, educational assessments, community outreach, and education while also conducting research. This center’s mission is “to advance the understanding of childhood development through clinical care, research, and education” (Johnson Center for Child and Health Development, n.d.). Formerly called the Thoughtful House, the Johnson Center serves individuals, families, and professionals within the developmental disorders community (Johnson Center for Child and Health Development, n.d.).

Located at Vanderbilt University in Nashville, Tennessee, the Vanderbilt Kennedy Center offers several programs for children, parents, and professionals within the special needs community. The center provides information, treatment, interventions, and support for families

who have a member with developmental disabilities. Within the Vanderbilt Kennedy Center is the Family Outreach Center, which serves as the point of entry for families needing services and resources offered at Vanderbilt University and services offered within the community (Vanderbilt Kennedy Center, n.d.). All of these centers, including the Clinical Education Complex (CEC), share similar core values and missions in serving individuals, families, caregivers, and professionals within the special needs community while also conducting research to further the knowledge of evidence-based practices within multiple disciplines. These multidisciplinary centers provide services, training, and research within the village of the special needs community.

Method

Consistent with the village approach, inductive methods of research produce the most effective and user-friendly methods of inquiry. Grounded theory can be used to capture the multiple dimensions of phenomena. According to Denzin and Lincoln (2000), grounded theory is currently the most widely used interpretive paradigm in the social sciences. The inductive nature of this partially qualitative research method provides a systematic set of procedures to develop a theory about a phenomenon that is grounded in data and the experiences of the participants (Tillman, 2002). Data collection, analysis, and theory construction are regarded as reciprocally related. This interweaving is a way to increase insights and clarify the parameters of emerging theory to ensure that the analysis is based on the data and not on presumptions (Padgett, 2008; Wilson, 2008). Subsequently, the emergent theory here is specifically focused on capturing themes related to the needs of families and children with special needs as well as the professionals who develop and provide services to them.

This study evaluated the community Summits held over two years by the CEC to determine if the training was useful and helpful and if it contributed to the knowledge and skills of the conference participants. Given the needs of children with special needs and their families, the researchers also wanted to explore whether participants thought that the resources were adequate in the area and to get more of a sense of training and service needs. The training evaluation instrument selected for this study has been utilized in several studies involving child welfare and mental health professionals (Antle, Barbee, & van Zyl, 2008; Sullivan, Antle, van Zyl, & Faul, 2009); it has been found to be a good measure of training utility and, in the Antle et al. study, appeared to be a factor in retention of knowledge gained in training. The instrument contained

questions measured on a 5-point Likert scale. The instrument asked participants to rate areas such as the training atmosphere, the methods utilized in the training, the confidence they felt to practice in the topic area, the usefulness of the material, the amount of material covered, and overall satisfaction with training. In addition, some needs assessment questions were asked to determine what supports and services were needed by families with children with special needs and the professionals who serve those families. In this study, the researchers wanted to know if the participants thought the available resources were adequate and wanted to explore themes around the needs of this targeted population, in order to consider possible interventions and begin to develop theory around gaps in services, unmet needs and a continuum of care for these children and families. Some demographic questions were included to capture information such as educational level, role of the participant (parent, professional, student, etc.), age, ethnicity, and length of time involved in the special needs community.

This study used a convenience sample of training attendees at the Summit. There was a consent preamble inviting the participants to complete the survey. They were informed that completing the survey and participating in the study were voluntary and that they could discontinue participation in the study at any time. The consent preamble indicated that their completion of the survey communicates their consent to voluntary participation in the study. The consent preamble and survey were included in the participant's training packet.

Results

Over the two years the Summit was held, 38 participants responded to the invitation to complete the survey, 20 the first year and 18 the second year. There were 128 total Summit participants over the two years, which made this a response rate of 29.6%. Of the participants, 92% were female. When asked about their ethnic origin, 76% identified themselves as Caucasian, 18% African American, 3% Hispanic/Latino and 3% selected the option "other." The participants had varying levels of education, with the majority of participants having a Master's degree ($n = 17$) or Master of Social Work degree ($n = 7$), 10 having Bachelor's degrees (2 were in social work), 1 each having a high school diploma and associate's degree, and 2 holding doctoral degrees.

The participants were asked their role within the special needs community. Thirty-two percent said they worked in an agency serving children with special needs and their families, 26% worked in a university setting, 16% were in some sort of private practice, 8% worked for public

school systems, and 3% were volunteers (number does not equal 100 because some chose “none of the above”). The participants represented different roles when attending the conference. Most respondents (73%) were attending as professionals that serve special needs children, 11% were parents of special needs children, and 16% were students. In terms of their length of involvement working with the special needs community, over half the sample had been involved for more than 6 years (51%), only 5% had less than a year’s involvement, while 32% had been involved 1 to 3 years and 11% between 4 and 6 years. Those who work in the field had been employed an average of 4 years ($Mean = 48$, $SD = 42.3$, $Range = 8 - 156$ months [one outlier of 39 years removed from analysis]).

Overall, the participants reported a high level of satisfaction with the training. When asked about the importance of the training, on a 5-point Likert scale, the mean was 4.38 ($SD = .83$), with 89% indicating they agreed or strongly agreed about the importance of the training. Their ratings of the helpfulness and practicality of the various training methods (role play, handouts, and lecture) were very high, ranging from 87% to 97% when combining the “agree” and “strongly agree” responses. See Figure 1 for a graph of these results. Nearly all respondents (97%) indicated that the method of training delivery was effective.

The training was seen as useful by 97% of the respondents, and 86.5% said their knowledge had increased as a result of participating in the Summit. More than half of the sample (62%) indicated the training had increased their skill in this area, and 65% indicated an increase in their confidence to practice in this area. A large majority (89%) indicated their likelihood to apply the knowledge gained from the training, with scores ranging from 2-5 on a 5-point Likert scale, with a mean score of 4.35 ($SD = .89$). See Figure 2 for a summary of these items.

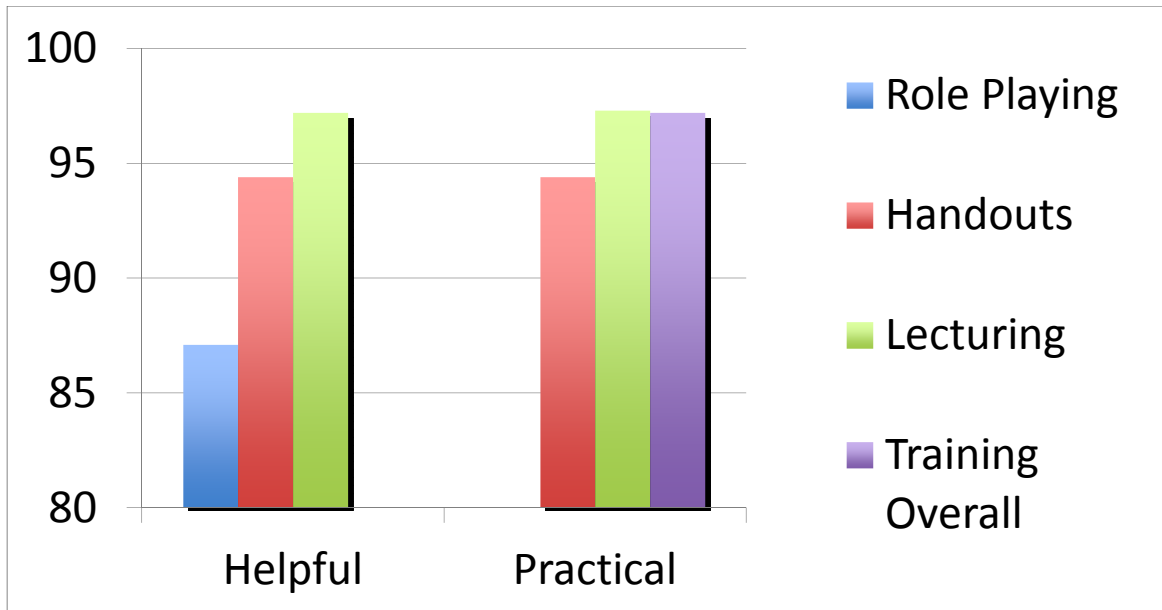


Figure 1. Helpfulness and practicality of training methods (combining “agree” and “strongly agree”).

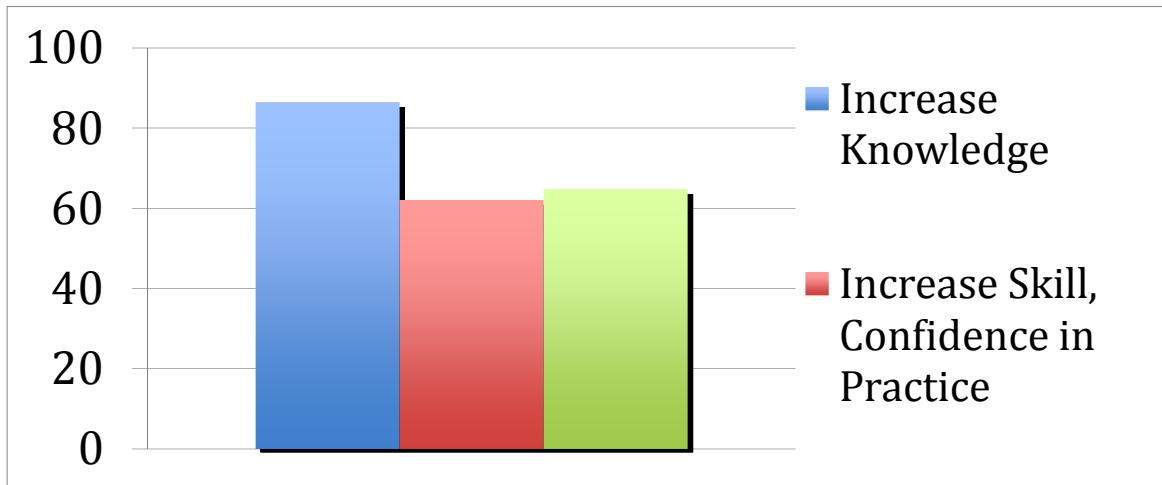


Figure 2. Impact of training on practice.

The majority of the participants (89.2%) indicated that they agreed or strongly agreed regarding the importance of the training, and the majority (86.5%) indicated their knowledge on the topic had increased after attending the training. Nearly two-thirds (64%) indicated the amount of material covered was the right amount while 21.4% indicated they would have liked more material to be covered during the event. When asked if they felt more equipped to be an advocate for special needs

children after attending the training, 88% indicated they did. Almost all of the participants (94%) indicated they felt more informed about children with special needs after attending the Summit. Several themes emerged regarding how participants felt more equipped to be advocates for children with special needs. Participants mentioned areas such as feeling better equipped for families when children have feeding concerns, feeling more comfortable working with this population, gaining a better understanding of autism spectrum disorders and related interventions/treatment, and gaining knowledge to pass on to others to raise awareness about how to best assist children and families.

Slightly over half (56.3%) indicated that the resources for special needs children and their families are adequate within the community. Some of the needed resources listed were as follows: help for learning resources when new to the area; awareness in the general population to the needs of children with ASD; more resources for feeding issues; decreased waiting lists; greater social interaction and assistance with activities of daily living; more play groups and support groups; financial resources; transportation to services; more in-home services; and respite care.

The preferred format for receiving information about working with special needs children was training events ($n = 34$), followed by individual work with staff ($n = 12$), then electronic sources ($n = 8$) and newsletters ($n = 6$). See Figure 3 for a summary. The training topics most requested by participants for future events were as follows: strategies for low-functioning autism, physical disabilities, feeding, sensory issues, speech behavior, auditory processing/hearing impairment, and in-depth information on therapy and intervention techniques.

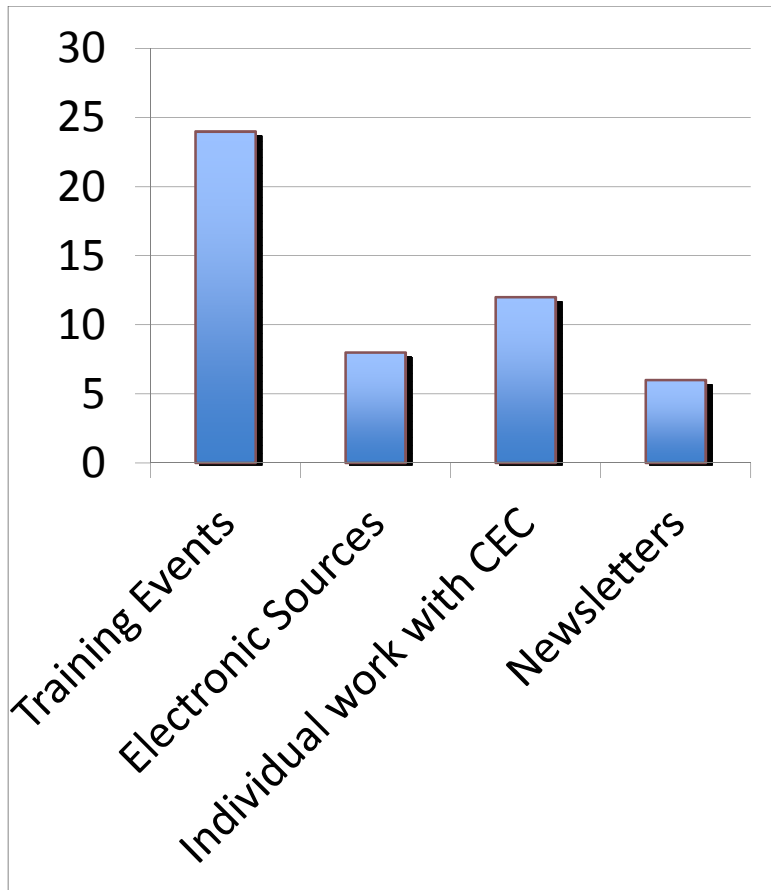


Figure 3. Preferred format for receiving information about working with special needs children

Discussion

The participants in this study had several years of work experience with children with special needs and had been involved in the special needs community for some time. They had varying levels of education, and more than half had been involved with the special needs community for more than 6 years. Professionals, parents, and students were all represented and came together to gain more information about children with special needs. Those who had worked in the field had been working there an average of 4 years, indicating that the sample had some experience already with this population and began the training with some familiarity of the issues related to this population.

Overall, the participants rated the training as useful, important, and practical. The qualitative comments indicated that the participants liked the speakers, that the training was interesting and helpful, and that a great

deal of good information was covered. Needed resources and future training topics were identified. Many of these topics are in line with the literature, which indicates these families need assistance in areas such as accessing services (Freedman & Boyer, 2000). The majority of participants indicated they felt better equipped after the training to be advocates for children with special needs. They were highly satisfied with the training and indicated an increase in knowledge, skills, and confidence to practice in this area. Even though many in this sample indicated that there are adequate resources for children with special needs, the small sample size limits the generalizability of these findings. Future studies should continue to explore the needs of children with special needs and their families as well as to examine outcomes from programs such as the CEC, programs which are designed to help meet these multiple needs.

Conclusion

The rise in prevalence of children with special needs presents challenges for families and communities. A child's disability affects several areas of family life, and parental well-being impacts the child's well-being. Therefore, it is imperative to address the whole family's needs and not just the needs of the individual with a disability. Particularly in rural areas, as more and more children are diagnosed with autism spectrum disorders and other developmental disabilities, families often struggle to locate information, support, and referrals for various therapies, services, and resources.

A review of the literature identifies several issues faced by parents of children with special needs such as chronic stress, social isolation, financial issues, difficulty locating and accessing services, and life span issues. In order to meet the needs of families with special needs, a holistic approach is critical (Freedman & Boyer, 2000). This holistic approach was supported by the results of the research conducted in this study. Linking families with needed resources and giving parents options to make choices and decisions about the services their children receive empowers them, and all family members benefit.

The Special Needs Summit was developed by a Clinical Education Complex (CEC) to provide education, support, and training for families, professionals, paraprofessionals, and students within the special needs community. The Summit provided the following for its participants, who were parents, caregivers, professionals, paraprofessionals, and students: workshops on relevant topics, continuing education credit, informational booths, panel of college students with autism spectrum disorders, a talent show featuring children with special needs, and family festival activities.

This forum allowed an opportunity for research, and data were collected through the use of an evaluation training instrument. Participants were able to provide feedback through the use of a survey that requested information about the following: 1) relevance of the training, 2) future needs for training, 3) needs for development of additional resources, and 4) the best vehicle for service delivery.

Based on data from participants, the majority agreed the training was important and rated highly the helpfulness and practicality of the training methods. As a result of the Summit, participants reported their knowledge and skill in a particular area had increased. Participants indicated they felt more equipped to advocate for children with special needs, and almost all felt more informed about children with special needs after attending the Summit. Some of the gaps in services or needed resources which were identified included: help in locating and accessing services when new to the area, community awareness of children with autism spectrum disorders, financial resources, transportation, and respite care; this list corresponds to the needs of parents found in the literature. The feedback from participants in this study will also contribute to the existing literature on diversity as it relates to families of children with special needs.

More studies are needed to further explore the challenges of members within the special needs community, particularly families. More detailed feedback regarding specific needs would be helpful in developing future Summits and parent training and support events. Forming a coalition of service providers dedicated to serving families with special needs could make service provision more effective and responsive to families. In order to connect the dots for these families, it will take a village approach. This village should be multidisciplinary, inclusive of parents, siblings, formal and informal caregivers, and the professional and academic communities.

References

- Abery, B. H. (2006). Family adjustment and adaptation with children with Down Syndrome. *Focus on Exceptional Children*, 38(6), 1-18.
- Aitken, M. E., McCarthy, M. L., Slomine, B. S., Ding, R., Durbin, D. R., Jaffe, K. M. . . . & Mackenzie, E. J. (2009). Family burden after traumatic brain injury in children. *Pediatrics*, 123(1), 199-206.
- Antle, B. A., Barbee, A. P., & van Zyl, M. (2008). A comprehensive model for child welfare training evaluation. *Children and Youth Services Review*, 30(9), 1063-1080.
- Autism Speaks Incorporated. (n.d.). *What is autism?* Retrieved from <http://www.autismspeaks.org/what-autism>
- Bachman, S. S., & Comeau, M. (2010). A call to action for social work: Minimizing financial hardship for families of children with special health care needs. *Health & Social Work*, 35(3), 233-238.
- Barker, R. L. (Ed.). (2003). *The social work dictionary* (5th ed.). Washington, DC: NASW Press.
- Barr, K. N. (2010, February). When parents of children with special needs divorce. *Exceptional Parent Magazine*, 4-7.
- Benson, P. R., & Karlof, K. L. (2009) Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism and Developmental Disorders*, 39, 350-362.
- Bumbalo, J., Ustinich, L., Ramcharran, D., & Schwalberg, R. (2005). Economic impact on families caring for children with special health care needs in New Hampshire: The effect of socioeconomic and health-related factors. *Maternal and Child Health Journal*, 9(2 Suppl.), S3-S11.
- Carpenter, B. (2000). Sustaining the family: Meeting the needs of families of children with disabilities. *British Journal of Special Education*, 27(3), 135-144.
- Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., Casey, E., . . . Reddihough, D. (2010). The impact of caring for a child with cerebral palsy: Quality of life for mothers and fathers. *Child: Care, Health, and Development*, 36(1), 63-73.
- Denzin, N. K., & Lincoln, Y. S. (2000). *Handbook of qualitative research*. Thousand Oaks, CA: Sage Publications.
- Dykens, E. M. (2005). Happiness, well-being, and character strengths: Outcomes for families and siblings of persons with mental retardation. *Mental Retardation*, 43(5), 360-364.
- Easter Seals. (2008). Living with autism study. Retrieved from

- http://www.easterseals.com/site/PageServer?pagename=ntlc8_living_with_autism_study_home
- Ello, L. M., & Donovan, S. J. (2005). Assessment of the relationship between parenting stress and a child's ability to functionally communicate. *Research on Social Work Practice, 15*(6), 531-544.
- Freedman, R. I., & Boyer, N. C. (2000). The power to choose: Supports for families caring for individuals with developmental disabilities. *Health & Social Work, 25*(1), 59-68.
- Ginsberg, L. H. (Ed.). (2005). *Social work in rural communities* (4th ed.). Alexandria, VA: Council on Social Work Education.
- Johnson Center for Child and Health Development. (n.d., para. 1). *What is the Johnson Center for Child Health and Development?* Retrieved from <http://www.johnson-center.org/index.php/site/FAQ>
- Kennedy Krieger Institute. (2011). Interactive autism network research report: Family stress—part 1. Retrieved from <http://www.autismspeaks.org/news/news-item/ian-research-report-family-stress-%E2%80%94part-1>
- Kentucky Youth Advocates. (2010). *Kentucky KIDS COUNT county data book*. Jeffersonville, KY: Kentucky Youth Advocates.
- Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., & van Dyck, P. C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005-2006. *Pediatrics, 122*(6), e1149-e1158.
- Lindley, L. C., & Mark, B. A. (2010). Children with special health care needs: Impact of health care expenditures on family financial burden. *Journal of Child and Family Studies, 19*, 79-89.
- Osborne, L. A., & Reed, P. (2009). The relationship between parenting stress and behavior problems of children with autistic spectrum disorders. *Exceptional Children, 76*(1), 54-73.
- Padgett, D. K. (2008). *Qualitative methods in social work research* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Parish, S. L., & Cloud, J. M. (2006). Financial well-being of young children with disabilities and their families. *Social Work, 51*(3), 223-232.
- Porterfield, S. L., & McBride, T. D. (2007). The effect of poverty and caregiver education on perceived need and access to health services among children with special health care needs. *American Journal of Public Health, 97*(2), 323-329.

- Reichman, N. E., Corman, H., & Noonan, K. (2008). Impact of child disability on the family. *Maternal and Child Health Journal*, 12, 679-683.
- Silverstein, M., Lamberto, J., DePeau, K., & Grossman, D. C. (2008). "You get what you get": Unexpected findings about low-income parents' negative experiences with community resources. *Pediatrics*, 122(6), e1141-e1148.
- Sloper, P. (1999). Models of service support for parents of disabled children: What do we know? What do we need to know? *Child: Care, Health, and Development*, 25(2), 85-99.
- Southwest Autism Research & Resource Center. (n.d.) About SARRC. Retrieved from http://www.autismcenter.org/about_sarrc.aspx
- Stoutimore, M. R., Williams, C. E., Neff, B., & Foster, M. (2008). The Florida child welfare behavior analysis services program. *Research on Social Work Practice*, 18(5), 367-376.
- Sullivan, D. J., Antle, B. F., van Zyl, M. A., & Faul, A. C. (2009). Implementing evidence-based practice into public mental health settings: Evaluation of the Kentucky Medication Algorithm Program. *Best Practices in Mental Health*, 5(2), 112-128.
- The Family Café. (n.d., para 1). The Family Café: About Us. Retrieved from http://familycafe.net/index.php?option=com_content&view=section&id=3&Itemid=90
- Tillman, L. C. (2002). Culturally sensitive research approaches: An African-American perspective. *Educational Researcher*, 31(9), 3-12.
- University of Louisville Autism Center at Kosair Charities. (n.d.) Our mission statement. Retrieved from <http://louisville.edu/autism/>
- Vanderbilt Kennedy Center (n.d.) The Family Outreach Center. Retrieved from <http://kc.vanderbilt.edu/site/services/disabilityservices/default.aspx>
- Williams, P. G., Sears, L. L., & Allard, A. (2004). Sleep problems in children with autism. *Journal of Sleep Research*, 13, 265-268.
- Wilson, S. (2008). *Research is ceremony: Indigenous research methods*. Winnipeg, Canada: Fernwood Publishing.
- Zastrow, C. (2002). *The practice of social work* (7th ed.). Pacific Grove, CA: Brookes/Cole Publishers.