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Service Needs of Foster Families with Children who have Disabilities

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We examined the service needs of foster families with children who have disabilities. Foster parents in a large Canadian city were asked "What services or supports would be helpful to you?" The responses to this question were edited for clarity and to eliminate redundancies, and sorted into piles of like statements by a group of 15 foster care professionals. Two types of statistical analysis were applied to the sorting of the statements to describe the relationship between statements and their groupings. The major concepts were identified according to the contents of the cluster and a map was constructed to provide a graphic representation of the conceptualization process. The major services and supports identified in this study were: support in the community, financial support, accommodating school system, good relationships with social workers, responsive professionals, information, comprehensive medical care, services for aboriginal children and families, transitional services, and respite.

KEY WORDS: foster parents; disabilities; service needs; concept map.

The success of a foster placement is dependent on both a successful match between foster family and foster child and the support received by the family from the community. Parents who foster children with disabilities may experience particular challenges and, require additional resources in order to function in the same way as a family caring for a child without a disability (Buboltz & Whiren, 1984). It is crucial to recognize the range of support needs these families face.

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However, few studies have focused on the experience of foster parents of children with a range of disabilities to understand their perspective. The literature suggests several areas of service need. In general, foster parents emphasize the value of training, communication with professionals, counseling services, respite, peer support, and community resources.

Foster parents caring for children with disabilities report that relevant training regarding special needs is very helpful (Hudson & Levasseur, 2002). One area of great concern to foster parents caring for children with disabilities is their lack of knowledge on the specific disability of the child in their care. Burry (1999) found specialized training on fostering a child with disabilities influences the attainment of skills and knowledge about the child's needs.

The availability of skilled support workers is related to effective care giving. Personal qualities of social workers valued by foster parents include: interest and commitment to the foster parent, warmth, reliability, trustworthiness, ability to listen, and competence in official matters (O'Hara, 1986). Social worker consistency, as well as frequency and intensity of contact with the foster parent and child are of the greatest importance during the early months of placement (Hudson & Levasseur, 2002; Jivanjee, 1999; Mason & Linsk, 2002). Redding, Fried, and Britner (2000) identified three agency variables associated with successful foster placement: rapport building between foster parent and case worker, overall rapport between foster parents and the agency, and rapport between the foster child and the caseworker. High caseloads and caseworker burnout present significant concerns for families fostering children with disabilities (Jivanjee, 1999). In addition, foster parents report frustration due to lack of organized communication between the agency, the medical system, the education system and various programs offered for children with disabilities (Cain & Barth, 1991; Jivanjee, 1999).

Counseling is often reported as a helpful service for parents fostering a child with a disability (Mason & Linsk, 2002; Vig & Kaminer, 2002). Crisis intervention and support is noted as one of the most important services needed by foster parents (Hudson & Levasseur, 2002). After receiving some counseling, many parents feel that other foster parents in a similar situation should also get counseling support (Laan, Loots, Janssen, & Stolk, 2001).

Families caring for children with disabilities report significantly lower stress levels following respite care (Hudson & Levasseur, 2002). Regular time away from the child(ren) for physical, emotional and social reasons is crucial.

Support groups are very beneficial to parents fostering children with disabilities. Some of the reported benefits include: feelings of being understood by others, learning new parenting skills, being able to express their feelings and concerns with people who understand their position, and learning to empathize with the child's biological family (Redding et al., 2000). Foster parents also report great benefits from resources designed to help them find specialized medical and recreational services. These include lists of potential physicians for their foster child, or information on special education programs, mental health services or transportation services available in their area (Cain & Barth, 1991; Redding et al., 2000; Zima, Bussing, Yang, & Belin, 2000).

Foster parents need financial resources (Banks & Jamieson, 1990). Foster parents report that their rates are insufficient to support the children in their care and need to be supplemented out-of-pocket (Edwards, 1980; Mason & Linsk, 2002). Families with children who have disabilities need additional resources (Buboltz & Whiren, 1984; Szymanski & Seppala, 1995).

METHOD

Initially developed for planning and management applications, concept maps have been used for evaluation, survey design, curriculum development or theory building (Trochim, 1989a). Concept mapping has been applied within the fields of psychology and human services (Goodyear, 2002; Paulson, Truscott, & Stuart, 1999).

According to Trochim (1989b), there are six major components to the concept mapping process. The first step is the generation of responses to a particular question. Second, these statements are edited for clarity and to eliminate redundancies. Third, the statements are sorted into piles of like statements. The piles are considered to represent general themes. Fourth, two types of statistical analysis are applied to the sorting of the statements to describe the relationship between statements and their groupings. A decision is made regarding the optimal number of concepts. Fifth, the major concepts are identified according to the contents of the cluster. Sixth, the map is used for its intended purpose: a graphic representation of the conceptualization process.

Generation of Statements

To prepare for the concept mapping process two steps were taken: participants were selected and the question was determined (Trochim, 1989b).

Participants were obtained through the registry of foster parents held by provincial authorities. A list of telephone numbers for all licensed foster parents in a large Canadian city was provided to the researchers. Telephone numbers were randomly selected from the list using a table of random numbers.

Foster parents were contacted by the researchers, informed about the study and told that their responses would be kept confidential and anonymous. Foster parents who verbally consented to participate in a telephone interview were asked if they had cared for a foster child with a disability in the past year. Those who had fostered a child with a diagnosed intellectual ($n = 22$) or physical disability ($n = 14$), blindness, deafness, or complex health issues ($n = 12$), or a disorder in the fetal alcohol ($n = 35$) or autism ($n = 5$) spectra were interviewed.

Foster parents were asked one open-ended question: What services or supports would be helpful to you? Each participant was sent an honorarium for participating in the interview.

Data collection continued until there were no new responses in five consecutive interviews across participants. A total of 44 foster parents were interviewed. The majority of participants were female (86%). More than half fostered with another parent (61%). In general, participants had fostered more than one child with a disability or had fostered a child with more than one disability. They had fostered for an average of 12.8 years (range = 0–40) and at the time of interview were fostering 2 children, on average (range = 0–4).

Inter-Rater Agreement

Participants generated responses to the question or focus of discussion. These statements represented the domain of interest. Statements were edited for clarity and essential meaning using an inter-rater agreement process (Trochim, 1989b). Three raters, including two of the study authors and a teacher, independently reviewed the statements. Statements identified as redundant or unclear by any reviewer were discussed. Changes were made to improve the clarity of statements, and redundant statements were removed.

Sorting

Professionals in the fields of disabilities and foster care known to members of the project advisory committee were asked to sort the responses. A total of 15 sorts were returned.

Sorting Procedure

Each statement was printed on a separate card. Sets of cards were given to each sorter in random order. Sorters were given the following instructions: read through the cards in the stack; sort the cards into piles in a way that makes sense to you (place similar statements together in the same pile); and record the ID numbers of the grouped statements in the space provided. Sorters were instructed to construct more than one pile, but have less than the total number of cards.

Data Analysis

The conceptual domain was analyzed by two statistical procedures and was followed by a decision about the optimal number of concepts for the final solution. Multidimensional scaling placed the statements spatially on a map, and cluster analysis placed the points into clusters representing higher order aggregates of the statements. The Concept System (Trochim, 1987) was used to perform the statistical analysis and construction of the concept maps.

Multidimensional Scaling

Each statement was placed on a map called a point map (Trochim, 1989b). Statements that were closer together on the map were more likely to be sorted into the same piles more frequently. Statements that were far apart were more likely to be sorted into different piles more frequently. The bridging index is a value between zero and one that indicated the relationships between a statement and others on the map. In general, the closer the value was to one for a particular statement, the more often that statement was sorted with statements in other regions of the map. As the value approached zero, the more likely the statement was sorted only with others situated in its area. A maximum value (1.00) occurred when the statement was sorted with statements found across all areas of the map. A cluster average was the average bridging value of statements contained in that cluster. A high value (e.g. over .75) suggested that the statements in the cluster were frequently sorted together with statements outside of the cluster by the sorters. A low value (e.g. under .25) suggested that the statements included in the cluster were infrequently sorted together with statements outside of the cluster.

Cluster Analysis

A second analysis was performed on the map data to represent the conceptual domain (Trochim, 1989b). Hierarchical cluster analysis (Anderberg, 1973; Everitt, 1980) of the multidimensional scaling X-Y coordinate values was used to group the statements on the map into clusters that represent similar concepts.

Number of Concepts

Initially, each statement was considered to be its own cluster. At each stage of the analysis, the algorithm combined two clusters until all statements ended up in one cluster. The decision regarding the most appropriate number of concepts was made based on the conceptual fit of the statements within the various cluster solutions generated, and the items contributing most to the uniqueness of each cluster using the average and individual bridging indices.

Interpretation and Utilization of Maps

Following the statistical analysis, the clusters were visually inspected and labeled to represent the constituent statements of which they were comprised. The resulting map provided a visual summary of the conceptualization process.

RESULTS AND DISCUSSION

There were 60 different responses to the question. The responses are shown in Table I as sorted by 15 professionals. The sort data were analyzed using the Concept System (Trochim, 1987). We examined maps with different numbers of concepts before arriving at a decision about the most appropriate number. The decision was based on what was the best conceptual and statistical fit between the statements and the concepts. Cluster solutions from 12 to 8 were examined before concluding that the ten cluster solution (see Fig. 1) fit the data best.

Foster parents indicated that there needed to be more support in the community. For example, they indicated that there needed to be more “public education about special needs.” Existing community organizations for all children could have been more accepting of children with disabilities (“community and church groups accepting of special needs children”). Specialized supports for parents of children with disabilities (“autism society”) and foster parents, such as “informal foster parent groups” and “support groups for foster moms where children can come along” were said to be helpful.

In the literature, peer support groups, transportation services, specialized recreational services and specialized education programs were reportedly beneficial for parents fostering children with disabilities (Cain & Barth, 1991; Redding et al., 2000; Zima et al., 2000). While foster parents in our study indicated that better public awareness and education about disabilities was necessary, as well as more integrated recreational and education opportunities for children with disabilities, we found no reference to these issues in other studies.

Foster parents reported that additional financial support would be helpful. They indicated that the costs of caring for a child with a disability required “more money for expenses,” and a need for “increased financial support for daily living expenses.” An “increase (to) foster parent money” would assist parents in providing access to community activities such as “sports equipment and registration” as well as structural changes to their homes necessary to accommodate children with disabilities (“renovate house to accommodate foster child”). They also indicated that “foster parents should get store discounts.”

The need for additional financial support for parents fostering children with disabilities has been reported in the literature. Several studies reported that fostering a child with a disability required additional financial support beyond what was needed for a child without a disability (Banks & Jamieson, 1990; Buboltz & Whiren, 1984; Edwards, 1980; Mason & Linsk, 2002; Szymanski & Seppala, 1995). However, we found no reference in the literature to the need for additional compensation for structural changes to the home, necessary to accommodate the needs of a child with a disability.

Foster parents provided a number of responses related to school. They reported that “schools that understand the child’s needs” were very helpful, as was

Table I. Cluster Items and Bridging Values for Concept Map

Cluster and statement	Bridging index
Cluster #1—Support in community	0.41
35. Public education about special needs	0.06
9. Community and church groups accepting of special needs children	0.31
1. Friends and family need to be supportive of the lifestyle change	0.46
36. Support groups for foster moms where children can come along	0.50
12. Informal foster parent groups	0.56
31. Autism society	0.57
Cluster #2—Financial Resources	0.13
38. Increased financial support for daily living expenses	0.00
10. More money for expenses	0.01
25. Increase foster parent money	0.01
18. Foster parents should get store discounts	0.05
47. Money for sports equipment and registration	0.08
23. Renovate house to accommodate foster child	0.66
Cluster #3—Accommodating School System	0.37
41. Schools that understand the child's needs	0.33
13. Good communication with the teachers	0.36
3. Supportive school with a good special needs program	0.40
Cluster #4—Good Relationships with Social Workers	0.56
7. Understanding and supportive social worker	0.54
11. Social workers who have a relationship with foster parents and children	0.54
33. Social workers need to return phone calls	0.54
40. Team of professionals	0.63
Cluster #5—Information	0.53
56. Information about community services, training and workshops	0.22
39. Education provided by experienced foster parents not professionals	0.41
19. Information about the child's history	0.54
46. Information for foster parents about FAS	0.58
22. Classes on Aboriginal culture	0.66
59. Medical information	0.77
Cluster #6—Comprehensive Medical Care	0.49
20. The hospital was great when she needed an artificial limb	0.38
4. Family doctors willing to take special needs patients	0.45
55. Advocacy in the medical system	0.50
2. Medical equipment	0.61
Cluster #7—Access to Professionals	0.27
44. Music therapy	0.19
60. Occupational therapy	0.19
37. Access to private therapists for assessments	0.23
6. Counseling for foster children and parents if needed	0.24
43. Speech therapy	0.25
24. Play therapy	0.26
51. Counseling services for children with brain damage	0.34
17. Treatment resources specific to their learning needs	0.34
5. In-home therapies	0.39
Cluster #8—Services for Aboriginal Children and Families	0.87
34. Aboriginal services for foster children	0.75
8. Home visits by social workers	1.00
Cluster #9—Transitional Services	0.55
42. Classroom aides	0.28

Table I. Continoued

Cluster and statement	Bridging index
49. Special services in schools	0.31
45. Preschool outreach programs that continue into school age	0.41
32. Tutor for school work	0.54
28. Employment and educational resources	0.55
58. Transition services for foster children when they turn eighteen	0.66
29. Group vacations for children with similar special needs	0.73
54. Crisis personnel for both foster parents and foster children	0.92
Cluster #10—Respite	0.26
27. More respite hours	0.12
48. Respite care	0.12
50. Babysitting	0.12
14. In home child care	0.14
15. Overnight care for shift work	0.14
26. In home housework support	0.14
57. List of respite workers	0.25
30. Someone to take child to appointments	0.27
21. Support workers come into the home to help with homework every week	0.28
52. Agency to organize respite and hire the workers	0.35
53. Increase money for respite care	0.58
16. Big brother/sister mentors for the foster children	0.66

"good communication with the teachers." They indicated that specialized program availability and access in the local school were very helpful ("supportive school with a good special needs program").

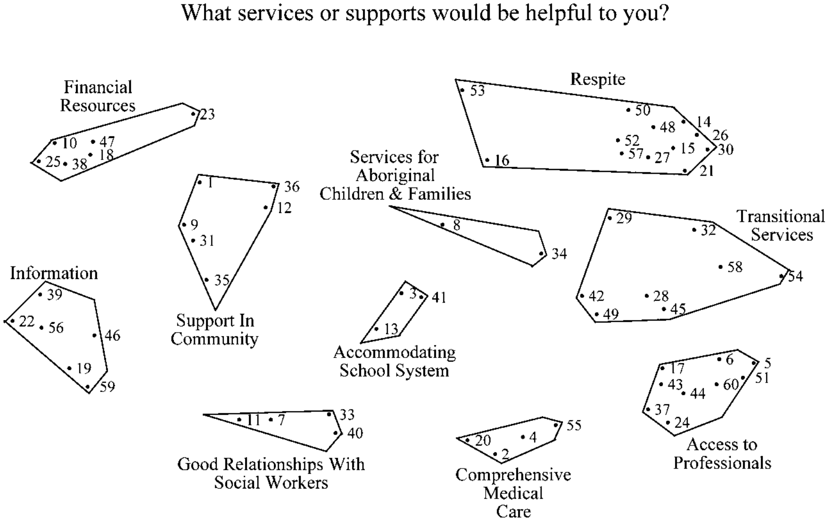

Fig. 1. Concept map.

These results are consistent with the fostering literature. Families fostering children with disabilities consistently reported the beneficial effects of having the support of an educational specialist (Appathurai, Lowery, & Sullivan, 1986), and a good special education program within the local school (Zima et al., 2000).

Foster parents provided several statements related to having good relationships with social workers and other professionals functioning as a team ("team of professionals"). An "understanding and supportive social worker" and "social workers who have a relationship with foster parents and children" were seen as very helpful. Foster parents also identified that having ready access to a social worker was helpful ("social workers need to return phone calls").

In several previous studies, foster parents of children with disabilities have endorsed the need for a good working relationship with their social workers (Hudson & Levasseur, 2002; Jivanjee, 1999; Mason & Linsk, 2002).

Foster parents saw a variety of types of information as helpful when caring for a child with a disability. They indicated that "information about the child's history," "medical information," as well as "information for foster parents about FAS" were important. As well, foster parents reported that "classes on Aboriginal culture" were helpful as was "information about community services, training and workshops." They noted that they received helpful training from their peers ("education provided by experienced foster parents not professionals").

Foster parents caring for children with disabilities have reported the need for more specific information on disabilities in general, and the disabilities of the children in their care, in particular (Hudson & Levasseur, 2002). In the literature, foster parent training received from peers was seen to be beneficial (Burry, 1999). Foster parents also perceived training on Aboriginal culture to be valuable (Brown & Calder, 2002).

Foster parents described several features of medical care that they saw as helpful. They indicated that community ("family doctors willing to take special needs patients") and hospital health care ("the hospital was great when she needed an artificial limb") were useful, as was specific "medical equipment" for their foster child to use. They also reported that they benefited from having "advocacy in the medical system."

Our results were consistent with existing literature. Foster parents caring for children with disabilities have often identified the importance of having a good family doctor willing to take on children with disabilities (Cain & Barth, 1991; Redding et al., 2000; Zima et al., 2000).

Parents reported that they found an array of professional services useful in fostering children with disabilities. The services included "music therapy," "occupational therapy," "speech therapy," and "play therapy." Foster parents indicated that they found having "access to private therapists for assessments" was useful, and that "in home therapies," or services provided in their homes, were of benefit. Counseling services for foster parents and foster families was helpful ("counseling for foster children and parents if needed"), as was counseling for foster children who had disabilities ("counseling services for children with brain damage," "treatment resources specific to their learning needs").

In the literature, foster parents of children with disabilities have reported that counseling for themselves and the children was beneficial (Mason & Linsk, 2002; Vig & Kaminer, 2002). However, the need for arranging and paying for an assessment as well as the range of additional therapies including in-home music, occupational, speech, and play, reported by foster parents in our study, has not been previously reported in the literature.

Foster parents identified that "Aboriginal services for foster children" and families were helpful, as were "home visits by social workers."

The importance of home visitations by social workers was reported in the literature. Studies have shown that the availability, frequency and quality of support from the social worker are very important for the success of foster placements (Chamberlain, Moreland, & Reid, 1992; Hudson & Levasseur, 2002). The need for services specifically for Aboriginal children was not reported in the literature. However, there are practice-based initiatives (e.g. the Manitoba Aboriginal Justice Inquiry, Child Welfare Initiative) that have led a movement to the restoration of authority to Aboriginal communities for the delivery of their own social services, including services to foster families.

Parents made several statements concerning services to support transitions of foster children into new school settings, home settings, and independent living situations. Foster parents reported that "preschool outreach programs that continue into school age" were necessary for foster children with disabilities to manage the transition into school. Additionally, "special services in schools," such as "classroom aides" or a "tutor for school work" were helpful to foster children. Transitional services from school to employment opportunities for children were seen as beneficial ("employment and educational resources"). As well, "transition services for foster children when they turn eighteen" were identified. Foster parents indicated that "crisis personnel for both foster parents and foster children" was crucial to assist with challenges faced during difficult transitions.

There is evidence in the literature of the need for a variety of community programs for foster children with disabilities (Zima et al., 2000). However, the results of our study indicate that there is a specific need for transitional services to help foster children and foster parents cope with changes between schools, from school and employment, from child to adult social services, as well as between biological and foster families.

Foster parents indicated that they saw "respite care" as very beneficial. They described respite care needs in terms of quantity ("more respite hours," "increase money for respite care"), and accessibility ("list of respite workers," "agency to organize respite and hire the workers"). Additionally, foster parents described the types of activities that could be engaged in by respite workers ("overnight care for shift work," "babysitting," "in home child care," "in home housework support," "someone to take child to appointments," "support workers come into the home to help with homework every week," "big brother/sister mentors for the foster children").

In the literature, the benefits of respite have been discussed. Among foster parents of children with disabilities, in general, there has been a significantly lower stress level found following respite care (Mason & Linsk, 2002; Vig & Kaminer, 2002).

Our research has identified ten major areas of services or supports foster parents perceive as helpful; support in the community, financial resources, accommodating school system, good relationships with social workers, information, comprehensive medical care, access to professionals, services for Aboriginal children and families, transitional services and respite. Based on these findings, several gaps in the literature on foster care have been identified.

Foster parents identified the need for public awareness and education on children with disabilities. This issue was not found in the literature. Additional issues such as more accepting community groups, transportation services and education programs are all linked to public awareness and education on children with disabilities. Increased public awareness of children with disabilities could have very positive effects on the lives and placement outcomes of foster children with disabilities. Increased public awareness through education may create a more supportive school environment for foster children.

Foster parents in this study also identified the need for an array of professional services not mentioned in the literature. Foster parents advocated the benefits of music therapy, occupational therapy, speech therapy and play therapy. This is another way that schools may provide additional support to foster families of children with disabilities. Schools provide families with the resources necessary to survive and flourish. Bublotz and Whiren (1984) stated that fostering a child with a disability results in families needing additional resources in order to function in the same way as a family caring for a child without a disability. The therapies mentioned by the foster parents in this study may be representative of the additional needs faced by foster families caring for children with disabilities. The impact of these therapies on placement success in families fostering children with disabilities is an area in need of further research.

This research has identified the need for Aboriginal services for foster children and their families that is not addressed in the literature. Provision of Aboriginal services may be an effective method to increase foster parent's resources, providing them with a means of meeting the specific needs of their foster child in culturally-appropriate ways, and increasing the likelihood of success. The multiple benefits of culturally appropriate services on family functioning are in need of further exploration.

Foster families in this study indicate the importance of transitional services for both the foster children and themselves. The issue of transitional services is not addressed in the foster care literature. Transition periods are always times of significant stress. Families fostering children with special needs require additional services and support during these times due to the complexity of their situations. Periods such as transition from the home to the school environment, from the school system to potential employment, and between the biological family and the foster family may be additionally stressful for families fostering children with disabilities due to special needs of the children. The impact of specialized service supports for families fostering children with disabilities during difficult transition periods is an area in need of more research.

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