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Developing a Support Group for Families with Children with Disabilities in a Canadian Chinese
Church Community

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This paper presents an overview of the difficulties families face when raising a child with disability. With language barriers and limited support, immigrant families have difficulties in locating necessary resources for their children. The experience of a support group for parents with children with disabilities in a Canadian Chinese immigrant church is reported.

Hauerwas proposes that by extending our hospitality to families with children with disabilities, the church holds great promise to be an agent in the healing process of these children and their families.¹ In this paper, we explore the roles Christian churches can play in supporting parents with children with disabilities, and present our experience in using a support group system to offer assistance and encouragement to these families in a Canadian Chinese immigrant church.

Background

Statistics Canada reported that in 2001 an estimate of 155,000 Canadian children between 5 and 14 years old, or 4% of all children of this age group require assistance for personal care because of a condition or health problem.² This statistical information does not include children with conditions such as attention disorders or mental disorders that do not interfere with personal care. Therefore, the actual number of children with disabilities should be bigger than what was reported in this document.

The discovery that the wished-for child has a disability destroys the hopes and dreams of the parents.³ Their reaction is similar to the grieving process: denial of severity, bargaining with God, anger, despair, and reconciliation. These grief stages may interchange with stages of acceptance periodically throughout the life of the child with disability.⁴ Studies found that while the severity of a child's disability is often linked with the higher level of parental stress, behavioral issues contribute more substantially to the level of stress for the parents.⁵

Parental concerns for a child with disability vary according to the child's age and include issues such as development of physical and mental functioning, medical care, educational placement, respite care, social adjustment of their child and after-school recreational opportunities. As children grow older, parents worry about their abilities to be financially and physically independent and be accepted by the society. Parents also struggle to find accurate information for medical, educational and social resources.⁶

Having a child with disabilities affects the family in many ways. Being employed or maintaining employment is more difficult for mothers of children with disabilities because it is not easy to find reliable child care for a child with disability. It is particularly true when serious behavior problems limit availability of child care services.⁷ Couples commonly blame

themselves and each other for causing the disability in their children. If not handled properly, the marriage can be challenged.⁸ Keller and Honig recommended that active involvement of the father in the child's care can positively affect marital relationship.⁹ The effect of having a child with disabilities in the family is also felt by the siblings of the child.¹⁰ Parents often worry about the emotional development and social lives of these siblings and the limited time and attention they can provide to the siblings. ¹¹

What have Christian churches done to help?

Searches on the ATLA and Proquest religious electronic databases using the following keywords: 'support', 'children', 'disabilities', 'parents', and 'family' for the period of 1996 to 2007 yielded no documentation on work that have been done by Christian churches to support parents with children with disabilities. An Internet search with Google using the same keywords but adding "Christian ministry" found 363 sites. It is evident that work has been done by churches around the world to address the needs of parents with children with disabilities. The work that is being done by ministry groups such as the Jonathan's Kids has been described in Christian magazine.¹² However, the effect of this type of ministry on parents has not been formally documented in religious journals.

Conversely, the experiences of parents with children with disabilities within the Christian churches have been widely documented in journals in the social work, psychology, educational and medical fields.¹³ In a qualitative study completed with 187 individuals, Poston and Turnbull learnt that about half of these individuals found their religious communities to be helpful and described their church to be a place of acceptance and of unconditional love.¹⁴ However, almost the same number of participants in the study felt rejected by their churches. Unfortunately, there are also many reports of individuals with disabilities and parents of children with disabilities who

have negative experiences with Christian churches¹⁵. The most common issues parents and children with disabilities encountered are characterized by Govig as “stares” and “stairs”.¹⁶ In addition, “faulty assumptions about the needs and gifts of people affected by disability, lack of knowledge of disability by others, discomfort with disabilities and avoidance by church staff” have been quoted as reasons why people with disabilities and their families are not coming to churches.¹⁷

Parents who had positive experiences with Christian churches found that the welcoming and accepting attitudes of the people in the churches alone made them feel supported.¹⁸ They also received practical help from their church communities.¹⁹ When parents are well received by their churches, their faith in God grows. Faith is a source of inner strength that helps parents to accept a child’s disability and overcome issues related to the disability.²⁰ It also provides a framework for the parents to make meaning of disability and events in life.²¹ Prayer is mentioned in the literature as an important venue for parents to gain spiritual and emotional support.²² With faith in God, parents can change from having a feeling of hopelessness to hope and develop virtues such as patience and love.²³

Experiences of Asian immigrant parents

Little is known regarding the adaptation of Asian parents to their children with disabilities in the North American context. Researchers reported that families from ethnic minorities were more likely to have high levels of unmet needs.²⁴ Ryan and Smith found that Chinese American parents experienced similar emotional stresses related to raising a child with disabilities as detailed above.²⁵ In addition, the Chinese parents in their report lacked the knowledge and understanding of the diagnoses and available resources in American communities because of cultural and language barriers. Some parents contributed the cause of their child’s

disability to inadequate prenatal practice and appealed to superstitious or supernatural way of healing such as offering incense to drive away the evil spirit. More recently, Cho et al. found that being away from their extended family, Korean American parents with children with disabilities depended heavily on social services or assistance from friends or religious organizations to help them in the care of their children.²⁶ They also experienced difficulties in locating information related to their child's disability and obtaining public services because of language difficulties. The lack of understanding of eligibility criteria to public services was problematic even with translation services because the translator often understood neither the planning processes nor the specialized language used by the service providers.

Support group for parents with children with disabilities

Information from the psychology and educational literature indicates that support group is a helpful venue for parents to share personal experiences.²⁷ Through the mutual support in the groups, parents develop confidence in their abilities to cope with their children's disabilities.²⁸ Understanding the needs for many families with children with disabilities in a Chinese immigrant church in Toronto, a support group for parents was started in September 2006. The objectives of the group were to 1) provide a venue for parents with children with disabilities to share and support each other; 2) demonstrate Christian love and values; 3) share resources and information. The group met once a month on Sunday afternoons. At the time of writing, eleven families attended the meetings. Two families only came once. Seven families attended the meetings more regularly. Of the eleven families, four families were new to the church. The content of the monthly meetings includes hymn singing, prayer time and a speech. The topics of the speeches in the meetings vary from biblical messages to information on social or educational resources. Social events are held seasonally.

A semi-structured interview was used to understand the effect of the support group on the parents, the children and the church. The goal of the evaluation was to provide information to guide the next step in this ministry.

Method

Participants

Interviews were conducted with the parents, all three members of the organizing committee and two pastoral staff. Seven families who regularly attended the support group participated in the evaluation study. Three families were single-parent families. For the other four families, both parents were invited to take part in the interviews. However, the mothers of the children answered most of the questions. Attempt has been made to contact the four families who did not attend the meetings regularly. Three families did not return calls. One parent provided feedback about the group and indicated her continual need for support but declined a full interview.

Procedures

The interviews were conducted at the church, at the families' homes or by phone depending on the availability and the preference of the respondents. Separate interview guides (Appendix 1 and 2) were used to guide the interviews with the pastoral staff, committee members and the families. The questions were modified from the instructions provided by Garland for evaluation of ministry.²⁹ Respondents were asked to provide specific examples if they answered with non-descriptive terms such as "good" and "helpful".

Data Analysis

The interviews were conducted in Chinese. Interview notes were taken during the interviews. The notes were translated into English as literally as possible to preserve the

respondents' original ideas. The typed notes were examined for convergence and divergence. The emergent key ideas were organized into themes and presented below.

Results

A mother's comment represented the generally positive experience of the interviewees. She said that "getting information and sharing the burden are the biggest things for me. I am feeling more relaxed now, knowing that there are many people who are walking the same journey with me." Pastoral staff and members of the organizing committee also felt that the group was making progress towards achievement of our objectives. In examining the parents' responses, five themes emerged: security, communication, emotional growth, knowledge and hope.

1. Security

Parents felt a general sense of comfort knowing that one was not alone in facing the challenges of bringing up children with disabilities. Parents acknowledged that God was using this group to help them. One mother said that "I thank God for this group. I know that it was God's plan for us to have this group so that we can help each other." Another mother shared her sentiment saying that "Now I feel cared for, understood and supported." The majority of the parents in this interview do not have extended families in Toronto. Some of these parents are also members of family small groups in the church. The parents experience emotional and physical support from their respective small group members.

2. Communication

One mother's expression represented the feeling of the group. "Finally there is somebody who understands what I am talking about. I could not talk to anybody about my feelings. People just don't understand."

3. Growth

Parents' comments indicated that their faith in God brought self-transformation and spiritual growth. One mother said that "through my son, God is training me to have patience and love, to bear fruits of the Spirit." Parents also gained inner strength. One mother who in the past felt embarrassed about bringing her son to the small group meetings felt at ease in the group now. Partially it was due to the acceptance of the group to the child with disabilities, but the mother also spoke of her own acceptance of her son. With God's blessings, a mother said that she learnt to "not give up on [her son]" and trust in God for guidance every day. A grateful heart allowed another mother to "celebrate every little gain of [her daughter]."

4. Knowledge

The information a mother learnt from attending the support group made her aware of what was available in the school system and how to access these resources. For more than three years, she thought that nothing more could be done to help her son, so she did not take him to the doctor. After learning what is available, the child has since been seen by a specialist for assessment with subsequent referral for therapy. She also learnt to ask questions at school so that her son could have access to school resources. From the sharing of a mother who had successfully advocated for her son, and a young person with severe disabilities, the group learnt that by trying hard and trusting in God, people with disabilities could lead a meaningful life. The responses from parents also highlighted the difficulties faced by immigrants who cannot speak English fluently. These families faced difficulties in acquiring necessary information about their children's disabilities and finding resources for their children.

5. Hope

The new believers and parents who did not know Christ before coming to the group learnt that there are higher purposes for their lives. One mother reported that she learnt about the greatness of God from the sharing in the group, and understood that with the faith in God, there was “no challenge that would be too hard to overcome.” In prayer, a parent learnt to “lift up [her] worries to God.” Another parent said that “praying to God gives [her] peace and hope.”

Although the support group was intended for the parents, the parents reported some indirect impact the group had on the children. This include:

1. integrated Sunday School and other children programs

With the increased visibility of children with disabilities in the Sunday School, the teachers were made more aware of the needs of the children and learnt to be more accommodative in their approaches. One teacher spent time learning how to communicate with a non-verbal child using sign language. Knowing the need for equipment to integrate a child with physical disabilities into the nursery program, a fellowship group donated the equipment for the child to use at church.

2. Spiritual growth of the children

One mother who came to our church because of the support group reported that she and her son had been attending worship services and Sunday School every week since the first support group meeting. Her son enjoyed the children service and the Sunday School. He often proudly showed his mother the new biblical words that he learnt and was able to re-tell the stories that he has heard in classes.

As to the impact of the support group on the congregation, most evidently, the group attracted a few new families to the church. The existence of the support group promoted some awareness of the needs of people with disabilities in the congregation. However, a lot more

needs to be done for the church body to show our support to the individuals and families in needs. Families reported that some people at the church stared at them and their children. Others avoided or ignored them totally. Not knowing that the behaviors of some children were beyond the parents and the children's control, well-meaning people in the church offered suggestions that were unhelpful or hurtful to the families. Physically, the stairs, narrow corridor, crowded foyer, tables that often blocked the entrance to the elevator were barriers that the families encountered in getting around the church. These barriers made it difficult for the families and the children to truly be part of the congregation.

Discussion and Ministry Implications

The responses from the families affirm that immigrant families with children with disabilities need the support of the church spiritually as well as practically. Parents without extended families require more extensive assistance. This information is important for the other immigrant churches because the families in their congregations may have similar needs. It also points to the responsibilities of the churches to reach out to the other immigrant families in their communities to offer care and assistance.

While the focus of this paper is on the experiences of parents with children with disabilities in a Chinese immigrant church in Canada, the majority of the information being presented in this paper is probably applicable to other churches. The parents in our support group experienced emotional and spiritual growth because of their faith in God. The importance of spiritual beliefs in helping people to cope with stresses related to disability issues is well supported in the literature.³⁰ The important elements that help parents to cope with stresses relate to their children's disabilities include the presence of others, prayers and acts of kindness. But the most important element seems to be a strong faith in God which brings the sense of hope

and feeling of peace. This understanding informs us that the spiritual element is what makes our support group different from the support groups that are offered by non-church organizations. The spiritual element should therefore receive special attention in the programming of the support group.

The attraction of four non-churched families to our support group within the first five months of operation of the group indicates the need of this type of service in the community. The support group not only helped the families find information and mutual support, it also introduced these new families to the Christian faith. However, church communities who are committed to welcome and support families with children with disabilities need to make sure that their buildings are accessible to individuals with disabilities. Church members need to be educated to be welcoming to individuals with disabilities so that the barriers of “stairs” and “stares” can be eliminated.

Our experience with the support group indicates that when we intervene with the parents, we trigger changes in the family system of the church. The existence of the support group for families with children with disabilities promoted the awareness of disability in the congregation. It also provided an opportunity for the faith community to grow in love and care for each other.

Not being able to interview families who did not attend the support group meetings regularly needs to be noted as a limitation because our results may only represent parents who viewed the group favorably. However, the examples provided by the people who were interviewed indicated that the support group for parents with children with disabilities was a necessary family ministry program. As a result of this study, the authors are planning to propagate this support system to other Chinese churches in the city. We hope that other church communities would look into ministering to these needy families also.

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Appendix 1

Interview Guide for Families

1. Does the attendance at the support group impact you, your family and your child in any way?

Prompts:

- a. Examples of impact on the parents
 - b. Examples of impact on the children
 - c. If the family doesn't understand the word 'impact', ask if there is anything good or bad about coming to the support group.
2. Do you see any impact of our group on the church?

Prompts:

- a. Ask about the family's experience with the church – building and people
 - b. Ask for specific examples on interaction with the congregation, draw out specific positive or negative examples if it seems to be necessary and appropriate
3. What can we do better in the support group to meet your needs?
 4. What can the church and the congregation do better to support your family and your children?

Appendix 2

Interview Guide for Pastoral Staff and Committee Members

1. Do you notice any changes since we started in September last year?
2. Are we meeting our objectives?
3. Do you see any impact the group has
 - a. on the parents?
 - b. on the children?
 - c. on the congregation?

Ask for specific examples

4. Are there better ways we could meet our objectives? What should we change?
5. What can we do to make our group's impact on the congregation more positive?