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Down Syndrome Caregivers' Support Needs: A Caregiver Perspective

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Abstract

The purpose of the study was to gain an understanding of the support needs caregivers of children with Down syndrome (DS) experience and to provide recommendations to services and advocacy agencies in the community. Caregiver perspectives were gained from individual interviews addressing the research question "Are parents of individuals with DS supported, why or why not?" Caregivers were involved in the analysis of the data through concept mapping procedures. Participants generated eight thematic clusters representing the support needs of caregivers of children with DS. The themes included online social support, community support gaps, areas where support is lacking, Down Syndrome community support, financial support, advocacy needs, educational support and concerns for community programming. The study highlights the need for more local organizations to offer support that is affordable and accessible for families. Results will support future program planning for services for individuals caring for those with DS.

Keywords

Down Syndrome, Caregivers, Support Needs, Concept Mapping

Summary for Lay Audience

The purpose of the study was to gain an understanding of the support needs of caregivers of children with Down syndrome (DS). The researcher conducted individual interviews with caregivers of children with DS and employed concept mapping analysis procedures to generate eight thematic concept maps. The concept maps represented caregivers' perspectives on their needs and will be provided as recommendations for community services to offer programming that is in line with caregiver needs.

Acknowledgments

I would like to recognize the invaluable assistance of Dr. Nicole Neil and thank her for her supervision and support. I would like to thank Dr. Elizabeth Nowicki for her assistance along the way and for the help I received from Kailee Liesemer and Aingeshaan Kubendran as well.

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Chapter 1

1   Introduction and Literature Review

Down syndrome is the most common cause of intellectual disability and it naturally occurs across all racial, gender and socio-economic lines. An individual born with DS possesses extra genetic material as a result of trisomy of all or a portion of their 21st chromosome (CDSS, 2016; Patterson, 2009; NDSS, 2018). The effect of possessing extra genetic material varies from person to person with individuals commonly experiencing mild to moderate degrees of intellectual disability and developmental delay (CDC, 2018; CDSS, 2016).

Individuals with DS display a specific behavioural phenotype, or pattern of strengths and challenges in their functioning across different domains of development (Fidler, et al., 2009). The DS behavioural phenotype includes social, cognitive, linguistic, and motor concerns. Children with DS may experience challenges related to cognitive development, learning difficulties, language delay, and physical challenges relating to balance, posture, strength and flexibility. Behaviourally, children with DS can experience hyperactivity, aggression, stubbornness, disobedience, inattention, and impulsivity (Fidler, et al., 2009). Behavioural problems among children with DS are lower than among children with many other developmental disorders, but higher when compared to typically developing siblings or peers (Dykens, 2007). Children with DS also experience a host of medical concerns including cardiac and hearing issues, complications with congenital heart disease, hypothyroidism, and recurrent respiratory infections (Canary, 2008). Additionally, individuals with DS face difficult challenges as they grow older including the development of dementia, depression, and end of life declines (Dykens, 2007). This unique profile results in both the individual with DS and their caregivers to present with unique needs for support (Dykens, et al., 1994; Nes, et al., 2014).

1.1 Literature Review

Families and mothers, specifically, will take on much of the care and support needs for an individual with DS and remain the main source of care throughout the individual's life (Hodapp, 2007; Raina, et al., 2004). Parents of children with disabilities will have the most influence on the personal health and wellness of a child with a disability, more so than any other individual or health care provider (Elliott & Mullins, 2004). To maintain a high quality of life, supports are often needed from birth and include early and intensive therapeutic services such as occupational and physical therapy as well as speech and motor therapies (Canary, 2008). Caregivers coordinate this care, communicate with family practitioners and doctors, and advocate for their child (Marshall, et al., 2014). Caregivers are also responsible for the physical care of their child such as dressing and toileting. The provision of this care requires physical, emotional, social and financial resources on behalf of the caregiver. This is done while also balancing the needs of other family members (Povee, et al., 2012; Silver, et al., 1998).

Increased demand for support and care can affect the overall well-being of caregivers (Nes, et al, 2014). Gath (1977) reports slightly higher rates of divorce and poor marital relationships for caregivers of children with DS as compared to caregivers of typically developing children. Studies commonly focus on the mother of the child with DS (Hodapp, 2007) and note specific concerns for mothers experiencing physical health problems (Brehaut, et al., 2009), psychological distress and adjustment problems, increased risk for clinical depression, and lower levels of life satisfaction compared to mothers of children without disabilities (Bailey, et al., 2007; Nes, et al., 2014; Singer, 2006). The additional psychosocial needs mothers of children with DS experience are a result of the compounding effect of the DS phenotypical behavioural characteristics, co-existing medical concerns, and the need these children have for long term care (Pelchat, et al., 1999).

The act of caregiving for a child diagnosed with DS also impacts families as a whole. Unique aspects of a child's expression of their DS impacts family functioning such as the child's maladaptive behavior and behavioral problems including stubbornness, tantrums, aggressiveness and social inappropriateness (Povee, et al., 2012). Families often restrict their activities due to fears of their child with DS wandering off or running away (Povee, et al., 2012). Caregivers also report that less attention is given to siblings and note the financial strain families experience from the costs of special education, medical and therapy appointments, childcare, and entertainment for their child with DS (Povee, et al., 2012).

To improve caregiver wellbeing a match between caregiver needs and resources to meet those needs is necessary (Resch, et al., 2010). Often caregivers of children with DS function as control groups in studies exploring the support needs of caregivers of children with other disorders, most commonly Autism Spectrum Disorders (ASD) (Sanders & Morgan, 1997; Siklos & Kearns, 2006). These studies point to an inaccurate representation of the support needs of caregivers of children with DS; they are found to need less support than children with ASD and thought to cope better by comparison (Hodapp, 2007). However, when caregivers of children with DS are compared to caregivers of typically developing children it is revealed they experience higher levels of stress and worse coping (Hodapp, 2007; Sanders & Morgan, 1997; Siklos & Kearns, 2006).

Other lines of research group the caregivers of children with various disabilities together. Support needs that are not currently met for caregivers of children with disabilities include access to information and services, financial barriers to obtaining services, school and community inclusion and family support (Resch, et al., 2010). Caregivers of individuals with disabilities have identified a lack of respite and counselling services available to them to assist in taking a break to attend to the needs of other family members and their own needs (Murphy, et al., 2007; Papageorgiou, & Kalyva, 2010).

Although some support needs overlap across diagnoses, others are unique to families with a child with DS. For example, Siklos and Kearns (2008) investigated the needs of caregivers of children with ASD and selected caregivers of children with DS as control subjects. A total of 88 caregivers were included in the study (ASD = 56, DS = 32) and only one-third of each group's important needs were identified as met. Caregivers of children with ASD and DS report unmet needs related to financial support, assistance dealing with fears for their child's future, a need for continuous service rather than crisis based, issues related to the social stigma associated with their child's disorder, recreational activities for their child, information of available services, consistent therapies, need for respite opportunities and information to better understand their child's diagnosis. Caregivers of children with DS reported a similar number of needs as caregivers of children with ASD but differed in the types of needs endorsed. Caregivers of children with DS report distinctly different needs related to educational supports, community programming, and friendship opportunities for their child. From the research it is clear that caregivers of children with DS require specific supports that differ from caregivers of children with ASD and that such needs are not currently met. Research is warranted to address the specific needs of caregivers of individuals with DS as the voices of such caregivers on this topic have yet to be heard (Hodapp, 2007).

A focus on the unmet needs of caregivers of children with DS is crucial to understanding how to improve current support services. Within the current literature, there is limited research focusing specifically on the support needs of caregivers of children with DS (Hodapp, 2007). To date, only a small number of studies have investigated the support needs of caregivers of children with DS. In these studies, caregivers of children with DS report concern for their child's quality of life as their child grows older, specifically concerning educational planning, social and community supports and long-term healthcare (Marshall, et al., 2014; Povee, et al., 2012; Siklos & Kearns, 2006). Caregivers of children with DS require support to navigate the education system and manage their child's transition to school

including finding the appropriate setting that will meet their child's educational and therapeutic needs (Marshall, et al., 2014). Caregivers report a need to have time to pursue their own interests and they identify the importance of having extended family members and friends to provide respite and emotional support (Boehm, et al., 2015; Povee, et al., 2012). Caregivers also face challenges for planning for the future care for their child after they have passed. With a steadily increasing average life span and individuals with DS living into their 50s and 60s caregivers must prepare for care when they can no longer provide it (Kapell, et al., 1998). Understanding caregivers' perspectives on support needs is an important first step to designing systems to improve family outcomes.

Research with other disability groups suggests various categories of needs for caregivers that may be generalizable. These include emotional and relational support, material and informational support as well as physical support (Derguy, et al., 2005; Kyzar, et al., 2012; Papageorgio & Kalyva, 2010). Additionally, Derguy et al. (2005) extend this list from research with caregivers of children with ASD to include needs associated with parental guidance and needs related to daily management of child behaviour. Caregivers of children with ASD report material needs, informational needs and parental guidance as main priorities to address (Derguy, et al., 2005).

Emotional support refers to the need caregivers have to be accompanied and supported from an emotional point of view including an outlet for sharing of experiences with other caregivers, support from family and friends as well as psychological support from professionals (Derguy, et al., 2005). Needs for relational support include the need caregivers have to develop satisfying relationships with others, their spouse, family members and a relationship with their child without a learning objective involved (Derguy, et al., 2005). Material needs include the need for resources that enable a caregiver to ensure their child has a stable environment and can include financial needs, the requirement to employ trained professionals and the use of appropriate institutions. Informational needs refer to the

knowledge that is necessary for a parent to understand and adjust to their child's diagnosis. This can include information related to their child's diagnosis, development, their child's educational needs, knowledge of necessary parent training, healthcare providers and administrative procedures (Derguy, et al., 2005). Parental guidance needs refer to the parent's development of skills to better fit the behaviour and emotions of their child while supporting their learning process. This category of needs includes guidance related to the child's behaviour, anxiety, skill development, independence, and social skills, management of relationships between siblings and for a caregiver to be reassured of their parenting skills (Derguy, et al., 2005). Daily management needs encompass the support needed in family life, marital, leisure and social life as well as work life (Derguy, et al., 2005).

In order to understand and appropriately address concerns for caregiver wellbeing, the perspective of caregivers must first be captured. Of importance is gaining their perspective related to their needs as a caregiver as well as their understanding and identification of the services, supports and barriers to having those needs met (Resch, et al., 2010). The current study addressed the gap in the research field specific to exploring the support needs of caregivers of children with DS. The purpose of the study was to learn directly from caregivers themselves and to gain an understanding of caregivers' needs from their perspective. Caregivers of children with DS are uniquely well positioned to effectively inform organizations of what their support needs are and the areas requiring further improvements. Caregiver perspectives were gained from individual interviews addressing the research question "Are caregivers of individuals with Down Syndrome supported, why or why not?" and participants were involved in the analysis of the data through Trochim (1989) concept mapping procedures.

Results of the current study will support future program planning for services for caregivers of individuals with DS. The researcher aimed to identify and prioritize the support needs specific to caregivers of children with DS through the creation of concept maps based on

caregivers' perspectives obtained in telephone interviews. In this way, organizations can be provided with recommendations for services that are in line with caregiver needs.

1.2   Concept Mapping Overview

Concept mapping is an integrated, mixed method research tool that enables researchers to apply quantitative analysis techniques to qualitative data (Jackson & Kane, 2007; Jackson & Trochim, 2002; Trochim, 1989). Concept mapping is a multi-step research method that uniquely engages participants in the coding and interpretation of study data (Jackson & Trochim, 2002). It is a structured methodology used to organize the ideas of a group and determine the underlying themes of the ideas (Kane & Trochim, 2007). The method allows researchers to view a variety of opinions from a group of people and results in a visual representation of participants' conceptual framework for a concept (Trochim, 1989; Kane & Trochim, 2007). Concept mapping is recognized as a valuable and effective research tool in planning and program evaluation research and has been extensively used with adult populations (Kane & Trochim, 2007).

The research tool allows participants to voice their ideas and invites them to categorize them in a manner that makes sense to them. Researchers avoid imposing their own biases by inviting participants to categorize the data and engage in the coding and analysis procedures (Kane & Trochim, 2007). Therefore, the content of the maps is entirely determined by the participant group and not an external analyst's interpretation of the data. Participants brainstorm ideas in interviews and through the sorting and rating tasks, provide insight into how their ideas are related. The resultant maps that are generated represent the participants' experiences with the phenomenon under study and represent a structured conceptualization of the relationships between ideas. The final product identifies areas of importance and priority from the perspective of those involved.

The concept mapping procedure includes five steps including project preparation, statement generation, statement structuring, data representation and interpretation of data. In the project preparation step, researchers develop a focus prompt question to guide participants' statement generation. It is ideal to create a broad, open-ended question that provides concise instructions to participants.. Researchers select their participant group, consisting of those with experience related to the research question (Kane & Trochim, 2007). Participants are then asked to generate responses to the focus prompt question in an interview. Interviews are then transcribed and unique statements answering the focus prompt question are extracted. Researchers edit the responses for clarity and compound ideas, removing redundancies from the set of statements. A final list of unique statements is compiled and provided to participants for step three, the structuring of the data, where participants sort and rate the statements (Kane & Trochim, 2007). Participants are instructed to sort the statements into groups that make sense to them. Participants then engage in the rating task and rate each statement on a Likert scale relevant to the research question. Multidimensional scaling and hierarchical cluster analysis are applied to the data in step four resulting in a two-dimensional map of the key concepts answering the research question. Multidimensional scaling is used to analyze the data and represent the relationships or proximity of statements from one another. Statements are then grouped into themes or clusters using hierarchical cluster analysis. These analyses produce a map of the concepts based on participant responses. The final step in the concept mapping procedure is the creation of a cluster map representing the participants' ideas. The map provides a view of the interrelations between the individual ideas. This is done so within thematic clusters and the cluster map demonstrates the position of each cluster grouping within the overall structure. The researcher then selects the final cluster solution, the optimal number of clusters to represent participants' ideas and clusters are given a descriptive label.

Concept mapping procedures have been used in a variety of contexts with various participant populations including adults and children and with individuals with disabilities. Concept

mapping has recently been used in investigations of social exclusion of children with intellectual and learning disabilities from the perspective of both educators and children (Nowicki, et al., 2018; Nowicki, et al., 2014a; Nowicki, et al., 2014b). It has been used to explore the perspectives of caregivers of youth with Fetal Alcohol Spectrum Disorder and their future plans and educational support needs (Brown, et al., 2017; Cleversey, et al., 2018). Concept mapping has not yet been employed to explore the support needs of caregivers of children with DS. The concept mapping methodology will be used in the current study to obtain the perspectives of caregivers of children with DS and assess the support they currently receive and areas where further support is needed.

Chapter 2

2 Methodology

2.1 Participants

All participants (N = 29) in the study self-reported being the caregiver of at least one child with Down Syndrome. Participants were excluded if they reported a comorbid diagnosis of Autism Spectrum Disorder. Participation occurred in two phases; data generation and data sorting and rating. Participants were recruited in two groups, for the initial interview (n = 23) and an additional group for the follow up sorting and rating tasks (n =10).

Demographic information was provided by 24 of the study participants. Participants included 20 mothers and four fathers with ages ranging from 34 years to 61 years of age with a mean age of 45.13 years (SD = 6.99, two participants did not provide their age). Nineteen participants indicated they were married and five were separated or divorced. Four participants indicated they lived in a rural geographical location and 20 lived in urban settings. The educational background of interview participants and their spouses included high school diploma (6), college diploma (16), university degree (15), master's degree (5) professional education including Juris Doctor, Chiropractor, Physical therapy and trades (3). All participants in the interview portion of the study had a gross annual family income over $25,000 with seven participants with a gross annual family income over $150,000. The age of participants' children ranged from eight months old to 23 years of age with an average age of 9.25 years (SD =6.75).

Interview Phase. Kane and Trochim (2007) recommend involvement from 10-20 participants when completing a concept mapping study. The interview sample for the current study consisted of 23 participants. Two participant's interviews were excluded from analysis due to ineligibility with the study inclusion criteria. The study included the interview data

from 21 participants (18 women and 3 men). Nineteen interviews were completed with caregivers living in Ontario and two living in Western Canadian provinces.

Sort Phase. The sorting task sample consisted of 22 participants. Three participants from the original interview sample (n=21) did not complete the sorting task. An additional four new participants were included in the sorting task. Four participants sorting results were excluded from analysis due to incorrect completion. Eighteen participants sorting results, 15 from the original interview sample and three from the new sample, were included in the study (16 women, 2 men). Kane and Trochim (2007) note it is not a requirement that the same participants or the same number of participants complete the sorting and rating tasks.

Rating Phase. The rating task sample consisted of 24 participants, (21 women and 3 men). Three participants from the original interview sample (n=21) did not complete the rating task and were not included in the analysis. An additional six new participants were included in the rating task.

2.2   Procedure

Ethics approval for this study was obtained from the university ethics review board (Refer to Appendix A for Ethics Approval Certificate). Prior to participation, all participants were sent information about the study and the research was carried out with the informed consent of each participant. Participants were recruited through convenience purposive sampling from Canadian Down Syndrome Associations. Study advertisements were sent via the organization's email lists and agencies offering services to individuals with developmental disabilities advertised the study (Refer to Appendix B for Recruitment Poster). Interested caregivers contacted the research team directly via email. Participants were also recruited from the participant pool of an ongoing quantitative research study and were given the opportunity to provide their email contact if they were interested in participating in the optional follow up interview.

Interviews took place over a two-week period and participants completed the sorting and rating phases over four weeks. Participants were provided compensation for their time and involvement in the current study with an honorarium of a $20.00 gift card; this was provided to participants who completed the concept mapping tasks of the study.

The Interview Phase. The researcher contacted all individuals who provided their email address and sent an overview of the study and description of their participation to each participant (Refer to Appendix C for Letter of Information and Appendix D for Verbal Assent). Interviews were scheduled at a time that was convenient for the participant. Participants were contacted via telephone at the scheduled time by the researcher and verbal assent was obtained from all participants at the beginning of the interview. All responses were audio recorded with participant consent.

During the interview participants were first asked demographic and warm up questions to increase their comfort with the interview task (Refer to Appendix E for Interview Protocol). Their eligibility was also confirmed. Questions pertained to the participant's relation to an individual with DS (mother, father, caregiver), their age, ethnicity, gender, level of education, range of household income, marital status as well as the number of additional children they had and the age and gender of their child with DS. Participants were also asked to indicate if they lived in a rural or urban setting. Following the introduction of the study and warm up question discussion, participants were asked the focus prompt question for the concept mapping study *"Are caregivers of individuals with Down Syndrome supported, why or why not?"* Participants were instructed to think of as many ideas and statements as they could to answer the question. To evoke further detailed responses, the researcher asked follow up questions as needed such as, "*Can you tell me more about that? Do you have any more thoughts on that? Could you provide me some examples of that?*" (Refer to Appendix C for Interview Protocol). The length of interviews ranged from eight minutes and 23 seconds to 26 minutes and 58 seconds (M = 13 minutes 6 seconds). Following the interviews,

participants were thanked for their participation and informed that they would be contacted via email with a link to perform the follow up sorting and rating tasks online. Participants were reminded of the honorarium they would receive after completing all phases of the study.

Data Preparation Phase. Participants' interviews were transcribed verbatim by the researcher. The researcher extracted all participants' statements from the recorded interviews that answered the focus prompt question. Two hundred and seventy-three statements (M = 13 responses per caregiver) were identified. The statements were entered in a spreadsheet. Each statement in the spreadsheet represented one unique statement related to the support needs of caregivers of children with DS. The primary investigator and researcher coded the statements as unique or redundant and unclear responses were edited. Compound ideas were split and broken into statements with one unique idea. Any discrepancies were resolved through discussion of the primary investigator and researcher. As a result, 159 statements were coded as redundant and excluded from the set. Statements were then entered into the web-based Concept System® Global Max© software (Concept Systems Inc., 2019). A final list of 114 unique statements was provided to study participants for the sorting phase (M = 5.42 responses per caregiver). Kane and Trochim (2007) note that it is ideal to obtain a final data set of approximately 100 statements from the interview data for the sorting and rating tasks so as to ensure a breadth of the contributed ideas are represented and a manageable number of statements is provided to participants that does not impose practical constraints on participants such as fatigue.

Sorting Phase. Participants were contacted via email and sent a link and login for the online concept mapping tool, The Concept System® Global Max© software (Concept Systems Inc., 2019). The Global Max software enabled online participation. Participants were instructed to sort the statements into categories in a way that made sense to them and to label each category they created (Kane & Trochim, 2007). Participants received instructions specific to

how to sort the statements and were informed that they could not put all statements in one pile, they could not group one statement into more than one pile and each statement could not be sorted in its own pile (Kane & Trochim, 2007). Specific instructions were given to participants to sort the statements into categories rather than to sort the statements according to priority or value, such as the level of importance, feasibility to complete it, or their level of agreement with the statement. Participants were instructed to label the categories they created. Participants completed the task by clicking on a statement to select it and dragging and dropping the statement into "on screen" categories on the virtual desktop.

Rating Phase. Participants were instructed to rate each individual statement according to their level of agreement that the statement was a need caregivers of children with DS experienced. The Likert scale ranged from one to five, with a rating of one indicating strong disagreement, two indicating disagreement, three indicating an undecided opinion, four indicating agreement and five indicating strong agreement. Participants used the Concept System® Global Max© software (Concept Systems Inc., 2019) to complete the rating phase, a numeric value corresponding to the Likert scale was provided in a drop-down tab beside each statement on the virtual desktop.

2.3   Data Analyses

Concept System® Global Max© software (Concept Systems Inc., 2019) was used to conduct data analyses. The web-based software program was specifically designed to accomplish the multidimensional and hierarchical cluster analysis procedures used within concept mapping and it is a proprietary data collection and analysis tool used in planning and evaluation research (Kane & Trochim, 2007).

Chapter 3

3   Results

3.1   Multidimensional Scaling

Using the software, a matrix is created for each participant's set of sorted data where the number of rows and columns equals the number of statements, and a value of 1 is entered when statements are sorted into the same pile. Individual matrices are then summed to create a group proximity matrix. Multidimensional scaling procedures were then employed to create a two-dimensional point map representing the sorting results of participants' statements (Kane & Trochim, 2007). The analysis locates each statement as a separate point on the map. The distances between the statements on the map represents the frequency that participants sorted statements together, with points more proximal to one another indicating statements that were sorted together more often and points more distal indicating statements that were sorted together less often (Jackson & Trochim, 2002).

The stress index is used as an indicator of the degree to which the distances between statements on the map are different from the values in the group proximity matrix. The index is similar to a measure of reliability (Kane & Trochim, 2007). The stress index ranges from 0 to 1, with lower values indicating better fit between the data and the point map, and higher values indicating poorer fit between data and the map. Trochim's (1993) meta-analytic study across multiple concept mapping projects estimated an average stress value of 0.285 (SD = 0.04), and approximately 95% of concept mapping projects yield stress values between 0.205 and 0.365. In the current study, the final stress index of 0.276 revealed there was a good fit of the data and the point map and that participants were reliable.

3.2　　Hierarchical Cluster Analysis

Hierarchical cluster analysis partitions participants' statements from the point map into clusters of statements reflecting similar concepts, providing a general conceptual grouping of statements (Kane & Trochim, 2007). The analysis begins with each statement as its own cluster and at each stage of analysis, statements are merged together until, in the final stage, all statements are merged into one single cluster (Kane & Trochim, 2007). At each stage, a cluster map is produced from the analyses and depicts the groupings of related statements overlaying the original multidimensional scaling point map (Kane & Trochim, 2007). Clusters that are closer together should be more similar conceptually than clusters that are farther apart (Concept Systems Inc., 2017). Concepts that are broader will be represented by larger cluster shapes on the map whereas more focused concepts will be represented by more compact cluster shapes (Kane & Trochim, 2007).
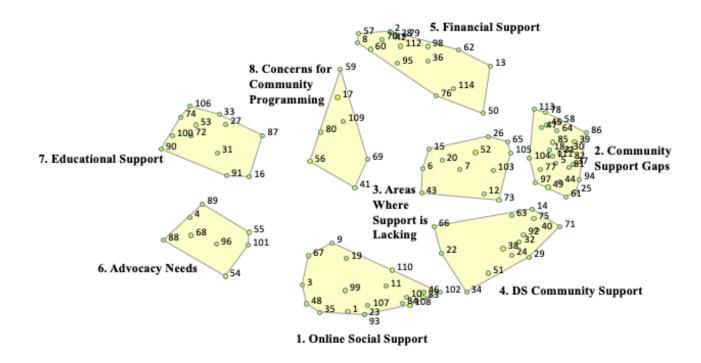
A bridging value is calculated for all statements in a cluster solution and ranges between 0 and 1. The value is an indication of whether a statement was sorted with others that are close to it on the map or whether it was sorted with statements that are farther away on the map (Concept Systems Inc., 2017). A low bridging value (0-0.30) represents a statement the was rarely sorted with statements in other clusters. A high bridging value (>0.70) indicates a statement was often sorted with statements in other clusters. Statements with a bridging value ranging between 0.31 and 0.69 indicates a statement was sometimes sorted with statements in other clusters.

An average bridging value is also calculated for each cluster and clusters with high bridging values are more likely to contain statements that were grouped with other statements outside of the concept. Clusters with low bridging values are usually more cohesive, easier to interpret, and indicate that the statements within the cluster and the cluster as a whole were not grouped with other concepts frequently (Refer to Figure 1 The Final Concept Map).

The decision of the final concept map is determined by the researcher and based on the understanding of the project's purpose and knowledge of how the map would be used (Kane & Trochim, 2007). There is no single correct number of clusters to be selected for the final solution or a mathematical calculation to determine the right answer (Kane & Trochim, 2007). The selection of the final solution is made by examining the clusters that are combined when merging or reducing the solution from a larger number cluster solution to a smaller number solution (e.g., merging from 20 clusters down to 19 clusters). This is done sequentially, ending with the clusters together as one. The researcher begins by deciding what the upper and lower limits of the solution will be; the highest number of clusters that would be useful and the absolute lowest number. In the current study, 20 clusters was determined to be the upper limit and five clusters was selected as the lower limit. It was determined these limits would be most appropriate because more than 20 clusters would be too much data for future researchers to manage and fewer than five clusters may not include the full breadth of participants' ideas.

Beginning with the 20-cluster solution, the researcher reviewed only the statements in the two clusters that merged when moving from 20 clusters to 19. In this instance, clusters 11 and 12 merged and resulted in the average bridging value of .40 for cluster 11. The researcher then used the quantitative and qualitative information in deciding to merge the clusters and the acceptance of the merger was documented in a ledger of decisions. The researcher continued this method of reviewing and recording decisions until the minimum number of clusters, 5 was reached. The decision of the final number of clusters in the solution was made by the researcher reviewing the pattern of judgments in the ledger of decisions and identifying the merger where the researcher's opinion was that the cluster solution would no longer be applicable. The solution was first reviewed by the researcher and then with the primary investigator, by consensus an eight-cluster solution was selected (See Figure 1).

Figure 1: Final Concept Solution

The number of statements per cluster ranged from eight to 25 with average bridging values ranging between .15 and .88. The concept mapping software identifies "closest fit" labels for each cluster based on participants' suggestions from the sorting phase (Concept Systems Inc., 2017). Once the final cluster solution was determined, the researcher reviewed the statements in each cluster as well as the suggested labels from participants' sorting and considered appropriate cluster labels. Participants generated eight thematic cluster including: (1) Online Social Support (average bridging value = 0.39, 19 statements); (2) Community Support Gaps (average bridging value = .15, 25 statements); (3) Areas Where Support is Lacking (average bridging value = .24, 12 statements); (4) DS Community Support (average bridging value = .34, 14 statements); (5) Financial Support (average bridging value = .23, 17 statements); (6) Advocacy Needs (average bridging value = .88, 8 statements); (7) Educational Support

(average bridging value = .70, 12 statements); (8) Concerns for Community Programming (average bridging value - .66, 7 statements).

3.3   Rating Analysis

Participants rated their level of agreement that the statements were a support need for caregivers of children with DS. This information can be used to identify priorities and what ideas, according to participants, have the most potential for impact (Kane & Trochim, 2007). Participants' rating data from the rating phase was then used to calculate the average ratings for individual statements as well as clusters (Kane & Trochim, 2007). The average cluster ratings ranged from 3.27 (Cluster 8, Concerns for Community Programming) to 3.74 (Cluster 6, Advocacy) ($M = 3.50$, $SD = 0.18$). See table 3 for statement ratings. The average individual statement ratings ranged from 1.57 (statement number 94, cluster 2) to 4.83 (Statement number 54, cluster 6) ($M = 3.54$, $SD = 0.70$). Thirty-four of the 114 individual statements were rated as agree or strongly agree that the statement was a need caregivers of children with DS experience. Twenty-one statements were rated by participants as disagree or strongly disagree.

Table 1: Cluster Statements with Bridging and Rating Values

Cluster and Statement	Bridging Value	Average Agreement Rating
Cluster 1. Online Social Support	0.39	3.64
1 There is lots of online support, so I was able to join a bunch of online forums through Facebook and was able to connect with [two nearby Down Syndrome Associations].	0.43	3.79
3 I feel like some of the challenges we experience [as parents of children with DS compared to typically developing children] might be sort of a step beyond and if there was more targeted DS parent talking to DS parent.	0.53	4.25
9 We don't necessarily see [our child's DS diagnosis] as something that we specifically need help with.	0.59	2.04

10	In terms of getting us together, I think it is much harder to build a live community group to gather children together.	0.35	3.63
11	We tend to use the playgroup as our main source of support where we can get together with other parents we can kinda hash out stories and a lot of the kids are the same age and so going through experiences and sort of what works for you and what doesn't. That sort of thing has been really helpful.	0.32	3.67
19	[One of my children is gifted and the other is high functioning with DS]. In both worlds I don't really fit into the conversation. It's more difficult to talk about the problems you are having because they seem more insignificant to people who are having more basic issues.	0.55	3.08
23	There's a Facebook group that's quite helpful, people post questions and then you can see all the answers.	0.21	3.92
35	I would definitely be looking for people to be sounding boards and to chat with.	0.4	4.21
46	I know [the local DS Association] does things for people with older children as well, I've read a lot of stuff about teenagers or young adults.	0.32	3.5
48	It's nice to get people who have been through it to provide their information but if you're going to these [online support groups] always as the person whose been through it providing information, then you don't ever really get ahead of it.	0.4	3.92
67	From our perspective, being relatively educated in the area and knowing how to ask questions we think we are pretty well supported.	0.55	3.39
83	Family and friends have of course been great. Like we are pretty connected that way. Our friends and family have all been fantastic, so that way there is lots of emotional and social support.	0.31	3.52
84	[The local DS Association] have a resource prenatally, to get connected with someone to tell you about their child and their life, living with someone who has DS.	0.35	3.43

93	To be honest with you, I found the majority of my support through social media. Things like Instagram. I found so many parents posting what they do on a daily basis, medications you know, alternative therapies, advice on everything and anything. I got so much invaluable information.	0.21	3.22
99	It takes time to build those community groups and get people aware and on board with including [my child] in their programs.	0.35	4.09
102	If there was a formalized network where you could reach out or someone reaches out to you, with someone whose kinda been there done that.	0.38	4.39
107	So, having an online support service I think would be something that would be helpful because then you could come to it where you are	0.38	4.3
108	The most important thing I found was being part of the [support] group.	0.28	3.78
110	Personally, we don't have any family who live near us or really if they did would be in a position to be helpful where [our child] is concerned [for babysitting].	0.43	3.09
Cluster 2. Community Support Gaps		0.15	3.65
5	It depends where you are geographically what services and supports you can access easily.	0.11	4.54
18	[The services and support] tend to be serviced at the lower functioning level.	0.09	2.92
21	There are not enough services out there.	0.1	4.29
25	We receive supports for specific delayed areas like OT, PT and speech and language that's hosted through [the local] children's centre.	0.3	3.42
30	For [our] whole region there's currently only one housing navigator offered through the system.	0.17	3.25
37	We have only one sort of Children's Centre where kids are assessed as early interventions services and from that we get very little support from them with regards to PT, OT and speech therapy.	0.16	3.67
39	I don't think that everybody is getting a similar service.	0.08	4.46
44	I think that our kids aren't served good, they're served systematically. And not personally.	0.12	3.48

45	I find that the government run agencies are not extremely helpful.	0.11	3.58
47	I think the services that come to us tend to be services originally geared for Autism because that's where the funding is.	0.13	3.25
49	There [are] a lot of hidden programs.	0.18	3.38
58	[The local government agency] has community outreach people to come to your home and talk to you and they do a lot of assessing. I don't feel like that amounts to a whole lot more than time spent.	0.2	3.17
61	In the more rural communities, you have to go looking for [supports] a little more. It is not as easy to access I would say as I would assume it is like in the cities.	0.27	4.04
64	Like a lot of things with the medical system and support, it takes a long time.	0.15	4.13
77	There are gaps [for service and supports] for sure.	0.06	4.57
78	I feel like [the government agencies] are very hesitant in terms of offering services and they're very selective in terms of who they offer the services to.	0.19	4.04
81	[Therapy] varies so much and the hands-on therapy that they provide is so limited.	0.15	4.22
82	It just seems like an uneven notification of services.	0.05	4.23
85	I think that we have such a wide spectrum of needs that it probably is difficult to provide support that's going to work for everyone.	0.13	3.7
86	We had [our child] on the list for PT, OT and social worker, [our child] had her own individual worker.	0.26	3.22
94	We don't feel that there is a gap [in services].	0.23	1.57
97	Right now [the support groups] are all for the older ages, there's none sort of that interest us directed toward [our child's] age group right now.	0.12	2.61
104	When you get the services, it's great, but it is so hard to get to the services and that's the issue right now.	0.05	4.13
111	It's really a hap-hazard slapped together support system.	0.05	3.48
113	Trying to get speech therapy is a struggle; [our child] gets it a couple times a year for a few weeks.	0.21	3.87

Cluster 3. Areas Where Support is Lacking		0.24	3.35
6	When we went to meet with the Social Worker, we were actually better prepared than they were, because my wife and I had done the research and reached out and talked to people.	0.33	3.5
7	Support for toilet training, I could really use another support group around that particular topic.	0.19	2.79
12	Anything outside of [DS groups] like the hospitals and Social workers we didn't get very much [support].	0.23	3.22
15	Sometimes there's that feeling where you wish that there were more programs that were just for kids with disabilities so that it wouldn't matter [that they were different].	0.3	3.71
20	I think it's dependent on parenting experience knowing when to ask for more because it's not necessarily offered.	0.34	4.54
26	I find that most of the supports you get disappear as soon as [children] start school.	0.21	3.25
43	We were lucky enough to go to a daycare centre that had a special needs program with a resource teacher. It just so happened that at that daycare we were at, all the special needs children had DS.	0.42	1.63
52	I feel as though children with DS are neglected in the sense that they do not get the services that they need, that they require to grow and develop.	0.18	3.75
65	I have accessed lots of psychologist support and things like that, social workers.	0.2	2.09
73	I would have liked to have some more support out the gate.	0.19	3.87
103	If you're at the right place, at the right time, and you get the right information in time, then maybe you'll be okay, if you don't, well that's too bad.	0.18	3.65
105	What I noticed is that it seems like the support is a bit inconsistent.	0.14	4.26
Cluster 4. DS Community Support		0.34	3.34
14	I did feel like it was hard to get support.	0.15	3.38
22	I find you build your supports.	0.4	4.21
24	Right here locally there is not much [of a DS community].	0.42	2.79

29	So, if you look at [our local town] for an example, there's no DS chapter here. All of the programs are run in [the nearby city].	0.45	3.08
32	Medically, I found I've been supported.	0.35	3.87
34	We have the DS Association which is supportive and offers a lot of events and information, and networking things.	0.42	3.67
38	You have to go to different organizations that aren't just Down Syndrome.	0.36	3.63
40	I think there is a lot [of supports] out there now more than ever.	0.3	3.38
51	We've had [...] good community support, our neighbourhood association our church have been pretty good supports.	0.37	3
63	A lot of the programs are not convenient timewise	0.25	3.43
66	[Our child] was showing some behaviour issues so we got in touch with a behavioural therapist. They were very helpful.	0.38	2.13
71	I think that we have lots of organizations and programs being run and they definitely work for a number of people.	0.4	3.3
75	I find there's more support early on.	0.23	3.7
92	The worker [our child] had was amazing with providing information, support, what to utilize in the community, that kind of thing.	0.3	3.13
Cluster 5. Financial Support		0.23	3.63
2	There really isn't [funding] that's just not based on income. It would be nice to just get that little break regardless of your income.	0	3.71
8	We get Disability tax credits, so we're supported that way.	0.36	4.04
13	If there was more funding put towards hiring more therapists that would be really beneficial.	0.31	4.17
28	[What is lacking is] being able to access where extra funding is.	0.03	4.04
36	[Funding] it does help, it gets [my child their] camps and some extra activities and stuff during the year so that's part of the yes of being supported.	0.3	4.17
42	We've utilized big funding for a support person.	0.03	2.42

50	There is a waiting list in the schools for speech and language, there's waiting list for PT, there's waiting list for OT.	0.29	4.3
57	You do have to reroute your money from your other children to your child in need, unfortunately but it's true.	0.16	3.5
60	If there was more funding put towards opening up more spaces in daycares getting more people in there to assist with people that would be really beneficial.	0.29	4
62	[A local government agency] gets lots of funding, well they used to get a lot of funding for the Autism program, and I felt like maybe 80% of their offering was for Autism children only. For all the other children with different disabilities they only got 20% of the offering.	0.28	3.17
70	We have come up to barriers against [getting our child the disability tax credit].	0.16	2.09
76	There is a lot of supports if you have private insurance.	0.52	3.57
79	We get [funding] each year through [a government organization] and that's supposed to pay for extra support that [my child] needs, we go through it within three months.	0.03	3.52
95	If you have money, there are many more supports available to you.	0.41	3.86
98	I think that the respite funding that we get from the government is super helpful, as far as it helps us pay for [my child's] horseback riding.	0.21	3.35
112	I do think the funds get misspent or it takes too long to get a hold of them.	0.23	3.7
114	We are left in the hands of having to outsource these services on our own, privately and have to pay for them out of pocket.	0.38	4.18
Cluster 6. Advocacy Needs		0.88	3.74
4	It really comes down to the fierceness of the parents.	0.92	4.33
54	We need him to have a community and a life and to be able to do things each day.	0.87	4.83

55	Because DS has been around, and it's been researched, there is sort of an understanding of the level of disability.	0.92	3.13
68	It's really up to the individual parents to advocate themselves.	0.85	4.7
88	I feel as your child gets older, you kind of become an expert.	0.84	4.3
89	There is not a way to advocate.	0.93	2.1
96	I think having a [Down Syndrome] association, you're kind of singling out DS kids. I want [my child] to be in a world where [they] are going to function along with every other person in the world, not just DS people.	1	1.96
101	Our experience is we've had to go out and make those connections and be very very very proactive. In utilizing and finding what's available.	0.75	4.3
Cluster 7. Educational Support		0.7	3.45
16	If we have issues with [my child] at school [a local organization] will come and advocate with us.	0.8	2.96
27	Where education is concerned, a lot of it falls on us as the parent.	0.69	4.25
31	I'm not really sure how things will look once we go to school.I don't know how supported kids are in school.	0.7	3.46
33	I think that educationally there is not enough support for kids with DS.	0.64	4.25
53	[Our worker] is helping us with transitioning to elementary school.	0.67	2.96
72	School wise [our child] has had the support that they've needed, [our child] went from 3 hours of support last year to 6 hours support.	0.66	2.35
74	We didn't really feel like we had the option of an inclusive classroom because [our child] wouldn't have the support [our child] needed if we sent [them] there.	0.55	2.43
87	I don't think that the medical community pushes enough awareness of DS when mothers are first diagnosed, or babies are first diagnosed.	0.94	4.04

90	I think the expectations [at our school] are a little bit high that [our child] needs to follow along with everybody else.	0.72	2.74
91	I especially worry about when [my son] graduates from high school.	0.86	4.36
100	I wish [the school board] would listen to us a little bit more and give [our child] a little bit more chance to do things their way.	0.57	3.68
106	What I have experienced, not one teacher in the [local school board] has been specifically taught how to teach kids with DS.	0.58	3.91
Cluster 8. Concerns for Community Programming		0.66	3.27
17	[The local DS Association] programs are expensive.	0.78	2.17
41	We are expected to be not only the parent of the child but also their therapist for all of those specialty therapies as well.	0.56	4.33
56	We go to a small community rural school. There's just not a lot of programs in there, I think, that they let [our child] sort of explore.	0.65	2.67
59	I find it really frustrating that the government has changed the rules about special needs people working they have to get minimum wage now	0.76	2.88
69	[Pediatricians and doctors] are not connecting you the way they need to.	0.5	3.52
80	My big peeve about a lot of stuff is that babysitting should be part of the package when you are going to information stuff to make it easier for parents to go.	0.78	3.65
109	From my experience with children with DS, it feels like sometimes they kinda just fit in the middle, so they're not disabled enough to go into certain classes and things like that, but then they're not necessarily able to be a part of a regular things.	0.61	3.7

3.4   Results by Cluster

Cluster 1: Online Social Support

Statements in this cluster reflected the belief that social support as well as support received via social media was an accessible and beneficial support for caregivers. Many of the statements reflected the idea that participants currently make use of such support. However, some statements reflected the belief that more could still be done in the areas of social support needs and some caregivers indicated social support was not a need they experienced. Statements about social support included 'Family and friends have of course been great. Like we are pretty connected that way.' 'Our friends and family have all been fantastic, so that way there is lots of emotional and social support.' Statements related to online social media support included 'There is lots of online support, so I was able to join a bunch of online forums through Facebook and was able to connect with [two nearby Down Syndrome Associations].' Statements indicating there is still further support needed in the area included 'If there was a formalized network where you could reach out or someone reaches out to you, with someone whose kinda been there done that.'

The low average bridging value of this cluster indicated that participants consistently sorted the majority of the statements together and had good inter-sorter reliability. Participants' agreement ratings of the statements in this cluster reflected a general sense of indecision with an average cluster rating of 3.64. Of the 19 statements in this cluster, participants rated one statement with disagreement and five statements with an agreement rating.

Cluster 2: Community Support Gaps

Statements within this cluster focused on caregiver opinions of the difficulty of accessing supports for their child with DS due to their geographical location, inadequate notification of services and the limited number of services available. Example statements included 'It depends where you are geographically what services and supports you can access easily,' 'I don't think that everybody is getting a similar service' and 'There are not enough services out

there.' Caregivers also recognized the difficulty that exists in providing support that works for everyone given the wide variety of needs children with DS have.

Statements within the cluster reflected differing opinions of whether a variety of services were offered to suit their child's needs and if they were viewed as adequate. These statements had similarly low bridging values, revealing participants consistently grouped the statements together even though they represented differing opinions. Examples included, 'We receive supports for specific delayed areas like OT, PT and speech and language that's hosted through [the local] children's centre,' (.30), 'We had [our child] on the list for PT,OT and social worker, [our child] had her own individual worker.' (.26), and 'We don't feel that there is a gap [in services].' (.23).

This cluster had the lowest average bridging value of all eight clusters and represented good inter-sorter reliability of participant's statement sorting. Participants' rating results represented consistent ratings of "undecided" opinion in this cluster with an average cluster rating of 3.65. Three statements of the 25 were rated with "disagree" to "strongly disagree" and 10 statements were rated "agree" to "strongly agree."

Cluster 3: Areas Where Support is Lacking

A lack of supports was identified by participants in the areas of initial support from birth, preparedness of staff to assist caregivers, specific training for caregivers and changes to support offerings when entering school. Additionally, participants indicated a belief that the services that are offered are inconsistent and based on timing of seeking support and matching with service offerings. Example statements within this cluster include 'What I noticed is that it seems like the support is a bit inconsistent.' and 'If you're at the right place, at the right time, and you get the right information in time, then maybe you'll be okay, if you don't, well that's too bad.'

This cluster also had a low average bridging value indicating consistent sorting of the statements and good inter-sorter reliability. Participants' rating results reflected consistent "undecided" opinion of whether the statements were support needs for caregivers with an average cluster rating of 3.35. Three of the 12 statements in the cluster were rated "disagree" to "strongly disagree" by participants, with two statements rated as "agree" or "strongly agree."

Cluster 4: Down Syndrome Community Support

Statements in cluster four were focused on ideas related to the services provided from DS associations. Some statements represented ideas that services for individuals with DS are mixed with other services and are not specific only to DS concerns. Statements suggested improvements to DS associations were necessary including the creation of new associations in communities that are not serviced currently. Statements included 'Right here locally there is not much [of a DS community],' 'You have to go to different organizations that aren't just Down Syndrome.' And still some statements reflected opinions that services were available and offer the support participants were searching for, 'We've had [...] good community support, our neighbourhood association our church have been pretty good supports. I think that we have lots of organizations and programs being run and they definitely work for a number of people.'

The low average bridging value for the cluster indicated statements were consistently sorted together. Ratings in this cluster represented participants' general indecision of their agreement of whether the statements were support needs caregivers experienced with an average cluster rating of 3.34. Two of the 14 statements were rated with disagreement and one statement was rated with agreement.

Cluster 5: Financial Support

Statements in cluster five focused on participants' thoughts of current available funding. Statements included ideas related to what participants use their funding for, the types of financial assistance available to participants, how funding could be better spent by agencies, issues with accessing funding and concerns related to the expense of private services. Participants' statements reflected a need to increase financial resources and create funding options for families that are not based solely on income. Participant' statements also included ideas of a need to increase funding to daycare services and hire more therapists for support services. Example statements in this cluster included the following '[What is lacking is] being able to access where extra funding is,' 'We get [funding] each year through [a government organization] and that's supposed to pay for extra support that [my child] needs, we go through it within three months,' '[Funding] it does help, it gets [my child their] camps and some extra activities and stuff during the year so that's part of the yes of being supported.'

This cluster had a low average bridging value indicating good inter-sorter reliability between participants and consistent grouping of the statements in the cluster. Rating results of the statements revealed on average participants experienced indecision about whether the statements reflected a support concern for caregivers of children with DS with an average cluster rating of 3.63. Two of the statements were rated as "disagree" and seven of the 17 statements were rated as "agree."

Cluster 6: Advocacy Needs

The theme of advocacy was clear within the statements of this cluster with some statements reflecting a need for more advocacy and others reflecting the belief that DS Associations have been helpful for families. Statements included 'There is not a way to advocate,' 'I feel as your child gets older, you kind of become an expert. It's really up to the individual parents

to advocate themselves,' 'Our experience is we've had to go out and make those connections and be very very very proactive in utilizing and finding what's available.'

This cluster had the highest average bridging value within the eight-cluster solution indicating inconsistent grouping and participants frequently sorting the statements into other clusters. High individual statement bridging values indicate that the statements were not a good conceptual fit for the cluster. The rating results of this cluster reveal participants consistently indicated they were "undecided" if the statement represented a caregiver support need with an average cluster rating of 3.74. This cluster however had the highest average cluster rating of all the clusters in the solution. Two of the eight statements in this cluster were rated with disagreement ratings and five of the eight statements in the cluster were rated with agreement ratings.

Cluster 7: Educational Supports

The statements in cluster seven focused on the supports provided by educational institutions and included both positive and negative opinions. Some statements suggested more supports are needed and reflected the belief that children with DS would benefit if school officials could better listen and understand their experiences. Three statements in the cluster reflected participants' thoughts that their educational support was sufficient for their child while the remaining nine statements reflected opinions that more was needed to support their children in school. Example statements included, 'I think that educationally there is not enough support for kids with DS, ' 'I think the expectations [at our school] are a little bit high that [our child] needs to follow along with everybody else' and 'School wise [our child] has had the support that they've needed, [our child] went from 3 hours of support last year to 6 hours support.'

 The high average bridging value for this cluster revealed that the statements were very frequently sorted with statements in other clusters. Rating results for cluster seven revealed

that participants were generally undecided about the statements reflecting caregiver support needs with an average cluster rating of 3.45. Five of the 12 statements were rated with disagreement and four were rated with agreement.

Cluster 8: Concerns for Community Programming

The statements in cluster eight reflected caregivers' concerns for the manner in which community programs are offered to caregivers and statements included concerns for the lack of services in rural areas, the expense of programming, opinions that professionals are not adequately connecting caregivers to services and issues raised with the lack of childcare available for children with DS. Example statements included 'We go to a small community rural school. There's just not a lot of programs in there, I think, that they let [our child] sort of explore' and 'My big peeve about a lot of stuff is that babysitting should be part of the package when you are going to information stuff to make it easier for parents to go.'

The high average bridging value for this cluster indicated that statements were frequently sorted with statements in other clusters. This cluster had the lowest average rating value, 3.27, of the eight clusters. The rating results revealed that participants consistently rated that they were undecided or disagreed with the statements representing caregiver needs. Three of the seven statements were rated with disagreement and one of the statements was rated with agreement.

Chapter 4

4   Discussion

The goal of the current study was to gain caregivers' perspectives on their support needs related to caring for their child with DS. Overall, participants in the current study sorted the data in a consistent way identifying eight clusters of statements representing the themes of support needs for caregivers of children with DS. The eight clusters included needs associated with online social support, community support gaps, areas where support is lacking, Down Syndrome community support, financial support, advocacy needs, educational support and concerns for community programming. The stress value of the point map was 0.276 indicating that the thematic structure of the data was consistently agreed upon by participants and there was good fit of the data to the input similarity matrix. This suggests that our group of caregivers perceived the support needs in a relatively consistent manner.

Similarities were found between the support needs identified in the current study and those identified in the literature. The current study confirms findings of previous research that there is a lack of necessary support available to caregivers to allow them to optimally care for their child with DS (Murphy, et al., 2006; Papageorgiou & Kalyva, 2010; Siklos & Kearns, 2008). Across the clusters, participants reported there is a general inconsistency in how caregivers are made aware of supports in the community and the manner in which support is offered as it is not the same for everyone. Participants' statements also reflected an understanding that there are differences in how support can be offered and recognition that it is impossible to offer support that would fit everyone's needs.

Some clusters identified in the current study overlap with the categorization of caregiver support needs found in the literature including emotional support needs, relational support needs and material and informational needs (Derguy, et al., 2005; Kyzar, et al., 2012). Statements in cluster one (Online Social Support) indicated that emotional and relational

support needs were unmet for some caregivers while others indicated this need was met by their current situations. Material and informational support needs were identified by caregivers in cluster two (Community Support Gaps), cluster three (Areas Where Support is Lacking), cluster five (Financial Support) and cluster seven (Educational Support). Caregivers reported needing support in the form of access to financial resources, more therapeutic services, and increased care in educational settings to meet children's goals. Caregivers in our study did not report needs related to physical care or parental guidance and daily management of child behaviour as found in previous literature (Derguy, et al., 2005; Kyzar, et al., 2012).

Similarly, statements regarding caregiver support needs have also been reported in past studies. Statements from clusters one (Online Social Support), two (Community Support Gaps), three (Areas Where Support is Lacking), five (Financial Support), seven (Educational Support) and eight (Concerns for Community Programming) have been reported in the literature before, where clusters four and six have not (Boehm, et al., 2015; Marshall, et al., 2014; Povee, et al., 2012; Siklos & Kearns, 2006). Caregivers' individual statements from clusters one, two, three, five, seven and eight overlap with previous research suggesting caregivers have concerns for social support both in person and online, there is a need for more services and hands-on, intensive therapies, caregivers desire more consistent program offerings and more available information for caregivers (Derguy, et al., 2005; Marshall, et al., 2014; Povee, et al., 2012; Siklos & Kearns, 2006). Additionally, caregivers have concerns for greater access to financial support including financial assistance and access to funding opportunities and have concerns for their child's educational opportunities, navigating the school system and their child's future in general (Kapell, et al., 1998; Marshall, et al., 2014; Povee, et al., 2012; Siklos & Kearns, 2006). Previous research substantiates concerns caregivers expressed regarding the lack of appropriate childcare that is available in the community (Povee, et al., 2012). Lastly, caregivers' statements questioned the preparedness of professionals such as social service workers and medical professionals to discuss care

options with families. Stigma from healthcare providers is a common concern experienced by those with disabilities and has been investiaged by Kaye, et al. (2005) and Nicolaidis, et al. (2015). Previous research reveals there is a need for health care professionals who are sympathetic, well-informed of DS concerns and good communicators to ensure individuals with disabilities are not discriminated against and are not left untreated (Kaye, et al., 2005; Nicolaidis, et al., 2015).

The results of the current study also revealed statements regarding caregiver support needs that do not overlap with support needs identified in previous literature. Caregivers shared the opinion that advocating for their child is left to them and concern was raised regarding the lack of opportunities for caregivers to advocate for their children. Previous research also does not cite caregiver concerns related to the lack of Down Syndrome Associations in smaller, rural cities and the difficulties caregivers experience in accessing services based on where they reside geographically. The current research highlights the need for more local community organizations to offer support and programming that is affordable and accessible for families. Participants' statements suggest that caregivers of children with DS experience a variety of support needs and these differ based on circumstances of the family including geographical location, access to funding and private insurance and the caregivers experience with advocacy. Previous research does report caregiver concerns related to access to financial resources but availability of resources due to families' location of residence or experience with advocating for their child are not noted in previous literature.

Sorting results reveal that participants consistently sorted statements into three clusters, clusters two (Community Support Gaps), three (Areas Where Support is Lacking) and five (Financial Support), indicated by low average bridging values. These clusters can be identified as possible key support needs for caregivers based on participants' general agreement of the sorting within the themes. From participants' rating results, four clusters were revealed to be the most agreed upon concerns, these included cluster one (Online Social

Support), cluster two (Community Support Gaps), cluster five (Financial Support) and cluster six (Advocacy Needs).

Within each cluster, individual statements reflected specific areas where needs were still to be addressed while other statements within the same cluster reflected the opinion that the needs had been met. Some statements reflected the opinion that many supports are available, and others indicated there are not enough services offered. Some statements indicated a belief that most supports are only available early on in a child's life while others indicated they wished they had more supports initially. The differences in opinion can be understood to be a result of the different experiences each caregiver has had in life and can be understood to be impacted by their differences in personal characteristics such as the age of the caregiver, ranging from 34 years to 61 years, and the age of their child, ranging from less than a year old to 23 years of age. Additional characteristics that may have resulted in differing caregiver experiences include the level of caregiver education, household income and access to funding and the families' geographical location of residence (Papageorgio & Kalyva, 2010). Some caregivers may have required support related to infant caretaking while others experienced difficulties related to their child beginning school and others still may have required supports related to assisting their child to gain employment. Within the varying stages of a child's life the caregiver will require multiple and varying supports. Differing experiences of support needs may be influenced by the specific pattern of strengths and challenges children with DS express given their unique phenotype of social, cognitive, linguistic and motor functioning (Fidler, et al., 2009).

The results of the sorting task indicate participants may have struggled with the placement of some statements, evidenced by the high average bridging values of cluster six (Advocacy Needs, .88), cluster seven (Educational Support, .70) and cluster eight (Concerns for Community Programming, .66). Statements with the highest average bridging values within these clusters included statement number 96 in cluster six 'I think having a [Down

Syndrome] association, you're kind of singling out DS kids. I want [my child] to be in a world where [they] are going to function along with every other person in the world, not just DS people.' (1.0). In cluster seven, statement number 87 'I don't think that the medical community pushes enough awareness of DS when mothers are first diagnosed, or babies are first diagnosed.' (.94) and in cluster eight, statement number 17 '[The local DS Association] programs are expensive.' (.78) and statement number 80 'My big peeve about a lot of stuff is that babysitting should be part of the package when you are going to information stuff to make it easier for parents to go.' (.78). Some statements did not fit the themes of the clusters well or were sorted consistently in multiple categories demonstrating that participants struggled to sort them. Additionally, there is concern for participants' overall ratings of "indecision" of whether statements reflected caregiver support needs. It is possible the statements were not representative of the true experiences of all caregivers participating as well as issues related to the instructions of the task.

4.1   Implications and Conclusions

The current study adds to literature in the field of Down Syndrome and caregiver support needs. Previous research suggests the use of mixed method designs to more effectively and accurately capture caregivers' experiences (Recsh, et al., 2010). The researcher aimed to collect the most accurate information related to support needs available by obtaining firsthand perspectives from caregivers of children with DS. The researcher avoided the inherent bias that is commonly associated with predetermined coding schemes by involving participants in the structuring of the data (Jackson & Trochim, 2002). Study participants, rather than the researcher, created the statement clusters, organized the groupings and labelled the clusters of ideas. The use of concept mapping techniques is new to this population of participants and effectively incorporates both qualitative and quantitative research methods. Individual interviews with caregivers has specifically been noted as a necessary next step to accurately identify caregivers' unmet needs (Siklos & Kearns, 2006).

The results of the current study will support future program planning that more effectively meets the needs of caregivers and is in line with their identified needs. Caregivers' perspectives can be used to inform the development of support groups for caregivers of children with DS. Providing recommendations for the design of a support group based on identified needs from the caregivers themselves should increase the likelihood of support group participants developing a positive therapeutic alliance and increase group adherence (Derguy, et al., 2005).

Previous research has indicated that caregiving for a child with DS is significantly less stressful than caregiving for children with other diagnoses, namely ASD. Results from this study contextualize the support needs caregivers of children with DS do experience and where more can be done to better support them. This study can begin to add to the literature of this population and prompt additional research in the area.

4.2   Limitations and Future Directions

Due to participants' self-selection and volunteer involvement the results of the current study may not be generalizable to all caregivers of children with DS. Individuals who volunteered for this study may be fundamentally different than those who did not; they may be more active and involved in community agencies, support or advocacy groups. In previous research, it has been common for more women to be involved in research studies than men and within the research on caregivers of persons with disabilities, more mothers tend to participate than fathers (Hodapp, 2007). In the current study, 16 more women participated in the study than men, results therefore cannot be generalized to all caregivers of children with DS. Further, specific attention was not given to the inclusion of caregivers from varying geographical locations or financial backgrounds. Lastly, the average age of the participants' children was 9.25 years of age, caution should be given to readers that the results of this

study represent support needs of caregivers of younger children with DS and may not be representative of all children with DS.

The number of statements in the study may have influenced participants' ability to accurately complete the sorting and rating tasks as Kane and Trochim (2007) recommend the use of 100 statements so as not to overburden participants. Additionally, some of the statements were found to contain more than one idea, this may have resulted in complex statements that could have hindered participants' sorting and rating processes. The goal of the researcher's statement structuring prior to sorting was to identify and reduce repeated statements and edit statements. Some statements with multiple ideas remained intact. This may have led to confusion during the sorting process. Lastly, the researcher's editing of the statements and addition of details to provide context, could have confused participants and made the connection to the focus prompt difficult to comprehend.

The mismatch between statements in the clusters may reflect the possibility that the instructions to complete the task were unclear or the statements did not reflect the participants' caregiver needs. The researcher did not require participants to complete the sorting task prior to the rating task. Restricting access to the rating task until completion of the sorting task could have aided in the loss of participant data and minimized concerns for priming (Kane & Trochim, 2007). The sorting task was more time consuming, labour intensive, and demanding of participants' effort. There is a possibility there was confusion of how to complete the sorting task as nine participants did not complete it or completed it incorrectly. Subsequently, their results were removed from analyses. Participants expressed the difficulty they experienced using the web-based software to complete the tasks and as such in-person card sorting with hard copy cards may have been helpful to minimize such issues.

In the future, studies should investigate the perspectives of siblings and extended family members through interviews and concept mapping tasks. This would account for the interactions among family members and allow researchers to approach support needs from a systems perspective for a more complete understanding of the needs within families (Canary, 2008). The rating task assessed participants' level of agreement of the indicated support need reflecting a need that caregivers of children with DS experience. Previous concept mapping studies have instead assessed participants' importance rating rather than agreement. Future research should consider importance ratings over agreement to understand caregivers' opinions of the priority of support needs. Lastly, future research could consider exploring the differences in support needs based on caregiver characteristics including educational background, household income, age of both the caregiver and child, marital status of the caregiver as well as the gender of the child. Research addressing such distinctions may produce different caregiver priorities and provide a more holistic representation of support needs.

In summary, the current study provides the perspective of caregivers of children with DS and their support needs unlike any previous research to date making use of concept mapping techniques. Caregivers provided insight into their support needs and identified eight areas requiring additional attention. This study filled the gap in the literature specific to caregivers of children with DS as past research has focused primarily on ASD and have included caregivers of children with DS as control subjects. This study identified similar support needs found in previous studies including online social support, financial support and educational support needs as well as support needs not identified in previous studies. This study revealed that caregivers have needs related to advocacy opportunities and identified a need for more accessible services in rural areas. It was revealed that all areas of support need in this study received an average undecided rating from participants that could be explained by varying life experiences and children's different stages of development. Caregivers experience many challenges unique to raising a child with DS and value a variety of support offerings and

services to assist them in caring for their child. These challenges will begin to be addressed most effectively with collaboration from caregivers, policy makers, researchers, and service providers offering of supports and services that are in line with caregivers identified needs.

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Appendices

Appendix A: Ethics Approval Certificate

Western Research

Date: 6 March 2019

To: Dr. Nicole Neil

Project ID: 113002

Study Title: Down Syndrome Parent Support Group Needs: Quantitative and Qualitative Parental Perspectives

Application Type: NMREB Initial Application

Review Type: Delegated

Full Board Reporting Date: April 5 2019

Date Approval Issued: 06/Mar/2019

REB Approval Expiry Date: 06/Mar/2020

Dear Dr. Nicole Neil

The Western University Non-Medical Research Ethics Board (NMREB) has reviewed and approved the WREM application form for the above mentioned study, as of the date noted above. NMREB approval for this study remains valid until the expiry date noted above, conditional to timely submission and acceptance of NMREB Continuing Ethics Review.

This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
DS recruitment flyer - V2 02.09.2018	Recruitment Materials	09/Feb/2019	2
DS Recruitment Flyer- study 2 V2	Recruitment Materials	22/Feb/2019	2
Email Script for Interview Contact	Tracked Changes Document	22/Feb/2019	1
Email Script for Recruitment of Organizations	Recruitment Materials	14/Dec/2018	1
Interview Protocol	Interview Guide	18/Jan/2019	3
Online Survey_DS Parent Needs V2_02262019	Online Survey	26/Feb/2019	2
Reminder Email Script for Recruitment	Recruitment Materials	18/Jan/2019	1
Study 1- LOIC v2 02092019	Implied Consent/Assent	09/Feb/2019	2
Study 2- V3 Letter of Information and Consent (2)	Verbal Consent/Assent	25/Feb/2019	3

No deviations from, or changes to the protocol should be initiated without prior written approval from the NMREB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

The Western University NMREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario. Members of the NMREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB. The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Kelly Patterson, Research Ethics Officer on behalf of Dr. Randal Graham, NMREB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Appendix B: Recruitment Poster

Appendix C: Letter of Information

Western

Document Title

Letter of Information and Verbal Consent

Project Title

Down Syndrome Parent Support Needs: Parental Perspective

Principal Investigator + Contact

Principal Investigator
Nicole Neil, PhD, BCBA-D, Faculty of Education
Western University, █████

████████████

1. Invitation to Participate

You are being invited to participate in this research study about the support needs of parents of individuals with Down Syndrome because you are a parent or caregiver/guardian
of an individual with Down Syndrome.

2. Why is this study being done?

Researchers are interested in understanding, from the perspective of parents, what the support needs are for parents of individuals with Down Syndrome. This information will be helpful in the development of a parent support group.
The purpose of this study is to interview parents about their thoughts on current support available to parents of individuals with Down syndrome and to learn of improvements, if any, that could be made.

3. How long will you be in this study?

It is expected that you will be in this study for a maximum of 2 hours comprising of a 15 minute telephone interview and a 30-60 minute follow up activity at a later time to be scheduled with the researchers.

4. What are the study procedures?

If you agree to participate you will be asked to:

Complete a 2 minute screening.

During the screening, we will confirm if you are eligible to participate in the study. You will complete a questionnaire asking information about your child's age and diagnosis. You will be eligible for this study if you are an English-speaking parent or caregiver/guardian of a child with a diagnosis of Down Syndrome.

Complete a 15-minute telephone interview
During the interview you will be asked a question pertaining to your thoughts of current support available to parents of individuals with Down Syndrome. You will provide your responses to the research assistant over the telephone. Telephone interviews will be audio recorded for data analysis purposes.

Complete a 30-60 minute Sorting and Rating Follow Up Task.
During the follow up activity, you will be asked to sort statements on an online computer program into categories that make sense to you and rate individual statements. Statements from participant interviews will be used in the subsequent sorting and rating task.

5. What are the risks and harms of participating in this study?

The procedures used in this study present no risks to you as a participant however the interview question could cause uncomfortable feelings or trigger negative emotions. Participants are free to withdraw from participation at any time.

A potential risk of participation in this research is a loss of confidentiality, but measures will be taken to protect identities of all participants, as described in the confidentiality section.

6. What are the benefits?

No direct personal benefit is expected from participation in this study. However, participants work will inform the development of a support group for parents of individuals with Down

7. Can participants choose to leave the study?

If you decide to withdraw from the study, you have the right to request withdrawal of information collected about you. If you wish to have your information removed please let the researcher know and all traces of your information will be destroyed from our records.

NOTE: Once the study has been published we will not be able to withdraw your information.

8. How will participants' information be kept confidential?

All information about participants will be coded with a number so that your name will not be readily associated with all the information. Identifiers will be kept separate from study data. All information (codes and corresponding names as well as video recordings) will be kept in a locked file cabinet in the principal investigator's office. Electronic files with be stored on a password protected device. Access to all data will be limited to the study personnel. In the dissemination of results, all participant information will be de-identified and de-identified quotes will be used.

Representatives of The University of Western Ontario Non-Medical Research Ethics

Board may require access to your study-related records to monitor the conduct of the research. While we do our best to protect your information there is no guarantee that we will be able to do so. However, since your child's age and diagnosis are the only identifying information it is unlikely that someone will link the data and identify your child.

The principal investigator will keep any personal information about you in a secure and confidential location for a minimum of 7 years. A list linking your study number with your name will be kept by the researcher in a secure place, separate from your study file. If the results of the study are published, your name will not be used.

Open Access: For the reasons of transparency and education, it is strongly encouraged by many journals and other authorities to publish the anonymized data from studies for public use (anonymized means no data which can identify you would ever be published). This data is visible to researchers or the general public after the study is over. Researchers may use this data to improve knowledge about group video-modelling for children with autism spectrum disorder.

Anonymized data from this study may be published in an open -access . All identifiable information will be deleted from the dataset collected so that individual participant's anonymity will be protected. The de-identified data will be accessible by the study investigators as well as the broader scientific community. More specifically, the data may be posted on an open-access data set OR made available to other researchers upon publication so that data may be inspected and analyzed by other researchers. The data that will be shared will not contain any information that can identify you.

Audio-Recordings: The telephone interview will be audio-recorded for the purpose of study procedures. Audio-recording is a mandatory part of participation. Audio recordings will be listened to by project staff only and will be kept in a locked office. Recordings will be destroyed following this study's completion.

9. Are participants compensated to be in this study?

Compensation will not be provided for participation in the interview. Compensation will be provided, in the form of a $20.00 gift card for participation in the sorting and rating tasks.

10. What are the Rights of Participants?

Your participation in this study is voluntary. You may decide not to be in this study. Even if you consent to participate you have the right to not answer individual questions or to withdraw from the study at any time. You do not waive any legal right by signing this consent form

11. Whom do participants contact for questions?

If you have questions about this research study please contact the Principal Investigator: Nicole Neil, 519-661-2111 X84761, nneil@uwo.ca

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics ███████████
████████

Appendix D: Verbal Consent

Verbal Consent

1.Project Title

Down Syndrome Parent Support Group Needs: Parental Perspectives
Letter of Information and Verbal Consent

2.Principal Investigator + Contact

Principal Investigator
Dr. Nicole Neil, PhD, BCBA-D, Faculty of Education
Western University,

Do you confirm you have read the letter of information and have had the nature of the study explained to you?   Yes   No

Do you agree to participate in the study?   Yes   No

Have all your questions been answered to your satisfaction?   Yes   No

Appendix E: Interview Protocol

To begin the interview portion of the study, participants will be greeted and asked to tell the research assistant about their family. Participants will be asked warm- up questions and demographic questions prior to beginning the telephone interview.

 Warm Up Questions and Demographic Questions

"I'd like to start off by getting to know a little more about your family.

1. What is your relationship with the child with Down Syndrome?

2. What gender does the child with DS identify with?

3. How old is the child with DS?

4. How old are you?

5. What is your gender and ethnicity?

6. Are you married?

7. What is your educational background?

8. Do you live in a rural or urban geographical setting in Ontario?

9. What range does your household income fall within?

    a. Less than $24,999

    b. $25,000 - $49, 999

    c. $50, 000 - $99, 999

    d. $100, 000 - $124, 999

    e. $125, 000 - $149, 999

    f. $150, 000 or more

10. Do you have additional children and what are their genders and ages?

11. Does your child with DS attend community programs?

Interview Question

Following the warm-up and demographic questions, the research assistant will begin the

interview with the focus prompt question, "Are parents of children with Down Syndrome

supported, why or why not?"

Additional follow up questions will be asked to prompt further detailed responses from

participants.

Probes:

- "Can you tell me more about that?

- Do you have any more thoughts on that?

- Could you provide me some examples of that?"

Participants will be thanked for their participation and reminded that they will be contact via

email to receive instructions for a follow up task. Participant will be reminded of the honorarium

they will receive upon completion of all study tasks.

Curriculum Vitae

Name: Katie Hart

Post-secondary   King's University College at Western University
Education and   London, Ontario, Canada
Degrees: 2011-2015 B.A.

                             Western University
                             London, Ontario, Canada
                             2018-2020 M.A.

Honours and   Breakfast of Champions Award for "Organization of the Year"
Awards: 2015

Related Work   Counselling Intern
Experience   King's University College at Western University
                             2019-2020