

Resource Needs, Availability and Use Amongst Children with Down Syndrome and  
their Caregivers in Galle, Sri Lanka

by

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Thesis submitted in partial fulfillment of  
the requirements for the degree of  
Master of Science in the Duke Global Health Institute  
in the Graduate School of Duke University

2018

ABSTRACT

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## **Abstract**

Background: Down Syndrome (DS) is the most commonly identified aneuploidy amongst children in Sri Lanka, with a prevalence of 76.3%. This study intended to determine the level of disability of children with DS aged 5-12, level of caregiver burden and impacts of family access to external services and social supports in Galle, Sri Lanka. Methods: A cross-sectional survey and interview study was conducted to determine caregiver burden, the level of disability for children with DS, and their access to social supports and external services. Within the study, 125 caregivers took the Caregiver Priorities and Child Health Index of Life with Disabilities (CP-CHILD) and Caregiver Difficulties Scale (CDS) assessments and 15 participated in interviews. Simple bivariate and multivariable regression were used to determine the impacts of resource usage on the child's level of disability and caregivers burden. Results: The mean level of disability of children with DS was 64.8 and caregiver burden was 50.2. Positively associated predictors of the level of disability include school, type, caregiver gender and income level. Approximately one-third (36.8%) of caregivers reported receiving assistance from external supports, 20% received government assistance, and 92.8% of caregivers relied on assistance from friends and family. Conclusions: Assistance from external sources and behavior therapy was shown to negatively moderate the relationship between the level of disability of the child and caregiver burden. Future longitudinal research, alongside more resource promotion and creation could improve resource access, disability levels and caregiver burden.

## **Dedication**

This thesis is dedicated to my parents, Logan Paramjothy and Devi Logan, and my sister, Monisha Logan for their unwavering support and encouragement. Their hard work, support and dedication consistently inspire me to pursue my dreams and take advantage of the great opportunities that have been presented to me.

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# 1. Introduction

## 1.1 *Global Burden of Down Syndrome*

An estimated 1 in 1,000 to 1 in 1,100 live births worldwide are diagnosed with Down Syndrome (DS), and are prone to a number of health complications (The Ability Foundation, n.d.; "WHO | Genes and human disease," n.d.). Globally, DS has a mortality rate of 0.5 per 100,000 people and 53.1 global annual years of healthy life are lost per 100,000 people (Health Grove, 2018). Furthermore, worldwide DS has the most severe impacts in low-income regions including Africa and Asia as based on an annual mortality rate per 100,000 people (Health Grove, 2018). It is predicted that as a result of increased access to substantially higher quality medical care in high income countries, there are generally higher populations of elderly people with DS in high income countries as opposed to low-and middle-income countries (Health Grove, 2018). Since 1990, the annual mortality rate for people with DS has seen average decreases of approximately 1.6% a year (Health Grove, 2018). DS has been shown to be most deadly around the world between the ages of 1 to 4 for both males and females, and least deadly at ages older than 75 for both men and women (Health Grove, 2018). A 2015 study on the comparison of prevalence and Years Lived with Disability (YLD) for DS found that DS had a relatively low levels of prevalence (~3.85%) and low YLDs (5-31%) (Global Burden of Disease Study 2013 Collaborators, 2015).

## **1.2 Background on Down Syndrome**

DS is caused by the presence of an extra chromosome (known as trisomy 21) ("WHO | Genes and human disease," n.d.). Duplications of small regions of the extra chromosome are thought to cause similarities in phenotypic features of patients with DS (Korenberg et al., 1994). In general, DS is associated as a major cause of mental retardation and congenital heart disease (Korenberg et al., 1994). Using characteristic clinical findings such as a genetic test known as chromosome analysis, DS can be diagnosed in infancy ("Learning About Down Syndrome," n.d.). In a chromosome analysis, skin and/or blood samples are taken and assessed for the presence of an extra chromosome 21 ("Learning About Down Syndrome," n.d.). It's also possible for individuals with DS to have a trisomy 21 in only some cells of their body (known as mosaic DS) ("Learning About Down Syndrome," n.d.). Individuals with DS have a characteristic set of facial and physical features, which are most often compounded with gastrointestinal tract anomalies and increased risks for leukemia, immune system defects, and an Alzheimer-like dementia (Korenberg et al., 1994).

Individuals with DS experience unique neurocognitive and neurobehavioral profiles which emerge throughout periods of development (Grieco, Pulsifer, Seligsohn, Skotko, & Schwartz, 2015). As children with DS reach school-age, delays become pronounced, with persistent deficits relating to verbal abilities, attention, and executive function (Grieco et al., 2015). Children aged 3 to 17 years old are at higher odds of

experiencing food/digestive complications and allergies, diarrhea/colitis, ear infections, head/chest colds, and additional developmental disabilities, when compared to children without DS (Schieve, Boulet, Boyle, Rasmussen, & Schendel, 2009). Furthermore, in individuals with DS, a variety of phenotypes that affect the central nervous system have been found including varying levels of intellectual disability, increased seizure disorders, motor dysfunction and neuropathologies that hold similarities to Alzheimer's disease (Costa, 2011).

Furthermore, children and adolescents with DS are prone to language delays and language development issues, as language delays are typically coupled with general cognitive delay (Chapman, 1997). During the sensorimotor period, sensorimotor development generally appears to be close to normal during the first year of life in children with DS but progressively more delayed and pronounced in the second year and beyond (Chapman, 1997). Additionally, studies have shown that for children with DS, the use of expressive language is significantly weaker than receptive language (Chapman, 1997). As children age with DS, their communication, daily living and socialization skills generally lag (Chapman, 1997).

### ***1.3 Globally Recommended Resources for Caregiving for Children with Down Syndrome***

As children with Down Syndrome are prone to a variety of co-morbidities and side effects, investing in some additional growth and development resources can aid in

the healthy development of the child and decrease the presence of some symptoms and side effects. Many of the ailments affecting children and infants with DS are treated using surgery. In particular, children with DS may have difficulties swallowing, bowel blockages, cataracts and strabismus (crossed eyes), which can all be assisted by surgery (“Learning About Down Syndrome,” n.d.).

Children with DS are generally prone to heart defects. Approximately 40 to 60 percent of infants with DS also have heart defects (“Learning About Down Syndrome,” n.d.). It is recommended that all newborns with DS undergo electrocardiograms and echocardiograms to get their hearts checked. In the event that a child is presents with heart defects, a referral is made to a pediatric cardiologist for medical management or surgical repair of the condition (“Learning About Down Syndrome,” n.d.). Infants with DS may also have issues with sucking due to low muscle tone and/or heart problems, which inhibit initial breast feeding (“Learning About Down Syndrome,” n.d.). To overcome these issues, mothers of newborns with DS are often referred to specialists including but not limited to occupational therapists, speech therapists, breast feeding consultants and support groups for mothers of children with DS (“Learning About Down Syndrome,” n.d.). However, it should be noted that recommendations around ‘best standards of care’ are not always possible or practical in many low-and middle-income communities.



Infants with DS often do not have good muscle tone, making it increasingly difficult for them to roll over and walk (“Learning About Down Syndrome,” n.d.). Physical therapy is commonly used and recommended for children with DS to help minimize abnormal compensatory movement patterns which sometimes emerge at a young age when children are developing motor skills (Fish & Winders, 2008). Children with DS are often prone to physical conditions that can inhibit the rate of their gross motor development. These physical conditions include: hypotonia, ligamentous laxity, decreased strength and shortened arms and legs (Fish & Winders, 2008). As a result of these conditions, children with DS often develop compensatory movement patterns that result in further physical development issues such as gait (i.e. posturing with hip abduction and external rotation, knee hypertension and foot pronation and eversion) and kyphosis (excessive outward curvature of the spine/hunching of the back) (Fish & Winders, 2008). Physical therapy can aid children by teaching them to properly sit, walk and stand along with developing other gross motor skills. In addition to motor skill development, enrolling children with DS in physical therapy can provide parents with an opportunity to learn about their child’s learning style and preferences, considering physical development is one of the first learning tasks that children with DS encounter (Fish & Winders, 2008).

To aid with slowed learning abilities and low normal to very slow levels of intelligence amongst children with DS, early referrals are often made to early intervention programs in high-income countries to aid with increasing language, intellectual abilities, and social and adaptive skills ("Learning About Down Syndrome," n.d.). By preschool age, programs often exist for children for a variety of therapies including physical, occupational, speech and education ("Learning About Down Syndrome," n.d.). Peer support groups are also an important resource for children with DS. Children with DS generally tend to experience limitations in regards to their peer social networks during key developmental segments, such as their early childhood and elementary years (Guralnick, Connor, & Johnson, 2009). Children with DS often face infrequent contacts with their peers and have trouble forming friendships, exposing them to feelings of loneliness, which can be aided with social contact with playmates in the home and school and through community activities (Guralnick et al., 2009). While extended social interactions are necessary, further studies are being pursued to develop an increased understanding of the social competencies of children with DS when interacting and playing with peers (Guralnick et al., 2009).

Recent research in mice has also shown promise for pharmacotherapies for the cognitive disabilities and neurodevelopment associated with DS (Costa, 2011). Pharmacotherapies to treat cognitive deficits in individuals with DS, also hold promise for

counteracting the neurodegenerative aspects of DS (Costa, 2011). These therapies are thought to hold promise as adjuvant therapies when combined with the aforementioned traditional therapies.

#### ***1.4 Defining Disability Supports in Galle, Sri Lanka***

In order to ameliorate the burden on both school-aged children with DS and their caregivers, the existence and promotion of therapeutic, respite and support services are important. To the best of our knowledge, previous research had not been pursued to evaluate the current availability, usage and awareness of such services amongst caregivers in the Galle District of Sri Lanka, as a means to better determine what services exist and the degree to which service amendments and/or service formations are required. In general, relatively little information is known or available in regards to DS in Sri Lanka. Sri Lanka was most recently quoted to have an annual mortality rate of 0.2 per 100,000 people, but little information is publicly accessible beyond that statistic (Health Grove, 2018). While studies regarding attitudes towards genetic services and other developmental disabilities have been previously recorded, relatively little information is accessible about the burden of care for DS in the country (Jayasekara, 1989).

A review of published literature relating to disability in Sri Lanka recently indicated that the country had studies that provided insights to varying dimensions of disability. However, there were many important research gaps in the country regarding the unmet

needs of people living with disability in Sri Lanka, specifically pertaining to their health and wellbeing (Peiris-John, Attanayake, Daskon, Wickremasinghe, & Ameratunga, 2014). Published disability research in Sri Lanka has predominantly focused on mental health, visual impairment and healthcare delivery over the course of 30 years (Peiris-John et al., 2014). However, large gaps presently exist in regards to information about people with intellectual disability, provider attitudes and the barriers to education and employment faced by people with disabilities (including but not limited to DS) (Peiris-John et al., 2014).

### ***1.5 Support Programs and Initiatives for Children with Disabilities and their Caregivers in Sri Lanka***

Within Sri Lanka, DS is the most commonly identified aneuploidy in children, with a prevalence of 76.3% amongst patients with chromosomal anomalies in a 2015 study (Thillainathan, Sirisena, Kariyawasam, Jayasekara, & Dissanayake, 2015). As a result of the range of health risks, complications and developmental delays associated with DS, there is a need for support services to assist children with DS. Caregivers bear the pressure to locate useful services, and support their kin of people with DS. While some demographic studies of the prevalence of DS have taken place in Sri Lanka, no research has been conducted in regards to the availability, use and effectiveness of support resources for patients with DS and their caregivers, such as physical therapy, educational programs, and caregiver support groups, for patients with DS and their caregivers.

A 2014 Sri Lankan study assessing factors associated with caregiver burden in Cerebral Palsy helped inform and hint at some of the possible needs addressed by DS (Wijesinghe et al., 2014). Within that study, caregiver burden was defined as a "...caregiver's response to various stressors associated with caregiving" and associations were studied between the sociodemographic, stressor and coping factors and caregiver burden (Wijesinghe et al., 2014). The study found that seeking social supports and psychosocial interventions could reduce the amplified caregiver burden that caregivers in Sri Lanka faced with having a child with increased functional impairments (Wijesinghe et al., 2014).

While no specific legislation can be located regarding DS, Sri Lanka has a number of policies in place to aid people with disabilities. Amongst their policies, the country has taken steps to ensure that all persons with disabilities shall not be discriminated against in mainstream vocational training and skills development programs and that all people with a disability have the right to work fulfilled with free choice of employment in both the private and public sector (Padmani, Cabral, & Galektuwa, 2003). Furthermore, the country policies assert that all children with disabilities have equal rights to education as all other children as is implied in the UN Convention on the Rights of the Child, of which Sri Lanka is a signatory (Padmani et al., 2003).

Within Sri Lanka's education legislation, there are mandates to ensure quality education for children with disabilities. The government has made moves to develop a concept of "Inclusive Education" to convey inclusion and equity and to prevent the

marginalization of children with disabilities through previous terminology such as “Special Education” (Padmani et al., 2003). The State also enacted legislation to develop and strengthen linkages between State and Private Special Schools to ensure that children who could be in mainstream classrooms are transitioned to them to make room for children who would most benefit from Special Schools and are unlikely to function successfully in mainstream classrooms (Padmani et al., 2003). To prevent children from being kept at home with no education, the Sri Lankan government has taken measures to place children with severe disabilities in Special Schools and attempt to ameliorate the burden of cost for families who are unable to pay the fees associated with Special Schools (Padmani et al., 2003). The legislation also specifically ensures that the choice of method of education is ultimately at the discretion of the parents of children who have the disability and not the government or any other third-party (Padmani et al., 2003). Additionally, through the Educational Reforms Act of 1997, children entering school must continuously be assessed by a medical officer and class-teacher. The information generated from these tests are then required to be used to give teachers knowledge about each child’s disabilities with the intent of using that knowledge to maximize the learning potential of the child in the class room (Padmani et al., 2003).

Searches of resources for children with DS and their caregivers in Sri Lanka yield limited results. Down Syndrome International (DSI) indicates that Sri Lanka has a few NGOs working on issues related to DS including the Kosala Dullewa Foundation, Diridaru Piyasa

and the Jinendhi Resource Centre for Down Syndrome (Down Syndrome International, 2018). It appears that many of these organizations are start-ups by parents and caregivers of children with DS and are kept alive through their efforts. DSI also indicates that a Down Syndrome Federation of Sri Lanka was created (Down Syndrome International, 2018). However, no further information is locatable for this group. Moreover, internet searches yield inconclusive results regarding the locations of these resource centers and resources for families of children with DS.

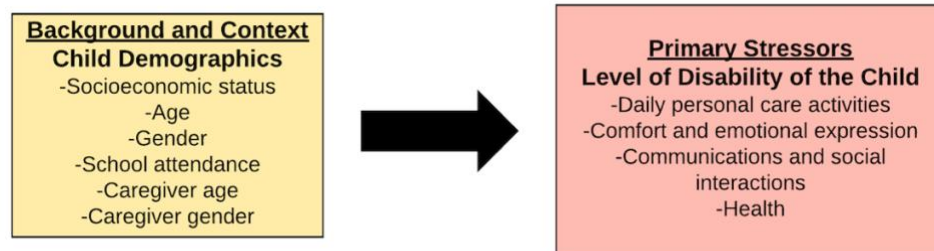
### ***1.6 Goals and Objectives: Defining the Research Problem***

This project intended to determine the general level of disability of children with Down Syndrome aged 5-12, the general level of caregiver burden, the access of families to formal programs, interventions and infrastructure within Galle, Sri Lanka and the impact of that access or lack thereof on caregivers and children. The specific objective of our study is to evaluate existing support resources and determine gaps in resource availability directed towards school-aged (i.e. 5-12 year-old) children with DS and their caregivers in Galle District through the use of a caregiver survey and qualitative interviews. Through the identification of possible gaps in services, it is hoped that larger institutional bodies will utilize this newly increased focus to re-evaluate, amend, and create improved support interventions which will facilitate feasible, accessible services to children with DS and their

caregivers, thus improving day-to-day quality of life. Outlined below are the study's specific aims and central hypotheses.

**Aim 1.** Describe the level of disability amongst school-aged children with Down Syndrome, and examine possible socioeconomic predictors of the level of disability.

**Hypothesis:** The level of disability will vary amongst school-aged children with Down Syndrome. Socio-demographic information such as income, age, and school attendance will influence the level of disability of the child, and can be utilized to predict the level of disability. It was predicted that older children, those of higher socioeconomic status, children who attend school, and those at disability-specific school programs will be higher functioning.

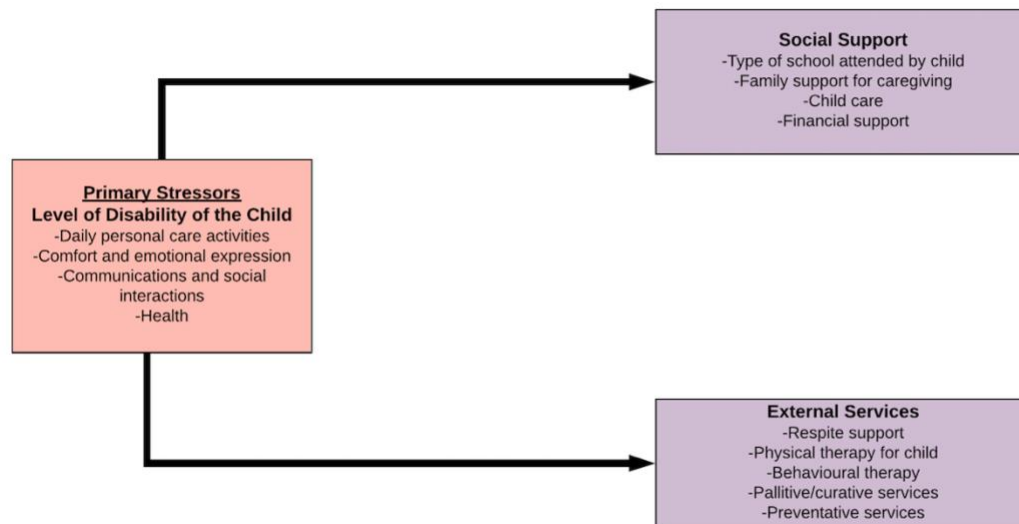


**Figure 1:** Aim 1: Effect of child demographics on level of disability of the child

**Aim 2.** Assess the need for external services by caregivers for their children. Describe the use of external services and social supports by caregivers for their children. External services that are likely to be sought out include: respite support, physical therapy for children, behavioral therapy, palliative/curative services and preventative services.



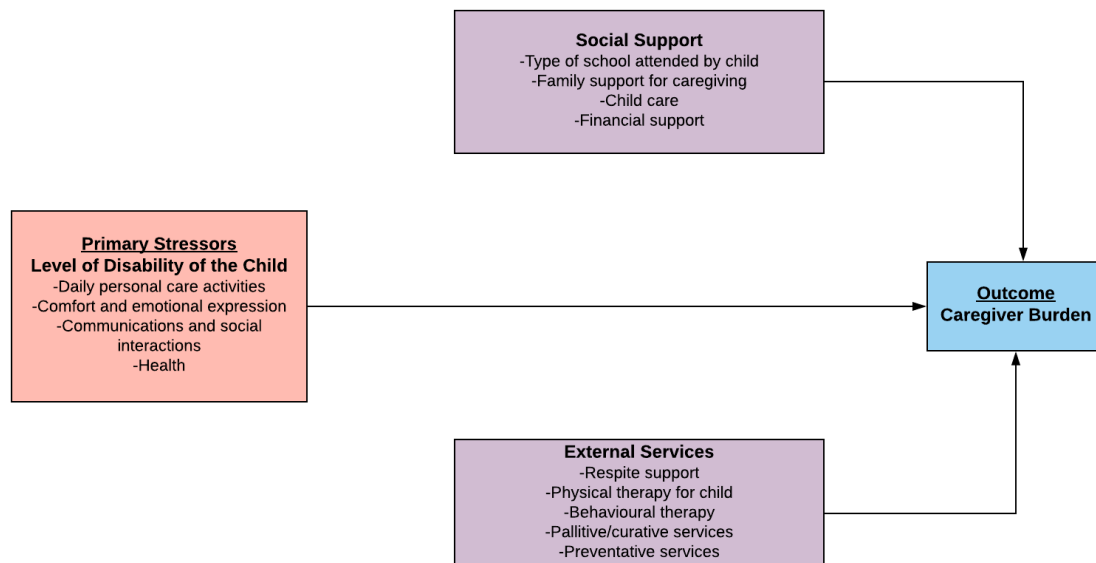
**Hypothesis:** It was predicted that caregivers of children with higher levels of disability will be more likely to use and seek external services to assist themselves and their children.



**Figure 2:** Aim 2: Effect of level of disability of the child on social supports and external services

**Aim 3a.** Describe the relationship of external services, social supports and primary stressors with overall caregiver burden.

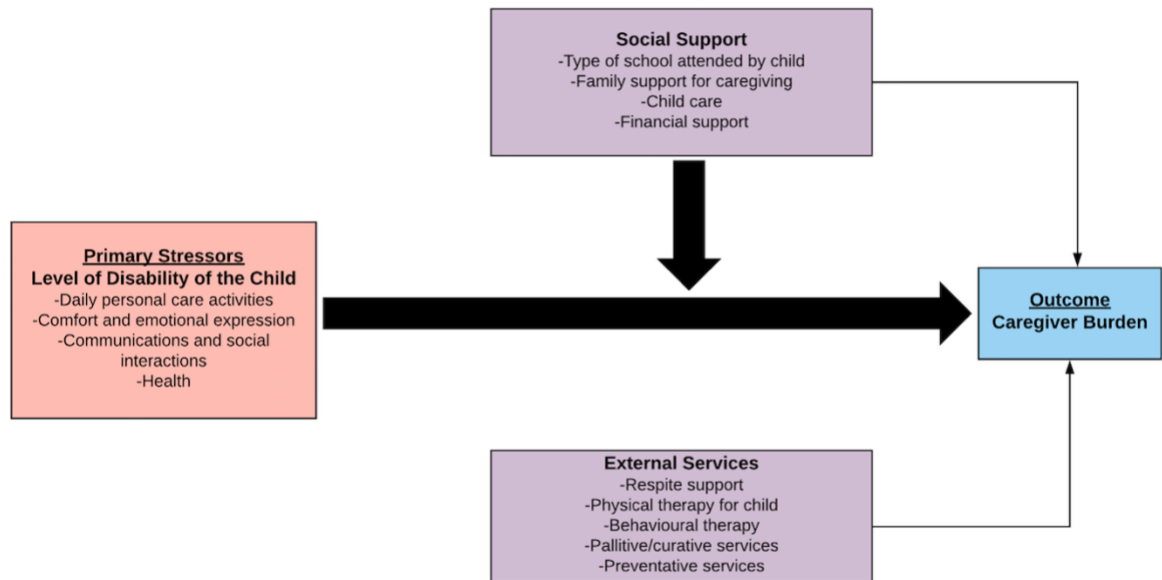
**Hypothesis:** Caregivers with access to more social supports and external services will experience decreased levels of caregiver burden, possibly as a result of decreased levels of disability in children with Down Syndrome, due to the use of resources that allow them to better manage their disabilities.



**Figure 3:** Aim 3a: Relationship of external services, social supports and primary stressors on overall caregiver burden

**Aim 3b.** Explore the extent to which social support acts as a moderator on the relationship between the level of disability of the child and caregiver burden.

**Hypothesis:** Caregivers of children with higher levels of disability will experience higher levels of caregiver burden. However, when coupled with increased social supports, we estimate that caregiver burden may be reduced for caregivers with children who have higher levels of disability.

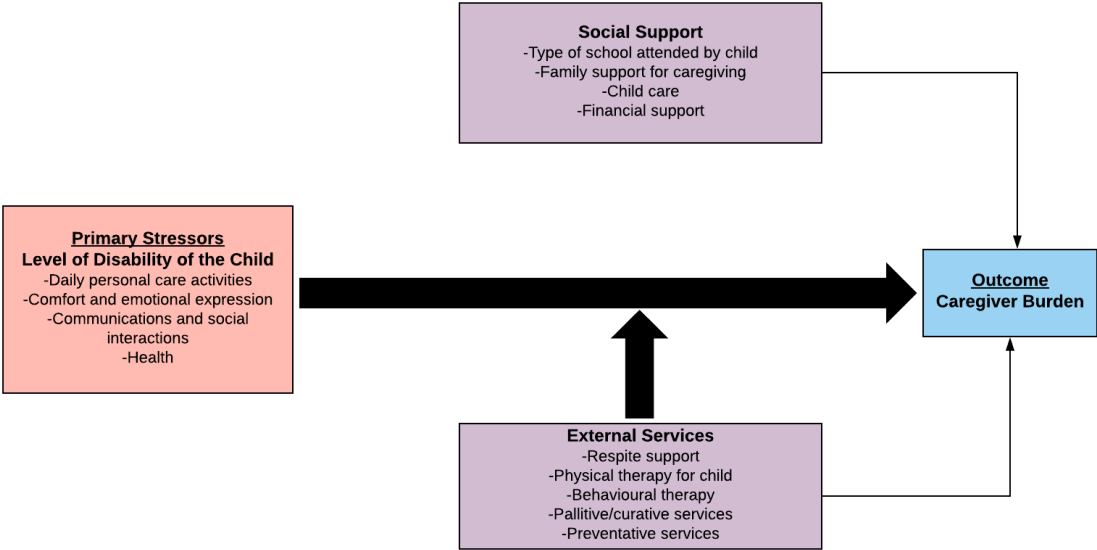


**Figure 4:** Aim 3b: Social supports as a moderator on relationship between level of disability of the child and caregiver burden

**Aim 3c.** Explore the extent to which external services acts as a moderator on the relationship between the level of disability of the child and caregiver burden.

**Hypothesis:** Caregivers of children with higher levels of disability were hypothesized to experience higher levels of caregiver burden. However, when coupled with increased use of external services, we estimated that caregiver burden may be reduced for caregivers with children who have higher levels of disability. Furthermore, we estimate when external services are sought out and used, it can

have a complimentary effect on caregiver burden, and increased service use will correlate with decreased caregiver burden.



**Figure 5:** Aim 3c: External services as a moderator on relationship between level of disability of the child and caregiver burden

## **2. Methods**

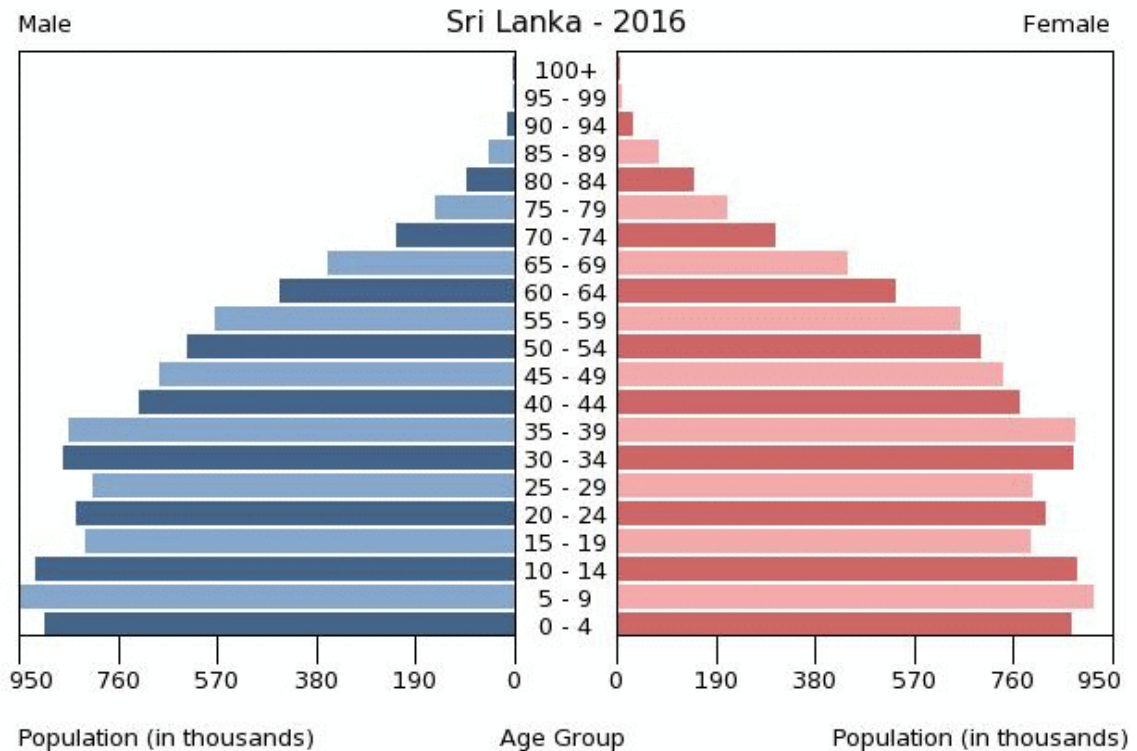
To assess concerns held by caregivers regarding the accessibility, needs, usage and gaps within existing DS services and programs in Galle, Sri Lanka, we conducted a survey of caregivers of children with DS, through a mixed-methods approach. The main part of the study took place through quantitative questionnaires administered to 125 caregivers in the Galle district, with some additional qualitative insights provided through 10 open-ended interview questions for a randomly selected subset of the overall quantitative sample population.

### **2.1 Setting**

#### **2.1.1 Galle, Sri Lanka**

This study took place in the Galle District in Sri Lanka which lies along Sri Lanka's southern-most coast. Given that no previous research had been conducted with individuals with Down Syndrome and/or their caregivers in the area, there was a lack of institutional materials that outlined DS prevalence in the region. In lieu of this information, we estimated the prevalence of DS within the area. With a district population of over 1.075 million and WHO estimations of the global prevalence of DS to be approximately 1 in 1,000, we estimated that there were approximately 1,075 individuals of varying ages who have DS within the Galle District ("WHO | Genes and human disease," n.d.). Utilizing a demographic population pyramid of the country, we estimated that of the estimated 1,075

individuals with DS in the area, 258 were children between the ages of 0 – 14 years of age. It is estimated that 24.06% of Sri Lanka’s population is between the ages of 0 to 14 years of age (Central Intelligence Agency, 2018).



**Figure 6:** Demographic histogram of population in Sri Lanka for 2016 (Source: (Central Intelligence Agency, 2018))

## 2.1.2 University of Ruhuna

This study was conducted through the Faculty of Medicine at the University of Ruhuna located in Karapitiya, a city within the Galle District. Members of the university were instrumental in the identification of possible recruitment sites, outreach to local

schools and organizations, data collection and data storage. All data collected within this study was safely and securely stored within the university's Department of Community Health unit.

### **2.1.3 Data Collection Sites**

Within the Galle District, there were three types of schools which our participants' children could possibly attend. Children with DS attend either standardized schools in standardized classes, standardized schools in special needs classes, special needs schools for children of varying developmental and physical disabilities or no school at all. We recruited caregivers who had children with DS who attended each of these types of schools or no school at all. We also utilized word-of-mouth, special needs drop-in centers and social services in district divisions to reach out to caregivers of children with DS who do not attend school.

## **2.2 Participants**

Our study's target population was primary caregivers of school-age children with DS between the ages of 5 and 12. While our teams actively recruited study participants from schools, we did not exclude children with DS who may not be attending school from participating, as we felt that they represented an important demographic when it came to analyzing access and use of resources for children with DS. We believed that they may receive less information regarding available support services for children with DS. As a

result, we wanted to ensure that the experiences of these individuals were incorporated into the study. To further achieve this, questions regarding school attendance (both previous attendance throughout childhood and current attendance for the current school year) were incorporated and analyzed in the survey. We got in contact with social services officers to recruit caregivers of children who are no longer students to reach out to them about participating in this survey as well.

Our inclusion/exclusion criteria were based upon a previous similar study regarding caregiver burden in the area of caregivers with children who had cerebral palsy (Wijesinghe et al., 2014). One primary caregiver per child with DS was recruited. Caregivers must have lived within the Galle District for at least 6 months (in order to have had enough time within the area to potentially access or seek out resources for people with DS); be able to speak, read, and understand Sinhala or English; and have additional caregiving responsibilities associated with caregiving for the child with DS that lie outside of the routine scope of caring for a child without DS (i.e. attending to specific needs of a child with a disability) (Wijesinghe et al., 2014). Of the 125 caregivers recruited, we aimed to have 75 caregivers of children who attended special classes at regular schools; 25 to be from designated special schools; and 25 to not be currently attending school. All participants were made aware of the purpose of the survey and interview both verbally



and in writing prior to their participation in the study. Both verbal and written consent was obtained at the time of meeting to conduct the survey, prior to their participation.

### **2.3 Procedures**

For this mixed methods, cross-sectional study, we used two methods of data collection. We first created a questionnaire by amalgamating questions from two pre-existing surveys. These surveys were utilized in conjunction with demographic and additional questions of interest regarding the availability of medical, rehabilitative (physical and cognitive), respite, counselling, and other resources. Upon receiving ethical clearance for the study from the Ethical Review Committee in Sri Lanka and the Arts & Sciences Institutional Review Board (IRB) at Duke University in Durham, North Carolina, we had the survey and interview questions translated into Sinhala by a local translator who was hired through the University of Ruhuna's Department of Community Health.

To recruit participants, we partnered with faculty members of the University of Ruhuna's Medical Faculty. Faculty at the University of Ruhuna have close ties to the schools within the Galle District given the university's proximity and reputation. As such, members of the faculty assisted with recruitment prior to our arrival in Sri Lanka. They contacted the Director of Special Needs for the district to obtain permission to pursue this study in the region through the recruitment of caregivers into the study. They also acted as point-people to apply for and receive Ethical Review Committee approvals within the district at

the local level, through the University of Ruhuna. Upon receiving these permissions, faculty and two hired research assistants at the University of Ruhuna visited public-general and disability-specific schools and centers for children with disabilities to speak to school and center heads to receive permission to access, solicit and recruit primary caregivers of students with DS at the schools into the study. Research assistants obtained permission to send letters home about the study with students with DS to notify and solicit caregivers. The letters clearly stated that caregivers would only need to complete a brief survey with one of our research enumerators and would be financially compensated for their time with a payment of 700 rupees. Interested caregivers were contacted and followed-up with on subsequent visits to the schools and care centers before and after school by our researchers, who scheduled times to meet to conduct the surveys. We aimed to have a sample size of 125 caregivers.

The primary caregivers who were responsible for the drop off and pick-up of each student at the school were approached and contacted in subsequent weeks by our research assistants in person. In order to additionally recruit caregivers of school-age children with DS who may not attend school, members at the university contacted the local social services officer within the district division to research whether there are children with Down Syndrome who were not currently attending school. Caregivers of children who were not attending school were also recruited through centers for children

with disabilities during day programs. The social services officer or head of the day programs gave eligible caregivers a memo containing our contact information and information regarding the study.

Upon contacting the team and scheduling an interview, our enumerators who were native Sri Lankans and spoke Sinhalese visited the caregivers at the schools, special needs centers or at their homes (based on what was agreed upon) and explained the intent and merits of the questionnaire orally to each participant prior to receiving their informed written and verbal consent. Once informed consent was received, enumerators orally asked caregivers the survey questions and recorded their responses. Amongst survey participants, 15 caregivers were later selected based upon the type of school their child attended and survey responses regarding having varying levels of difficulty accessing social supports and external services. This selected group of caregivers was asked if they wished to participate in an additional one-hour interview portion where they would be asked to elaborate on their experiences caregiving for a child with DS and accessing resources through an approximately hour-long interview with the enumerator. Participants of the interviews were compensated with an additional 700 rupees for their time and responses. When a survey participant declined participation in the interview portion, enumerators went back to the database and randomly selected another willing participant to meet the target of 15 interviews. Interviews were conducted after the

completion of surveys, and took special care to include a purposive sample that was representative of the varying ages, academic and socioeconomic backgrounds of caregivers and their children which were represented within the study. Data from the paper surveys were inputted into REDCap within a week of data collection, and were visually checked a second time to ensure the accuracy of the information entered. Written notes from the interviews were recorded into Microsoft Word.

Within this study, we aimed to recruit 125 caregivers to participate in the quantitative survey portion. We aimed to recruit approximately 75 caregivers of children in special programs at regular schools; 25 from caregivers of children in special schools; and approximately 25 caregivers of children who were no longer attending school. Amongst those who were contacted, a random sample was asked to participate in a subsequent interview portion consisting of 10 open-ended questions. We aimed to recruit 15 participants in the qualitative interview portion and randomly chose participants based on distinct characteristics that were highlighted in the surveys, with the intent of representing a diverse array of experiences and backgrounds. If someone who was randomly selected refused to participate in the interview, we randomly selected and asked another caregiver to participate in the interviews.

## **2.4 Measures**

For the survey, we included scales and subsections of the Caregiver Priorities and Child Health Index of Life with Disabilities (CP-CHILD) questionnaire by healthcare professionals from the Hospital for Sick Kids and The Bloorview Research Institute in Toronto, and the Caregiver Difficulties Scale (CDS) by researchers at the University of Ruhuna, Galle. Between our aims, the independent and dependent variables sometimes shifted. However, in general, our independent variable was the demographic characteristics of the population for both caregivers and children with DS. Our dependent variables were the overall and sub-scale scores generated from the CP-CHILD and CDS surveys.

### **2.4.1 CP-CHILD Assessment**

Children were classified in term of DS severity based upon the caregiver's assessment of child ability through the CP-CHILD assessment, which when summarized provided continuous variables (based on one overall mean score and four subscale mean scores). Within the CP-CHILD section of the assessment, caregivers were asked to rank their children's abilities, emotions and health conditions on either frequency or feeling Likert scales in four topics: Personal Care/Activities of Daily Living; Comfort and Emotions; Communication and Social Interaction; and Health (Narayanan et al., 2006). For each question, raw scores were later translated into a scale ranging from 0 (worst

outcome) to 100 (best outcome) through dividing the raw score for each question out of the highest possible ranking for that question and multiplying by 100. (Narayanan, Weir, & Fehlings, 2007). The scores for each subset of questions were later aggregated into the aforementioned sections and a final total score by finding the arithmetic mean of scores for questions per each participant. A final total score and subscale score was later generated by finding the arithmetic mean of each participants mean total and sub-scale scores.

The mean data from this aspect of the study was regressed against demographic and resource access/knowledge questions to determine relationships between the level of disability in the child and particular demographic and resource access information. Given that the CP-CHILD is a particularly long assessment designed for varying disabilities, the set of questions employed within our study was shortened and amended from its original form for relevance within our study to reflect the needs and characteristics of children with DS specifically. One prominent change between the CP-CHILD survey we used was the removal of the 'Mobility' section, for which questions were not felt to be particularly relevant to children with DS by our team. We assessed whether the children had functional deficits, including the presence of hearing or visual problems, learning difficulties, seizures, communication, emotional and behavioral problems (Wijesinghe et

al., 2014). These responses were regressed against the dependent variable of burden of care experienced by the caregiver.

#### **2.4.2 CDS Assessment**

Caregiver burden was also measured through the CDS assessment. This assessment asked a series of 25 questions associated with “concern for the child”, “impact on self”, “support for caregiving”, and “social and economic strain”, which participants ranked on a 5-point Likert scale (0-4) for frequency (Wijesinghe et al., 2014). These scores were later totaled into final scores ranging from 0 to 100, where 0 was the best possible scenario with minimal burden and 100 was the worst with high caregiver burden. A final overall aggregate score for all participating caregivers was calculated for overall caregiver burden of all participants within our study by calculating the arithmetic mean of all CDS scores.

Based upon the identified resources for children with DS and caregivers, and the self-reported information regarding usage of the services or infrastructure, correlations were analyzed to determine whether existing resources were being utilized and accessed through later regressions with CDS and CP-CHILD scores and general demographic information. The usage of services and infrastructure were assessed through a series of yes or no questions that asked specifically about resource usage based on varying types and focused on support services (i.e. medical, rehabilitative - physical, rehabilitative-

cognitive/mental, respite, family and neighbor support, counselling, etc.). When a participant answered 'yes' to any of these questions, further questions were asked in regards to the frequency and levels of support utilized for that particular support service.

## **2.5 Analysis**

For this study, we utilized a sample size calculator as provided by my mentor, Dr. Truls Østbye. In order to have a study with a 95% confidence interval, with a confidence margin of 10 for the number of children with DS currently enrolled in school, we required a sample size of at least 88 caregivers. Subsequently, we aimed to recruit 125 caregivers to maintain for plausible participant drop-out (attrition). We chose a slightly larger margin of error as a result of limited time, funds and resources. In order to account for possible drop-out or refusal to do the survey by caregivers after enrolling in the study and other forms of plausible attrition, we sought to recruit a minimum starting sample size of 125.

We utilized STATA to analyze the data. Descriptive statistics including mean, standard deviation, minimums and maximums for the child and caregiver demographics, child disability level, caregiver burden level and resource usage sections were first generated. For categorical variables, raw data frequencies and percentages were analyzed and recorded. Following this, the scores for CP-CHILD and CDS were calculated per participant and aggregated to find overall subsection and total means, standard deviation, and minimum and maximum values. For each question on CP-CHILD and CDS, raw



scores for each question were converted to be out of 100, and a mean of the responses to each question was aggregated and determined. Following this, we stratified our child and caregiver demographic information against CP-CHILD and CDS scores to analyze for any particular relationships or demographic indicators of level of child disability or caregiver burden through generating simple bivariate regressions and standard deviations. Variables that yielded significant associations were then taken and tested in multivariable regressions to analyze the effect on CP-CHILD and CDS scores. CP-CHILD and CDS scores were also regressed against each other to determine if there were relationships between the child's level of disability and the level of burden faced by caregivers.

Furthermore, to describe and summarize our independent variables (the characteristics of the sample population of caregivers and children with DS), we used STATA to find descriptive statistics to summarize and generate an understanding of the average characteristics of the sample. After pursuing research and using descriptive statistics of the overall data and questions, we performed simple bivariate and multivariable regression analysis at significance levels of 0.05 to understand, determine, and analyze possible correlations that may exist between particular characteristics of varying levels of disability amongst children with DS, caregiver attributes and burden, and the usage, accessibility and desire of support services for children with DS and caregivers. We analyzed whether the access of particular kinds of support services [i.e.

medical, rehabilitative (physical and cognitive), respite, counselling, and other resources] correlated with particular characteristics of children with DS and their caregivers. Following a study of sub-categorical means, demographic information was regressed against CDS and CP-CHILD values at a significance level of 0.05.

Qualitative information was analyzed separately. Results of each interview were aggregated into Microsoft Excel, and responses for each question were individually analyzed to look for trends or key reoccurring words or phrases. Utilizing this information, per question summaries were drafted and later revisited to determine recurring themes or words across questions. A subsequent summary section was drafted to highlight the cross-sectional trends.

### 3. Results

#### 3.1 Participant Characteristics

Study participant characteristics for children with DS are presented in Table 1 and Table 2. Ultimately within this study, we recruited the caregivers of 125 children, of which 50.4% of children were male. The mean age of participants was  $8.4 \pm 2.2$  years and the ages ranged from 5 to 12 years old. Of the caregivers surveyed, 18.4% had children who never attended school, 5.6% were currently non-schooling and 76% were attending school at levels of pre-school and higher. The majority of children (88%) did not identify with a standardized school grade and most attended either a special class in a general school (38.5%) or a special school (32.8%) for children with disabilities. On average children had attended  $1.4 \pm 0.9$  years of school at the time of the survey, with a range of 0 to 8 years. Children with DS had on average  $1.4 \pm 0.9$  siblings, with a range of 0 to 4, and the majority (91%) were first- or second-born in the family.

Table 1: Child demographics: Descriptive statistics

Variable	Frequency	%	Mean (SD)	(Min, Max)
<b>Sex (n=125)</b>				
Male	63	50.40		
Female	62	49.60		
<b>Child Age (n=125)</b>			8.424 (2.164)	(5, 12)
5	14	11.20		
6	18	14.40		
7	15	12.00		
8	13	1.40		
9	17	13.60		
10	23	18.40		
11	17	13.60		
12	8	6.40		

<b>Educational Status (n=125)</b>				
Never schooled	23	18.40		
Currently non-schooling	7	5.60		
Attending preschool	5	4.00		
Attending school	90	72.00		
<b>Variable</b>	<b>Frequency</b>	<b>%</b>	<b>Mean (SD)</b>	<b>(Min, Max)</b>
N/A	110	88.00		
1 <sup>st</sup> grade	8	6.40		
2 <sup>nd</sup> grade	3	2.40		
3 <sup>rd</sup> grade	2	1.60		
4 <sup>th</sup> grade	1	0.80		
5 <sup>th</sup> grade	1	0.80		
<b>School Type (n=122)</b>				
Not applicable	29	23.77		
General school – general class	6	4.92		
General school – special class	47	38.52		
Special school	40	32.79		
<b>Number of School Years Attended (n=122)</b>				
			1.950 (1.770)	(0, 8)
0	26	21.49		
1	37	30.58		
2	15	12.40		
3	21	17.36		
4	13	10.74		
5	5	4.13		
6	1	0.83		
7	1	0.83		
8	2	1.65		
<b>Siblings (n=125)</b>				
			1.424 (0.927)	(0,4)
0	18	14.40		
1	55	44.00		
2	34	27.20		
3	17	13.60		
4	1	0.80		
<b>Birth Order (n=125)</b>				
			2.016 (0.907)	(1,4)
1	41	32.80		
2	50	40.00		
3	25	20.00		
4	9	7.20		

Children within the survey had a variety of co-morbidities. Of those surveyed, about

one-fifth (18.4%) of children had some form of a cardiovascular comorbidity, with the majority suffering from atrial septal defect (65.2%). A smaller portion (5.6%) of children had respiratory comorbidities such as wheezing and bronchial asthma. About one-quarter (25.6%) of children suffered from gastrointestinal comorbidities such as cholecystitis and reverse colostomy. Almost half (49.6%) of all children suffered from some other comorbidity that wasn't cardiovascular, respiratory or gastrointestinal-related. Common issues included difficulty speaking (7.2%), difficulty walking (7.2%), epilepsy and seizures (4.8%), and vision problems (1.6%). A small portion (2.4%) of caregivers reported that their children had more than one comorbidity.

**Table 2: Child's co-morbidities: Prevalence**

<b>Variable</b>	<b>Frequency</b>	<b>%</b>
<b>Cardio Comorbidities (n=125)</b>		
Yes	36	28.80
<b>Type of Cardio Comorbidity (n=23)</b>		
Atrial Septal Defect	15	65.22
Ventricular Septal Defect	3	13.04
Patent Ductus Arteriosus	1	4.35
More than one cardio comorbidity	4	17.39
<b>Respiratory Comorbidities (n=125)</b>		
Yes	7	5.60
<b>Type of Respiratory Comorbidity (n=4)</b>		
Wheezing	3	75.00
Bronchial Asthma	1	25.00
<b>Gastrointestinal Comorbidities (n=125)</b>		
Yes	32	25.60
<b>Type of Gastrointestinal Comorbidity (n=2)*</b>		
Cholecystitis	1	50.00
Reverse Colostomy	1	50.00
<b>Other Comorbidities (n=125)</b>		
Yes	62	49.60
<b>Types of Other Comorbidities (n=32)</b>		

Difficulty speaking	9	28.12
Difficulty walking	9	28.12
Reduced hearing	1	3.12
Epilepsy and seizures	6	18.75
Vision problems	2	6.25
Kidney problems	1	3.12
Hypothyroidism	1	3.12
More than one comorbidity	3	9.38

\*Only 2 of the 32 caregivers who responded 'yes' to GI comorbidities specified their child's medical conditions.

Table 3 features the study participant characteristics of caregivers who were surveyed. The majority (83.2%) of caregivers surveyed were female. On average, caregivers were  $46.7 \pm 8.8$  years old at the time of the survey with a range of 18.6 to 76.0 years. Caregivers had a mean age of  $37.9 \pm 8.9$  years at the time of their child's birth. The majority (90.4%) of caregivers surveyed were married and almost all (96%) were the biological parent of the child with DS. Three-quarter (75.2%) of caregivers and their children resided in a nuclear family structure.

Approximately one-third (32%) of caregivers were unemployed as a result of their child's health status and 40% self-identified as homemakers. Of those surveyed, only 27.2% of caregivers worked either full-or part-time in or out of the home. Two-fifths (40.8%) of caregivers reached an ordinal level of education and 29.6% of caregivers reported having attained either a post-high school diploma or having attained an advanced level in their education, but only 5.6% reported receiving a degree or diploma beyond high school. Half (50.4%) of those surveyed earned between 5,001 to 20,000 rupees per month, and a little more than one-tenth (13.6%) earned less than 5,000 rupees per

month with a marginal fraction (1.6%) bringing in over 50,000 rupees per month in income. On average, caregivers reported to spending time doing caregiving activities for at least  $18.8 \pm 6.9$  hours per day on weekdays (ranging from 3 to 24) and  $20.9 \pm 5.5$  hours per day on weekend days (ranging from 0 to 24).

**Table 3: Caregiver demographics: Descriptive statistics**

Variable	Frequency	%	Mean (SD)	(Min, Max)
<b>Sex (n=125)</b>				
Male	21	16.80		
Female	104	83.20		
<b>Age at Birth of Child (n=125)</b>			37.9 (8.9)	(9.0, 64.4)
<30	29	23.20		
31-40	53	42.40		
>40	43	34.40		
<b>Age on Date of Survey (n=125)</b>			46.7 (8.8)	(18.9, 76.0)
<30	5	4.00		
31-40	23	18.40		
>40	97	77.60		
<b>Work Status (n=125)</b>				
Unemployed (due to child's health)	40	32.00		
Unemployed (for other reasons)	0	0.00		
Searching for a job	0	0.00		
Working full- or part-time (outside the house)	26	20.80		
Working full- or part-time (at a home-based business)	9	7.20		
Homemaker	50	40.00		
<b>Marital Status (n=125)</b>				
Single	2	1.60		
Married	113	90.40		
Widowed	5	4.00		

Divorced/Separated	5	4.00		
<b>Relation to Child (n=125)</b>				
Biological parent	120	96.00		
Adoptive parent	1	0.80		
Other	4	3.20		
<b>Family type (n=125)</b>				
Nuclear family	94	75.20		
Three generation family	17	13.60		
Extended family	14	11.20		
<b>Weekday Caregiving Hours (n=124)</b>			18.8 (6.8)	(3,24)
0 to 8	21	16.94		
7 to 16	16	12.90		
17 to 24	87	70.16		
<b>Weekend Caregiving Hours (n=124)</b>			20.9 (5.5)	(0,24)
0 to 8	6	4.84		
7 to 16	17	13.71		
Variable	Frequency	%	Mean (SD)	(Min, Max)
17 to 24	101	81.45		
<b>Education Level (n=125)</b>				
No school	2	1.60		
Below grade 5	7	5.60		
Fifth to tenth grade	21	16.80		
Up to ordinal level	51	40.80		
Post-high school diploma or up to advanced level	37	29.60		
Degree or diploma	7	5.60		
<b>Monthly Income (in rupees) (n=125)</b>				
Less than 5,000	17	13.60		
5,001 - 20,000	63	50.40		
20,001 - 35,000	24	19.20		
35,001 - 50,000	19	15.20		
Over 50,000	2	1.60		
<b>AGA Electorate Division (n=122)</b>				
Four Gravets	7	5.74		
Akmeemana	16	13.11		
Ambalangoda	1	0.82		
Baddegama	17	13.93		
Bope Poddala	11	9.02		
Diwithura	10	8.20		
Galle	7	5.74		
Gonapinawala	17	13.93		
Habaraduwa	1	0.82		



Hikkaduwa	22	18.03
Nagoda	5	4.10
Poddala	1	0.82
Thalapitiya	1	0.82
Wanduraba	1	0.82
Weligama	1	0.82
Yakkalamulla	4	3.28

### **3.2 Aim 1: Child Demographics and Level of Disability (CP-CHILD)**

Table 4 depicts the findings of the mean CP-CHILD scores which described the level of disability amongst school-aged children with Down Syndrome. The CP-CHILD assessment ranges in score from 0 to 100, with larger values being associated with lower-levels of child disability. The overall mean level of child disability as assessed by CP-CHILD was 64.8 with sub-scores of 59.6 for personal care and activities of daily living; 68.4 for comfort and emotions; 68.4 for communication and social interaction; and 47.8 for health.

**Table 4: Level of disability amongst school-aged children with Down Syndrome, as assessed by CP-CHILD**

<b>CP-CHILD Category</b>	<b>Mean (SD)</b>	<b>(Min., Max.)</b>
Overall Score	64.8 (13.5)	(22.4, 86.4)
Personal Care/Activities of Daily Living (ADL)	59.6 (27.3)	(0, 100)
Comfort and Emotions	68.4 (11.1)	(11.1, 85.7)
Communication and Social Interaction	68.4 (11.1)	(11.1, 85.7)
Health	47.8 (9.1)	(26.7, 66.7)

Table 5 demonstrates simple linear bivariate regressions of the level of disability amongst school-aged children with DS against possible child demographic predictors of

that relationship, stratified by overall and sub-scores for the CP-CHILD assessment. Through the regressions, the model intercept remained relatively similar to the overall scores displayed in Table 4. Beta coefficients were generated that represent mean differences from the model intercept per level of each particular variable. There was a significant relationship between children with DS attending school and the overall CP-CHILD score ( $B = 15.3, p < 0.05$ ), CP-CHILD personal care/ADL sub-score ( $B = 31.7, p < 0.05$ ) and communication and social interaction sub-score ( $B = 15.1, p < 0.05$ ). There was also a significant relationship between children who were non-schooling and/or attending pre-school and the CP-CHILD communication and social interaction sub-score ( $B = 10.9, p < 0.05$ ). The non-schooling and attending pre-school groups were combined to form one group since each group individually was too small to assess.

The type of school that children attended was also significantly associated with CP-CHILD overall, personal care/ADL and communication and social interaction scores. Children attending general classes in general schools had significant associations with the CP-CHILD overall score ( $B = 17.7, p < 0.05$ ), personal care/ADL ( $B = 33.2, p < 0.05$ ), and communication and social interaction ( $B = 13.0, p < 0.05$ ). Overall CP-CHILD score ( $B = 13.4, p < 0.05$ ), personal care/ADL ( $B = 28.7, p < 0.05$ ) and communication and social interaction ( $B = 13.1, p < 0.05$ ) scores were significantly associated children who attended special classes in general schools. Attendance in special schools was significantly associated with CP-

CHILD overall score ( $B=12.8, p<0.05$ ), personal care and activities of daily living ( $B=27.3, p<0.05$ ), and communication and social interaction ( $B=12.1, p<0.05$ ).

Female caregivers had significant associations with the overall CP-CHILD score ( $B=7.5, p<0.05$ ), personal care/ADL ( $B=14.5, p<0.05$ ) and communication and social interaction ( $B=6.2, p<0.05$ ). Working outside the home was significantly associated with personal care/ADL ( $B=13.4, p<0.05$ ) and communication and social interaction scores ( $B=6.0, p<0.05$ ). Moreover, caregivers working full- or part-time at home-based businesses had significant relationships with CP-CHILD overall ( $B=10.3, p<0.05$ ), personal care/ADL ( $B=23.0, p<0.05$ ), and communication and social interaction ( $B=8.3, p<0.05$ ) scores. Caregivers who self-identified as homemakers were significantly associated with all of the CP-CHILD measurements including: overall ( $B=5.6, p<0.05$ ), personal care/ADL ( $B=13.4, p<0.05$ ), communication and social interaction ( $B=6.8, p<0.05$ ), and health ( $B=-5.3, p<0.05$ ). There was a significant relationship between unmarried or separated caregivers and the health sub-score ( $B=5.5, p<0.05$ ).

Caregiver's education levels were significantly associated with CP-CHILD scores. In particular, caregivers who had a fifth to tenth grade highest educational status experienced significant associations with the CP-CHILD sub-scores of comfort and emotions ( $B=-12.2, p<0.05$ ) and communication and social interaction ( $B=13.5, p<0.05$ ). Caregivers who had studied up to an ordinal level were significantly associated with the

overall CP-CHILD score ( $B=12.9, p<0.05$ ), personal care/ADL ( $B=27.0, p<0.05$ ), comfort and emotions ( $B=-9.4, p<0.05$ ) and communication and social intervention ( $B=15.2, p<0.05$ ).

Finally, caregiver income levels were also significantly associated with different aspects of the level of disability of the child. In particular, for caregiver's who had a monthly income level of 5,001 to 20,000 rupees, there was a significant associations with communication and social interaction scale ( $B=7.5, p<0.05$ ). Families with monthly incomes between 20,001 to 35,000 rupees, significant associations were found with the overall CP-CHILD score ( $B=11.4, p<0.05$ ), personal care/ADL ( $B=27.2, p<0.05$ ), communication and social intervention ( $B=12.1, p<0.05$ ), and health ( $B=-7.0, p<0.05$ ). Families with monthly incomes exceeding 35,001 rupees per month were also significantly associated with the same four categories: overall CP-CHILD score ( $B=9.8, p<0.05$ ); personal care and activities of personal living ( $B=22.7, p<0.05$ ); communication and social interaction scale ( $B=11.9, p<0.05$ ); and health ( $B=-5.8, p<0.05$ ).

Variables which were found to have significant associations with the CP-CHILD assessment were further analyzed together within linear multivariable regression models to analyze their joint effects on overall CP-CHILD scores in Table 6. Models first assessed only educational status, with subsequent regressions adding on school type, caregiver gender, caregiver work status, caregiver education level and income level. The model intercept progressively declined from 65.4 in the education status only model to 29.1 as

more variables were added into the model. In the final model, both caregiver gender and child's school type were significantly associated with higher CP-CHILD scores. Both caregiver gender and child's school type consistently held significant positive associations with CP-CHILD scores throughout the multivariable regressions. After adjusting for the child's educational status, we found that school type, caregiver gender and caregiver work status were positively associated with lower levels of disability in children.

Table 5: Association between child demographics and level of disability of the child: simple linear regression analysis

	CPCHILD Overall Score	CPCHILD Personal Care/Activities of Daily Living	CPCHILD Comfort and Emotions	CPCHILD Communication and Social Interaction	CPCHILD Health
	Coefficient (95% CI)	Coefficient (95% CI)	Coefficient (95% CI)	Coefficient (95% CI)	Coefficient (95% CI)
<b>Child's Gender (n=125)</b>					
Male (REF)	64.4 (61.0, 67.8)	59.7 (52.8, 66.6)	77.5 (74.4, 80.7)	68.9 (66.1, 71.6)	46.3 (44.1, 48.6)
Female	0.9 (-3.9, 5.7)	-0.1 (-9.8, 9.6)	3.7 (-0.7, 8.2)	-0.8 (-4.8, 3.1)	3.0 (-0.2, 6.2)
<b>Child's Age (n=125)</b>					
5 (REF)	62.1 (54.9, 69.3)	50.8 (36.5, 65.0)	80.5 (73.7, 87.3)	68.4 (62.5, 74.3)	50.5 (45.6, 55.4)
6	-0.7 (-10.3, 8.9)	0.4 (-18.6, 19.4)	-4.6 (-13.6, 4.5)	1.9 (-6.0, 9.8)	-3.4 (-9.9, 3.1)
7	-1.8 (-11.8, 8.2)	-3.8 (-23.6, 16.1)	0.9 (-8.6, 10.3)	-1.5 (-9.8, 6.7)	-1.1 (-7.9, 5.6)
8	5.3 (-5.1, 15.7)	16.7 (-3.8, 37.3)	-2.5 (-12.3, 7.3)	0.3 (-8.2, 8.8)	-4.3 (-11.4, 2.7)
9	4.5 (-5.2, 14.2)	15.2 (-4.0, 34.5)	-0.1 (-9.3, 9.1)	-2.1 (-10.1, 5.9)	-4.6 (-11.2, 2.0)
10	5.3 (-3.8, 14.4)	13.2 (-4.9, 31.3)	-0.8 (-9.4, 7.9)	2.6 (-4.9, 10.1)	-2.1 (-8.3, 4.1)
11	4.5 (-5.2, 14.2)	14.9 (-4.3, 34.1)	0.3 (-8.9, 9.5)	-3.1 (-11.1, 4.9)	-1.8 (-8.4, 4.7)
12	5.5 (-6.5, 17.4)	15.2 (-8.5, 38.8)	-2.1 (-13.4, 9.1)	2.8 (-7.0, 12.6)	-4.6 (-12.7, 3.4)
<b>Educational Status (n=125)</b>					
Never schooled (REF)	53.2 (48.2, 58.2)	35.7 (25.7, 45.8)	82.3 (77.1, 87.5)	56.5 (52.6, 60.4)	49.6 (45.8, 53.3)
Currently non-schooling AND/OR Attending preschool	6.1 (-2.5, 14.6)	11.5 (-5.7, 28.6)	-7.3 (-16.1, 1.5)	10.9 (4.2, 17.6)**	1.0 (-5.4, 7.4)
Attending school	15.3 (9.7, 20.9)**	31.7 (20.4, 42.9)**	-3.1 (-8.9, 2.8)	15.1 (10.7, 19.5)**	-2.5 (-6.7, 1.7)

	CPCHILD Overall Score	CPCHILD Personal Care/Activities of Daily Living	CPCHILD Comfort and Emotions	CPCHILD Communication and Social Interaction	CPCHILD Health
	Coefficient (95% CI)	Coefficient (95% CI)	Coefficient (95% CI)	Coefficient (95% CI)	Coefficient (95% CI)
<b>Child Grade (n=125)</b>					
2nd grade	-3.7 (-19.7, 12.2)	-5.5 (-37.6, 26.6)	-1.9 (-16.6, 12.9)	-4.8 (-17.7, 8.2)	0.8 (-9.8, 11.5)
3rd grade	8.0 (-11.4, 27.4)	18.5 (-20.6, 57.7)	7.0 (-11.0, 25.0)	2.0 (-13.8, 17.8)	-8.1 (-21.0, 4.9)
4th grade	6.4 (-21.0, 33.7)	13.0 (-42.1, 68.1)	0.4 (-25.0, 25.7)	5.6 (-16.7, 27.8)	-1.4 (-19.7, 16.9)
5th grade	-2.5 (-29.8, 24.8)	-9.2 (-64.3, 45.9)	7.0 (-18.3, 32.4)	-4.0 (-26.2, 18.3)	5.3 (-13.0, 23.5)
<b>School Type (n=122)</b>					
Not applicable (REF)	54.7 (50.1, 59.2)	38.1 (29.0, 47.2)	81.3 (76.8, 86.0)	58.8 (55.2, 62.4)	50.1 (46.8, 53.4)
General school - general class	17.7 (6.6, 28.7)**	33.2 (11.1, 55.2)**	4.2 (-7.0, 15.3)	13.0 (4.3, 21.8)**	4.3 (-3.7, 12.4)
General school - special class	13.4 (7.6, 19.2)**	28.7 (17.1, 40.3)**	-3.5 (-9.4, 2.3)	13.1 (8.5, 17.7)**	-3.7 (-8.0, 0.5)
Special school	12.8 (6.8, 18.8)**	27.3 (15.4, 39.3)**	-2.5 (8.6, 3.5)	12.1 (7.3, 16.9)**	-3.3 (-7.7, 1.1)
<b>Caregiver Gender (n=125)</b>					
Male (REF)	58.6 (52.8, 64.3)	47.6 (36.0, 59.2)	78.1 (72.6, 83.6)	63.3 (58.6, 68.0)	47.9 (44.0, 51.9)
Female	7.5 (1.3, 13.8)**	14.5 (1.7, 27.2)**	1.6 (-4.4, 7.6)	6.2 (1.1, 11.4)**	-0.1 (-4.4, 4.2)
<b>Caregiver Age at Birth of Child (n=125)</b>					
<30 (REF)	64.3 (59.3, 69.3)	57.9 (47.8, 67.9)	82.1 (77.4, 86.7)	66/1 (62.0, 70.2)	49.7 (46.3, 53.0)
31-40	-0.3 (-6.5, 5.9)	-0.1 (-12.6, 12.4)	-3.3 (-9.1, 2.4)	2.6 (-2.5, 7.7)	-2.5 (-6.6, 1.7)
>40	2.0 (-4.4, 8.5)	5.3 (-7.7, 18.4)	-3.6 (-9.6, 2.4)	3.6 (-1.6, 8.9)	-2.2 (-6.5, 2.1)

	CPCHILD Overall Score	CPCHILD Personal Care/Activities of Daily Living	CPCHILD Comfort and Emotions	CPCHILD Communication and Social Interaction	CPCHILD Health
	Coefficient (95% CI)	Coefficient (95% CI)	Coefficient (95% CI)	Coefficient (95% CI)	Coefficient (95% CI)
<b>Caregiver Work Status (n=125)</b>					
Unemployed (due to child's health) (REF)	60.6 (56.4, 64.8)	49.9 (41.5, 58.2)	81.7 (77.7, 85.6)	63.7 (60.3, 67.0)	50.5 (47.7, 53.3)
Working full- or part-time (outside the house)	6.1 (-0.6, 12.7)	13.4 (0.1, 26.7)**	-2.9 (-9.3, 3.4)	6.0 (1.6, 12.2)**	-2.8 (-7.2, 1.6)
Working full- or part-time (at a home-based business)	10.3 (0.6, 20.0)**	23.0 (3.5, 42.5)**	-3.9 (-13.1, 5.4)	8.3 (0.5, 16.1)**	0.6 (-5.9, 7.1)
Homemaker	5.6 (0.0, 11.2)**	13.4 (2.2, 24.6)**	-3.4 (-8.7, 1.9)	6.8 (2.3, 11.3)**	-5.3 (-9.0, -1.6)**
<b>Caregiver Marital Status (n=125)</b>					
Married (REF)	64.7 (62.2, 67.2)	59.5 (54.4, 64.6)	78.9 (76.5, 81.2)	68.7 (66.6, 70.7)	47.3 (45.6, 49.0)
Single/Widowed/Divorced/Separated	1.6 (-6.6, 9.7)	1.1 (-15.4, 17.6)	5.6 (-2.0, 13.1)	-2.4 (-0.1, 4.3)	5.5 (0.1, 10.9)**
<b>Caregiver Education Level (n=125)</b>					
Less than grade 5 (REF)	54.5 (45.9, 63.1)	38.3 (20.9, 55.6)	87.4 (79.2, 95.6)	55.8 (49.0, 62.6)	45.2 (39.2, 51.2)
Fifth to tenth grade	7.1 (-3.1, 17.4)	14.6 (-6.1, 35.4)	-12.2 (-21.9, -2.4)**	13.2 (5.1, 21.4)**	2.4 (-4.8, 9.6)
Up to ordinal level	12.9 (3.6, 22.1)**	27.0 (8.2, 45.8)**	-9.4 (-18.2, -0.5)**	15.2 (7.8, 22.6)**	2.0 (-4.5, 8.5)
Post-high school diploma or up to advanced level	9.2 (-0.4, 18.7)	19.0 (-0.4, 38.3)	-6.7 (-15.8, 2.4)	10.4 (2.8, 18.0)**	3.5 (-3.2, 10.2)
Degree or diploma	21.5 (8.6, 34.5)**	41.1 (14.9, 67.3)**	-2.6 (-15.0, 9.7)	19.7 (9.4, 30.0)**	7.2 (-1.0, 16.3)
<b>Caregiver Income Level (n=125)</b>					
Less than 5,000 (REF)	58.0 (51.7, 64.4)	44.8 (32.2, 57.3)	83.1 (77.1, 89.1)	60.4 (55.3, 65.4)	50.6 (46.4, 54.8)



	<b>CPCHILD Overall Score</b>	<b>CPCHILD Personal Care/Activities of Daily Living</b>	<b>CPCHILD Comfort and Emotions</b>	<b>CPCHILD Communication and Social Interaction</b>	<b>CPCHILD Health</b>
	<b>Coefficient (95% CI)</b>	<b>Coefficient (95% CI)</b>	<b>Coefficient (95% CI)</b>	<b>Coefficient (95% CI)</b>	<b>Coefficient (95% CI)</b>
5,001 - 20,000	5.9 (-1.2, 13.1)	11.6 (-2.6, 25.8)	-2.4 (-9.2, 4.4)	7.5 (1.8, 13.2)**	-0.9 (-5.6, 3.9)
20,001 - 35,000	11.4 (3.1, 19.7)**	27.2 (10.8, 43.7)**	-7.0 (-14.9, 0.8)	12.1 (5.5, 18.6)**	-7.0 (-12.5, -1.5)**
Over 35,001	9.8 (1.3, 18.3)**	22.7 (5.8, 39.6)**	-6.9 (-15.0, 1.1)	11.9 (5.1, 18.6)**	-5.8 (-11.5, -0.2)**

Note: CI, confidence interval  
\*\*P<0.05

**Table 6: Child and caregiver demographics with level of disability of child (CP-CHILD scores): multivariable linear regression models**

	CPCHILD Total Mean	CPCHILD Total Mean	CPCHILD Total Mean	CPCHILD Total Mean
	Coefficient (95% CI)	Coefficient (95% CI)	Coefficient (95% CI)	Coefficient (95% CI)
<b>Model Intercept</b>	65.4 (62.9, 67.9)	54.5 (49.5, 59.4)	43.8 (36.1, 51.6)	29.1 (14.3, 43.9)
<b>Educational Status</b>				
Never schooled (REF)				
Currently non-schooling AND/OR Attending preschool	-3.7 (-14.0, 6.7)	3.8 (-7.0, 14.6)	3.6 (-6.9, 14.1)	5.6 (-5.2, 16.4)
Attending school	-9.6 (-21.7, 2.6)	-13.1 (-27.8, 1.6)	-11.4 (-25.6, 2.9)	-13.7 (-28.0, 0.6)
<b>School Type</b>				
Not applicable (REF)				
General school - general class		20.0 (8.8, 31.3)**	18.4 (7.4, 29.4)**	18.1 (6.3, 29.9)**
General school - special class		13.8 (7.8, 19.8)**	11.3 (5.2, 17.4)**	11.6 (5.1, 18.2)**
Special school		13.0 (6.8, 19.3)**	11.8 (5.5, 18.0)**	12.0 (5.4, 18.6)**
<b>Caregiver Gender</b>				
Male (REF)				
Female			10.5 (3.7, 17.2)**	9.3 (2.6, 16.1)**
<b>Caregiver Work Status</b>				
Unemployed (due to child's health) (REF)				
Working full- or part-time (outside the house)			7.6 (0.9, 14.4)**	5.2 (-2.3, 12.7)
Working full- or part-time (at a home-based business)			10.7 (1.2, 20.3)**	9.1 (-0.7, 18.9)
Homemaker			2.2 (-3.1, 7.5)	1.3 (-4.3, 6.9)
<b>Caregiver Education Level</b>				
Less than grade 5 (REF)				
Fifth to tenth grade				-0.3 (-10.7, 10.1)
Up to ordinal level				8.0 (-1.5, 17.5)
Post-high school diploma or up to advanced level				5.5 (-4.2, 15.1)
Degree or diploma				11.7 (-2.5, 25.8)
<b>Caregiver Income Level</b>				
Less than 5,000 (REF)				

	CPCHILD Total Mean	CPCHILD Total Mean	CPCHILD Total Mean	CPCHILD Total Mean
	Coefficient (95% CI)	Coefficient (95% CI)	Coefficient (95% CI)	Coefficient (95% CI)
5,001 - 20,000				2.3 (-4.8, 9.3)
20,001 - 35,000				2.8 (-5.7, 11.2)
Over 35,001				-0.8 (-10.6, 9.0)

Note: CI, confidence interval

\*\*P<0.05

### **3.3 Aim 2: Use of Social Supports and External Services**

Descriptive statistics of the use and details of social supports by caregivers for themselves and their children with DS are outlined in Table 7. The majority (56%) of caregivers stated that they had more than one co-caregiver, but overall spouses were most selected to be the main co-caregiver (31.2%). Contrastingly, almost all (92.8%) caregivers reported receiving assistance from family and friends for taking care of their child with DS, and of this subset, 89.3% reported that this support came from family member who was not their spouse. The level of support ranged from full (37%) to almost full (42.24%) to partial (21.6%) and minimal (4.3%).

Approximately one-fifth (20%) received assistance from the Sri Lankan government and social services, while no caregivers reported receiving support from non-governmental organizations (NGOs). Of the caregivers surveyed, over three-quarters (77.6%) attended religious observances. The majority (94.4%) of these caregivers observed Buddhist rituals. Participation in recreational activities was very low (3.2%) amongst caregivers.

**Table 7: Social supports for children with DS and their caregivers: descriptive statistics**

<b>Variable</b>	<b>Frequency</b>	<b>%</b>
<b>Main Co-Caregiver (n=125)</b>		
Spouse	39	31.20
Grand-caregivers	1	0.80
Siblings of the child	9	7.20
Other relatives	4	3.20
Neighbors	1	0.80
None	1	0.80
Other – More than one co-caregiver	70	56.00

Variable	Frequency	%
<b>Receive Government Assistance (n=125)</b>		
Yes	25	20.00
<b>Receive Social Services (n=125)</b>		
Yes	25	20.00
<b>Receive NGO Assistance (n=125)</b>		
Yes	0	0.00
<b>Religious Observances (n=125)</b>		
Yes	97	77.60
<b>Type of Religious Observance (n=36)</b>		
Buddhist rituals	34	94.44
Islamic rituals	1	2.78
Going to temple (unspecified religion)	1	2.78
<b>Participate in Recreational Activities (n=125)</b>		
Yes	4	3.20
<b>Family and Friend Support (n=125)</b>		
Yes	116	92.80
<b>Provider of Support (n=28)</b>		
Spouse	3	10.71
Other family member	25	89.29
<b>Support Level Provided by Family/Friends (n=116)</b>		
Full	37	31.90
Almost full	49	42.24
Partial	25	21.55
Minimal	5	4.31

Table 8 describes the usage of external services by caregivers for both themselves and their child with DS. Of those surveyed, 7.2% said they had special facilities in their home to support their child. A little more than one-third (36.8%) of caregivers admitted to utilizing external supports for caregiving, with half of those caregivers (50%) using almost full levels of support. The majority (64.4%) required support 1 to 2 days per week. Less than one-fifth (16.8%) of caregivers used behavioral therapy for their kids. Of those

who did utilize behavior therapy, more than half (57.1%) used almost-full levels of therapy for their child.

Physical therapy use was even less than behavior therapy at 12%, and the majority of those who used behavior therapy for their children used almost full (53.3%) levels of physical therapy. Very few (6.4%) of the population reported to using palliative therapy for their kids. The majority of those who (75%) did use palliative therapy for their child, and most (50%) used palliative therapy services 1-2 days per week. Finally, a little over one-tenth (12%) utilized preventative therapies for taking care of their child. The level of preventative therapy use was relatively the same at each level of full (33.3%), almost full (33.3%) and partial (33.3%). Of those who used preventative therapy, the majority (6-7 days) utilized it 6-7 times per week for their child.

**Table 8: External service use for children with DS and their caregivers: descriptive statistics**

<b>Variable</b>	<b>Frequency</b>	<b>%</b>
<b>Special Facilities at Home (n=125)</b>		
Yes	9	7.20
<b>External Support (n=125)</b>		
Yes	46	36.80
<b>External Support Level (n=46)</b>		
Almost full	23	50.00
Partial	16	34.78
Minimal	7	15.22
<b>External Support Frequency (n=45)</b>		
1 - 2 days per week	29	64.44
3 - 5 days per week	8	17.78
6 -7 days per week	8	17.78
<b>Behavioral Therapy (n=125)</b>		
Yes	21	16.80
<b>Level of Behavioral Therapy (n=21)</b>		
Full	1	4.76
Almost full	12	57.14
Partial	7	33.33

Variable	Frequency	%
Minimal	1	4.76
<b>Frequency of Behavior Therapy (n=21)</b>		
1 - 2 days per week	18	85.71
3-5 days per week	1	4.76
6-7 days per week	2	9.52
<b>Physical Therapy (n=125)</b>		
Yes	15	12.00
<b>Level of Physical Therapy (n=15)</b>		
Full	3	20.00
Almost full	8	53.33
Partial	4	26.67
Minimal	0	0.00
<b>Frequency of Physical Therapy (n=15)</b>		
1 - 2 days per week	8	53.33
3-5 days per week	6	40.00
6-7 days per week	1	6.67
<b>Palliative Therapy (n=125)</b>		
Yes	8	6.40
<b>Level of Palliative Therapy (n=8)</b>		
Full	0	0.00
Almost full	6	75.00
Partial	2	25.00
Minimal	0	0.00
<b>Frequency of Palliative Therapy (n=8)</b>		
1-2 days per week	4	50.00
3-5 days per week	3	37.50
6-7 days per week	1	12.50
<b>Preventative Therapy (n=125)</b>		
Yes	15	12.00
<b>Level of Preventative Therapy (n=15)</b>		
Full	5	33.33
Almost full	5	33.33
Partial	5	33.33
Minimal	0	0.00
<b>Frequency of Preventative Therapy (n=15)</b>		
1-2 days per week	1	6.67
3-5 days per week	2	13.33
6-7 days per week	12	80.00

Almost all of the caregivers that were interviewed stated that they had very little knowledge about DS or what the disability entailed prior to caregiving for their child. Of

the 15 caregivers that were interviewed, only three caregivers reported having some knowledge of DS ahead of their caregiving responsibilities. Most caregivers obtained information about DS from hospital staff and doctors following the delivery of their child. Of this subset, caregivers stated attending clinics conducted by the hospital in tandem with literature and internet searches aided in their research of DS. All of the interviewed caregivers stated that there were still aspects of caring for someone with DS that they still were not familiar with. To combat this issue, caregivers explained that they use a variety of strategies including engaging with television, newspaper and internet sources to learn more and speaking to doctors and other parents of children with DS.

Caregivers varied broadly in their experiences finding resources such as physical, behavioral and speech-language therapies for their child. Approximately half (46.7%) of all caregivers interviewed reported having no trouble finding therapies for their child or not requiring any therapy for their child. However, despite reporting not having trouble finding therapy, almost half (42.8%) of those caregivers reported having trouble accessing resources such as physiotherapy and speech-language therapy as a result of transportation or timing issues, such as not being able to receive time off work to take the child to therapy. Caregivers appeared to have varying levels of difficulty accessing speech-language therapy as responses varied between having an extremely easy time accessing speech therapy and not being able to find or access any speech therapy. Almost everyone (86.7%) of caregivers interviewed reported looking for social support services



for their child and receiving assistance from school and special programs in learning how to better care for their child and receiving assistance from center and school staff.

All of the interviewed caregivers received some level of support with their caregiving responsibilities from family members, but the level of support differed between respondents. Caregivers specified that their spouses and other children (immediate siblings of the child with DS) provided the most support, whether it be financial or otherwise.

Of the 15 interviewed caregivers, 12 stated that they sent their children to either special schools or special units in general schools. Some of the reasoning behind this decision included proximity to the school, rejection of the child from general classrooms in general schools, referrals from parents of other children who have DS or similar disabilities, and wanting to give their child increased attention from instructors. Some parents stated sending their children to general classes initially but eventually switching to special programs as a result of either the child being rejected from general schools or the curriculum eventually becoming too rigorous for their child.

Caregivers faced a range of different challenges in caregiving for their child, subsequently had varying coping mechanisms. The most prominent struggles amongst caregivers appeared to be related to family finances, managing the child's comorbidities and finding adequate schooling. Many parents stated that they had unsatisfactory incomes to keep up with family expenses (sometimes as a result of other family problems),

but also struggled to find economic opportunities to increase income due to having insufficient time to dedicate to working at a job. Moreover, caregivers struggled to find ways to cope with their child's co-morbidities such as learning how to interact with their child when they had an inability to speak or talk, or faced additional medical problems that required more serious interventions such as surgery. In the event of facing both financial issues and an inability to support their child's co-morbidities, one caregiver reported to utilizing the internet to find materials to conduct speech therapy herself to assist her son. Furthermore, finding an appropriate school that supported children's needs in the classroom was also a commonly encountered challenge, as some parents identified that it was difficult to find teachers and classrooms that could support their child's pace of development.

When asked about the biggest void in coping resources for themselves or their children, caregivers commonly cited issues finding speech-therapists, unstable financial situations and a lack of financial support from the government. Some caregivers stated that part of their issue with finding speech-therapists and other forms of therapy or medical attention for their child was associated with their economic problems and being unable to afford particular services to improve their child's day-to-day function.

Some caregivers reported trying to spread awareness through interactions with other parents with children with DS, assisting to teach other children with DS in their personal time and putting in requests to local government authorities to develop facilities

and education units that would be better suited to the interests of children with DS. Of those who had not taken action, many stated that they had not done anything to date or were unsure or what to do, but wanted to take steps to advocate and help in the future.

In general, reported social support and external resource use was low amongst caregivers. However, most received some form of support from family members, generally from immediate family members such as spouses or other dependents.

### ***3.4 Aim 3A: Relationship of External Services, Social Supports and Primary Stressors on Overall Caregiver Burden (CDS)***

Overall, CDS scores for caregiver burden were 50.2 with a standard deviation of 12.3 and a range of 17 to 74, on a scale of 100. A simple linear regression model for mean CDS score (for level of caregiver burden) and the level of disability (CP-CHILD) scores was used to study the relationship between both variables, and the results are found in Table 9. The beta coefficient values represented the change in overall caregiver burden (CDS score) for each unit of change in CP-CHILD score. The model intercept for the overall CP-CHILD score regressed against the CDS mean was 74.0 and had a beta coefficient value of -0.4, but was not found to be statistically significant. Significant negative associations were found between CP-CHILD sub-scores and caregiver burden. In particular, sub-scores had significant negative associations for: personal care/ADL (B= -0.2,  $p<0.05$ ), communication and social interaction (B= -0.2,  $p<0.05$ ), comfort and emotions (B= -0.3,  $p<0.05$ ), and health (B= -0.5,  $p<0.05$ ).

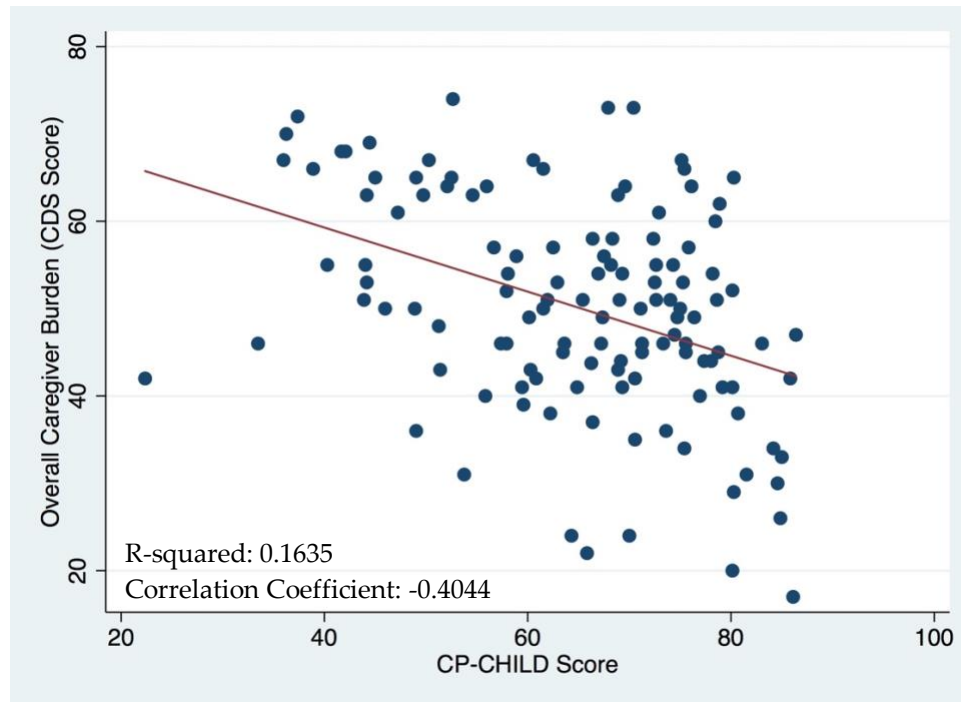
**Table 9: Relationship between level of disability of child (CP-CHILD score) with overall caregiver burden (CDS score): simple linear regression**

	CDS Mean
	Coefficient (95% CI)
<b>CPCHILD Personal Care/Activities of Daily Living</b>	
Model intercept	59.7 (54.8, 64.6)
Coefficient	-0.2 (-0.2, -0.1)**
<b>CPCHILD Comfort and Emotions</b>	
Model intercept	71.5 (58.1, 84.9)
Coefficient	-0.3 (-0.4, -0.1)**
<b>CPCHILD Communication and Social Interaction</b>	
Model intercept	67.1 (53.7, 80.5)
Coefficient	-0.2 (-0.4, -0.1)**
<b>CPCHILD Health</b>	
Model intercept	71.9 (60.8, 82.9)
Coefficient	-0.5 (-0.7, -0.2)**
<b>CPCHILD Overall</b>	
Model intercept	74.0 (64.1, 83.7)
Coefficient	-0.4 (-0.5, -0.2)

Note: CI, confidence interval

\*\*P<0.05

As the level of the child’s disability decreased (high CP-CHILD score), the level of caregiver burden decreased (high CDS score), as is seen in Graph 1. In general, higher numerical scores in CP-CHILD were associated with lower levels of disability in the child. Whereas, higher numerical scores in CDS were associated with higher levels of caregiver burden. Thus, Graph 1 illustrates that within this study there is an association between higher levels of caregiver burden with higher levels of child disability. The level of caregiver burden decreased as the level of child disability decreased.



**Figure 7:** Graph: CP-CHILD score regressed against overall caregiver burden (CDS score)

To assess the relationship between the use of social supports by caregivers and children and the overall caregiver burden (CDS score), simple linear regressions were used, as reported in Table 10. School type was found to be statistically significant and negatively associated with caregiver burden scores ( $B=-15.1, p<0.05$ ). Receiving family support for caregiving activities was negatively associated with caregiver burden ( $B= -14.2, p<0.05$ ). Lastly, government assistance was positively associated with caregiver burden scores ( $B= 5.7, p<0.05$ ) and thus were positively associated with increased caregiver burden.

**Table 10: Relationship between social supports with overall caregiver burden (CDS score): simple linear regression**

	CDS Mean
	Coefficient (95% CI)
<b>School Type (n=122)</b>	
Not applicable (REF)	50.4 (46.0, 54.8)
General school – general class	-15.1 (-25.8, -4.5)**
General school – special class	1.4 (-4.2, 7.0)
Special school	0.1 (-5.7, 5.9)
<b>Caregiver Marital Status (n=125)</b>	
Married (REF)	50.0 (47.7, 52.3)
Single/Widowed/Divorced/Separated	1.5 (-5.9, 8.9)
<b>Relationship of Caregiver to Child (n=125)</b>	
Biological Parent (REF)	50.1 (47.8, 52.3)
Other	2.5 (-8.6, 13.6)
<b>Family Type (n=125)</b>	
Nuclear family (REF)	50.3 (47.8, 52.8)
Three generation family	1.1 (-5.3, 7.6)
Extended family	-2.8 (-9.8, 4.2)
<b>Family Support for Caregiving (n=125)</b>	
Model intercept	63.3 (55.6, 71.1)
Coefficient	-14.2 (-22.2, -6.1)**
<b>Main Co-Caregiver (n=125)</b>	
Spouse (REF)	52.8 (49.0, 56.7)
Siblings of the child	2.4 (-6.5, 11.2)
Other	-4.6 (-9.3, 0.1)
<b>Caregiver Recreational Activities (n=125)</b>	
Model intercept	50.5 (48.3, 52.7)
Coefficient	-9.7 (-22.0, 2.5)
<b>Government Assistance (n=125)</b>	
Model intercept	49.0 (46.6, 51.4)
Coefficient	5.7 (0.4, 11.1)**
<b>Religious Observances (n=125)</b>	
Model intercept	52.1 (47.6, 56.7)
Coefficient	-2.5 (-7.8, 2.7)

**Note:** CI, confidence interval; Model intercept represents ‘no’ response to assistance received (REF) and coefficient represents ‘yes’ response to assistance received

\*\*P<0.05

Table 11 outlines the simple linear regressions of the relationship between external service use with overall caregiver burden (CDS score). Of these analyzed relationships, none of the external services yielded significant associations, and all of the variables

yielded similar model intercepts ranging from CDS scores ranging from 49.9 (for palliative/curative therapy and at-home special facilities) to 51.6 (assistance from external sources). Negative associations were yielded for assistance from external sources (B = -3.8,  $p < 0.05$ ) and physical therapy (B = -3.8,  $p < 0.05$ ). Meanwhile, positive associations were found for at-home special facilities (B = 3.2,  $p < 0.05$ ), behavior therapy (B = 0.4,  $p < 0.05$ ), palliative/curative therapy (B = 3.4,  $p < 0.05$ ) and preventative care services (B = 0.6,  $p < 0.05$ ).

**Table 11: Relationship between external services with overall caregiver burden (CDS score): simple linear regression**

	CDS Mean Coefficient (95% CI)
<b>At-Home Special Facilities (n=125)</b>	
Model intercept	49.9 (47.7, 52.2)
Coefficient	3.2 (-5.2, 11.6)
<b>Assistance from External Sources (n=125)</b>	
Model intercept	51.6 (48.9, 54.3)
Coefficient	-3.8 (-8.3, 0.7)
<b>Behavior Therapy (n=125)</b>	
Model intercept	50.1 (47.7, 52.5)
Coefficient	0.4 (-5.4, 6.3)
<b>Physical Therapy (n=125)</b>	
Model intercept	50.6 (48.3, 52.9)
Coefficient	-3.8 (-10.5, 2.8)
<b>Palliative/Curative Therapy (n=125)</b>	
Model intercept	49.9 (47.7, 52.2)
Coefficient	3.4 (-5.5, 12.3)
<b>Preventative Care Services (n=125)</b>	
Model intercept	50.1 (47.8, 52.4)
Coefficient	0.6 (-6.1, 7.3)

**Note:** CI, confidence interval; Model intercept represents 'no' response to assistance received (REF) and coefficient represents 'yes' response to assistance received

\*\* $P < 0.05$

Multivariable regressions were developed based on significant associations from the simple linear regressions for social supports and external services with overall

caregiver burden. Within this analysis, only CP-CHILD overall scores were used, despite the fact that sub-scores were found to have significant associations in the simple regression models. Multivariable models started with an analysis of only CP-CHILD and CDS scores, and subsequently added in the variables of school type, family support, government assistance and assistance from external sources. Since none of the external service variables were found to be significant in the simple regression models, only the assistance from external sources variable was analyzed. The model intercept for the four models ranged from 74.0 and decreased down to 65.5 as more variables were added into the model. CP-CHILD scores were only significantly associated with CDS scores in the final score, when we controlled for the effects of the other variables and had a beta coefficient of -0.4. There was a significant positive association between attendance in general classes in general schools with caregiver burden across all three multivariable models. Significant positive associations were also found for attendance in special schools in the final multivariable model, when the other four variables were controlled for.

Family support for caregiving had significant positive associations and government assistance had significant negative associations with caregiver burden in both of the models they were included in.



**Table 12: Relationship between level of disability, social supports and external services with overall caregiver burden (CDS score): multivariable regression**

	<u>CDS Score</u>	<u>CDS Score</u>	<u>CDS Score</u>	<u>CDS Score</u>
	Coefficient	Coefficient	Coefficient	Coefficient
	(95% CI)	(95% CI)	(95% CI)	(95% CI)
<b>Model Intercept</b>	74.0 (64.1, 83.8)	74.7 (65.3, 84.2)	81.1 (70.3, 91.8)	80.4 (69.6, 91.2)
<b>Total CP-CHILD Score</b>	-0.4 (-0.5, -0.2)	-0.4 (-0.6, -0.3)**	-0.4 (-0.6, -0.3)**	-0.4 (-0.6, -0.3)**
<b>School Type</b>				
No school	REF	REF	REF	REF
General school - general class		-7.3 (-17.2, 2.6)	-5.4 (-15.0, 4.1)	-4.7 (-14.4, 4.9)
General school - special class		7.3 (1.9, 12.8)**	8.3 (3.0, 13.6)**	8.9 (3.5, 14.3)**
Special school		5.8 (0.2, 11.3)**	5.3 (0.0, 10.7)	6.0 (0.5, 11.5)**
<b>Family Support for Caregiving</b>			-10.5 (-17.7, -3.3)**	-10.1 (-17.3, -2.9)**
<b>Government Assistance</b>			4.8 (0.0, 9.6)**	5.0 (0.2, 9.8)**
<b>Assistance from External Sources</b>				-2.4 (-6.3, 1.6)

Note: CI, confidence interval

\*\*P<0.05

### ***3.5 Aim 3b: Social Supports as a Moderator of Level of Child's Disability (CP-CHILD) on Overall Caregiver Burden (CDS)***

Next we assessed the extent to which specific social supports acted as moderators on the relationship between the level of disability of the child and caregiver burden. For these models, we selected the three variables (school type, family support for caregiving and government assistance) that had significant associations in the simple linear regressions from aim 3A, as is displayed in Table 13. We ran a multivariable regression, interacting each of the terms of each variable of interest with the total CP-CHILD mean

score. The overall model intercept was 81.1 with an R<sup>2</sup> value of 0.376. No significant associations were observed for any of the tested variables within this multivariable model.

**Table 13: Extent to which social support acts as a moderator on the relationship between the level of disability of the child (CP-CHILD score) and caregiver burden (CDS score): multivariable regression**

	CDS Score
	Coefficient (95% CI)
<b>Model Intercept</b>	<b>81.1 (41.2, 121.0)</b>
Overall CP-CHILD Score	-0.4 (-1.0, 0.29)
School Type	
No school	REF
General class in general school	-1.0 (-79.4, 77.5)
Special class in general school	10.6 (-13.0, 34.2)
Special school	10.6 (-13.0, 38.9)
Family support for caregiving	-10.3 (-47.5, 26.9)
Government assistance	-17.6 (-44.8, 9.7)
Overall CP-CHILD Score*No school	REF
Overall CP-CHILD Score*General class in general school	-0.1 (-1.2, 1.0)
Overall CP-CHILD Score*Special class in special school	-0.1 (-0.4, 0.3)
Overall CP-CHILD Score*Special school	-0.1 (-0.6, 0.3)
Overall CP-CHILD Score*Family support for caregiving	-0.0 (-0.6, 0.6)
Overall CP-CHILD Score*Government assistance	0.4 (-0.1, 0.8)

Note: CI, confidence interval

\*\*P<0.05

### **3.6 Aim 3C: External Services as a Moderator of Level of Child's Disability (CP-CHILD) on Overall Caregiver Burden (CDS)**

Finally, we assessed the extent to which external services acted as a moderator on the relationship between the level of disability of the child and caregiver burden. For this model, which is shown in Table 14, we decided to include all of our external service variables since none of them were individually found to be significant in our simple linear regressions with overall caregiver burden in aim 3A. Again, we ran a multivariable regression, interacting each of the external service variables with the total CP-CHILD

mean variable to observe for significant associations on the outcome of CDS mean. The model intercept for this combined model was 67.4 with an  $R^2$  value of 0.283. When assessed individually, the overall CP-CHILD score ( $B=-0.3$ ;  $p<0.05$ ) and receiving behavior therapy ( $B=38.4$ ,  $p<0.05$ ) were found to be significant. However, when interacted with the total CP-CHILD score variable, three of the variables (assistance from external sources, behavior therapy and preventative care) showed significant associations. Receiving assistance from external sources was negatively associated with caregiver burden ( $B= -0.3$ ,  $p<0.05$ ). There was a significant negative association between receiving behavior therapy and caregiver burden ( $B= -0.7$ ,  $p<0.05$ ), and a significant positive association between receiving preventative care services and caregiver burden ( $B= 0.6$ ,  $p<0.05$ ).

Similar to social supports, beta coefficients for each variable was much larger than individually than when incorporated within the interaction terms. The direction of associations inverted for each variable when acted on its own versus when assessed in an interaction term with total CP-CHILD score (i.e. positive beta coefficients became negative), thereby changing the effect on caregiver burden when interacted with the level of disability.

**Table 14: Extent to which external services acts as a moderator on the relationship between the level of disability of the child and caregiver burden: multivariable regression**

	CDS Score
	Coefficient (95% CI)
<b>Model Intercept</b>	<b>67.4 (51.8, 83.0)</b>
Overall CP-CHILD Score	-0.3 (-0.5, -0.0)**
At-Home Special Facilities	16.9 (-14.0, 47.8)
Assistance from External Sources	21.6 (-0.9, 44.0)
Behavior Therapy	38.4 (8.9, 67.8)**
Physical Therapy	-11.5 (-40.9, 17.9)
Palliative/Curative Therapy	-27.3 (-70.6, 16.1)
Preventative Care Services	-34.6 (-61.3, -7.9)
Overall CP-CHILD Score*At-Home Special Facilities	-0.3 (-0.8, 0.2)
Overall CP-CHILD Score*Assistance from External Sources	-0.3 (-0.7, 0.0)**
Overall CP-CHILD Score*Behavior Therapy	-0.7 (-1.2, -0.2)**
Overall CP-CHILD Score*Physical Therapy	0.2 (-0.3, 0.6)
Overall CP-CHILD Score*Palliative/Curative Therapy	0.5 (-0.2, 1.3)
Overall CP-CHILD Score*Preventative Care Services	0.6 (0.1, 1.1)**

**Note:** CI, confidence interval

\*\*P<0.05

## **4. Discussion**

This study assessed the relationship between the level of disability amongst school-aged children with DS and overall caregiver burden, and the effects of social support and external service access on that relationship. The level of disability amongst school-aged children was 64.8 which was closer to lower levels of disability. Female caregivers and attendance of the child in general classes in general schools were positively associated with lower levels of child disability. Meanwhile caregivers reported lower levels of disability for their children when they were working either full or part-time inside or outside of the home. Additionally, those with higher incomes reported lower levels of child disability. Only a small subset of surveyed caregivers reported using social supports and/or external services to aid in the care of their child. Attendance in general classes in general school, lower levels of child disability and receiving government assistance were all positively associated with lower levels of caregiver burden. Assistance from external sources and behavior therapy had negative moderator effects on the relationship between the level of disability of the child and caregiver burden. Meanwhile, access to preventative care services has positive moderator effects on the relationship between the level of disability of the child and caregiver burden.

### ***4.1 Socioeconomic predictors of the level of disability***

Despite its use to measure disability in other studies, CP-CHILD has not been previously used to measure disability levels for DS. Therefore, it is difficult to compare

the level of disability of the children in this study to other populations. Previous studies level of disability for children with cerebral palsy found severe scores to range between 52.0 to 56.2 (Narayanan et al., 2006; Zalmstra et al., 2015). In this study, children had a mean level of disability score of 64.8, which is associated with a lower level of disability than the studies for children with cerebral palsy. It should be noted that our amended CP-CHILD omitted the mobility section of the original CP-CHILD scale, which could attribute to differences in scale scores as well.

Significant predictors of the level of disability included school type, caregiver gender, caregiver work status, caregiver education level and family income level. Interestingly, level of disability was lower amongst children who attended general classes at general schools when compared to children who attended special classes or special schools. While different schooling types are offered to children with disabilities in Sri Lanka, the decision of which school to attend is ultimately at the discretion of the caregiver (Padmani et al., 2003). It is possible that children attending general classes are able to do so because they have lower levels of disability. Within this study, it was also found that there was a significant relationship between children attending general classes in general schools and lower caregiver burden scores. Therefore, this could supplement theories that children in general classes may be there because they have reduced levels of disability. Previous studies have also indicated that the mental age scores of children with DS have been strongly related to the type of school attended (Sloper, Cunningham, Turner, &

Knussen, 1990). Corroborating well with existing literature, female caregivers were more prevalent within this, which could be associated with historical and cultural traditions that place more caregiving responsibilities on women (Barros et al., 2017). Lower levels of caregiver burden were associated with older children. This could also suggest that there might be an association between lower levels of perceived disability of the child by caregivers as children age possibly occurring from caregivers having a better understanding of how to manage their child's condition and understanding their child's learning styles better with time (Fish & Winders, 2008).

#### ***4.2 External services and social supports for children and caregivers***

More than half (56%) of all caregivers reported having more than one co-caregiver, with many in the interviews citing children and their spouses as key sources of support for differing reasons (i.e. financial vs. caretaking). Overall, external service uptake was low amongst surveyed caregivers with low frequencies of use for behavioral therapy (16.8%), physical therapy (12%), palliative therapy (6.4%), and preventative therapy (12%). Only 36.8% of caregivers reported using unspecified external supports, which could have been broadly construed by caregivers to include social supports or school. This could be attributed to many caregivers reporting within the interviews that they were often self-reliant for information or relied on the information relayed to them by doctors and hospital clinics. Through interviews, it appeared that locating speech-language therapy was one of the key resources issues that caregivers faced. Barriers to accessing

speech-language therapy included an inability to afford services, a lack of access to services (either through transportation or lack of time), and/or a lack of knowledge on where to locate services. Enhanced discussions regarding speech-language therapy relates well with pre-existing literature which has confirmed that as children age, disability related to language and particularly the use of expressive language declines, which could be of primary concern to caregivers (Chapman, 1997; Grieco et al., 2015).

#### ***4.3 Relationship of external services, social supports and primary stressors with overall caregiver burden***

Overall, as the level of disability decreased amongst children with DS, the overall level of caregiver burden also decreased. This corroborates well with previous studies where CDS was utilized to measure caregiver burden for children with cerebral palsy in Sri Lanka, where it was found that a child's functional deficits contributed to caregiver burden (Wijesinghe et al., 2014). Furthermore, findings from that study also found that family support was a significant predictor for caregiver burden also correlated well with our study results (Wijesinghe et al., 2014). Family support was negatively associated with caregiver burden, thus supporting past findings that family support reduces caregiver burden. Meanwhile, government services were found to increase caregiver burden. Although we did not specify what type of government services within the context of our survey, these findings conflict with our qualitative data where interview respondents ascertained that government subsidies helped reduced financial burdens. Interestingly, external service use was not found to be significant for any of the services we specified.



However, this could also be impacted by the low numbers of caregivers reporting to access resources within our study as well.

#### ***4.4 Moderator effects of social supports and external services on level of disability and caregiver burden***

Within our study, no support services were found to have a significant moderating role on the relationship between the level of disability and caregiver burden. This information conflicts with previous literature that has shown social supports to be a moderator of caregiver well-being (which could be associated with caregiver burden) (Demirtepe-Saygılı & Bozo, 2011). This further conflicts with data that has demonstrated that the level of social support received by mothers plays a moderating role on caregiver burden, and could be a result of a power issue within our analysis (Plant & Sanders, 2007).

Contrastingly, certain external services were shown to have significant associations with caregiver burden, and thereby, potentially acted as moderators of the disability level/caregiver burden relationship. In particular, receiving assistance from external sources and attending behavioral therapy was found to be associated with lower levels of caregiver burden. As these sources are designed to help mitigate the child's level of disability and likely improve daily coping mechanisms (for the child and/or caregiver), this association would be consistent with preexisting knowledge. Preventative care, however, was demonstrated to also be significant as a moderator but was associated with higher levels of caregiver burden. These findings are inconsistent with pre-existing research which found that prevention support programs minimized the effects of

caregiver burden for children with DS (Barros et al., 2017). One possibility to explore for future studies is why preventative care services was associated with higher levels of caregiver burden, and whether this result is consistent within the Galle region. As this was a cross-sectional study, reverse causation is a possible reasoning for this finding. It is possible for preventative care services to alarm caregivers of conditions or symptoms they may not have previously considered for their child, thereby increasing their level of worry or burden.

#### ***4.5 Implications for policy and practice***

Considering the prevalence of DS in Sri Lanka, it is important to ensure that adequate, useful and accessible support tools and services are available to enhance quality of life for children with DS, and ameliorate the burdens and stresses placed upon caregivers. By addressing the use of existing programs and services, and noting gaps that have demand, this study pinpoints key target demographic and service points to focus on in assisting individuals with DS. Given the low rates of resource usage amongst caregivers for services that have been previously shown to decrease caregiver burden and improve level of disability in past studies in other countries, it would be in the best interest of families with children with DS to develop resource guides or a method through which information about how to access local services. Making resource information guides more available within schools or healthcare settings could be potentially useful, given that caregivers cited health providers as key informational resources in interviews and a large

majority of children within this study attended school. Furthermore, taking steps to decrease financial strain on families through forms such as government assistance could improve levels of disability amongst children (through allowing caregivers to afford better resources) and subsequently, decrease overall caregiver burden. Larger institutional bodies have room to re-evaluate, amend, and create improved support interventions which will facilitate feasible, accessible services to children with DS and their caregivers, thus improving day-to-day quality of life. At the moment, our plans to disseminate the information include sending a report to our collaborators at the field site to encourage improvement and development of services for children with DS and their caregivers.

#### ***4.6 Implications for further research***

This project was an initial study to assess the level of disability and caregiver burden as well as possible sociodemographic contributors in Galle. While this study was able to provide base information in regards to the disability and resource landscape faced by caregivers of children with DS, this study warrants future research on resource availability and usage for children with DS and their caregivers within the region. Future studies should seek to understand reasons as to why external service use is so low within the region. The low numbers of families accessing resources and caregivers looking for services such as speech-language therapy suggests that future research should focus on increasing resource knowledge and access by better acquainting families with existing

resources. Moreover, research should also look into what resources are currently available for caregivers and their children, and what types of barriers caregivers face in accessing specific resources. Further research should also be pursued regarding the level of child disability in more objective terms but utilizing physical tests and medical expertise. Lastly, this study also identified several co-morbidities of children with DS, that were not explored in depth. Further studies on the implications of those co-morbidities for patients and their caregivers could also draw attention to the need for additional resources or supports.

#### ***4.7 Study strengths and limitations***

This study was the first of its kind within the region of Galle and within Sri Lanka, studying a disease that has not previously received attention, making it valuable in generating new knowledge. The measures used in this study to test level of disability and caregiver burden were widely accepted and internationally reputable, making it comparable to studies with other similar developmental disabilities. Limitations of this study include a lack of questions framing the issue of accessibility such as measures of barriers that may prevent caregivers from attaining resources for their child (i.e. geography, timing, eligibility requirements, etc.) and availability, because caregivers may not be accessing resources because they do not currently exist within the area.

Furthermore, the level of disability assessed within this study came from the perspective of caregivers within the study, who would subjectively differ in opinion and

perceptions from one another. To mitigate this issue, future studies could include medical based tests with children to develop a more objective understanding of the child's level of disability. Moreover, within this study, external services and social supports were also spoken about broadly and left room for interpretation by each individual caregiver. To minimize differences and ensure a better association can be made, questions could have been more specific to ensure caregivers had the same impression of vague concepts such as social supports and external services, that aligned with our perceptions.

As this was a cross-sectional study, we were only able to analyze resource usage and availability for the present moment. It is difficult to ascertain whether knowledge and usage of resources for DS have improved from the past, and what the overall effectiveness is of existing resources. When analyzing aspects such as the effect of resources on the child's level of disability, we solely looked at current resource use. It is difficult to know whether the correlations we are drawing are a result of the use of resources or some other confounding factors. To overcome this issue, longitudinal studies on resource use and availability could be employed to better assess the effects of access and availability on determining level of child's disability or caregiver burden.

## 5. Conclusion

In a survey of 125 caregivers of children with DS, the level of disability amongst children with DS aged 5 to 12 years of age was 64.8 and caregiver burden was 50.2. A number of different factors was found to act as positively significant predictors of the level of disability including school type, caregiver gender, and income level. Overall, higher levels of child disability were found to be associated with higher levels of caregiver burden. Despite a moderate level of child disability, only 36.8% of caregivers reported receiving assistance from external supports and only 20% received government assistance, with 92.8% of caregivers relying on assistance from friends and family. Assistance from external sources and behavior therapy was shown to positively moderate the relationship between the level of disability of the child and caregiver burden, and further access could help improve both child outcomes and caregiver burden. Of surveyed caregivers, knowledge of services and information attainment was highlighted to be a challenge with caregivers having to proactively receive information from the internet, hospitals and other sources, but sometimes being unable to access the resources due to transportation and financial issues. To improve supports for child and decrease caregiver stress, access to external resources such as behavior therapy and speech-language pathologists should be improved in terms of financial and geographical accessibility and improved knowledge amongst caregivers of services. Future research could include longitudinal studies to determine the impact of resource usage and availability on child

and caregiver outcomes, and further analysis into the barriers preventing caregivers from accessing resources for their children.

## Appendix A: Consent Form

### STATEMENT OF CONSENT

#### Research Study: Resource Needs and Usage Amongst Children with Down Syndrome and their Caregivers in Galle, Sri Lanka

You are invited to be in a research study about the needs and usage of resources for children with Down Syndrome and their caregivers in Galle, Sri Lanka. This study is being led by a team from University of Ruhuna, Galle and Duke University, US. We hope that this study will help us understand the resource availability and needs of children with Down Syndrome and their caregivers. We also hope that this study can help health programs for children with Down Syndrome and their caregivers. This study will take place between August 2017 and November 2017.

If you choose to be in our study, you will be asked a set of questions, using a questionnaire, on your experiences as a caregiver for a child with Down Syndrome, the external services and social supports you receive for your child and for yourself, and your feelings towards your caregiver experiences. The questions will be asked in Sinhalese, by a graduate from University of Ruhuna Faculty of Medicine. Most questions will either require an answer in the form of a Yes or No, or will require you to choose one answer from a list of potential answers. If you are selected for the interview portion, we will ask you short answer questions, enabling you to provide whatever response you desire and to any length you desire. Although we do not think our questions are problematic, you may find some of them to be personal or sensitive. While we hope that you will reply honestly and to the best of our abilities, you can skip any questions that you do not wish to answer. You can also ask us to stop asking you questions at any time for any reason.

Whatever you decide will not affect your employment or relationship with University of Ruhuna or Duke University. The total time required to answer our questions is about 1 hour to 75 minutes. You will be compensated 700 Rupees for your time. If you are selected for the interview portion of the study, it will take an additional 1 hour and you will be compensated an additional 700 Rupees for your time.

Your privacy is important to us. All the information we collect will be kept locked in a cabinet at the University of Ruhuna. Only members of the research team will have access to this information. Later the information will be incorporated into a written report and possibly a journal article. The findings will also be presented to students, faculty and possibly headmasters of elementary schools to improve resource access and awareness. Although we ask you to provide us with a lot of information about you, any information that can lead someone to identify you will not appear on any document we create and share with others.

Our goal is to use the information we collect during our research study to help health programmes for children with Down Syndrome and their caregivers in Sri Lanka. Please be assured



that being in this research study is completely voluntary. You do not have to agree to answer questions or be observed if you do not want to. Even if you agree but you later change your mind, you can let us know and we can erase all the information you shared with us if you prefer.

If you have any questions or concerns before we begin, please feel free to ask them now. You will be given a separate copy of this document for your records. If you have any additional questions about this study after your participation, please contact Dr. Vijitha De Silva by phone at 077760970, or by email at . You may also contact Dilani Logan by phone at **[Sri Lankan Phone Number]**, or by email at [dilani.logan@duke.edu](mailto:dilani.logan@duke.edu). For information about your rights as a participant, you may contact University of Ruhuna at +94 91 2234801.

**If you agree to participate in this study, please sign the statement of consent below:**

**Printed name of Participant:** \_\_\_\_\_

**Signature of Participant:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Signature of Investigator:** \_\_\_\_\_ **Date:** \_\_\_\_\_

## Appendix B: Caregiver Survey

Date (MM/DD/YYYY): \_\_\_\_\_

Interviewer: \_\_\_\_\_

ID Number: \_\_\_\_\_

Gender of Child: \_\_\_\_\_

Estate Name: \_\_\_\_\_

I am going to read you a series of questions about you, your child, your role as a caregiver, and the social, economic, mental and physical health of yourself and your child. Everyone in this study will be asked the same questions. I will read each one carefully. If you do not want to answer, just say so. If you do not understand something, please ask. Please give me the best answer you can for each question. At the completion of this study, you will be compensated 700 Rupees for your participation.

Time interview started: \_\_\_\_\_

Time interview ended: \_\_\_\_\_

### Down Syndrome Resource Availability Survey

Date: \_\_\_\_\_ Study \_\_\_\_\_ ID: \_\_\_\_\_ School \_\_\_\_\_ ID: \_\_\_\_\_

1. **Child's Gender:**  Female  Male  Other: \_\_\_\_\_
2. **Child's Date of Birth (MM/DD/YYYY):** \_\_\_\_/\_\_\_\_/\_\_\_\_
3. **Child's Age (in completed years):** \_\_\_\_\_
4. **Child's Educational Status:**  Never schooled  
 Currently non-schooling  
 Attending preschool  
 Attending school
5. **What is the highest school grade your child has completed? (Check only one grade)**  
 1<sup>st</sup> grade  2<sup>nd</sup> grade  3<sup>rd</sup> grade  4<sup>th</sup> grade  5<sup>th</sup> grade  6<sup>th</sup> grade  7<sup>th</sup> grade  
 N/A; If ungraded, how many years of school has your child attended? \_\_\_\_\_
6. **If your child is attending school, what type of education is received by the child?**  
 General school/general class  General school/special class  Special school  
 Other (Please specify: \_\_\_\_\_)
7. **A) No. of siblings:** \_\_\_\_\_  
**B) Birth order of the child:** \_\_\_\_\_
8. **Co-morbidities of the child:**  Cardiovascular conditions (Specify: \_\_\_\_\_)  
 Respiratory conditions (Specify: \_\_\_\_\_)  
 Gastrointestinal conditions (Specify: \_\_\_\_\_)  
 Other (Specify: \_\_\_\_\_)

For each question, regarding the activities performed, rank the difficulty level and level of assistance required by your child to perform these activities.

<b>Personal Care/Activities of Daily Living</b>			
<i>During the past 2 weeks, how difficult was the following:</i>			
Question	Level of difficulty required by child		
	Substantial	Minimal	Independent
9. Eating/drinking or being fed?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
10. Maintaining oral hygiene?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
11. Bathing/washing?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
12. Toileting activities? (bladder and bowel function, hygiene, etc.)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
13. Changing diapers/underwear?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
14. Putting on/taking off clothing? (shirt, pants, etc.)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
15. Hair care? (washing, drying, brushing/combing, braiding, etc.)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
16. Getting in and out of a motor vehicle? (Car, van, or bus)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
17. Visiting public places? (Park, theatre, sightseeing, etc.)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

<b>Comfort and Emotions</b>				
<i>During the past two weeks, how often did your child experience pain or discomfort:</i>				
Question	Level of difficulty required by child			
	Severe	Moderate	Mild	None

<b>18. While eating/drinking or being fed?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 0
<b>19. During toileting (bladder and bowel function, hygiene, diapering, etc.)</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 0
<b>20. While dressing/undressing?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 0
<i>During the past two weeks, how often was your child:</i>				
<b>21. Agitated, upset or angry?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 0
<b>22. Unhappy or sad?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 0

<b>Communication and Social Interaction</b>							
<i>During the past 2 weeks, how much difficulty did you child have?</i>							
Question	Level of difficulty required by child						
	Not possible	Very difficult	Difficult	Slightly difficult	Easy	Very easy	No problem
<b>23. Understanding you?</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>24. Being understood by you?</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>25. Communicating with those who don't know your child well?</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>26. Playing alone?</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>27. Playing with others?</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>28. Attending school/child care?</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

<b>29. Participating in recreational activities? (Swimming, interacting with family and friends, etc.)</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
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<b>Health</b>						
<i>In the past two weeks:</i>						
Question	Number of Visits					
	Admitted >7 days	Admitted <7 days	3 or more times	Twice	Once	None
<b>30. How many times has your child had to visit the doctor or hospital?</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Question						
	Very poor	Poor	Fair	Good	Very good	Excellent
<b>31. How would you rate your child's overall health?</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
<b>32. How would you rate your child's overall quality of life?</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**33. Caregiver gender:**  Male  Female  Other: \_\_\_\_\_

**34. Caregiver date of birth (MM/DD/YYYY):** \_\_\_\_/\_\_\_\_/\_\_\_\_

**35. Which of the following best describes your current work status? (Check all that apply)**

- Not working due to my child's health
- Not working for other reasons
- Looking for work outside the home
- Working full or part-time (outside the home)
- Working full or part-time (at a home-based business)
- Full-time homemaker

**36. What is your marital status?**

- Single  Married  Widowed  Divorced/Separated
- Other (Please explain: \_\_\_\_\_)

**37. Relationship of caregiver to child:**

- Biological parent  Step parent  Foster parent  Adoptive parent
- Guardian  Professional caregiver  Other (Please explain: \_\_\_\_\_)

**38. Type of family:**  Nuclear family  Three generation family  Extended family

**39. On average, how many days per week are you responsible for caregiving activities for your child? Hours per week? Hours per day?**

\_\_\_\_\_ days per week \_\_\_\_\_ hours per week \_\_\_\_\_ hours per day

**40. What is the highest level of school you have completed?**

- No school
- Below grade five
- Fifth to tenth grade
- Up to ordinal level

- Post-high school diploma or up to advanced level
- Degree or diploma
- Post-graduate

**41. What is your average monthly household income?**

- Less than 5,000
- 05,001 – 20,000
- 20,001- 35,000
- 35,001 – 50,000
- Over 50,000

**42. What is your AGA (electorate) division?**

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Question	Completely	To a greater extent	To some extent	To a lesser extent	Not at all	N/A
43. Are you satisfied about the improvement in your child's condition after receiving treatment/therapy?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 0
Question	Always	Often	Sometimes	Rarely	Never	N/A
44. Does your child fall ill from time to time?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
45. Do you fear what your child's future might be?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
46. Do you worry about your child's present state?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
47. Do you worry that your child cannot function like other children (e.g. going to school, playing)?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
48. Do you feel sad that your child is not as independent as you would like them to be?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
49. Do you worry that your child gets insulted and/or ridiculed by others?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
50. Do you fear your children will have accidents as a result of his/her disability?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
51. Does caring for the child make you feel tired and exhausted?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

<b>52. Does your child's condition prevent you from being relaxed?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>53. Do you have enough time to look after your own health?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>54. Do you have enough time for your basic daily needs such as having meals, sleeping, bathing, etc.?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>55. Do you feel that you will never have enough time to get everything done?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>56. Do you think that your health has been affected because of your child's condition?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>57. Does the child's condition prevent you from attending to the needs of other family members?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>58. Does your spouse help you with the care of this child?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>59. Does your spouse support you in other family responsibilities?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>60. Are you able to discuss your child's problems with other family members?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>61. Are the other family members well aware about your child's condition?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>62. Do your relatives/neighbors help you with caring for your child?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

<b>63. Do you have to restrict your social visits and relationships due to your child's condition?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>64. Do you have to face embarrassing situations when you are travelling with your child?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>65. Is there an increase in your family expenses due to your child's condition?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>66. Is your income adequate to provide the necessities for your child?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
<b>67. Do you worry that you are unable to provide special facilities needed by your child?</b>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

**68. Who is the main person who assists you in the provision of care for the child?**

- Spouse
  Grandcaregivers
  Siblings of the child  
 Other relatives
  Neighbors
  Friends  
 None
  Other (Please specify: \_\_\_\_\_)

**69. A) Are there any special facilities for the child at home?**  Yes  No

**B) If yes, what are the facilities?** \_\_\_\_\_

**70. A) Do you receive any assistance from government or other organizations for the care of the child?**  Yes  No

- B) If yes, what is the organization?**  Social services department  
 Non-governmental  
 Other (Please specify: \_\_\_\_\_)

**71. Do you practice any religious observances or spiritual activities on behalf of the child?**

Yes (Please specify: \_\_\_\_\_)  No

**72. Do you spend some time on recreational activities without your child (meeting friends, watching TV, etc.)?**

Yes (Please specify: \_\_\_\_\_)  No

**73. A) Do you receive assistance from family or friends with caregiving responsibilities?**

Yes (Please specify: \_\_\_\_\_)  No

**B) If yes, how much support does this person provide?**

Full  Almost full  Partial  Minimal

**74. A) Do you receive assistance from external sources for child care?**

Yes  No

**B) If yes, how much support does the child receive?**

Full  Almost full  Partial  Minimal

**C) If yes, how many times per week?**

1-2 days per week  3-5 days per week  6-7 days per week

**75. A) Does your child receive behavioral therapy?**

Yes  No

**B) If yes, how much support does this person provide?**

Full  Almost full  Partial  Minimal

**C) If yes, how many times per week?**

1-2 days per week  3-5 days per week  6-7 days per week

**76. A) Does your child receive physical therapy?**

Yes  No

**B) If yes, how much support does this person provide?**

Full  Almost full  Partial  Minimal

**C) If yes, how many times per week?**

1-2 days per week  3-5 days per week  6-7 days per week

**77. A) Does your child receive palliative/curative services?**

Yes  No

**B) If yes, how much support does this person provide?**

Full  Almost full  Partial  Minimal

**C) If yes, how many times per week?**

1-2 days per week  3-5 days per week  6-7 days per week

**78. Does your child receive preventative care services?**

Yes  No

**B) If yes, how much support does this person provide?**

Full  Almost full  Partial  Minimal

**C) If yes, how many times per week?**

1-2 days per week  3-5 days per week  6-7 days per week

**Thank you for taking the time to complete this survey. Please contact us if you have any questions or concerns. We appreciate your participation.**

## Appendix C: Caregiver Interview Guide

Date (MM/DD/YYYY): \_\_\_\_\_

Interviewer: \_\_\_\_\_

ID Number: \_\_\_\_\_

Gender of Child: \_\_\_\_\_

Estate Name: \_\_\_\_\_

I am going to read you a series of questions about you, your child, your role as a caregiver, and the social, economic, mental and physical health of yourself and your child. Everyone in this study will be asked the same questions. I will read each one carefully. If you do not want to answer, just say so. If you do not understand something, please ask. Please give me the best answer you can for each question. At the completion of this study, you will be compensated 700 Rupees for your participation.

Time interview started: \_\_\_\_\_

Time interview ended: \_\_\_\_\_

**1. How much did you know about Down Syndrome prior to caregiving for your child?**

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**2. How did you find information about Down Syndrome?**

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**3. Please describe your experiences with finding resources (physical therapy, behavioral therapy, etc.) for your child.**

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**4. Have you looked for respite support services for yourself? If yes, please describe your experiences and whether these services have been helpful to you. If no, why not?**

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**5. In terms of caregiving for your child, what is the biggest challenge/thing you struggle with? How do you cope?**

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**6. Are there aspects of caring for someone with Down Syndrome that you still do not feel you know enough about? Have you tried to find information in regards to this?**

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**7. What is the biggest void in resources for either yourself or your child for coping with Down Syndrome?**

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**8. What type of school does your child go to? How did you make the decision to send them to that school?**

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**9. What type of supports do you receive from your family? Do you feel this is sufficient? Why or why not?**

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**10. Do you try to advocate on behalf of children with Down Syndrome as a result of your experiences? If yes, why and how? If no, have you ever considered it? Why or why not?**

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