

STIGMA EXPERIENCED BY PARENTS OF ADULTS WITH  
INTELLECTUAL DISABILITIES

by

AHANA SARKAR

A thesis submitted to the Department of Community Health & Epidemiology in  
conformity with the requirements for the degree of Master of Science

Queen's University

Kingston, Ontario, Canada

May, 2010

Copyright © Ahana Sarkar, 2010

## **ABSTRACT**

### **Background:**

Stigma can not only affect the stigmatized individual, but also those closely associated with that individual, such as parents. Parents are often in the role of primary caregivers for individuals with intellectual disabilities. However, few studies have looked at the experiences of stigma in parents of adults with intellectual disabilities.

### **Objectives:**

Three objectives of the current study were to test the internal consistencies of three scales aimed to measure experiences of parents of adults with intellectual disabilities (two stigma scales and one scale looking at positive personal, perspective on life, and relational changes in parents), test the inter-correlation between the scales and describe the parents' experiences.

### **Methods:**

A self-administered survey containing the three scales was mailed to parents of adults with intellectual disabilities by agency staff on the investigators' behalf. The participants were identified through a database of anonymized information about individuals with intellectual disabilities within the six counties of South Eastern Ontario. A total of 97 participants (parents) were eligible for the study.

### **Results:**

The scale measuring positive changes experienced by parents had significant item non-response. However, all three scales achieved good to excellent internal consistencies when tested in the current sample. The two stigma scales were moderately correlated with one another in a positive direction, while the scale measuring positive changes in parents

did not significantly correlate with either of the stigma scales. Mothers and younger parents (less than 65 years) were more likely to report that stigma affected their ability to interact with relatives than fathers and older parents. Parents of adults with dual diagnosis (having both an intellectual disability and mental health problems) were more likely to report that stigma affected their family's quality of life than parents of adults with an intellectual disability only.

**Conclusion:**

Both of the stigma scales are recommended with caution, with recommendations ranging from rewording of items, change in item order within the survey, more conservative item response categories, reconsideration of dichotomizing responses and a mode of survey administration which lowers the potential for non-response. Certain groups of parents of adults with intellectual disabilities experience stigma differently than others.

## ACKNOWLEDGEMENTS

The journey of my master's thesis has been a great learning lesson which tested my capacity and ability to face significant challenges, external and internal. Now I look back and see the support, encouragement, faith, knowledge and wisdom from others that have been invaluable stepping stones enabling me to reach the end.

This project would not have been possible without the funding by South Eastern Ontario Community-University Research Alliance in Intellectual Disabilities (SEO CURA in ID) and the financial support by the Department of Community Health and Epidemiology, Queen's University.

I want to extend my gratitude to the agencies and their staff for their interest, time and work in helping me recruit participants for my study. I am also thankful for the feedback from the parents in *The Family Advisory Committee*, SEO CURA in ID, whose comments greatly helped me in focusing the initial direction of my study.

To the parents of adults with intellectual disabilities, I am grateful for their willingness to participate in my study and to share a part of their personal experiences. Many times, these stories served as inspiration for my continued commitment to this project.

To the individuals whose guidance helped me see the end:

- To my supervisors, H el ene Ouellette-Kuntz and Heather Stuart, I acknowledge my deep debt of gratitude and take this opportunity to offer my heartfelt thanks. Without both of your insights, encouragement, guidance, and knowledge, I would not have been able to reach the end. Thank you for the invaluable lessons you taught me about how to look deeper, more critically, and to uphold the integrity of scientific research.

- To the staff and students at Ongwanada, Maureen, Aileen, Helen, Hilary and Iwona, who were always open and willing to offer help, and because of whom, my work environment fostered positivity and encouragement, your support is appreciated.
- To the individuals in the Department of Community Health and Epidemiology: to Katherine Cook and Lee Watkins, thank you for your always-ready helping hands and words, to Dr. Miu Lam, thank you for all your guidance with my statistical inquiries, and to Michelle Koller, thank you for your assistance in familiarizing me with the data from the original study involving the mental health sample.
- To Bert, who worked tirelessly alongside me, making hundreds of survey packages, you made the work and time pass by effortlessly.
- To Thy Dinh, you were there at the inception of this journey. I could not have taken the first steps without your faith and support. To Amandev Aulakh, who gladly bore witness to the end of my journey, I could not have reached the finish line without all that you did to make the last hurdle seem possible and reachable.
- To my friends who listened to my seemingly never-ending “thesis stories”, thank you for your words of encouragement and for the patient ears. To the others who, without words, offered me moments of levity, you were invaluable in my moments of stress.
- To H el ene, you were there from the very beginning until the very end. Your first act of support in this journey started as my academic advisor and ended with being my mentor. You championed for me when I lost my way. My deepest gratitude for everything that you did to ensure that I had the confidence to face the end.
- To my parents, you taught me about sacrifice, integrity and the courage to fulfill my goals. This journey was a testament to those lessons learned.

## **TABLE OF CONTENTS**

ABSTRACT	i
ACKNOWLEDGEMENTS	iii
TABLE OF CONTENTS	v
LIST OF TABLES	viii
LIST OF FIGURES	x
CHAPTER 1: INTRODUCTION	1
1.1 Purpose of study	1
1.2 Background	1
1.2.1 Classification of intellectual disabilities	1
1.2.2 History of intellectual disabilities	4
1.2.3 Epidemiology of intellectual disabilities	8
1.2.4 Relevance of stigma to intellectual disabilities	12
1.2.5 Stigma by association	12
1.3 Rationale	14
CHAPTER 2: LITERATURE REVIEW	16
2.1 The nature of stigma	16
2.2 Stigma related to mental health problems and intellectual disabilities	21
2.3 Family experiences of stigma	23
2.4 Availability of measurement tools	26
2.5 Implications	28
CHAPTER 3: GOALS AND OBJECTIVES	29
CHAPTER 4: STUDY DESIGN AND METHODS	30
4.1 Study design	30
4.2 Sampling strategy	30
4.3 Measures	33
4.3.1 Stigma Experience Scale	34
4.3.2 Stigma Impact Scale	35
4.3.3 Parental Changes Subscale	36
4.4 Data management	36
4.5 Data analysis	39

CHAPTER 5: RESULTS	42
5.1 Demographic information	42
5.2 Psychometric testing of scales	46
5.2.1 Stigma Experience Scale	46
5.2.2 Stigma Impact Scale	49
5.2.3 Parental Changes Subscale	52
5.2.4 Inter-correlation between scales	56
5.3 Association between characteristics of respondents and experiences of stigma	56
5.4 Summary of results	65
CHAPTER 6: DISCUSSION	68
6.1 Evaluation of the individual scales	68
6.1.1 The inter-correlation between the scales	76
6.2 Experiences of parents	77
6.3 Strengths and limitations	83
6.4 Future direction of study	87
CHAPTER 7: CONCLUSION	90
REFERENCES	91
APPENDIX A: ETHICS APPROVAL	103
APPENDIX B: INITIAL LETTER OF INVITATION TO AGENCIES	104
APPENDIX C: LETTER TO AGENCY CONTACT WITH LIST	106
APPENDIX D: LETTER TO AGENCY- MAILING INSTRUCTIONS	108
APPENDIX E: COVER LETTER FOR PARENT PARTICIPANTS	110
APPENDIX F: SURVEY	112
APPENDIX G: POSTCARD FOR PARTICIPANTS	131
APPENDIX H: COMPARISON OF RESPONDENTS WITH EITHER SOME OR COMPLETED PUBLIC SCHOOL EDUCATION VERSUS RESPONDENTS WHO EITHER HAD SOME OR COMPLETED HIGH SCHOOL	132
APPENDIX I: DISTRIBUTION OF THE FREQUENCY OF THE TOTAL SCORES FOR EACH OF THE THREE SCALES	134
APPENDIX J: GRAPHICAL REPRESENTATION OF CORRELATION BETWEEN SCALES	137

APPENDIX K: ASSOCIATION BETWEEN DESCRIPTIVE CHARACTERISTICS AND ITEMS IN THE STIGMA EXPERIENCE SCALE	140
APPENDIX L: SAMPLE SIZE CALCULATIONS FOR INTERNAL CONSISTENCY	166
APPENDIX M: COMPARISON OF RESPONDENTS AND NON-RESPONDENTS FOR THE STIGMA EXPERIENCE SCALE	167
APPENDIX N: COMPARISON OF RESPONDENTS AND NON-RESPONDENTS FOR THE PARENTAL CHANGES SUBSCALE	171

## LIST OF TABLES

Table 1. Characteristics of parent respondents, N = 97	43
Table 2. Characteristics of adult children as reported by parent respondents, N = 97	45
Table 3. Reliability Analysis of the <i>Stigma Experience Scale</i> , N = 82	48
Table 4. Reliability Analysis of the <i>Stigma Impact Scale</i> , N = 93	50
Table 5. Reliability Analysis of the <i>Parental Changes Subscale</i> , N = 51	54
Table 6. Association between gender of parent and whether stigma affected parents' ability to interact with other relatives, N = 93	57
Table 7. Association between adult child's dual diagnosis status and whether parents report that stigma affected their family's quality of life, N = 96	58
Table 8. Association between age of parent and whether parents report that people think less of those with intellectual disabilities, N = 88	59
Table 9. Association between age of parent and whether parents report that people are afraid of those with intellectual disabilities, N = 86	59
Table 10. Association between age of parent and whether stigma affected parents' ability to interact with other relatives, N = 89	60
Table 11. Association between parents' employment status and whether parents report that people think less of those with intellectual disabilities, N=94	61
Table 12. Association between parents' employment status and whether parents report that people are afraid of those with intellectual disabilities, N=92	61
Table 13. Association between parents' employment status and whether stigma affected parents' ability to interact with other relatives, N = 94	62

Table 14. Association between adult child's age and whether parents report that people think less of those with intellectual disabilities, N = 93	63
Table 15. Association between adult child's age and whether parents report that people are afraid of those with intellectual disabilities, N = 91	64
Table 16. Association between adult child's age and whether stigma affected parents' ability to interact with other relatives, N = 94	64
Table 17. Association between adult child's age and whether parents report that stigma affected their family's quality of life, N = 95	65

## LIST OF FIGURES

Figure 1. Recruitment Flowchart	32
Figure 2. <i>Stigma Impact Scale</i> – frequency of responses at item level (impact on respondent)	51
Figure 3. <i>Stigma Impact Scale</i> – frequency of responses at item level (impact on respondent’s family)	51
Figure 4. Percentage of missing responses for each item in the <i>Parental Changes Subscale</i> , N = 97	55

## **CHAPTER 1: INTRODUCTION**

### **1.1 Purpose of study**

The purpose of the current study was to develop an understanding of the experiences of parents of adults with intellectual disabilities residing in South Eastern Ontario. Three scales that measured parents' experiences were evaluated to achieve the proposed aim of the study.

### **1.2 Background**

In this section, background information about intellectual disabilities will be presented to introduce the study's population of interest. The primary lens used to focus on the experiences of this population is stigma. As such, a background on stigma will be presented. The effect of stigma related to intellectual disabilities will be further explored as it pertains to those closely associated with such individuals, their parents.

#### **1.2.1 Classification of intellectual disabilities**

There are four main classification systems for intellectual disabilities: (1) the Tenth Revision of the International Classification of Disease (ICD-10) (WHO, 1992), (2) the current Diagnostic and Statistical Manual of Mental Disorders (DSM-IVTR) (American Psychiatric Association, 2000), (3) the International Classification of Functioning, Disability and Health (IFC) (WHO, 2001), and (4) the American Association of Intellectual and Developmental Disabilities (formerly - American Association of Mental Retardation) (Luckasson et al., 2002).

According to the Tenth Revision of the International Classification of Disease (WHO, 1992), intellectual disability is defined as a condition of incomplete or arrested development of the mind, characterized by impairment of skills (i.e., language, motor, cognitive and social abilities) that are manifested during the developmental period such that it contributes to the individual's level of intelligence. Within the system there are five categories used to classify the individual's particular diagnosis: (1) severity of retardation and problem behaviours, (2) associated medical conditions, (3) associated psychiatric conditions, (4) global assessment of psycho-social disability, and (5) associated abnormal psychosocial conditions.

Like the Tenth Revision of the International Classification of Disease (WHO, 1992), the Diagnostic and Statistical Manual of Mental Disorders-IVTR (2000) has multiple criteria to classify intellectual disability. They are as follows: (1) an IQ of approximately 70 or below, (2) concurrent deficits or impairments in present adaptive functioning in at least two of the following areas: self-care, home living, social/interpersonal skills, self-direction, use of community resources, functional academic skills, health, work, leisure and safety, and (3) age of onset before 18 years.

The International Classification of Functioning, Disability and Health (WHO, 2001) shifts the focus from a medical model highlighting a disease, as in the Tenth Revision of the International Classification of Disease (WHO, 1992), to a social model of disability. As such, this system not only focuses on the individual and the body but also the impact of society on the expression and degree of disability. In order to evaluate intellectual disability, this system allows for the evaluation of the individual's general mental functions which are required to comprehend and usefully integrate various mental capabilities, including all cognitive functions and their development over the life span.

The American Association of Intellectual and Developmental Disabilities defines intellectual disability as having significant impairment in both “intellectual functioning and conceptual, social and practical adaptive behaviour”, with onset prior to the age of 18 (American Association of Intellectual and Developmental Disabilities, 2009). The focus of this system has been to place greater emphasis on the individual’s systems of support and capability of adaptive functioning, more so than the intellectual deficit.

Of the four systems of classification, only two highlight the onset of intellectual disability to be prior to the age of 18 (Diagnostic and Statistical Manual of Mental Disorders-IVTR, 2000, and American Association of Intellectual and Developmental Disabilities, 2009) with the Diagnostic and Statistical Manual of Mental Disorders-IVTR (2000) being the only system that additionally outlines a criterion for IQ level. The Tenth Revision of the International Classification of Disease (1992) and the Diagnostic and Statistical Manual of Mental Disorders-IVTR (2000) both also place importance in recognizing the disability by classifying severity. As well, both these classification systems place intellectual disability within mental disorders, which is different from the two classification systems developed by WHO. WHO recommends that the Tenth Revision of the International Classification of Disease (1992) be used in conjunction with International Classification of Functioning, Disability and Health (2001) to comprehensively classify a disability. In this way, a medical model and a social model are both applicable in understanding a disability. The International Classification of Functioning, Disability and Health’s (2001) integration of a social model allows it to focus on health years lost due to lack of positive medical, community and educational support when classifying an individual’s intellectual disability.

In Canada, the classification system set forth by the American Association of Intellectual and Developmental Disabilities (Luckasson et al., 2002) is accepted with additional updates, as per the Developmental Services Act (2008). Specifically in Ontario, eligibility for governmental support due to intellectual disability in children is mandated by the Child and Family Services Act (2009) which recognizes intellectual disability as “a condition of mental impairment, present or occurring during a person's formative years, that is associated with limitations in adaptive behaviour.” Eligible services include respite care, specialized community support to help integrate children with intellectual disabilities into their communities, and residential services.

Terms such as ‘mental deficiency’, ‘mental handicap’, ‘feeble-mindedness’ and ‘mental retardation’ have historically been applied to this group (Griffiths, Stavrakaki & Summers, 2002). The Diagnostic and Statistical Manual of Mental Disorders-IVTR, the Tenth Revision of the International Classification of Disease and the International Classification of Functioning, Disability and Health all still use the term ‘mental retardation’, while the American Association of Intellectual and Developmental Disabilities chose to revise its terminology by using the term ‘intellectual disability’. The current paper will also use the term intellectual disability.

### **1.2.2 History of intellectual disabilities**

Historically, the population defined by intellectual disabilities was first treated as a homogeneous group where distinctions between etiologies of different types of intellectual disabilities were not made. At present, the etiology of intellectual disability is reported to be genetic or congenital in approximately half of the cases while the specific

causes for the rest of the cases may either be due to adverse events like trauma or the cause is unknown (Arvio & Sillanpaa, 2003).

Within Western society, the history of intellectual disability leading to its current status, as well as the strategies used for the care of such individuals, has shown marked development. Available literature on the history of intellectual disability has mostly profiled the United States of America and Britain. During the Middle Ages in England, the term for such individuals was ‘idiot’ which was derived from the Latin word, *idiota*, to mean an ignorant person, and the Greek word, *idiotos*, which meant unfit for public life (Payne & Patton, 1981). These individuals were thought to have no understanding or reason with regards to their own functioning (Payne & Patton, 1981). During the Middle Ages, such individuals were seen as resulting from ‘sin’ (Szymanski & Wilska, 1997), while during the Reformation in Europe, Martin Luther claimed that individuals with disabilities were the workings of the ‘devil’ (Miles, 2001). The use of the term ‘idiot’ to refer to individuals with intellectual disabilities and the lack of understanding with regards to causes of such disabilities carried over from the Middle Ages well into the 20<sup>th</sup> century. Still today, the term ‘idiot’ is often used as a pejorative.

At the end of the 18<sup>th</sup> century, in France, Phillipe Pinel’s idea of “moral management” allowed for a shift in the social perspective towards individuals with intellectual disabilities by promoting humane care, education and recreation rather than the previous approach of forcing obedience (Winzer, 1993). A student of his, Edouard Seguin, built on Pinel’s work and further advocated educational systems as well as physical therapies to improve the skills of such individuals (Winzer, 1993). By the mid-19<sup>th</sup> century, Seguin’s influence reached the United States of America, and there, he himself, along with some physicians, founded the first schools for individuals with

intellectual disabilities – American Institutions for the Feeble Minded (now an interdisciplinary organization called American Association on Intellectual and Developmental Disabilities) (Winzer, 1993). However, during the late 19<sup>th</sup> century and early 20<sup>th</sup> century, the care of individuals with intellectual disabilities experienced another shift in perspective to one of less humane care.

In 1905, Alfred Binet and Theodore Simone found a way to group children in need of specialized education given their abilities; this was the application of the first usable intelligence test (modern day, IQ test) (Scheerenberger, 1983). The eugenics movement and Social Darwinism occurred around the same time, and they proposed that intellectual disability was inherited and weakened the human species and burdened the society (Scheerenberger, 1983). Custodial care and protection of the community from such individuals, who were considered to be the “menace of the feeble-minded”, were promoted (Brockley, 1999). They were considered to be a menace to society because criminality, drug abuse and antisocial behaviour were associated with intellectual disabilities. This perspective continued on until the 1920s when a growing emphasis on community care and integrating such individuals into communities started to be advocated and this is the perspective to this day (Brockley, 1999). The civil rights movement also prompted parents to advocate for social integration for their children with intellectual disabilities.

One notable influence on the modern history of intellectual disabilities in Canada was the principle of normalization, introduced by Wolfensberger in the early 1970s (Wolfensberger, 1972). Up until the 1970s, in Canada most of the care for those with intellectual disabilities occurred in institutional settings (Radford & Park 2003). Normalization advocated for the acceptance of the individuals’ disabilities and

subsequent availability of everyday living conditions and services that are afforded to typically developing members within the same society (Wolfensberger, 1972). This ‘disability movement’ allowed intellectual disabilities to be seen not just as a medical issue but a social one. The principle of normalization prompted the deinstitutionalization movement in Canada.

When deinstitutionalization occurred in the 1970s and the 1980s, it meant that intellectual disabilities were no longer under the directive of provincial health services as they were de-medicalized and social inclusion was advocated (Lunsky et al., 2007). In Ontario specifically, the introduction of the *Developmental Services Act* in 1974 meant that individuals with intellectual disabilities living in psychiatric institutions regulated by the *Mental Health Act* would be discharged and fall under the regulation of the new *Developmental Services Act*. This movement created a separation of intellectual disabilities from mental illness, as well as separating services and supports between these two groups. Approximately 30,000 Canadians with intellectual disabilities were living in institutions in 1999 (Kaiser, 1999). Those individuals living in institutions were likely to be older, have behavioural problems and would have been more physically disabled than those individuals with intellectual disabilities not living in institutions (McGuigan et al., 1995). A review of studies researching the outcomes of deinstitutionalization in the USA found that the movement of individuals with intellectual disabilities into community settings showed a significant difference in challenging behaviours for those that moved into the community versus those that continued to remain in institutions (Kim, Larson & Lakin, 2001). Individuals with intellectual disabilities who continued to remain in institutions were more likely to have challenging behaviours than those who moved into the community.

In the USA, families of individuals with intellectual disabilities initially opposed the deinstitutionalization movement, but after the resettlement of the individuals with intellectual disabilities into community settings, the families tended to change their minds (Tossebro, 2004). However, case managers and families were still the primary social support for individuals with intellectual disabilities in transitioning from institutions to community settings such as smaller residential homes or group homes, often with supported living, or living with their families again. Presently, families no longer have the option of having their young children with intellectual disabilities live in institutions.

### **1.2.3 Epidemiology of intellectual disabilities**

Intellectual disabilities affect 1–3% of the population (Arvio & Sillanpaa, 2003). Roeleveld et al. (1997) reviewed prevalence studies on intellectual disabilities and found large gaps in knowledge about intellectual disabilities and issues with study designs which affected accurate calculation of prevalence rates. They concluded that the prevalence rate of intellectual disabilities in a given population is as follows: (1) for mild intellectual disability (IQ range between 50-69), 2.5% of a given population, (2) for moderate intellectual disability (IQ range between 35-49), 0.4% of the population, and, (3) for severe and profound intellectual disability (IQ range below 35), 0.1% of the population. Roeleveld et al. (1997) also noted that the prevalence rate for mild intellectual disability was more difficult to estimate than for severe (or profound) intellectual disability. McLaren and Bryson (1987) reviewed epidemiological studies looking at prevalence rates, etiology and associated disorders in those with intellectual disabilities. They reported that the prevalence of intellectual disability seemed to increase with age up to about age 20 and that significantly more males were identified than females.

The etiology of intellectual disability has been subdivided into three general areas, prenatal causes, perinatal causes and postnatal causes, by the American Association of Intellectual and Developmental Disabilities. However, as McLaren and Bryson (1987) stated, most causal relationships must be inferred. Down syndrome and other chromosomal abnormalities can be identified with more certainty than some postnatal infections (Biasini et. al., 1997). In many countries, Down syndrome is attributed as the most common cause of mild and severe intellectual disabilities, with Fetal Alcohol Syndrome as the second most common cause (Minns, 1997). Deficiency in iodine leading to endemic cretinism is a common global cause of severe intellectual disabilities, and it is preventable (Fryers, 1995).

McLaren and Bryson (1987) reviewed and reported approximate percentages from epidemiological studies looking at causes (prenatal, perinatal, postnatal and unknown) associated with levels of intellectual disabilities. For moderate to severe intellectual disabilities, approximately 20 to 30% of those identified had prenatal causes such as chromosomal abnormalities associated with their disabilities. Eleven percent of the cases were associated with perinatal causes, such as perinatal hypoxia, while 3 to 12% were associated with postnatal causes, such as brain injury, to account for their intellectual disabilities. For 30 to 40% of the individuals, the cause of their moderate to severe intellectual disabilities was unknown. It was also found that determining etiology of mild intellectual disabilities was much less clear. For most of the cases (45 to 63%) the cause of their mild intellectual disabilities was unknown.

Some risk factors for intellectual disabilities include low to extremely low birth weight in newborns (Halsey, Collin & Anderson, 1996), maternal smoking during pregnancy (Drews et. al., 1996), maternal age (especially relevant for Down syndrome),

and as reported by Camp et al. (1998), low socio-economic status, maternal IQ, multiple births, low weight gain during pregnancy (<10 pounds), maternal anemia and maternal urinary tract infection.

The financial costs of caring for individuals with intellectual disabilities demands attention from various government-funded programs. These individuals have special needs not only for their healthcare, but also for their housing, education and vocational placements. In 2003, the United States spent \$30 billion taking care of those with intellectual disabilities (O'Grady, 2007). In the Netherlands, the intellectual disability population made up 9% of the total disease-specific cost of care in 1994 (Polder et al., 2002). Added to the cost of caring for such individuals is the fact that individuals with intellectual disabilities have seen longer life expectancies (McCallion & McCarron, 2004). However, they experience more health problems compared to non-disabled individuals paired by age and sex (van Schrojenstein Lantman-de Valk et al., 1997). Hand (1994) found that in New Zealand for the ageing population of individuals with intellectual disabilities (i.e., those born before 1940), epilepsy, cerebral palsy and neurological impairment were the most common physical impairments. Forty-two percent of the sample did not have any major or chronic physical impairment. Other common physical impairments reported were hearing and visual impairments, heart disease, mobility issues, diabetes, fractures and osteoporosis (Hand, 1994).

Individuals with intellectual disabilities are also at a greater risk for developing a mental illness than non-disabled individuals (Borthwick-Duffy & Eyman, 1990). Those who have an intellectual disability comorbid with mental illness and/or behavioural problems [henceforth collectively termed, mental health problems] are considered to have a 'dual diagnosis' (Yu & Atkinson, 1993). Although the prevalence for dual diagnosis

varies by sample, studies estimate that mental health problems affect 10 to 40% of adults with intellectual disability (Reiss, 1990). Individuals with more severe intellectual disabilities are less likely to be given a dual diagnosis than those with mild intellectual disabilities (Borthwick-Duffy & Eyman, 1990). It may be that for those with severe intellectual disabilities, evaluations of mental health problems are more challenging. Mental health professionals have a tendency to ascribe behaviour problems, which may be arising out of behaviour disorders, to being symptomatic of the individual's intellectual disability (Biasini et al., 1997).

Along with morbidity issues that differ from the general population, those with intellectual disabilities also have differing mortality rates than the general population. In a study investigating the mortality rates of individuals with intellectual disabilities, the mortality rates of those with Down syndrome were comparable to the typically developing population until the age of 35 years (Strauss and Eyman, 1996). However, the mortality rates doubled every 6.4 years for those with Down syndrome as compared to every 9.6 years for those without Down syndrome (Strauss and Eyman, 1996). Frid et al. (1999) reported that the common causes of death for those with Down syndrome were congenital abnormalities, respiratory infections and neonatal complications. The age-specific standardized mortality rates for individuals with intellectual disabilities were found to be higher than in the general population, regardless of gender (McGuigan et al., 1995).

#### **1.2.4 Relevance of stigma to intellectual disabilities**

From a sociological perspective, stigma is a social process that negatively labels an individual. This labeling occurs due to an attribute that is perceived as a *mark*, such as intellectual disabilities or mental health problems which subsequently devalues the individual's identity within their society (Goffman, 1963). Link and Phalen (2001) more recently defined stigma as a process that allows not only for labeling, but also leads to stereotyping, separation, status loss and discrimination within a power situation. Specific to defining stigma, the setting of a *power* situation [i.e., imbalance] is the likely trigger for a *negative* label. Thus, the conceptualization of stigma is not only contingent on the label [i.e., identifying mark/disability] but the *process* of labeling as well [i.e., the identified responding to actions of the identifier]. Additionally, the *process* of labeling can be examined through two areas. One can either examine the group which partakes in labeling (e.g., society), or the group which is identified/identifies with said label (attached to disability).

#### **1.2.5 Stigma by association**

As well, stigma has far-reaching consequences that go beyond the stigmatized individual, affecting those closely associated with them. This is known as 'courtesy stigma' (Goffman, 1963) or 'stigma by association' (Mehta & Farina, 1988). Thus, further entangling the matter is when stigma is indirectly identified, such as in stigma by association, where the type of relation plays a role.

Social support most often comes from caregivers and family members who are active participants in the lives of the individuals with intellectual disabilities. Parents are often the primary social support for such individuals. Those who are parents of adults

with intellectual disabilities in Canada today, have had unique experiences. They have dealt with their child's condition since its early onset and have lived through a period of significant changes in outlook with regards to care for individuals with intellectual disabilities as their child has become an adult. Their experiences would reflect how they coped with such changes and how stressors associated with parenting a child with intellectual disability influenced their perceptions. Of particular interest, are parents' perceptions of their own caregiving role, the impact on their family, their social contacts, the impact on their child with special needs, and their perceptions of society.

Qualitative studies have shown that parents of individuals with intellectual disabilities do experience stigma (Kearney & Griffin, 2001; Grey, 2002). Stigma increases the perceived burden of caregiving tasks in parents (Green, 2003) and parents sometimes blame themselves for their child's condition (Mak & Kwok, 2010). Yet, far less quantitative research has been done looking at the effects of stigma on these individuals - the parents of individuals with intellectual disabilities.

### **1.3 Rationale:**

For individuals with intellectual disabilities, the role of the primary caregiver falls on the parents, and will likely continue on even as these individuals become adults. As previously mentioned, parents were one of the key advocacy groups for recognition of needs, in terms of support and services, for such individuals. As primary caregivers, parents' advocacy for better support and services for their children speaks to the gaps in their own unmet needs in being able to provide sufficient care for their children. When compared to parents of typically developing children, a predictor for morbidity of mental health problems (depression and anxiety) in parents of individuals with intellectual disabilities has been caregiver burden (Gallagher et al., 2008). As their children age and become adults, new sets of caregiving challenges are likely to appear. Individuals with intellectual disabilities are living longer, meaning their parents are taking on caregiving at an even older age. Compounded with the fact that co-morbidities for physical ailments and mental health disorders are higher in those with intellectual disabilities than in typically developing individuals, these parents have to additionally provide for and navigate such manifestations of added disabilities. It is thus necessary to understand the parents' experiences; especially possible barriers to their caregiving experiences, such as stigma.

To understand this further, we undertook a literature review which is presented in the next chapter. We reviewed the literature surrounding the nature of stigma, examples of stigma via comparison of stigma in intellectual disabilities with the related, but more prolific, stigma research on mental illness. We also looked at research evaluating stigma's effect on family members (stigma by association) along with a brief overview of the availability of measurement tools to quantify such experiences. This provides insight into

the current state of research looking at stigma experiences of parents of adults with intellectual disabilities.

## CHAPTER 2: LITERATURE REVIEW

### 2.1 The Nature of Stigma

The term ‘stigma’ is used to refer to a mark of social disgrace. Its roots lie in ancient Greece, where *stizein* was a physical mark placed on slaves in order for the public to identify their position and social standing, as indicative of their lower social value. The Latin word for it became *instigare* which means ‘to urge’, meaning that the marking would lead to an action; an act of devaluation against the stigmatized individual (Lopez-Ibor, 2002).

In modern society, Goffman (1963) first conceptualized stigma as a mark of social disgrace in which the marked person was discredited or tainted on the basis of attributes such as mental health problems, physical disability, intellectual disability, ethnicity, or drug use. Those who bore a stigma were perceived as different from others and of a ‘less desirable kind’. As such, the process of stigmatization starts with an acceptance of the labeled difference by others, which leads to devaluation of the individual.

Of direct relevance to this thesis, stigma may also affect individuals, such as family members or even health care providers, who are closely associated with the stigmatized person (Ostman & Kjellin, 2002; Goffman, 1963).

Having a disability can become a two-fold challenge for an individual. Firstly, one has to navigate in a primarily able-bodied society and face its accompanying struggles. Additionally, society’s misconceptions about disability, rising from stereotypes and prejudice, can lead to discrimination. Within this milieu, stigma becomes an important topic of focus.

Sociologists have focused on stigma as a societal phenomenon rising from the labeling of a person, which creates and maintains the disability or difference. Labeling theory, first conceptualized by Howard Becker in his book *Outsiders* (1963), posits that the behaviours and process of self-identification by an individual is dependent on the influence of the terms used to label or classify the individual. Scheff (1968; 1984) first applied labeling theory to mental health problems and suggested that a label could create deviance as a consequence of society's response to the labeled individuals. In the case of mental illness, this meant that a diagnostic label could trigger negative social stereotypes and stigmatizing responses which could, in turn, *create* a mental illness. Jones et al. (1984) conceptualized stigma as occurring when a mark or label linked an individual, due to his or her attributes, to undesirable characteristics. They outlined six dimensions of stigma: concealability, course (whether the deviance was reversible with time), disruptiveness, aesthetics (to what degree the perceived label elicited disgust), origin (how the deviance came to be) and finally, peril (to what degree the mark elicited feelings of fear and danger in others) (Jones et al., 1984).

Critics of labeling theory pointed out that diagnostic labels were not to blame. It was the disorganized illness-related behaviour, rather than the diagnosis per se, that triggered social stigma and discrimination. Modified labeling theory (Link et. al., 1989; Link & Phelan, 2001) has since reconceptualized the labeling process and allows for both possibilities. From this perspective, stigma is viewed as a complex social process in which cognitive, emotional, and socio-structural elements converge within a power situation, first to label, then to stereotype group differences; next to invoke prejudicial reactions; then to create a separation between 'us' and 'them'; and finally result in status loss and discrimination. Internalization of stereotypes by the labeled individuals and the

resulting marginalization can exacerbate their existing conditions and increase their vulnerability to additional disorders.

In comparison to sociologists, such as Goffman or Link, social psychologists are interested in the cognitive and emotional processes that give rise to stigma, known as stereotyping and prejudice, which may lead to discrimination (Dovidio, Major & Crocker, 2001). Stereotyping represents the collective concept of groups of persons, and effectively allows people to make quick generalizations and expectations of individuals belonging to the stereotyped group (Hamilton & Sherman, 1994). Prejudice, however, occurs when people agree with stereotypes and, consequently, develop an emotional reaction to the stereotype (Corrigan et al., 2001). When people act on their prejudice, they demonstrate discrimination (Corrigan et al., 2001). From this perspective, the term stigma is often used to refer to negative and prejudicial attitudes, whereas discrimination is reserved for the behavioural outcomes. Additionally, Corrigan and Watson (2002) outline two major components to stigma: a public stigma, and self-stigma. The former is when the general public has a reaction towards individuals with the deviance, and the latter is when the individual applies the prejudice to self, leading to self-imposed marginalization and withdrawal. It is important to note that in cases of self-stigma, the individual not only applies the prejudice to self, but, also forms an identification with the 'deviant group' (Jacobsson, 2002). Thus, stigma begets stigma (Lopez-Ibor, 2002).

Self-stigma and fear of rejection by others can lead to an individual avoiding social situations and failing to pursue opportunities such as employment and housing (Corrigan & Watson, 2002b). Studies have also shown a negative correlation between self-stigma and self-esteem such that higher levels of self-stigma were associated with lower levels of self-esteem (Abraham et al., 2002; Holmes & River, 1998; Crocker &

Major, 1989). However, for some individuals, the effect of self-stigma may lead them to become ‘righteously angry’ towards the perceived prejudicial treatment, which empowers them to become advocates for fair treatment (Corrigan & Watson, 2002). Additionally, the reaction to stigma for some others is neither one of hurt, nor one of empowerment, but, general apathy and indifference to stigma (Corrigan & Watson, 2002).

Another approach to looking at stigma is by looking at ‘public stigma’. Public stigma can have four types of consequences, as suggested by Corrigan and Watson (2002): withholding help, coercive treatment, avoidance and segregated institutions. Such process of stigmatization leading to discrimination towards individuals (for example, those with mental illness) can create barriers in access to health care (Corrigan, 2000), housing opportunities (Angermeyer et al., 2003), or even, employment (Corrigan & Penn, 1999).

In developing a public health oriented model of the process of stigma, Sartorius (1999) suggests that stigma is a cycle of disadvantage. It begins with the condition which manifests into a disability or impairment within society, such that stigma gets linked to the condition as an impairment. This leads to discrimination which can reduce an individual’s ability and opportunity for rehabilitation. In turn, such barriers can create a malfunction in the individual’s social role such that the condition and its impairment are more pronounced and the cycle starts again. Relevant to stigma by association, Sartorius and Schulze (2005) also describe a ‘vicious cycle’ of stigma that reduces a family member’s self-esteem, internal and external supports, and access to resources, which in turn diminishes their capacity to resist further stigma and provide social support for their relative with the condition.

The public health perspective on stigma is based on an ecological view that includes both individual-level cognitive and emotional determinants, as well as the broader psycho-social and political determinants of stigma. As such, public health interventions may target actions at the legislative, economic, policy, research and public awareness (education and communication) fronts (Stuart, 2008). For example, a report by Senator Kirby, *Out of the Shadows at Last* (2006), calls for the need for a national strategy to target mental illness in Canada, whereby he outlines the roadblocks towards promoting mental health; stigma being a main hurdle. He outlines that stigma not only affects community-based services and interventions, but that government also contributes to stigma (Kirby, 2006). As employers of mental health care professionals, the provincial government contributes to the stigma of mental illness by their treatment of the health care professionals. As well, he states that the federal government had lacked initiative to make mental health a national focus. This results in discrimination, as financial resources for advocacy, research, prevention, and intervention programs are also lacking at all levels of the government. In Canada, individuals with intellectual disabilities have health disparities that prevent them from coping as well as the general population (Ouellette-Kuntz et al., 2005). Some key health indicators which point to the disparities are issues with mobility, lack of access to health and other services, as well as society's perception of intellectual disabilities. In 2007, a report to the Mental Health Commission of Canada assessed stigma and discrimination and set forth recommendations to the government of Canada to tackle the issue (Mental Health Commission of Canada, 2007).

Even though intellectual disabilities have historically been classified under the category of mental health, specifically psychological disorders, initial interest in the study of stigma as it related to psychological disorders arose mainly from mental illness

advocacy groups. Most of our understanding of stigma and mental health is based on such mental illness research. As well, studies looking at stigma related to intellectual disabilities have often focused on this group by comparing to stigma in those with mental illness. The next section will review relevant literature dealing with stigma as broadly relating to mental health, with specific comparisons between mental illness and intellectual disabilities.

## **2.2 Stigma related to mental health problems and intellectual disabilities**

Research has demonstrated that people with mental illness and intellectual disabilities are among the most stigmatized of all social groups (Tringo, 1970; Thomas, 2000). It has been said that the consequences of stigma are more limiting, long-lasting and devastating than the illness or disability itself (Schulze & Angermeyer, 2003).

The public perceives people with mental illness as potentially violent and unpredictable (Royal College of Psychiatrists, 1999). Consequently, persons with mental illness are feared and there is a clear desire to limit social interaction (Link et al., 1999). While persons with an intellectual disability are frequently viewed as being more benign and less fearsome than those with a mental illness (Hartlage & Roland, 1971; Rubin & Roessler, 1983), they are less often perceived as stable (Corrigan et al., 2000), or as potential friends (Gordon et al., 2004). Altman (1981), in reviewing findings of past research, found that common stereotypes attributed to those with an intellectual disability were dependency, sadness, and isolation which reduced role expectations and led to restrictions on their behaviours and opportunities. In a study comparing the attribution ascribed to persons with a physical disability, with a mental illness, and with an intellectual disability, the latter were rated as least stable, while persons with a mental

illness were rated as least controllable (Corrigan et al., 2000). Some studies have found that knowledge and experience with members of a group (Corrigan et al., 2001) is inversely associated with prejudicial attitudes, both towards people with a mental illness (Holmes et al., 1999) and those with an intellectual disability (Tak-fai Lau & Cheung, 1999). These studies highlight the complex interaction between cognitions, attitudes, and socially discriminating behaviours.

A perspective less often taken by stigma researchers has been to look at the experience of stigma from the viewpoint of the stigmatized individuals (e.g., Chung & Wong, 2004; Dickerson et al., 2002; Stuart, et al., 2005; Stuart et al., 2008). To date, this research has focused disproportionately on those with mental illness, perhaps because persons with an intellectual disability often have serious communication impairments.

Persons with mental illness are aware of being stigmatized (Nuehring, 1979) and often report feelings of demoralization, low self-esteem, and low self-confidence about the future as a result of being negatively labeled (Holmes & River, 1998, Jones et al., 1984; Link, 1987). Some persons with an intellectual disability are also aware that they have a condition that is socially stigmatized. They report personal experiences of stigma (Jahoda & Markova, 2004), and may suffer a loss of self-esteem as a result (Abraham et. al., 2002). Research as old as thirty years has suggested that social interactions (Farina et. al., 1971), job seeking (Farina & Felner, 1973), and house hunting (Page, 1977) are among the many activities of daily life that are made more difficult for people with mental health related disabilities.

### **2.3 Family experiences of stigma**

Stigma is pervasive. It not only affects individuals who carry the stigmatizing label, but also others who regularly associate with them (Ostman & Kjellin, 2002; Goffman, 1963). For individuals with an intellectual disability, social support most often comes from family members who are active participants in their lives and who may themselves become targets for stigma (Lefley, 1987; Phelan et al., 1998; Struening et al., 2001). Thus, as previously mentioned, this process whereby an individual is stigmatized due to his or her association with a stigmatized individual is referred to as ‘courtesy stigma’ (Goffman, 1963) or ‘stigma by association’ (Mehta & Farina, 1988). For example, Mehta & Farina (1988) found that family members of individuals with mental illness felt that they could not disassociate with the stigmatizing situation because they, themselves, were not only the ‘marker’ but also the ‘marked’. By labeling their family member’s disability, they became the ‘marker’, and by association to that family member, they were also ‘marked’ by society.

Past family research in this area has generally been qualitative and focused on the stigma experiences reported by families caring for someone with a mental illness. Families have reported being avoided by others (Phelan et al., 1998) and feeling worried they would be blamed for their relative’s mental illness (Shibre et al., 2001). Stigma experiences were associated with feelings of hardship, psychological suffering, sleep disturbances, relationship disturbances, poor quality of life (Kadri et al., 2004), and low self-esteem (Wahl & Herman, 1989; Lefley, 1992; Shibre et al., 2001). Family members have also reported strains on extended family relationships, along with distancing of other relatives (Shibre et al, 2001; Struening et al., 2001). Especially for parents, guilt becomes

a manifestation of the internalization of stigma (Fink & Tasman, 1992; Turnbull & Turnbull, 1978).

To date, only one study has looked at the stigma experiences of caregivers (mothers, siblings, spouses and others) of individuals with a mental illness compared to those of individuals with an intellectual disability (Mak & Cheung, 2008). They used a 22-items scale to measure respondents' internalization of stigma with responses captured using a 4-point Likert scale (strongly disagree to strongly agree). They found that subjective burden, as perceived by the caregivers, was significantly related to levels of stigma in both groups (mental illness and intellectual disability).

Though less often studied, *parents*, as primary caregivers of children with intellectual disabilities, appear to report similar stigma experiences to those who have a family member with mental health problems. For example, Gray (2002) looked at two types of stigma experienced by parents of children diagnosed with high functioning autism. *Felt stigma* was defined as the internalization of the stigmatizing ideas leading to feelings of shame or fear of rejection (Gray, 2002). *Enacted stigma* was defined as experiences of overt discrimination and rejection (Gray, 2002). The majority of the parents reported feeling both types of stigma. Mothers were more likely to report stigma than fathers, with aggressive behaviour in their child playing a role in the amount of stigmatization that was felt (Gray, 2002). Birenbaum (1970) and Levinson and Starling (1981) found that parents of children with intellectual disabilities reported feeling socially excluded and having strained relationships. Sigelman et al. (1991) theorized that for family members with blood ties to a stigmatized individual, it may be perceived that family members share the gene responsible for the condition, thereby, tainting them.

Especially for parents, the perception may become that of self-blame for their child's stigmatizing condition (Mak & Kwok, 2010).

Other areas of research, though not directly looking at stigma, have evaluated the negative outcomes that a parent might experience when raising a child with an intellectual disability. Such negative outcomes include prolonged sorrow (Damrosh & Perry, 1989), altered self-concept (Childs, 1985), decreased self-esteem (Cummings, 1976), depression (Spangerberg & Theron, 2000), social isolation (Birenbaum, 1970), increased marital problems (Bristol et al., 1988) and issues surrounding employment such as delayed entry into the workforce or low employment rates (Seltzer et al., 2001).

However, parents of children with intellectual disabilities also report positive experiences which may mitigate stigma. Parents who reported anguish and sorrow while raising a child with an intellectual disability also spoke of positive impacts such as hope, strength, joy and love (Kearney & Griffin, 2001). Abbott and Meredith (1986) found that parents reported acquiring strength from raising a child with an intellectual disability in the form of increased patience, increased compassion and greater appreciation for the simple things in life. These studies suggest that in order to understand the impact of having a child with an intellectual disability, we must look at negative (e.g., stigma), as well as positive experiences of parents.

Finally, the impact of stigma on family members may vary (Gray, 2002; Sigelman et al., 1991) though the factors that might predict this have not been systematically studied. Research into coping strategies has shown that family members may use different tactics such as concealment to avoid shame and stigma (Phelan et al., 1998; Angermeyer et al., 2003; Ohaeri & Fido, 2001; Shibre et al., 2001; Stengler-Wenzke et al., 2004).

These studies show that family members can experience considerable social isolation and emotional distress because of stigma (Ablon, 1990; Blum, 1991; MacRae, 1999).

An area of research which incorporates the effects of stigma by association has been research on the caregivers' experiences (burden). Through such research, we have seen initial attempts at measuring some aspects of stigma by association in parents of individuals with mental health-related disabilities.

#### **2.4 Availability of Measurement Tools**

In most studies focusing on caregivers, stigma has been assumed to be a contributing stressor in caregiver burden. This is illustrated mainly through research in caregiving of individuals with mental illness. For example, Greenberg et al. (1993) asked mothers of individuals with schizophrenia questions about stigma indirectly as part of a measurement of caregiver burden, and found that lower levels of physical well-being in the mothers were related to subjective burden of stigma and worrying. Szmukler et al. (1996) included a 5-item stigma scale which was part of a larger inventory measuring the caregiving experiences of family members of individuals with mental illness. They found that stigma was one of the dimensions that made up the multidimensional construct of "caregiving experiences".

Struening et al. (2001) developed a 7-item scale that looked at the extent to which family members believed that society devalued families with a member who had a mental illness. They found that 70% of the caregivers felt that most people devalued their family member with a mental illness, while 43% felt that most people devalued *them*, the family members of those with a mental illness. Green (2003) incorporated qualitative and quantitative approaches to evaluate stigma by association in families of children (under

18) with disabilities. She found that maternal perceptions of stigmatization against individuals with disabilities increased maternal distress (subjective burden). Children of mothers who perceived high levels of stigma were found to be less interactive with peers in informal social settings.

At the time of the present study, there were no measurement tools identified in the literature aimed to directly measure experiences of stigma in caregivers of individuals with an intellectual disability. Subsequently, one study has been published. Mak and Cheung (2008) looked at stigma experiences in caregivers of individuals (children and adults) with either an intellectual disability or a mental illness. They proposed that the internalization of stigma by family members be known as *affiliate stigma*, distinguishing it from stigma by association which may or may not be internalized psychologically at the individual level, even if reported present. Within the cultural milieu of Chinese society, caregivers, including mothers, siblings, spouses, and others, completed a self-administered questionnaire comprised of scales measuring affiliate stigma, caregiving stress, subjective burden and positive perceptions. They found that only in the intellectual disability group of caregivers (i.e., mothers only), was there a significant negative relationship between affiliate stigma and positive perception of caregiving, which failed to be seen in the other group of caregivers (i.e., family members, such as parents, spouse, siblings, children, and others, caring for those with a mental health problem).

## 2.5 Implications

In summary, tools aimed to measure stigma by association in caregivers of individuals with mental health-related disabilities have mainly focused on mental illness with only one recent tool focusing on intellectual disabilities (Mak & Cheung, 2008). As well, no studies have looked specifically at *parents of adults* with intellectual disabilities. Phases of caregiving bring significantly different stressors depending on whether the individual being cared for is a child or an adult. With all the considerations of past research and our direction of interest for a public health perspective of stigma in parents, we looked to the field of research in stigma by association due to mental illness to offer us a psychometric tool that could be adapted to capture stigma experiences in our current study's sample of parents of adults with intellectual disabilities (Stuart, et al., 2005; Stuart et al., 2008).

### CHAPTER 3: GOALS AND OBJECTIVES

There are two primary goals for this current study, with each containing objectives for fulfilling those goals.

The two goals are:

(1) To test psychometric properties of three scales aimed to measure experiences of parents of adults with intellectual disabilities.

***Objectives:***

(a) The first objective was to perform reliability testing; specifically, evaluating the internal consistencies of three scales aimed to measure stigma and positive changes experienced by parents.

(b) The second objective was to test the inter-correlation between all three scales.

(2) To describe the parents' experience of having an adult child with an intellectual disability.

***Objective:***

(a) Through sub-group analysis, possible associations between descriptive characteristics of the sample and items measuring experiences of stigma were evaluated.

## **CHAPTER 4: STUDY DESIGN AND METHODS**

### **4.1 Study design**

This cross-sectional study surveyed a sample of parents of adults with intellectual disabilities in South Eastern Ontario, Canada. The survey was self-administered and took approximately thirty minutes to complete. The Queen's University Research Ethics Board approved this study (see Appendix A for a copy of the certificate).

### **4.2 Sampling strategy**

Potential parent participants were identified through information about their adult child with an intellectual disability, contained within the Geographic Registry in Intellectual Disability (GRID). GRID is a database of anonymized information about individuals with intellectual disabilities within the six counties of South Eastern Ontario, Canada, who are using, or waiting for, supports and services offered by 36 community-based agencies. The information is updated annually and the database is maintained by the South Eastern Ontario Community-University Research Alliance in Intellectual Disabilities (SEO CURA in ID; [www.seocura.org](http://www.seocura.org)).

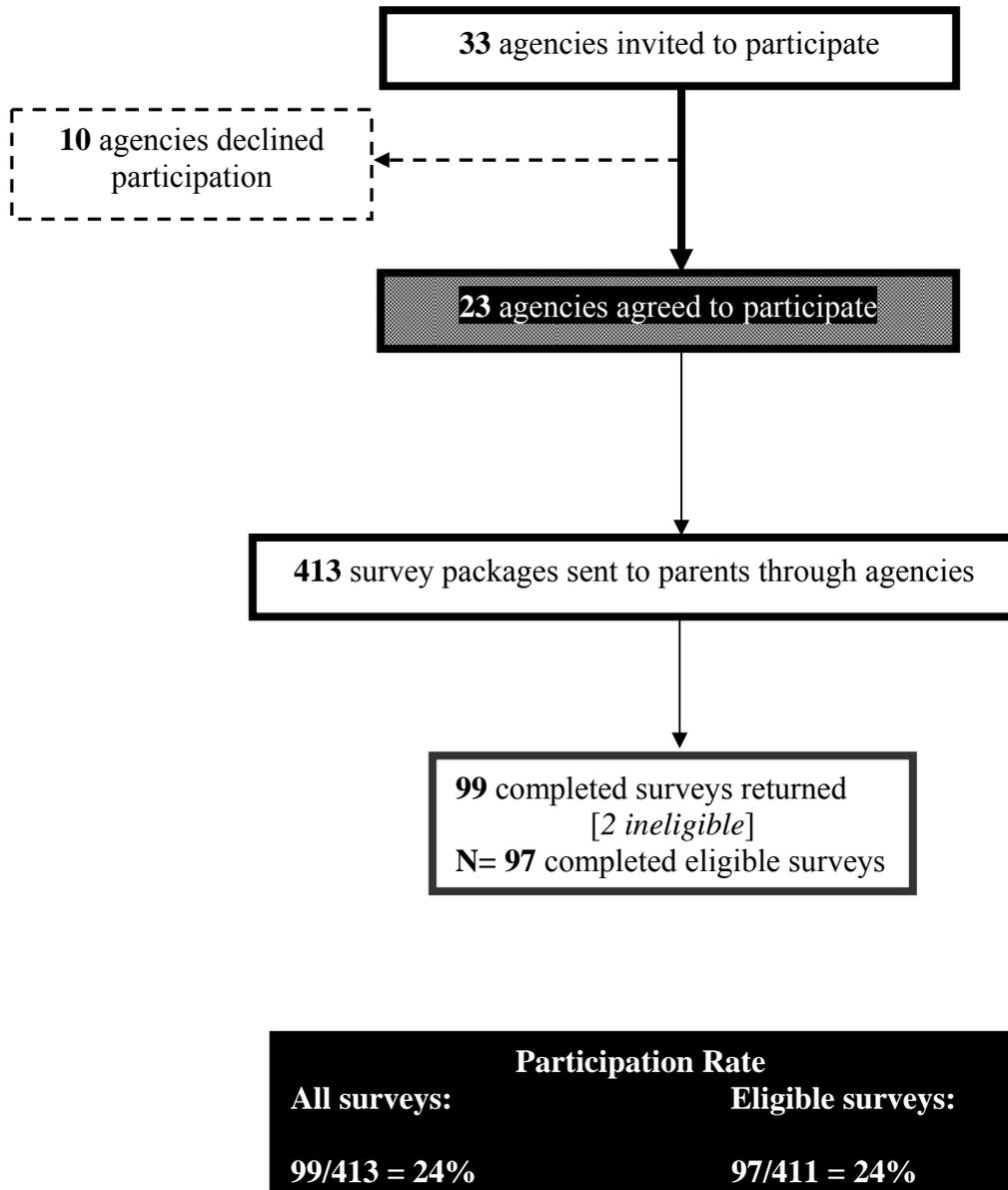
Although 36 agencies provide data for the GRID database, only 33 of those agencies serve adults with intellectual disabilities, while the rest serve children only. The 33 agencies were sent an initial invitation (see Appendix B) to participate in the current study. Agencies that agreed to participate (23 in total) were sent a letter along with a list compiled through GRID of all adult clients served by them (see Appendix C). The list identified the adult clients through an agency number, initial of last and first name, residential setting, date of birth and gender. Staff from the agency indicated for which

adults the agency had contact information for a parent who was eligible for this study and mailed the list back to the investigators. The investigators then sent a letter of instruction (see Appendix D) and the appropriate number of packages to the agency contacts, who mailed the packages, on the investigators' behalf, to those potential parent participants previously identified by the agency.

The survey package included a cover letter (see Appendix E), a response booklet, i.e., the survey questionnaire (see Appendix F), which consisted of two parts, and a postcard (see Appendix G). The postcards were included to identify those participants who were interested in the results of the study. The participants were instructed to mail the postcard separately from the survey questionnaire so that their anonymity would be maintained.

A total of 413 packages were sent to the 23 agencies. The parent participants filled out and mailed back the completed surveys to the investigators using postage-paid envelopes provided within their survey packages. A total of 99 packages were returned between the recruitment times of November, 2008 to July, 2009. Of those 99 completed surveys returned, two were ineligible as they were not filled out by parents but other family members (grandparent, sister), giving a total of 97 usable surveys for the study. Thus, the participation rate for the study was 24%. The recruitment of participants is outlined in a flowchart (Figure 1).

**Figure 1. Recruitment flowchart**



### 4.3 Measures

As mentioned, the survey questionnaire consisted of two parts. The first part asked parents to provide information about their adult child with special needs including type of relationship to parent respondent (biologic, adoptive, step parent or other), whether the child lived with the parent, whether the child had ever lived or was currently living, in a group home or institution, the child's age, gender, specific type of disability and whether the child had ever been in conflict with the law. It also asked for socio-demographic information about the parent completing the survey, such as gender, year of birth, highest level of education, living arrangement (alone, with a spouse, a relative, unrelated person, or other), marital status, employment status and whether the parent had been the primary caregiver of the adult child with special needs. The second part consisted of *The Inventory of Stigmatizing Experiences: Family Version* (Stuart et al., 2008), containing two stigma scales, reworded to be appropriate for the current study population, and the *Parental Changes Subscale (The Life Management Survey Part III-Parental Changes Subscale, Scorgie & Sobsey, 2000)*.

The *Inventory* is comprised of 19 fixed-response items and 18 open-ended descriptive questions to provide qualitative data to give further insight to the scale questions. It consists of the *Stigma Experience Scale* and the *Stigma Impact Scale*. When tested in a Canadian population of family members of adults with severe mental health problems (n=61), 20% indicated that they had been personally stigmatized due to their relative's mental health problems while 52% reported that stigma had negatively affected their family's "quality of life" (Stuart et. al., 2008).

A pilot test of the *Inventory* was conducted once it was developed for the current study's population by asking a focus group of parents of adults with intellectual

disabilities for feedback on the scales. One comment was that the scales were ‘too negative’ and that to truly understand the scope of parents’ experiences, a positive scale should be included. Such recommendation is supported by research as well. For example, Kearney and Griffin (2001) found that the parents, although reporting anguish and sorrow, also reported positive impacts of having children with intellectual disabilities, including hope, love, strength, and joy. Thus, it was considered important to investigate the impact of stigma experienced by parents of adults with intellectual disabilities within a broader context that includes positive changes that may have resulted from caring for a child with a disability. Another study conducted in the same geographic region, which looked at the experiences of preschoolers and their parents as the children transitioned to school, applied a scale that captured positive experiences reported by parents (Clifford, 2007). The same scale, *The Life Management Survey Part III-Parental Changes Subscale* (Scorgie & Sobsey, 2000), was included in the current study to capture positive changes associated with having an adult child with a disability which was used to compare to stigma experiences.

#### **4.3.1 *Stigma Experience Scale***

As established by Stuart et al. (2008), the *Stigma Experience Scale* is a frequency scale based on 7 items which was developed to be applied to people who have serious mental health problems and are living in the community. Four items are scored on a 5-point Likert-type scale, ranging from ‘never’ to ‘always’. Items are then recoded into binary variables to reflect the presence or absence of each specific stigma experience such that ‘never’, ‘rarely’ and ‘sometimes’ are recoded as zero to reflect the absence of stigma,

and ‘often’ and ‘always’ are recoded as one to reflect the presence of stigma. The remaining three items are scored using the response categories (yes, no, unsure) and recoded to reflect the presence (yes) or absence (no and unsure) of stigma. Values are then summed across the seven items for a scale score ranging from 0 to 7. The coefficient of reliability for this scale was good (KR-20=0.76) when applied to family members of adults with serious mental health problems meaning that the scale achieved an acceptable level of internal consistency (acceptable being  $\geq 0.70$ ; Nunnally, 1978).

Dichotomizing the responses in the *Stigma Experience Scale* was done so that parents’ responses of stigma experiences could first be evaluated as either present or absent. The degree of their stigmatizing experiences would be subsequently captured using the *Stigma Impact Scale*.

#### **4.3.2 *Stigma Impact Scale***

The *Stigma Impact Scale* (Stuart et al., 2008) is an intensity scale based on 7 items. The items are rated on an 11-point scale ranging from 0 (no impact) to 10 (highest impact). The values for the items are summed, giving a scale score that ranges from 0 to 70. The coefficient of reliability for this scale was excellent ( $\alpha=0.93$ ) when applied to family members of adults with serious mental health problems which greatly surpasses the acceptable level of internal consistency.

### **4.3.3 Parental Changes Subscale**

The *Parental Changes Subscale* aims to measure the positive changes associated with having a child with intellectual disabilities. This scale consists of 18 items. Each item in the scale is rated on a 5-point Likert scale ranging from 1 (Strongly Disagree) to 5 (Strongly Agree), for a total score ranging from 18 to 90. For the current study, a response choice of ‘not applicable’ was applied to a question related to marriage. No reports of the internal consistency (reliability) for this subscale were found.

## **4.4 Data management**

Responses to questions were double-entered into a database using SPSS Data Entry Builder 4.0. Due to the sensitive nature of certain questions, all surveys were anonymous. As such, there was no possibility of follow-up with respondents for resolving missing data. A clean up of the database was initially performed by agreement between two investigators who corrected for obvious missing information for scale questions as inferred by answers to their related open-ended questions. For the rest of the scale questions, missing values were left unaltered. The number of missing values per scale item ranged from 1 to 7 for the stigma scales and from 1 to 18 for the *Parental Changes Subscale* once the above-noted corrections were performed. The *Stigma Experience Scale* had loss in sample size as, out of a total of 97 respondents, 82 responded to all items pertinent to this scale. For the *Stigma Impact Scale*, 93 out of 97 respondents responded to all items pertinent to this scale while for the *Parental Changes Scale*, only 51 out of 97 respondents answered all items within the scale. Two imputation techniques were applied

to the incomplete dataset: median imputation and hierarchical hot-deck imputation.

Median imputation is when the missing value is replaced with the median score of the observed values for that item within the total sample of respondents. Hierarchical hot-deck imputation (Aday & Cornelius, 2006) is a way of imputing data where sub-classes are created for respondents and non-respondents based on cross-classification of broader groups (e.g., age, gender, employment status). The non-respondent with the missing item is matched to a respondent based on matching sub-class grouping. If a match fails to be made, the more detailed subclass is collapsed to a broader grouping (e.g., age by gender only) until a match is found. In our study, we used the 13 descriptive parent and adult child characteristics to create sub-class groupings when performing hierarchical hot-deck imputation. If more than one match was found, we used the nearest neighbour (closest in dataset) to impute the missing value. The coefficients of reliability showed comparable results for each of the three scales between the original database containing the missing values and the databases with median imputation and hierarchical hot-deck imputation applied. This indicated that missing values probably did not affect the reliabilities of the three scales, and thus, the original data (i.e., without imputation) was used for analysis.

Certain demographic questions were recoded to either make the variable categorical (age) or the set of responses within a category were collapsed to manageable and meaningful subgroups, for analyses. Age of parent, which was a continuous variable, was made into a categorical variable, representing three age categories that also logically defined and divided our group of parents: 45-54, 55-64 and 65 years and up. The respondent's employment status was initially categorized as full-time, part-time, or not employed with the last category further specifying to reflect whether the respondent was a homemaker, a volunteer, retired, or other. This was recoded into a dichotomous variable

reflecting full-time and part-time employment as employed competitively while the rest of the responses reflected unemployed. The respondent's highest level of education was initially categorized as public school or less, some high school, completed high school, some college or technical training, completed college or technical training, some university, completed university and graduate or professional degree. Those whose highest education level was either some or completed public (n=8) did not differ significantly from those whose highest level of education was some high school or completed high school (n=40) for any of the seven items in the *Stigma Experience Scale* (see Appendix H for all contingency tables and their accompanying Fisher's exact test statistic with p-values). Thus, given the small sample of respondents representing the education category of "some or completed public school", this category was collapsed into a broader category including all respondents whose highest level of education ranged from either public school or less, some high school or completed high school. As such the eight categories representing the sample's highest education level were collapsed into three categories reflecting: (1) either some or completed public school or some or completed high school, (2) some or completed college or technical training, and (3) some or completed university or graduate/professional degree.

The parent's living arrangement initially reflected five categories: alone, with spouse or partner, with another relative, with an unrelated person and other. These five categories were collapsed to reflect three categories: alone, with a spouse or partner, and other. The parent's relationship to the adult child was initially categorized as biological parent, adoptive parent, step parent, or other, in which case the respondent was asked to specify. These four categories were collapsed to reflect two categories: biological parent or other. The adult child's age was also a continuous variable which was recoded into a

categorical variable reflecting four groups of adult children: 18-24, 25-34, 35-44 and 45 years and older. Mental health problem (including behaviour problems) in the adult child as reported by the parent was recoded as having a dual diagnosis.

#### **4.5 Data analysis**

Data were analyzed using SPSS 17.0. Descriptive statistics were performed including frequency distributions of parent and child characteristics.

*Objective 1a*): “The first objective was to perform reliability testing; specifically, evaluating the internal consistencies of three scales aimed to measure stigma and positive changes experienced by parents.”

For the *Stigma Experience Scale*, frequency of endorsement of scale items was presented where endorsement signified a recoded response corresponding to the dichotomous category where 1 reflects a presence of stigma. The median of the total scale score was calculated. The internal consistency of the scale was evaluated. First, the item-rest correlation for each scale item was analyzed along with the coefficient of reliability if the item was removed. Finally, Kuder-Richardson 20 statistic was computed for the *Stigma Experience Scale* due to the binary nature of the adjusted responses.

For the *Stigma Impact Scale*, the median of the total scale score was calculated. The median and range of responses were also evaluated at the item level. The item-rest correlations, alpha if item was deleted and the overall Cronbach’s alpha for the scale were also reported. The endorsement of a response, reflecting an impact ( $\geq 1$ ), was calculated

per item. As well, the distributions of the responses (possible range of 0-10), for each of the 7 items, were presented graphically.

The frequency of responses for each response category within an item in *The Parental Changes Subscale* were calculated and presented, along with the median for each item, the item-rest correlation and the alpha if an item was deleted. The overall median and range for the total score were computed for this scale. The number of missing responses, per item, was also noted and presented graphically. Finally, the Cronbach's alpha for the scale was calculated.

All analyses for the three scales were performed using only those respondents who answered all relevant items pertaining to the scale. The distribution of the total scores for each of the three scales was graphed to evaluate whether each appeared to be normally distributed (see Appendix I). If the sample size dropped noticeably (>10), cross-tabulations were performed between 13 descriptive characteristics of the respondent group and the non-respondent group to see whether there were any significant differences ( $p < 0.05$ ) between the respondents included in the scale analysis compared to the group of non-respondents. The statistics performed were chi-square analysis and when individual cell count was 5 or less, Fisher's exact test was applied in its place.

***Objective 1b***): “The second objective was to test the inter-correlation between all three scales.”

Spearman's rank order correlation was performed between the total scores on the *Stigma Experience Scale* and the *Stigma Impact Scale*, between the *Stigma Impact Scale* and the *Parental Changes Subscale* and finally between the *Stigma Experience Scale* and

the *Parental Changes Subscale* to evaluate whether there was a significant correlation between the scales. Graphical representations of the inter-correlations between the scales are presented in Appendix J.

**Objective 2a):** “Through sub-group analysis, possible associations between descriptive characteristics of the sample and items measuring experiences of stigma were evaluated.”

For each of the seven scale items in the *Stigma Experience Scale*, a contingency table analysis was performed against each of the thirteen categorical demographic variables: gender of child, age of child, relationship of parent to child, whether the child lived with parent respondent, whether the child ever lived or were currently living in a group home or institution, whether the child ever had a conflict with the law, dual diagnosis status of the child, age, gender, employment status, living arrangement, highest level of education of the parent respondent and whether the parent was the primary caregiver to the adult child. All chi-square analyses (or Fisher’s exact tests) that achieved a p-value of less than 0.05 are presented in text while the remaining analyses are presented in Appendix K.

Sample size calculations were performed before the study was undertaken. The focus of our sample size calculations were aimed to be able to meet our primary objective (1a) (see Appendix L). As such, power analysis was not conducted to determine the minimum sample size required to fulfill our secondary objective (2a) which is exploratory in nature.

## **CHAPTER 5: RESULTS**

### **5.1 Demographic information**

The total sample size was 97 but descriptive data for all respondents and their adult children were not available resulting in missing data for some categories.

Table 1 presents the characteristics of the parent respondents and the number of missing respondents for each category. For the parent respondent characteristics, most were mothers (78%), biological parents (90%) and slightly more than half (52%) of the respondents were seniors (i.e. 65 years or older), with respondent age ranging from 44 years to 89 years. Approximately three-fourths of the respondents were currently the primary caregivers of their adult child (76%). Most respondents lived with a spouse or partner (69%). The majority of respondents were not employed (72%), specifying that they were either retired or a homemaker, and 50% of the respondents had either undergone some or completed public school or some or completed high school for their highest level of education.

**Table 1. Characteristics of parent respondents, N=97**

<b>Characteristic of parent</b>	<b>n</b>	<b>%*</b>
Gender		
Male	21	22
Female	74	78
Missing	2	
Age group (years) – age range, 44-89 years		
<55	21	23
55-64	23	25
65 +	47	52
Missing	6	
Relationship to adult child		
Biological parent	86	90
Parent – other	10	10
Missing	1	
Highest level of education		
Some or completed public school or some or completed high school	48	50
Some or completed College or technical Training	31	33
Some or completed University	16	17
Missing	2	
Employment status		
Competitive employment	27	28
Not employed	69	72
Missing	1	
Primary caregiver of child through most of his/her life		
Yes	73	76
No	23	24
Missing	1	
Living arrangement		
Alone	22	23
Spouse/Partner	66	69
Other	8	8
Missing	1	
* % calculated out of valid replies		

Table 2 presents the characteristics of the adult children as reported by parents along with the number of missing items for each category. Approximately 60% reported that their child was male and the age of the adult children ranged from 18 to 67 years. Forty-seven percent of the adult children currently lived with their parents, even though, as seen in Table 1, 76% of the parents reported that they were the primary caregivers of their adult children. Thus, although three-fourths of the parents listed themselves as the primary legal caregivers to their adult children, not all of them had their children currently living with them. Forty-eight percent of the total sample of parents reported that their child was either currently living, or had lived, in a group home setting or institution. We could not ascertain how many respondents' children were *currently* living in those settings at the time of the study because our survey did not ask them to specify. Eighteen percent of the parents reported that their adult children had been in conflict with the law.

**Table 2. Characteristics of adult children as reported by parent respondents, N=97**

<b>Characteristic of adult child</b>	<b>n</b>	<b>%*</b>
Gender		
Male	59	61
Female	37	39
Missing	1	
Age Group (years) – age range, 18-67 years		
18-24	18	19
25-34	26	27
35-44	21	22
45+	31	32
Missing	1	
Does the adult child live with parent respondent?		
Yes	45	47
No	51	53
Missing	1	
Has the child ever lived in a group home or institution?		
Yes	46	48
No	50	52
Missing	1	
Has ever been involved in conflict with the law?		
Yes	16	18
No	75	82
Missing	6	
* % calculated out of valid responses		

Parents were also asked to report on the specific condition(s) their adult child had. Ninety-six of the ninety-seven parents reported specific condition(s) as pertinent to their child’s disability. Seventeen parents reported that their child had an autism spectrum disorder, 16 parents reported Down syndrome and 12 parents reported that their child had cerebral palsy. Thirty-two of the adult children had mental health problems in addition to their intellectual disability (33% of the total sample), with behaviour problems and anxiety disorder being the most common accompanying mental health problems. In

addition, some adult children lived with epilepsy or seizure disorder (n=23), vision impairments (n=18), hearing impairments (n=13), and/or mobility issues (n=18).

## **5.2 Psychometric testing of scales**

### ***5.2.1 Stigma Experience Scale***

Only those respondents who had a complete set of responses for all seven items were included in determining the internal consistency of the *Stigma Experience Scale*. Eighty-two of the 97 respondents met this criterion. This subgroup did not differ significantly from the non-respondents in terms of respondent and child characteristics (refer to Appendix M for all contingency tables and accompanying chi-square or Fisher's exact test statistics).

The overall scale scores (sum of all seven dichotomized items in the scale) ranged from 0 to 6 (out of a possible maximum of 7), with a median scale score of 1.

Table 3 reports the number and percentage of endorsement for each item in the scale, the item-rest correlation, the coefficients of reliability for the scale if each item is removed and the overall Kuder-Richardson coefficient of reliability for the scale scores.

For the 82 respondents, endorsement for each of the seven items within the *Stigma Experience Scale* ranged from 10% to 40%. Approximately a quarter of the parents responded that they believe that the average person is afraid of individuals with intellectual disabilities, that their son or daughter has been stigmatized due to his/her condition, or felt that stigma by association had affected their family's ability to interact with relatives, or their family's quality of life. In addition, forty percent of the parents

agreed that people think less of those with an intellectual disability, yet only 10% said that they felt personally stigmatized due to their child's condition. Three of the seven items on the *Stigma Experience Scale* fell below the 0.40 recommended level for item-rest correlation. Two of these items also had low endorsement: those querying whether the parents felt stigmatized due to their child's disability (endorsement: 10%, item-rest correlation: 0.37), and whether stigma affected the parent's ability to make or keep friends (endorsement: 17%, item-rest correlation: 0.30). The Kuder-Richardson coefficient of reliability (KR-20) for the *Stigma Experience Scale* was 0.70, which falls within the minimal acceptable range for reliability (Nunnally, 1978). None of the individual items significantly increased the overall KR-20 if they were to be deleted. The KR-20, if individual item was deleted, ranged from 0.63-0.70, with only one coefficient of reliability falling within the minimal acceptable range of 0.70 if the item was deleted (item: whether stigma affected respondent's ability to make or keep friends).

**Table 3. Reliability analysis of the *Stigma Experience Scale*, N=82**

Scale Item	Number of endorsements <sup>§</sup>	% Endorsed <sup>§</sup>	Item-rest correlation	KR-20 if item deleted
Do you think that people think less of those with an intellectual disability?*	33	40%	0.49	0.65
Do you think the average person is afraid of someone with an intellectual disability?*	23	28%	0.42	0.67
Has your child been stigmatized because of their intellectual disability?*	21	26%	0.56	0.63
Have you felt stigmatized because of your child's intellectual disability?*	8	10%	0.37	0.68
Has stigma affected your family's ability to make or keep friends?***	14	17%	0.30	0.70
Has stigma affected your ability to interact with your other relatives?***	24	29%	0.33	0.69
Have your experiences with stigma affected your family's quality of life?***	19	23%	0.44	0.66
* response categories: never, rarely, sometimes, often, always Recoded to dichotomous responses: 0 (never/rarely/sometimes) or 1 (often/always)				
** response categories: no, not sure, yes Recoded to dichotomous responses: 0 (no/not sure) or 1 (yes)				
<sup>§</sup> Endorsement of item: response corresponds to dichotomous category, 1				
<b>Kuder-Richardson (KR-20) reliability coefficient = 0.70</b>				

### 5.2.2 *Stigma Impact Scale*

Only those respondents who had a complete set of responses for all seven items were included in the analysis of reliability for the *Stigma Impact Scale*. Ninety-three of the 97 respondents met this criterion. The range of possible responses for the sum of all seven items in the scale was from 0 to 70, with the range of responses for each item scaling from 0 to 10. The total median scale score was 13. At the item level, the median scores for all items were 1 except for the item asking about the impact of stigma on the respondent, personally, with regards to social contact, for which the median was 2.

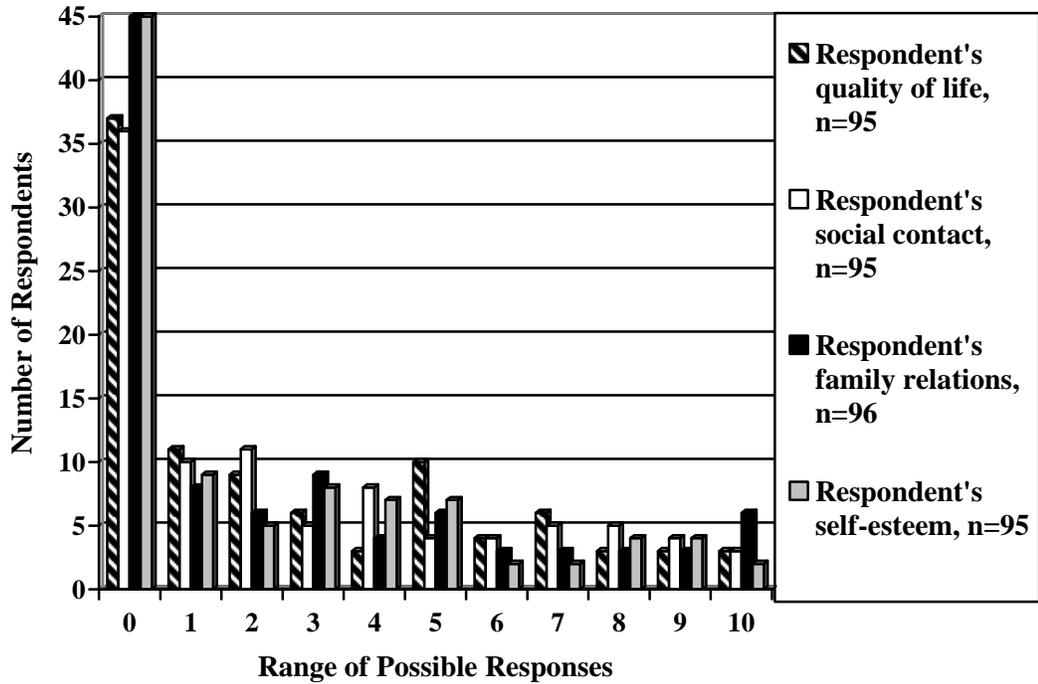
Table 4 reports the item-rest correlation coefficients for each item, the alpha if the item is removed, as well as, the reliability coefficient for the scale. Item-rest correlation coefficients ranged from 0.74 to 0.91. The Cronbach's alpha, coefficient of reliability, for the *Stigma Impact Scale* was 0.95, indicating excellent internal consistency of the scale scores. As reported in Table 4, removing any one of the seven items from the scale still maintained an alpha within the range of 0.94-0.95.

**Table 4. Reliability analysis of the *Stigma Impact Scale*, N=93**

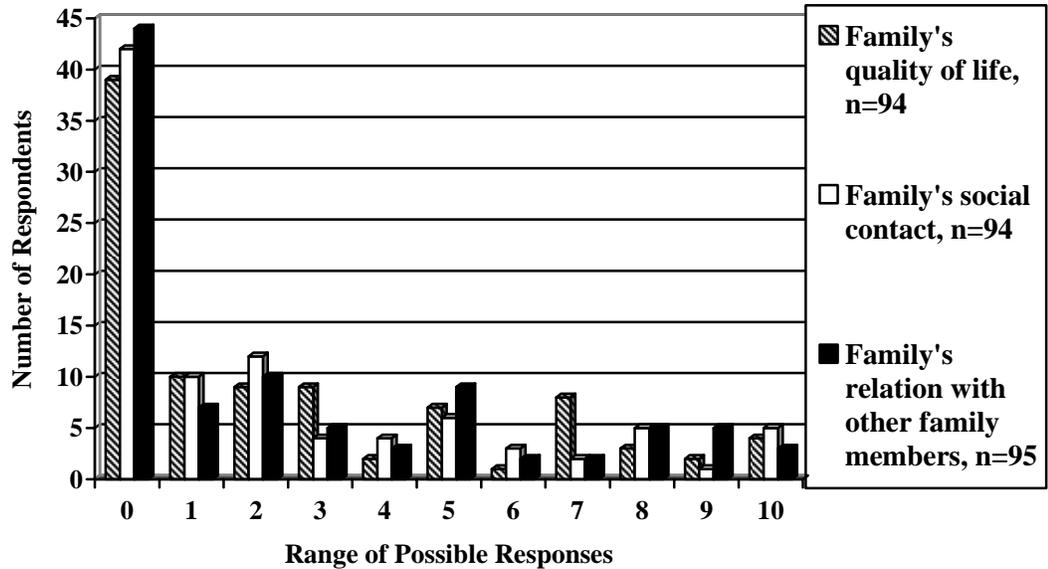
Scale Item	Item-rest correlation	Alpha if item deleted
<i>On a 10-point scale, where 0 is the lowest possible amount, and 10 is the highest possible amount, how much has stigma affected you personally?</i>		
Quality of life	0.87	0.94
Social contacts	0.85	0.95
Family relations	0.82	0.95
Self-esteem	0.74	0.95
<i>On a ten-point scale where 0 is the lowest possible amount, and 10 is the highest possible amount, how much as stigma affected your family as a whole?</i>		
Quality of life	0.91	0.94
Social contacts	0.87	0.94
Family relations	0.84	0.95
Cronbach's alpha reliability coefficient = <b>0.95</b>		

Additionally, for the total sample of respondents, the percentages of people who endorsed an impact score of  $\geq 1$  for individual items, ranged from 54% to 63% across the seven items. This indicates that over half of the respondents reported some level of impact of stigma (i.e., a score ranging from 1 to 10), for each individual item within the *Stigma Impact Scale* (see Figures 2 and 3). However, as one response category out of a possible eleven (range of responses, 0-10), a response of no impact (i.e., 0) was chosen by over 30% of the respondents, for each item, with no other response categories achieving such high endorsements.

**Figure 2. *Stigma Impact Scale* - Frequency of responses at item level  
(impact on respondent)**



**Figure 3. *Stigma Impact Scale* - Frequency of responses at item level  
(impact on respondent's family)**



### ***5.2.3 Parental Changes Subscale***

Only those respondents who had a complete set of responses for all eighteen items were included in the analysis of reliability for the *Parental Changes Subscale*. Fifty-one of the 97 respondents met this criterion. In terms of parent respondent and child characteristics, this subgroup differed significantly from the non-respondents in terms of the age, employment status, level of education and living arrangement of the respondent, as well as the age of the adult child (see Appendix N for all contingency tables and accompanying chi-square or Fisher's exact test statistics). Seniors (60%) were more likely to not respond to all the questions in the *Parental Changes Subscale*. Those who were employed (70%) were more likely to answer all 18 items. In terms of level of education, respondents who had either only some or completed public school or had some high school education or graduated from high school, were less likely than those who reported higher levels of education to respond to all the items within the scale (62% of the respondents with the lower level of education did not respond to all items). Those respondents who lived with a spouse or partner (65%) were more likely to answer all items within the scale compared to respondents who lived alone (27% did not answer all items) or with other relations (25% did not answer all items). Respondents with older adult children (aged 45 years and up) were more likely to answer all questions in the *Parental Changes Subscale* than respondents with adult children aged 18 to 34 years.

For the 51 respondents who responded to all items within the scale, the range of responses for the sum of all 18 items in the scale was between 35 to 90 with minimum possible score of 18 and a maximum of 90. The median for the total score was 69.

Table 5 reports on all 51 respondents' percentage endorsement for each of the five response categories per item, the median score for each item, the item-rest correlation per item, the coefficient of reliability if the item was removed and the Cronbach's alpha for the scale given all 18 items.

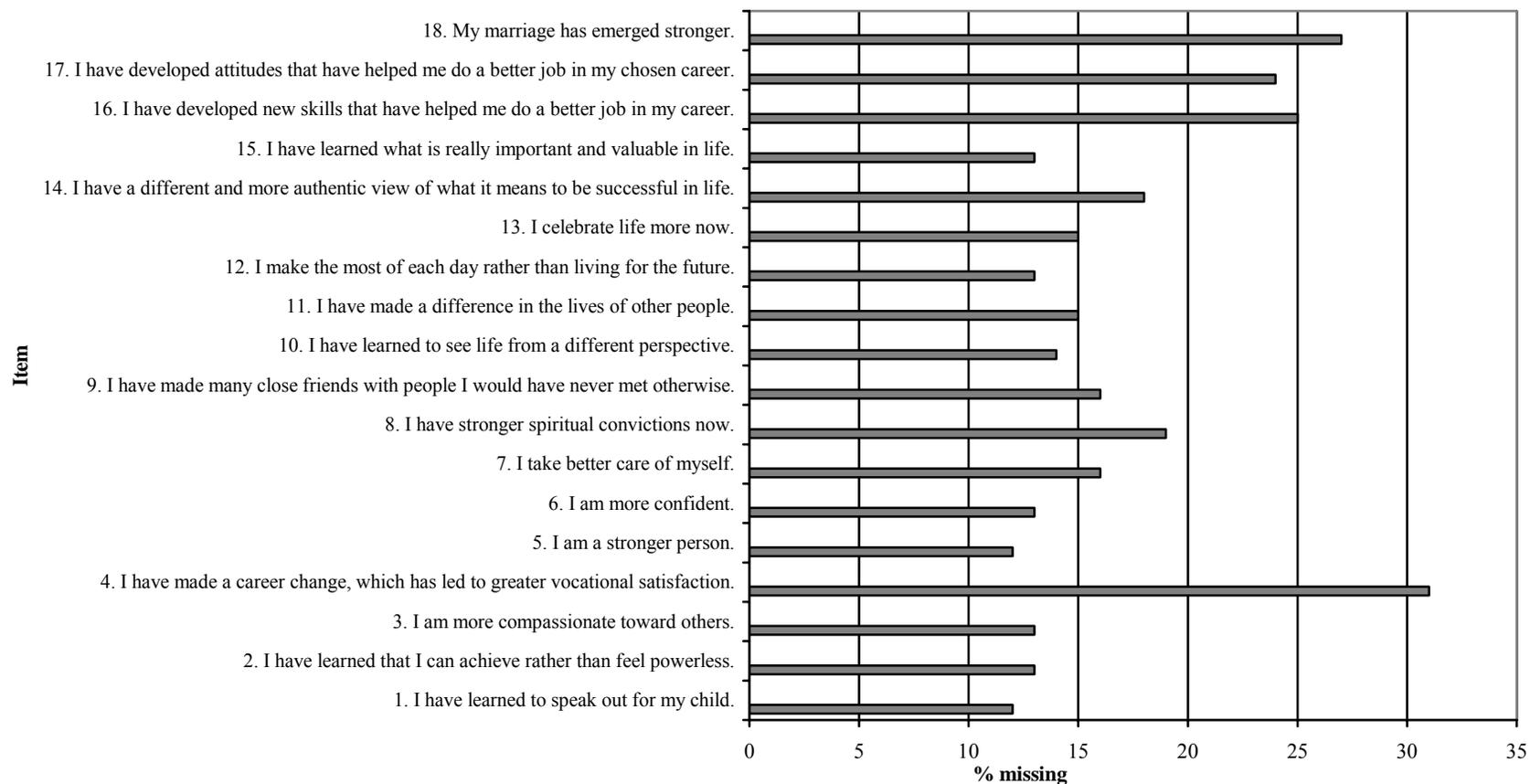
Median scores of 5 were achieved for four of the eighteen items when parents reported positive changes in themselves, due to their child, in the following ways: (1) learned to speak out for their child, (2) became a stronger person, (3) became more compassionate towards others, and (4) learned to see life from a different perspective. For only one item, the item-rest correlation dropped below the acceptable level of 0.40 to 0.31 (item: marriage emerged stronger due to child's disability). Alpha if an item was removed stayed within the range of 0.92-0.93 for all eighteen items in the scale. The Cronbach's alpha for the *Parental Changes Subscale* was 0.92.

Endorsement for each of the five response categories, at the item level, showed that for the majority of the items, parents mostly agreed or strongly agreed with each of the 18 items. However, 24% of the parents strongly disagreed that caring for their adult child led to a vocational or career change. Responses from parents evenly ranged across all response categories when asked if they made close friends due to their child's condition, if they felt a change towards stronger spiritual conviction and if they felt that their marriage emerged stronger due to their child's disability. Thus, there were no trends in positive changes, for those domains, due to their child's disability. Out of the three scales, the *Parental Changes Subscale* experienced the largest number of missing items. Questions which asked about the respondent's marriage and vocation/career had over 20% missing for those items (see Figure 4).

**Table 5. Reliability Analysis of the Parental Changes Subscale, N=51**

<b>Parental Changes Subscale</b> <i>Responses:</i> 1- strongly disagree, 2- disagree, 3 – don't know, 4- agree, 5 – strongly agree	<b>% endorsement of response categories</b>					<b>Median</b>	<b>Item-rest correlation</b>	<b>Alpha if item removed</b>
	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>			
1. I have learned to speak out for my child.	2	2	4	34	58	5	0.53	0.92
2. I have learned that I can achieve rather than feel powerless.	5	2	12	43	38	4	0.57	0.92
3. I am more compassionate toward others.	1	1	3	25	70	5	0.52	0.92
4. I have made a career change, which has led to greater vocational satisfaction.	24	22	24	16	14	3	0.69	0.92
5. I am a stronger person.	2	1	6	40	51	5	0.69	0.92
6. I am more confident.	5	5	19	41	30	4	0.73	0.92
7. I take better care of myself.	6	8	30	41	15	4	0.54	0.92
8. I have stronger spiritual convictions now.	11	22	15	25	27	4	0.64	0.92
9. I have made many close friends with people I would have never met otherwise.	9	22	20	22	27	3	0.50	0.92
10. I have learned to see life from a different perspective.	2	5	6	34	53	5	0.66	0.92
11. I have made a difference in the lives of other people.	6	16	26	28	24	4	0.77	0.92
12. I make the most of each day rather than living for the future.	2	4	21	43	30	4	0.58	0.92
13. I celebrate life more now.	4	11	24	34	27	4	0.71	0.92
14. I have a different and more authentic view of what it means to be successful in life.	1	9	21	46	23	4	0.68	0.92
15. I have learned what is really important and valuable in life.	1	1	7	51	40	4	0.70	0.92
16. I have developed new skills that have helped me do a better job in my career.	4	19	29	25	23	3	0.78	0.92
17. I have developed attitudes that have helped me do a better job in my chosen career.	4	14	24	34	24	4	0.74	0.92
18. My marriage has emerged stronger.	13	15	13	32	27	4	0.31	0.93
Cronbach's alpha reliability coefficient = <b>0.92</b>								

**Figure 4. Percentage of missing respondents for each item in the *Parental Changes Subscale* , N=97**



#### **5.2.4 Inter-correlation between scales**

The total scores from the two scales, *Stigma Experience Scale* and *Stigma Impact Scale*, were positively moderately correlated. Spearman's rank order correlation was 0.67 ( $p=0.01$ ,  $n=79$ ) showing the scales share a degree of common variance but measure slightly different constructs. However, the score from the *Stigma Experience Scale* was not correlated with the score from the *Parental Changes Subscale* since the Spearman's rank order correlation was -0.009 ( $p=0.95$ ,  $n=46$ ). The *Parental Changes Subscale* score was not correlated with the *Stigma Impact Scale* score as its Spearman's rank order correlation was -0.03 ( $p=0.84$ ,  $n=49$ ). Although neither of the stigma scales achieved significant correlations with the *Parental Changes Subscale*, which measures positive changes undergone by parents of those with a disability, the direction of correlations hinted at a negative association. For a graphical representation of three inter-correlations, see Appendix J.

### **5.3 Association between characteristics of respondents and experiences of stigma**

The association between each of the thirteen descriptive variables of parent and child characteristics and each of the seven items in the *Stigma Experience Scale* were evaluated using a chi-square analysis or Fisher's exact test when individual expected cell count was 5 or less. Out of all 91 analyses, only those that reached statistical significance at  $p$ -values  $<0.05$  are presented in Tables 6 to 17 (see Appendix K for the rest of the contingency tables and their chi-square or Fisher's exact test statistics).

Seven descriptive variables were found to be associated with one or more scale items: gender, age and employment status of the parent; and the age and dual diagnosis

status (having both an intellectual disability and a mental health problem) of their adult child.

The parent’s gender was significantly associated with whether stigma affected the parent’s ability to interact with other relatives as shown in Table 6. Mothers (32%) were more likely to report that stigma affected their ability to interact with other relatives as compared to fathers (10%).

**Table 6. Association between gender of parent and whether stigma affected parents’ ability to interact with other relatives, N = 93**

Descriptive characteristic of parent	<i>Stigma Experience Scale Item - Whether stigma affected parent’s ability to interact with other relatives</i>			Fisher’s exact test statistic, p-value
	Yes	No	Total	
<b>Gender of parent</b>				<b>4.2, 0.04</b>
Male	2 (10%)	19 (90%)	21 (23%)	
Female	23 (32%)	49 (68%)	72 (77%)	
<b>Total</b>	25 (27%)	68 (73%)	93 (100%)	

As presented in Table 7, the dual diagnosis status of the adult child was significantly associated with parents’ experience of stigma affecting their family’s quality of life. Parents of adult children who had a dual diagnosis were more likely to report that stigma affected their family’s quality of life, compared to parents of adults who did not have a dual diagnosis (45% versus 14%).

**Table 7. Association between adult child’s dual diagnosis status and whether parents report that stigma affected their family’s quality of life, N = 96**

Descriptive characteristic of child	<i>Stigma Experience Scale</i> Item - Whether stigma affected family’s quality of life			X <sup>2</sup> , df, p-value
	Yes	No	Total	
<b>Dual diagnosis</b>				<b>11.3, 1, 0.001</b>
Yes	14 (45%)	17 (55%)	31 (32%)	
No	9 (14%)	56 (86%)	65 (68%)	
<b>Total</b>	23 (24%)	73 (76%)	96 (100%)	

A major finding in our study was that the age of the parents was significantly associated with three items from the *Stigma Experience Scale*: (1) whether people thought less of those with an intellectual disability (see Table 8), (2) whether people were afraid of those with an intellectual disability (see Table 9), and, (3) whether parents’ experiences of stigma affected their ability to interact with other relatives (see Table 10). The age of the parents was grouped into three categories indicating less than 55 years old, between 55 and 64 years old and seniors (parents who were 65 years or older). Seniors were less likely to report that people thought less of, or were afraid of, those with an intellectual disability, or that stigma affected their ability to interact with other relatives, as compared to parents in the other two age categories (<55 years and 55-64 years). Only 28% of seniors felt that people thought less of those with intellectual disabilities compared to 63% of parents aged less than 55 years, and 43% of parents aged 55 to 64 years. Eleven percent of seniors felt that people were afraid of those with intellectual disabilities compared to 35% of parents aged 55 to 64 years, and 63% of parents aged less than 55

years. Fifteen percent of seniors felt that stigma affected their ability to interact with other relatives, compared to 32% of parents aged 55 to 64 years and 48% of parents aged less than 55 years.

**Table 8. Association between age of parent and whether parents report that people think less of those with intellectual disabilities, N = 88**

Descriptive characteristic of parent	Stigma Experience Scale Item - Whether people think less of those with an intellectual disability			X <sup>2</sup> , df, p-value
	Yes	No	Total	
Age (years)				<b>7.0, 2, 0.03</b>
<55	12 (63%)	7 (37%)	19 (22%)	
55-64	10 (43%)	13 (57%)	23 (26%)	
65+	13 (28%)	33 (72%)	46 (52%)	
<b>Total</b>	<b>35 (40%)</b>	<b>53 (60%)</b>	<b>88 (100%)</b>	

**Table 9. Association between age of parent and whether parents report that people are afraid of those with intellectual disabilities, N = 86**

Descriptive characteristic of parent	Stigma Experience Scale Item - Whether people are afraid of those with an intellectual disability			X <sup>2</sup> , df, p-value
	Yes	No	Total	
Age (years)				<b>17.8, 2, 0.0001</b>
<55	12 (63%)	7 (37%)	19 (22%)	
55-64	8 (35%)	15 (65%)	23 (27%)	
65+	5 (11%)	39 (89%)	44 (51%)	
<b>Total</b>	<b>25 (29%)</b>	<b>61 (71%)</b>	<b>86 (100%)</b>	

**Table 10. Association between age of parent and whether stigma affected parents' ability to interact with other relatives, N = 89**

Descriptive characteristic of parent	<i>Stigma Experience Scale</i> Item - Whether stigma affected parent's ability to interact with other relatives			X <sup>2</sup> , df, p-value
	Yes	No	Total	
<b>Age (years)</b>				<b>8.0, 2, 0.02</b>
<55	10 (48%)	11 (52%)	21 (23%)	
55-64	7 (32%)	15 (68%)	22 (25%)	
65+	7 (15%)	39 (85%)	46 (52%)	
<b>Total</b>	24 (27%)	65 (73%)	89 (100%)	

As shown in Tables 11, 12 and 13, the employment status of the parent was significantly associated with the same three items from the *Stigma Experience Scale* which were associated with the age of the parents (see Tables 8 to 10). Parents who were not competitively employed were less likely to report that others thought less of, or were afraid of, those with an intellectual disability, or that stigma affected their ability to interact with other relatives, as compared to parents who were employed. Sixty-four percent of those who were employed felt that people thought less of those with an intellectual disability compared to 32% of respondents who were not employed. Sixty percent of respondents who were employed also felt that people were afraid of individuals with intellectual disabilities compared to 15% of respondents who were not employed. Forty-four percent of employed parent respondents felt that stigma affected their ability to interact with other relatives compared to 18% of unemployed parent respondents who felt the same.

**Table 11. Association between parents' employment status and whether parents report that people think less of those with intellectual disabilities, N = 94**

Descriptive characteristic of parent	<i>Stigma Experience Scale Item - Whether people think less of those with an intellectual disability</i>			<i>X<sup>2</sup>, df, p-value</i>
	Yes	No	Total	
<b>Employment status</b>				<b>7.9, 1, 0.005</b>
Employed	16 (64%)	9 (36%)	25 (27%)	
Not employed	22 (32%)	47 (68%)	69 (73%)	
<b>Total</b>	38 (40%)	56 (60%)	94 (100%)	

**Table 12. Association between parents' employment status and whether parents report that people are afraid of those with intellectual disabilities, N = 92**

Descriptive characteristic of parent	<i>Stigma Experience Scale Item - Whether people are afraid of those with an intellectual disability</i>			<i>X<sup>2</sup>, df, p-value</i>
	Yes	No	Total	
<b>Employment status</b>				<b>18.7, 1, 0.0001</b>
Employed	15 (60%)	10 (40%)	25 (27%)	
Not employed	10 (15%)	57 (85%)	67 (73%)	
<b>Total</b>	25 (27%)	67 (73%)	92 (100%)	

**Table 13. Association between parents' employment status and whether stigma affected parents' ability to interact with other relatives, N = 94**

Descriptive characteristic of parent	<i>Stigma Experience Scale</i> Item - Whether stigma affected parent's ability to interact with other relatives			$X^2$ , df, p-value
	Yes	No	Total	
<b>Employment status</b>				<b>9.0, 1, 0.003</b>
Employed	13 (44%)	14 (56%)	27 (29%)	
Not employed	12 (18%)	55 (82%)	67 (71%)	
<b>Total</b>	25 (27%)	69 (73%)	94 (100%)	

Another major finding was that the age of the adult children showed significant associations with four items in the *Stigma Experience Scale*, two of which asked parent respondents about their perception of people's view about those with intellectual disabilities, one item asking about stigma affecting their ability to interact with other relatives and another item asking parents if stigma affected their family's quality of life. The majority of the parents with older adult children (45 and over) did not believe that people thought less of those with intellectual disabilities compared to parents with younger adult children (see Table 14). Seventeen percent of parents with adult children aged 45 and older believed that people thought less of those with intellectual disabilities compared to 48% to 56% of parents whose adult children ranged in age from 18 to 44 years. Parents with adult children aged 35 or older were also less likely to report that people are afraid of those with intellectual disabilities compared to younger parents with adult children aged 18 to 34 years (see Table 15). Parents with adult children aged 35 years and older who believed that people were afraid of those with intellectual disabilities ranged from 8% to 21% compared to 35% of the parents whose adult children were 25-34 years old, and 57% of the parents whose children were 18 to 24 years old.

Parents with younger adult children (aged 18 to 34 years) were more likely to report that stigma affected their ability to interact with other relatives compared to parents of adults with intellectual disabilities aged 35 years and older (see Table 16). Parents with children aged 18 to 34 years who felt that stigma affected their ability to interact with other relatives ranged from 33% to 38% compared to 17% of parents with adult children aged 35-44 years and 12% of parents with adult children aged 45 years and older who reported the same. Parents whose children were younger (between the ages of 18 to 44) years were more likely to report that stigma affected their family's quality of life than those parents who had older adult children (aged 45 years and up) (see Table 17). Twenty-six percent of those parents whose children were aged 18 to 24 years, 30% of those parents whose children were aged 25-34 years and 35% of parents whose children were aged 35-44 years felt that stigma affected their family's quality of life compared to 9% of parents whose children were older (aged 45 years and up) who reported the same.

**Table 14. Association between adult child's age and whether parents report that people think less of those with intellectual disabilities, N = 93**

Descriptive characteristic of child	<i>Stigma Experience Scale Item - Whether people think less of those with an intellectual disability</i>			Fisher's exact test statistic, p-value
	Yes	No	Total	
Age (years)				<b>10.7, 0.025</b>
18-24	9 (56%)	7 (44%)	16 (17%)	
25-34	13 (50%)	13 (50%)	26 (28%)	
35-44	10 (48%)	11 (52%)	21 (23%)	
45 +	5 (17%)	25 (83%)	30 (32%)	
<b>Total</b>	37 (40%)	56 (60%)	93 (100%)	

**Table 15. Association between adult child's age and whether parents report that people are afraid of those with intellectual disabilities, N = 91**

Descriptive characteristic of child	<i>Stigma Experience Scale Item - Whether people are afraid of those with an intellectual disability</i>			Fisher's exact test statistic, p-value
	Yes	No	Total	
<b>Age (years)</b>				<b>13.69, 0.006</b>
18-24	9 (57%)	7 (43%)	16 (17%)	
25-34	9 (35%)	17 (65%)	26 (29%)	
35-44	4 (21%)	15 (79%)	19 (21%)	
45+	2 (8%)	28 (92%)	30 (33%)	
<b>Total</b>	24 (26%)	67 (74%)	91 (100%)	

**Table 16. Association between adult child's age and whether stigma affected parents' ability to interact with other relatives, N = 94**

Descriptive characteristic of child	<i>Stigma Experience Scale Item - Whether stigma affected parent's ability to interact with other relatives</i>			Fisher's exact test statistic, p-value
	Yes	No	Total	
<b>Age (years)</b>				<b>8.67, 0.03</b>
18-24	8 (33%)	10 (14%)	18 (19%)	
25-34	9 (38%)	17 (24%)	26 (28%)	
35-44	4 (17%)	16 (23%)	20 (21%)	
45+	3 (12%)	27 (39%)	30 (32%)	
<b>Total</b>	24 (25%)	70 (75%)	94 (100%)	

**Table 17. Association between adult child’s age and whether parents report that stigma affected their family’s quality of life, N = 95**

Descriptive characteristic of child	<i>Stigma Experience Scale</i> Item - Whether stigma affected family’s quality of life			Fisher’s exact test statistic, p-value <b>9.79, 0.02</b>
	Yes	No	Total	
Age (years)				
18-24	6 (26%)	12 (17%)	18 (19%)	
25-34	7 (30%)	19 (26%)	26 (27%)	
35-44	8 (35%)	12 (17%)	20 (21%)	
45+	2 (9%)	29 (40%)	31 (33%)	
<b>Total</b>	23 (24%)	72 (76%)	95 (100%)	

#### 5.4 Summary of results

Reliability testing of all three scales, *Stigma Experience Scale*, *Stigma Impact Scale* and *Parental Changes Subscale* showed that all the scales achieved acceptable levels of internal consistency (coefficient of reliability, 0.70 or greater). However, since only respondents who had answered all items within a scale were included for the analysis of reliability for that scale, both the *Stigma Experience Scale* and the *Parental Changes Subscale* had smaller sample sizes, n=82 and n=51 respectively, compared to the total sample (N=97). The subgroup of respondents that was used to evaluate the *Parental Changes Subscale* showed significant differences when compared to non-respondents with regards to the age of the parent respondent, their employment status, highest level of education, their living arrangements and the age of their adult child.

As well, three items within the *Stigma Experience Scale* and one item within the *Parental Changes Subscale* had item-rest correlations below the acceptable level of 0.40.

Conversely, the *Stigma Impact Scale* not only achieved excellent internal consistency, but, at the item-level, the item-rest correlations were high.

With regards to the correlation between each of the three scales, the score from the *Stigma Experience Scale* and the *Stigma Impact Scale* score were moderately correlated in a positive direction. However, the *Parental Changes Subscale* did not correlate with either of the stigma scales.

Some parent and child characteristics were significantly related to a few items from the *Stigma Experience Scale* indicating that these key parent or child characteristics may be influencing their responses to the scale's items. The characteristics which showed significant association with scale items were age, employment status, and gender of parent; and age and dual diagnosis status of the adult child. The scale items that were found to be associated with the above characteristics were whether parents felt that people thought less of, or were afraid of, those with an intellectual disability, whether stigma affected the parent's ability to interact with other relatives and whether stigma affected the respondent's family's quality of life.

Given the results, the reliability testing of the three scales should be discussed. Recommendations for future development of each of the scales should also be explored. Additionally, commentary on the inter-relationship between the three scales can add to the evaluation of whether future applications of the scales should consider all three scales. Evaluation of respondent and child characteristics and their associations with items in a scale measuring the presence or absence of stigma can shed light on possible factors that influence certain experiences of stigma in parents of adults with an intellectual disability. Thus, the next section aims to present an in-depth discussion of such points for consideration, with an additional comparison of results of the current sample of parents

with a different sample of family members (of those with severe mental health problems) who were given the same two stigma scales to measure stigma by association.

## CHAPTER 6: DISCUSSION

In this next section, each of the three scales will be discussed with regards to future recommendations. The inter-correlation between the scales will be then addressed, followed by the experiences of the parent respondents. Finally, the strengths and limitations of the current study will be presented along with suggestions for future research directions and concluding remarks.

### 6.1 Evaluation of the individual scales

In the literature for scale development, a reliability coefficient greater or equal to 0.70 (Nunnally, 1978) is considered suitable to describe the distribution of the construct of interest and comment on groups of individuals based on high and low scores (i.e. discriminant validity). This study demonstrated acceptable coefficients of reliability for the three scales, *Stigma Experience Scale* (KR-20=0.70), *Stigma Impact Scale* ( $\alpha=0.95$ ) and *Parental Changes Subscale* ( $\alpha=0.92$ ), which aimed to measure the experiences of parents of adults with intellectual disabilities. However, the exceptionally high coefficients of reliability for the *Stigma Impact Scale* and the *Parental Changes Subscale* may suggest that individual items within the scales may be redundant. Although it is necessary for there to be a certain level of redundancy and similarity between items aiming to measure an underlying construct, a high degree of redundancy is not exemplary (Hulin, Netemeyer & Cudeck, 2001). For example, in the *Stigma Impact Scale*, the alpha once an item was deleted remained within the range of 0.94-0.95.

This scale had previously been tested in a sample of family members of adults with severe mental health problems (Stuart et al., 2008). The internal consistencies of the *Stigma Impact Scale* were comparable between both samples (i.e. mental health sample,  $\alpha=0.93$ , current sample,  $\alpha=0.95$ ). The item-rest correlation in the mental health sample ranged from 0.69 to 0.87, while in the current sample, the item-rest correlation ranged from 0.74 to 0.91 (acceptable range: 0.40-0.50 for narrowly defined constructs; Clark & Watson, 1995). The range, as determined by the difference between the highest item-rest correlation and the lowest, were comparable between the mental health sample and the current sample. This would indicate that although the desirable item-rest correlations were not reached in either sample, the *Stigma Impact Scale* seemed to behave similarly in both samples giving support for its utility across different samples.

However, it should be noted that the placements of the questions in the *Stigma Impact Scale* may have invoked a response set bias in which there was a tendency for the respondents to answer the series of questions in a certain direction regardless of their content. The responses for the seven individual items within this scale were prompted through two general questions and presented as a set to enhance instructional clarity. The first general question, asking about the parent respondent personally, was a prompt for four of the seven scale items (quality of life, social contacts, family relations and self-esteem). The second general question, asking the parent respondent to report on their family as a whole, was a prompt for the remaining three items (quality of life, social contacts and family relations). As such, there were only slight modifications in wording between the seven items which may have reflected redundancy across items within the scale (Clark & Watson, 1995). Such similarly worded items added as a scale would tend to increase the coefficient of alpha without substantially contributing to the theoretical

internal consistency of the scale. The *Stigma Impact Scale* also gave respondents a range of response categories from 0 to 10, to rate the impact of stigma, thus, nuances in response differences could potentially be captured by this scale (Bandalos & Enders, 1996). Yet, the medians for items within this scale, in the current sample, were mostly 1. In the original sample of family members of adults with severe mental health problems, the item-level medians ranged from 2.5 to 6 (Stuart et al., 2008). Thus, there was more variability in responses when the scale was applied to the mental health sample than in our current sample. It may be that the degree of impact of stigma on family members, aimed to be captured by the *Stigma Impact Scale*, was more effective in capturing a range of responses in the mental health sample because the respondent's family member had *severe* and differing mental health problems while we do not know the severity of intellectual disabilities of the adult children of our current sample. Such finding could also indicate that stigma by association does not contribute meaningfully to the current experiences of parents of adults with intellectual disabilities.

Items within the *Stigma Impact Scale* which were redundant should be considered for removal. The overall alpha remained the same ( $\alpha$ : 0.94 to 0.95), if each of the seven individual items was deleted, and the inter-correlations between items were high (range: 0.74-0.91). Thus, we cannot narrow down the recommendation for removal of specific items within the scale due to redundancy. However, recommendation for the future use of the *Stigma Impact Scale* would be to re-structure the survey instrument containing this scale, such that items within the scale can be reworded and reorganized (dispersed) to minimize response set bias. Additionally, the range for the response categories could be more conservative if applied to a sample similar to the current study. A visual analogue

scale could be applied to develop the range of response categories aimed to capture the degree of impact of stigma for such parents.

Like the *Stigma Impact Scale*, the *Parental Changes Subscale* also achieved an excellent coefficient of reliability. However, unlike the *Stigma Impact Scale*, the *Parental Changes Subscale* had a high number of missing responses where only 51 out of a possible total sample of 97 answered all 18 items in the scale and were thus included in the analysis of the internal consistency of the scale. The *Parental Changes Subscale* also had more than double the number of questions/items than the *Stigma Impact Scale*. The subgroup that was used to analyze the *Parental Changes Subscale* differed significantly from the non-respondents. Non-respondents were more likely to be seniors, not employed, had either some or completed public school or had some or completed up to high school as their highest level of education, did not live with a spouse or partner, and whose children were aged between 18 to 34 years. Parents with only either some or completed public school or some or completed high school education may have had difficulties understanding and answering all the questions in this scale. The difference between respondents and non-respondents suggests that item non-response bias would skew the results as, for example, older parents would not be represented in the responses of how their child's disability affected positive changes in them.

The distribution of the range of responses (1-5) at the item level was narrow, with four items having a median of 5, and most item-level responses aggregated around 3 to 5, likely due to a ceiling effect. This indicates that for the current sample, the items within the *Parental Changes Subscale* failed to capture the possible range of responses. Items which had strong agreement were when parents felt that they were: (1) becoming a stronger person, (2) learning to speak out for their child, (3) learning to be more

compassionate towards others, and, (4) gaining a different perspective on life. It may be that in asking *parents* such questions, the purpose of which was to reflect the effect of having their child in their life; a type of response bias was induced, such as social desirability which can be present even in anonymized surveys (Makimoto et al., 2001). The items which showed greatest range of responses across the response categories were also items that had the most missing data. Thus, the distribution in responses may be indicative of the relevance of such items to the current sample. Questions such as vocational change and marriage may not be applicable to all the respondents' situations, considering that most of the respondents were seniors (65 years or older) and not employed (e.g., retired or homemaker) and, as previously mentioned, these subgroups of parents were also less likely to respond to all the items within this scale.

As well, the alpha when an item was removed stayed within a tight range of the overall coefficient of reliability (0.92-0.93) in the *Parental Changes Subscale*. This indicated that removing a specific item was negligible to the overall coefficient of reliability which was 0.92. Individual items, therefore, were redundant to the theoretical internal consistency of the scale. It should be noted that this scale, applied to the current sample of respondents, was a subscale taken out of a longer, comprehensive scale (Scorgie & Sobsey, 2000). It was not feasible in the current study to apply the longer, original version. Due to the issues discussed arising from the *Parental Changes Subscale*, it should not be recommended in the future in its current form and should be administered differently (than in our study), for a similar sample of respondents. Items should be reworded to reduce the effect of social desirability, and an option of "not applicable" should be added to all items to potentially lower item non-response. As well, the mode of

administration in a future study using this scale on a similar sample should consider the possibility of follow-up to reduce item non-response.

The *Stigma Experience Scale* achieved a marginally acceptable coefficient of reliability (KR-20=0.70). When it was originally applied to family members of individuals with severe mental health problems (Stuart et al., 2008), the *Stigma Experience Scale* achieved a slightly higher internal consistency (KR-20=0.76) than in the current study (KR-20=0.70).

As well, unlike the two previously mentioned scales, the responses originally given by the parents to the items within the *Stigma Experience Scale* were recoded into dichotomous variables (extremes) to indicate the presence or absence of stigma. Additionally, compared to the *Stigma Impact Scale*, this scale had much lower item-rest correlation for the seven individual items (ranging from 0.30 to 0.56), with three items falling below the acceptable level of 0.40. The lower item-rest correlations for items in the *Stigma Experience Scale* in the current study compared to the item-rest correlations for items in the mental health sample (ranging from 0.29 to 0.69 with two items falling below 0.40) may be due to differences between the samples and/or due to differences in stigma experiences (e.g., likely type of interactions with others in daily life engaged in by the family member with the disability). The three items with low item-rest correlations in the present sample were feeling stigmatized due to their adult child's condition, making and keeping friendships, and interacting with relatives. Additionally, two of these three items also had low endorsements, with only 8 parents (10%) who felt stigmatized due to their child's condition and 14 parents (17%) who felt that stigma affected their family's ability to make and keep friends. The two items with low item-rest correlations in the sample of family members of adults with severe mental health problems were general

questions asking whether the respondent believed people thought less of those with mental health problems and whether most people were afraid of such individuals.

Another possible reason for the low item-rest correlations for individual items in the *Stigma Experience Scale* may be due to the dichotomous nature of the scale responses used for analyses. Responses of parents were re-coded into dichotomous variables to indicate the presence or absence of stigma. Parents who reported that they “sometimes” perceived or experienced stigmatization as outlined by a specific question or were “not sure” if that stigmatizing experience was applicable to them were re-coded as having an absence of that stigmatizing experience. As such, we were conservative with our interpretation of the presence of stigmatizing experiences in our sample. However dichotomizing the responses likely ignored the fact that there are varying levels to a stigmatizing experience. As such, error (misclassification) would be introduced into the re-coded responses as uncertainty or confusion on the part of the respondents in either understanding or answering the question as indicated by “sometimes” or “not sure” was equated to an absence of that stigmatizing experience. Another consequence of dichotomizing a variable is that it leads to loss of efficiency of the scale with a reduction in its correlation with other measures (Streiner & Norman, 2003). Thus, larger sample sizes are required to show an effect for a scale that uses dichotomous responses, such as our *Stigma Experience Scale* (Streiner & Norman, 2003).

In the current sample, only 10% of the *parent* respondents believed that they were stigmatized due to their adult child’s intellectual disability, compared to 20% in the mental health sample of *family members* (Stuart et al., 2008). The group of family members in the original mental health sample included spouses, siblings, and other relations, who may be more likely to feel stigmatized due to their relative’s disability

compared to parents. In our sample, approximately a quarter of the parents said that stigma had affected their family's quality of life compared to half of the family members in the mental health sample. Previous studies indicate that parents of children with intellectual disabilities often blame themselves for their child's condition (Fink & Tasman, 1992; Turnbull & Turnbull, 1978). The severity of the disability in the mental health sample compared to the current sample could also explain the comparatively lower reporting of effects to family's quality of life, friend relations and interactions with relatives, due to stigma, in the current sample. Additionally, parents of adults with intellectual disabilities have had their child's lifetime to set up social support networks, while family members of adults with severe mental health problems most likely encountered their relative's condition later in life (e.g. onset of schizophrenia is usually during late teens to early 20s). Given that only 10% of the parents reported that they felt stigmatized due to their child's intellectual disability, it may be that for the parents in our sample, such experiences of stigma are currently not a significant part of their daily reality. These parents may have had time and experience to adapt to such stigmatizing conditions and adopted effective coping strategies.

However, for the *Stigma Experience Scale*, with a range of possible total scores from 0 to 7, the median of the total score in the current sample was only 1. Thus, the *Stigma Experience Scale* may either be measuring an accurate phenomenon of low stigmatizing experiences in parents of adults with intellectual disabilities or such results may indicate that the scale, as currently constructed, is problematic for evaluating experiences of stigma in parents of adults with intellectual disabilities. It is recommended that additional items be added as the items in the current scale may be too narrow or irrelevant to capture the range of stigma experiences that *are* relevant to the current

study's sample. Such additional items could be developed with the aid of responses from the parents in our current sample to open-ended questions asked within the survey. For example, items can be added to circumvent the likely feeling of guilt that parent respondents feel in order to improve the range of their stigma experiences. Rather than asking parents directly whether they "felt stigmatized because of their child's [intellectual disability]", the question could be reworded to ask whether parents felt that *others* stigmatized them due to being parents of children with intellectual disabilities.

### ***6.1.1 Evaluating the inter-correlation between the scales***

As seen by the graphical representations of the frequency of total scores for each of the three scales (see Appendix I), with a normal distribution curve fitted to the data, none of the total scores for the scales seemed like they followed a normal distribution. Thus, inter-correlations between the scales were assessed using Spearman's rank order correlations. The Spearman's rank order correlation showed that between the *Stigma Experience Scale* and the *Stigma Impact Scale*, a moderate correlation coefficient was achieved (0.67,  $p=0.01$ ). In the original sample of family members of adults with severe mental health problems, a correlation coefficient of 0.66 ( $p=0.001$ ) was achieved. This indicated that for both samples, the two scales target different dimensions of the same construct(s).

Spearman's rank order correlation was also evaluated between the *Stigma Impact Scale* and the *Parental Changes Subscale* and between the *Stigma Experience Scale* and the *Parental Changes Subscale*. The correlation coefficient was only -0.03 ( $p=0.84$ ,  $n=49$ ) for the former, and -0.009 ( $p=0.95$ ,  $n=46$ ) for the latter, although the direction for

both implied a negative correlation, as expected, between the *Parental Changes Subscales* (measuring positive changes) and each of the stigma scales. Such low correlation coefficients may be attributed to response bias and given the small sample sizes due to missing data. We may not have had enough power to test the associations between each of the stigma scales and the *Parental Changes Subscale*. It further indicates that the constructs being compared through their strength of associations show that the scale measuring positive changes and each of the stigma scales are not predictive of one another. Such lack of significance in correlations may be indicative that experience of positive changes in parents is not mutually exclusive to also experiencing negative effects of stigma. The moderate strength in correlation between the two stigma scales and lack of significance in correlations between the *Parental Changes Subscale* and each of the stigma scales also supports the construct validity of the stigma scales in measuring different aspects of an underlying construct (assumed to be stigma) which were not related to positive changes experienced by parents. Finally, given that the responses in the *Stigma Experience Scale* were dichotomized, this may have reduced its correlation with the *Parental Changes Subscale* (Streiner & Norman, 2003). As well, the ceiling effect present in the *Parental Changes Subscale* may have also contributed to the lack of significance in correlation with either of the two stigma scales.

## **6.2 Experiences of parents**

In the current sample, most of the respondents were biological parents, mothers, who were 65 years and older, and as expected, most did not work in competitive employment, indicating that they were retired or homemakers. The majority of the

respondents also lived with a spouse and were the primary caregivers of their adult children. However, only about half of the adult children currently lived with the parent respondent. As well, half of the children had lived or were currently living (at the time of the study) in a group home or institution. Given that a noticeable proportion of the parents were ageing and were the current daily primary caregiver of their adult child (with most in the sample being of retirement age and not working), caregiver burden and its stressors would be relevant issues for these parents.

Most of the adult children were males which matched other studies' findings of higher prevalence of intellectual disabilities in males as compared to females (Kirgiss, 2002). The range in age of the adult children, as reported by our sample of parents, was broad, from 18 years to 67 years. Eighteen parents reported that their adult children had mobility issues. Limitations to mobility, within this population of individuals with intellectual disabilities, are a common concern (Cleaver et al., 2007). Another challenge facing this population is dual diagnosis such that the individual has not only an intellectual disability but a concurrent diagnosis of a mental health problem (which may include behaviour problems). Within the current sample, 32 of the total sample of parents reported an accompanying mental health problem in their adult child with an intellectual disability, meaning approximately 33% of the adult children had a likely dual diagnosis. This reflects the findings in Ontario for the prevalence of dual diagnosis within the intellectual disabilities population, which was found to be between 30% and 40% (Yu & Atkinson, 1993). Thus, not only is the current sample of parents ageing with likely increase in health concerns of their own due to age, but other stressors and burdens to caregiving are present (e.g., mobility issues and dual diagnosis in their child).

Similarities were also seen between the respondent demographics in the original sample of family members of adults with severe mental health problems and the current sample of parent respondents. For both samples, most of the respondents were female, mothers, 60 years or older, and lived with a spouse or partner. The relatives/children with the disabilities in both samples were mostly males and the age ranges were comparable between the two samples with the relatives of the original mental health sample ranging from 20 to 60 years and older and the current sample's children ranging from 18 to 67 years. One difference between the samples was that half of the respondents in the current study had either some or completed public school education or had some or completed high school as their highest level of education while the education level in the mental health sample indicated that most of the respondents had completed college or university. Thus, the respondents in the original mental health sample were more educated compared to our current sample. Stigma related to mental health problems have shown that levels of education may be associated with perceived stigma (Elbogen et al., 2005). Those with higher levels of education may feel more shame from perceived stigma due to a lack of control over their disability when they had achieved certain levels of mastery in other areas of their lives in the past (such as education) (Elbogen et al., 2005). Achieving a higher level of education may also reflect a hierarchical standing of social class. Thus, influence of the level of education on experiences of stigma may be relevant not only for the stigmatized individuals but also their family members' experiences of stigma by association. This may explain the difference in stigma experiences seen in the more educated family members in the original mental health sample compared to the less educated sample of parents in our current study. As well, the lower endorsements for stigma items seen in the current sample compared to the original mental health sample

may due to lower education level of the parents in our current sample which might reflect an inability to understand the questions and/or be familiar with the concept of stigma as presented in the study.

The recruitment for the mental health sample used convenience sampling as it was aimed at developing the psychometric tool, thus, not needing to be representative. It was conducted in person at a conference that appealed to family members who were career advocates, and as such, they were much more aware of the concept of stigma and its applicability as conceived by the investigators who developed the tool. However, the recruitment for the current sample was done through indirect mailing of surveys and self-administered by respondents in their homes. The reliability of a scale depends on the characteristics of the respondents, the setting where the scale was administered and its purpose of use, thus there are limitations to comparisons between the mental health sample and our current sample.

Since the *Stigma Experience Scale* is recommended with caution, for the current population of parents, evaluation of parents' experiences of stigma due to their child's condition was undertaken by assessing the association between parent and adult characteristics with the presence or absence of stigma as measured by individual items within the scale. A significant association was found between the gender and age of the parent and whether stigma affects their ability to interact with relatives. Research dating back 20 to 30 years had found that some parents of children with intellectual disabilities report feeling socially excluded and having strained relationships (Birenbaum, 1970; Levinson & Starling, 1981). As well, in a previous study, Gray (2002) found that mothers were more likely to report stigma than fathers. In our current study, as most parents were mothers who likely had to undertake the primary caregiver role for their adult children,

time for maintaining social contacts with other relatives would have had to become secondary to their adult child's caregiving and well-being. Fathers also were less likely to report that stigma affected their ability to interact with relatives compared to mothers. It may be that the gender of the parents influences their experiences of stigma. There are also differences in caregiving relations between fathers and mothers such that interaction with others (like relatives) may be more important for mothers than for fathers. Mothers, as the more likely caregivers, may be more attuned than fathers, to changes in social support, closeness and quality of interaction with other family relations like relatives.

Younger parents (under 55 years), as compared to older parents (65 years and up), were more likely to report that stigma affected their ability to interact with relatives. As well, age of the parents played a role in how they perceived what others thought of individuals with intellectual disabilities. The younger parents were more likely to report that others thought less of and were afraid of, individuals with intellectual disabilities, as compared to older parents. These associations may indicate a cohort effect influencing the expectations of the younger parents, whereby the older parents have had more years (experience) to adopt coping strategies and acclimatize, and thus, desensitize themselves to the stigmatizing responses of others, including their relatives.

Age of the respondents' adult children were also significantly associated with whether the respondents believed that most people thought less of, or were afraid of, those with intellectual disabilities, whether stigma affected their ability to interact with other relatives and whether stigma affected their family's quality of life. Parents with older adult children (aged 45 years and up) were less likely to perceive that others thought negatively of individuals with intellectual disabilities and that stigma affected their ability to interact with other relatives than parent with younger adult children. As the

respondents with older children will likely be older themselves, such an association is reflective of the previous finding of significant association between age of parent respondent and how they perceive other people view individuals with intellectual disabilities and whether stigma had an effect on their family relations.

Parents with older children (aged 45 years and older) were also less likely to feel that stigma affected their family's quality of life than parents of younger adult children. This, too, may be attributed to the previously mentioned cohort effect, with parents of older children having had more years and experience to learn how to better cope with their child's disability such that they do not feel it affecting their family's quality of life, like the parents who have younger children.

Employment status of the parent was also associated with parents' perception of others' thinking less of, and being afraid of, those with intellectual disabilities, as was reporting whether stigma had an effect on their interactions with relatives. Seltzer et al. (2001) found that parents of individuals with intellectual disabilities reported issues with employment such as delayed entry into the workforce or low employment rates. Parents who were employed were more likely to report that others had such stigmatizing perceptions about individuals with intellectual disabilities and that they felt the effects of stigma in their interaction with relatives, than parents who were not employed. As previously mentioned, most parents who reported that they were unemployed were so because they were either retired or homemakers. Since age of parent has been associated with these perceptions of stigma from others, including relatives, it is likely that those parents who are employed are younger. As well, they have more exposure to others' through daily workplace interactions, and other social obligations (relatives), which increases the likelihood of encountering such stigmatizing perceptions in others. The

employed parents in our sample may have also felt that certain barriers that they may have faced in their places of employment (e.g., needing time-off to care for child with special needs, or being granted emergency leave related to their child with intellectual disability) may be a reflection of the perceptions carried by the employers about their children with intellectual disabilities.

Lastly, dual diagnosis status in the adult children was significantly associated with the current sample's perceived effect of stigma on their family's quality of life. Gray (2002) reported that parents were more likely to report stigma if their child had aggressive behaviour along with their intellectual disability than parents whose children did not have added aggressive behaviour. Given that dual diagnosis means having an intellectual disability and added mental disorders and/or behaviour problems, the results in our current study validates such previous findings. Parents of adult children with dual diagnosis were more likely to report that stigma had affected their family's quality of life than parents of adults with an intellectual disability only. Such a finding is predictable given that the challenges of caregiving for an individual with an intellectual disability is likely to be more pronounced with an added disability of a mental health problem. This would increase stress within the parents which would diffuse towards the rest of the family, thus affecting their quality of life.

### **6.3 Strengths and Limitations**

This study was the first to apply a set of scales measuring stigma in families of individuals with severe mental health problems (Stuart et al., 2008) to parents of adults with intellectual disabilities. One other study has applied stigma scales to families of

individuals with an intellectual disability (Mak & Cheung, 2008). However, unlike the two studies above, the current study limited the sample to only parents (versus *family member/caregivers*) such that variance due to relationship type was removed. Compared to family members in the original mental health sample (Stuart et al., 2008), which included spouses and siblings, we found that in our current sample, parents were more hesitant to ascribe stigmatization to themselves due to their child's condition (20% of family members in the original mental health sample versus 10% of parents in our current sample); perhaps feeling like such an outlook could be seen as indirectly blaming their child. As such, stigma may not be internalized by the parents as stigma by association like in other family relations. Also, given the nature of their adult child's condition (i.e., intellectual disability) which had onset early in life, when compared with the mental health sample, where individuals likely developed their condition later in life, the parents in our sample likely had longer time and more experience to adapt to their child's condition. This indicates a unique experience of stigma in parents of adults with intellectual disabilities, where stigma by association due to their adult child's disability may not be relevant for our sample of parents. Focusing on adult children has also allowed for similar control over effects of life experiences; such as controlling for likely differences between childhood to adulthood. Thus, a strength of our study was that it allowed us to focus on a target group of individuals, *parents of adults* with intellectual disabilities, who, as a sample, had never before been evaluated with regards to their experiences of stigma. Although it was not evaluated for the current study, the returned surveys had a substantial amount of qualitative data derived from open-ended questions which can be useful for future analysis of the data, further explaining experiences of parents, as well as, utilized for recommendations for the scales used in the study.

Another strength of the study is the relatively large sample size achieved from an extensive sampling frame. Unlike the Stuart et al. (2008) study which applied a convenience sampling approach, the current study chose a census approach. Thus, given that we recruited the parents through identification of their adult children with intellectual disabilities and given that we mailed our surveys to potential participants, without possibility of follow-up and/or incentives, our achieved participation rate of 24% was expected for our study (Evenhuis et al., 2004; Kanuk & Berenson, 1975).

However, there are limitations to the present study. Due to our indirect method of accrual, there was no possibility of follow-up by investigators, which resulted in a substantial amount of item non-response (missing data/values). This lowered the sample sizes for analyses of two of the three scales, *Stigma Experience Scale* and *Parental Changes Subscale* which would also lower the power to detect correlation between the scales.

There is the potential for selection bias as 10 agencies declined participation in our study. We do not know whether the parents affiliated with those 10 agencies were significantly different than the parents recruited through our 23 participating agencies.

Dichotomizing the *Stigma Experience Scale* may have also introduced misclassification of stigma experiences where parents who reported that they either were “not sure” or that they “sometimes” felt that a particular stigma experiences were relevant to them, were analyzed as having an absence of that stigma experience. Another limitation of the study was in regards to the structure of items within the survey. Specifically for scale items, a response option for “Not Applicable” would have likely decreased the amount of item non-response. As well, presenting items within a scale as an

obvious set, e.g., the *Stigma Impact Scale*, may have contributed to the occurrence of response set bias.

There were also limitations to the evaluation of the *Parental Changes Subscale*. Only 51 out of a total sample of 97 parents responded to all items within this scale indicating large item non-response. Such low sample size likely did not afford us enough power to evaluate its association with each of the two stigma scales. Response bias was also present for this scale as those parents who responded to all items within this scale were significantly different from non-respondents. Given the narrow range of item responses with most responses aggregating around the “agree” and “strongly agree” response categories, social desirability bias may also be present along with a ceiling effect limiting the measurement of positive changes in such parents.

Finally, the sample size for the subgroup of parents who reported that their child had a likely dual diagnosis was small (n=32 out of a total, 97), which restricted analysis options of this group. Given that parents of adults with a dual diagnosis were more likely to report that stigma affected their family’s quality of life than parents whose children had only an intellectual disability, it would seem that parents have differing family experiences given the added diagnosis of mental health problems. Thus, it would have been informative to be able to undertake a comparison of experiences (stigma and positive) to explore how additional disability in an adult child impacts the parental experience. Originally, the stigma scales were developed for a mental health sample, so it would be of interest to see how the scales function in a group that deals with *both* an intellectual disability and mental health problems. To date, there have been no studies that have looked at stigma related to families of individuals with a dual diagnosis.

## 6.4 Future Direction of Study

The current study was exploratory in its analysis of some of the psychometric properties of three scales aimed to measure the experiences of parents of adults with an intellectual disability. The factor structure of the two stigma scales was assumed because it was demonstrated in the mental health sample (Stuart et al., 2008). As such, the dimensionality of the construct(s) aiming to be measured for each of the three scales (experiences of stigma, impact of stigma and parental changes undergone by parents, due to their adult child with intellectual disability) was not verified, only assumed. This assumption is likely given that the coefficients of reliability of all the three scales were high, whereas if a scale was truly multi-dimensional yet assumed otherwise, the coefficient of reliability would be lower than expected (Miller, 1995). Miller (1995) advocated that the coefficient of reliability be used to assess internal consistency only after there is an established unidimensionality. However, it is also proposed that without reliability, validity of a psychometric tool cannot exist (Cronbach, 1990). Thus, given that validity of a scale cannot be confirmed without reliability, the current exploratory study aimed to first determine the internal consistencies of each of the scales.

As previously discussed, due to its limitations, the *Parental Changes Subscale* is not recommended for future use in parents of adults with an intellectual disability. Both the *Stigma Impact Scale* and the *Stigma Experience Scale* are cautiously recommended given some necessary changes to the scales. Scales with good psychometric properties are necessary to adequately fulfill the goal of describing the experiences of parents of adults with an intellectual disability. Future studies should further develop the two stigma scales to tackle the issues previously discussed surrounding each scale, with consideration of the

relevance of the scale items to parents of adults with an intellectual disability. The internal consistency of the modified scales should be re-analyzed, and if found to be acceptable, a factor analysis should be undertaken. Consideration should be given to developing a global stigma score by somehow combining the two stigma scales.

Most research surrounding stigma has focused on mental health problems. The current study, with its use of two stigma scales that had originally been applied to families of individuals with mental health problems, has demonstrated how the psychometric properties, specifically, internal consistencies of the scales, hold when applied to families of individuals with an intellectual disability. Such applications of the stigma scales to different samples add to the instruments' further development and breadth of utility. It also allows for an opportunity to understand the process of stigma as it manifests in different populations.

The current study has future implications for its underlying population, parents of adults with an intellectual disability residing in South Eastern Ontario, in providing an exploratory analysis of their stigma experiences, caregiving stressors and needs. We found that age of adult children and age of parents were significantly associated with a number of stigmatizing experiences. This may be indicative of an age cohort that highlights differing caregiving stressors and needs of parents. Gender and employment status were also significantly associated with some experiences of stigma with mothers or those who were employed reporting more stigmatizing experiences than fathers or those who were likely retired or homemakers (i.e., unemployed). Parents of those with a dual diagnosis were more likely to report that stigma affected their family's quality of life compared to parents whose adult children only had an intellectual disability. Given sufficient sample size, future studies may be able to stratify according to these

characteristics of interest to evaluate whether such variables may be mediating, moderating or confounding the stigma experiences of parents. Additionally, focusing on the experiences of such sub-groups specifically can allow for a better understanding of how to direct supports and services for such families and their unique needs while also being able to better target anti-stigma advocacy for intellectual disabilities.

## CHAPTER 7: CONCLUSION

To date, only one previous study had applied a scale to measure stigma in families of those with an intellectual disability (Mak & Cheung, 2008). The findings of the current study mainly recommend two stigma scales, to be used in conjunction with one another. One scale measures the experiences of stigma and the other scale measures the degree of impact due to such experiences of stigma. Given that this study aimed to describe the positive and negative experiences of *parents of adults* with an intellectual disability, further development of the stigma scales should be undertaken and re-tested amongst the same population of interest, along with an exploration of a more suitable scale to capture the parents' positive experiences. Originally developed for a mental health sample, future development of the two scales used in our study, aiming to capture the experience and impact of stigma, should focus on answering whether stigma is expressed in parents of individuals with intellectual disabilities to the same magnitude as parents of those with mental health problems, or whether stigma is even significantly relevant to parents of adults with intellectual disabilities. Subgroups of parents differ significantly in terms of certain stigma experiences so future studies should further explore characteristics of parents that may influence experiences of stigma.

## REFERENCES

- Abbott, D. A. & Meredith, W. H. (1986). Strengths of parents with retarded children. *Family Relations*, 35(3), 371-376.
- Ablon, J. (1990). Ambiguity and difference, families with dwarf children. *Social Science & Medicine*, 30, 879-897.
- Abraham, C., Gregory, N., Wolf, L., & Pemberton, R. (2002). Self-esteem, stigma and community participation amongst people with learning difficulties living in the community. *Journal of Community & Applied Social Psychology*, 12(6), 430-443.
- Aday, L. A. & Cornelius, L. J. (2006). *Designing and conducting health surveys: a comprehensive guide (3<sup>rd</sup> edition)*. San Francisco, CA: Jossey-Bass.
- Altman, B. M. (1981). Studies of Attitudes toward the Handicapped: The Need for New Direction. *Social Problems*, 28, 321-333.
- American Association on Intellectual and Developmental Disabilities. (2009). *Definition of Intellectual Disabilities*. Accessed on November 06, 2009 at: [http://www.aamr.org/content\\_100.cfm?navID=21](http://www.aamr.org/content_100.cfm?navID=21)
- American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision*. Washington, DC: American Psychiatric Association.
- Angermeyer, M. C., Schulze, B., & Diertrich, S. (2003). Courtesy stigma – a focus group study of relatives of schizophrenia patients. *Social Psychiatry and Psychiatric Epidemiology*, 38, 593-602.
- Arvio, M. & Sillanpaa, M. (2003) Prevalence, aetiology and comorbidity of severe and profound intellectual disability in Finland. *Journal of Intellectual Disability Research*, 47, 108-112.
- Bandalos, D. L. & Enders, C.K. (1996). The effects of nonnormality and number of response categories on reliability. *Applied Measurement in Education*, 9(2), 151-160.
- Becker, H. S. (1963). *Outsiders: Studies in the Sociology of Deviance*. New York: The Free Press of Glencoe.
- Biasini, F. J., Grupe, L., Huffman, L., & Bray, N.W. (1997). The prevalence of mental retardation: a critical review of recent literature. *Developmental Medicine and Child Neurology*, 39, 125-32.
- Birenbaum, A. (1970). On managing a courtesy stigma. *Journal of Health and Social Behavior*, 2(3), 196-206.

- Blum, N. (1991). The management of stigma by Alzheimer family caregivers. *Journal of Contemporary Ethnography*, 20, 263–284.
- Borthwick-Duffy, S. A. & Eyman, R. K. (1990). Who are the dually diagnosed? *American Journal on Mental Retardation*, 94, 586-595.
- Bristol, M. M., Gallagher, J. J., & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and nondisabled boys: Adaptation and spousal support. *Developmental Psychology*, 24, 441–451.
- Brockley, J. A. (1999). History of mental retardation: An essay review. *History of Psychology*, 2(1), 25–36.
- Camp, B. W., Broman, S. H., Nichols, P. L., & Leff, M. (1998). Maternal and neonatal risk factors for mental retardation: defining the 'at-risk' child. *Early Human Development*, 50(2), 159-173.
- Child and Family Services Statute Law Amendment Act. (2009). *An Act to amend the Child and Family Services Act and to make amendments to other Acts, CHAPTER 2*. Accessed on January 17, 2010: [http://www.e-laws.gov.on.ca/html/source/statutes/english/2009/elaws\\_src\\_s09002\\_e.htm](http://www.e-laws.gov.on.ca/html/source/statutes/english/2009/elaws_src_s09002_e.htm)
- Childs, R. (1985). Maternal psychological conflicts associated with birth of a retarded child. *Maternal Child Nursing Journal*, 14,175–182.
- Chung, K.F. & Wong, M.C. (2004). Experience of stigma among Chinese mental health patients in Hong Kong. *Psychiatric Bulletin*, 28, 451-454.
- Clark, L. A. & Watson, D. (1995). Constructing validity: Basic issues in scale development. *Psychological Assessment*, 7, 309-319.
- Cleaver, S., Ouellette-Kuntz, H., & Hunter, D. (2007). Relationship Between Mobility Limitations and the Places Where Older Adults With Intellectual Disabilities Live. *Journal of Policy and Practice in Intellectual Disabilities*, 5(4), 253-258.
- Clifford, T. (2007). Transition to school: Experiences of children with intellectual disabilities and their families. *Autism Matters*, 4(4), 22-24.
- Corrigan, P. W. & Penn, D. L. (1999). Lessons from social psychology on discrediting psychiatric stigma. *American Psychologist*, 54, 765–776.
- Corrigan, P. W. (2000). Mental health stigma as social attribution: implications for research methods and attitude change. *Clinical Psychology: Science and Practice*, 7, 48–67.

- Corrigan, P. W., River, L. P., Lundin, R. K., Penn, D. L., Uphoff-Wasowski, K., Campion, J., Mathisen, J., Gagnon, C., Bergman, M., Goldstein, B. H., & Kubiak, M. A. (2000). Stigmatising attributions about mental illness. *Journal of Community Psychology*, 28, 91-102.
- Corrigan, P. W., Edwards, A. B., Green, A., Diwan, S. L., & Penn, D. L. (2001). Prejudice, social distance, and familiarity with mental illness. *Schizophrenia Bulletin*, 27 (2), 219-225.
- Corrigan, P. W. & Watson, A. C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology*, 9, 35-53.
- Corrigan, P. W. & Watson, A. C. (2002b). Understanding the impact of stigma on people with mental illness. *World Psychiatry*, 1(1), 16-20.
- Crocker, J. & Major, B. (1989). Social stigma and self-esteem: the self-protective properties of stigma. *Psychological Review*, 96, 608-630.
- Cummings, S. (1976). The impact of the child's deficiency on the father: A study of fathers of mentally retarded and chronically ill children. *American Journal of Orthopsychiatry*, 46, 246-255.
- Dagnan, D. & Sandhu, S. (1999). Social comparison, self-esteem and depression in people with intellectual disability. *Journal of Intellectual Disability Research*, 43(5), 372-379.
- Damrosch, S. P. & Perry, L. A. (1989). Self reported adjustment, chronic sorrow, and coping with parents of children with Down syndrome. *Nursing Research*, 38, 25-30.
- Davis, N. J. (1972). Labelling theory in deviance research: a critique and reconsideration. *Sociological Quarterly*, 13, 447-474.
- Developmental Service Act. [1990] (2008). *R.S.O. 1990, CHAPTER D.11*. Accessed on January 17, 2010 at:  
[http://www.elaws.gov.on.ca/html/statutes/english/elaws\\_statutes\\_90d11\\_e.htm](http://www.elaws.gov.on.ca/html/statutes/english/elaws_statutes_90d11_e.htm)
- Dickerson, F. B., Sommerville, J., Origoni, A. E., Ringel, R. B., & Parente, R. (2002). Experiences of stigma among outpatients with schizophrenia. *Schizophrenia Bulletin*, 28, 143-147.
- Dovidio, J.F., Major, B., & Crocker, J. (2000). Stigma: Introduction and overview. In: Heatherton, Kleck, R. E., Hebl, M. R., & Hull, J.G., editors. *The social psychology of stigma*. New York: Guilford.

- Drews, C. D., Murphy, C. C., Yeargin-Allsopp, M., & Decoufle, P. (1996). The relationship between idiopathic mental retardation and maternal smoking during pregnancy. *Paediatrics*, 97(4), 547-553.
- Elbogen, E. B., Swanson, J. W., Swartz, M. S., & Van Dorn, R. (2005). Family Representative Payeeship and Violence Risk in Severe Mental Illness. *Law and Human Behavior*, 9(5), 563-574.
- Evenhuis, H., van Splunder, J., Vink, M., Weerdenburg, C., van Zanten, B. & Stilma J. (2004). Obstacles in largescale pidemiological assessment of sensory impairments in a Dutch population with intellectual disabilities. *Journal of Intellectual Disability Research*, 48, 708–18.
- Farina, A., Gliha, D., Boudreau, L. A., Allen, J. G., & Sherman, M. (1971). Mental illness and the impact of believing others know about it. *Journal of Abnormal Psychology*, 77, 1-5.
- Farina, A. & Felner, R. D. (1973). Employment interviewer reactions to former mental patients. *Journal of Abnormal Psychology*, 82, 268-272.
- Feinberg, J. (1978). Mentally handicapped. In: Reich, W.T., editor. *Encyclopedia of Bioethics*. New York: Free Press.
- Fink, P. J. & Tasman, A. (1992). *Stigma and Mental Illness*. Washington, DC: American Psychiatric Press.
- Freeman, H. E. & Simmons, O. G. (1961). Feelings of stigma among relatives of former mental patients. *Social Problems*, 8, 312-321.
- Frid, C., Drott, P., Lundell, B., Rasmussen, F., & Anneren, G. (1999). Mortality in Down's syndrome in relation to congenital malformations. *Journal of Intellectual Disability Research*, 43, 234-41.
- Fryers, T. (1995). Epidemiological concerns in current literature. *Current Opinion in Psychiatry*, 8(5), 272-275.
- Gallagher, S., Phillips, A. C., Oliver, C., & Carroll, D. (2008). Predictors of Psychological Morbidity in Parents of Children with Intellectual Disabilities. *Journal of Pediatric Psychology*, 33(10), 1129-1136.
- Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. New York: Touchstone.
- Gordon, P. A., Feldman, D., Tantillo, J. C., & Perrone, K. (2004). Attitudes regarding interpersonal relationships with persons with mental illness and mental retardation. *Journal of Rehabilitation*, 70, 50–56.

- Gray, D. E. (2002). 'Everybody just freezes. Everybody is just embarrassed': felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness*, 24 (6), 734–749.
- Green, S. E. (2003). “What do you mean ‘what’s wrong with her?’”: stigma and the lives of families of children with disabilities. *Social Science & Medicine*, 57, 1361–1374.
- Greenberg, J. S., Greenley, J. R., McKee, D., Brown, R., & Griffin-Francell, C. (1993). Mothers caring for an adult child with schizophrenia: The effects of subjective burden on maternal health. *Family Relations*, 42, 205-211.
- Griffiths, D., Stavrakaki, C. & Summers, J. (editors) (2002). *An introduction to the mental health needs of persons with developmental disabilities*. Sudbury, ON: Habilitative Mental Health Resource Network.
- Halsey, C. L, Collin M. F., & Anderson, C. L. (1996). Extremely low-birth-weight children and their peers. A comparison of school-age outcomes. *Archives of Pediatrics & Adolescent Medicine*, 150(8), 790-794.
- Hamilton, D. L. & Sherman, J. W. (1994). Stereotypes. In: Wyer, R.S. Jr., & Srull, T.K., editors. *Handbook of social cognition* (2nd ed., Vol. 2). Hillsdale, New Jersey: Erlbaum.
- Hand, J. E. (1994). Report of a national survey of older people with lifelong intellectual handicap in New Zealand. *Journal of Intellectual Disability Research*, 38, 275-87.
- Hartlage, L. C. & Roland, P. E. (1971). Attitudes of employers toward different types of handicapped workers. *Journal of Applied Rehabilitation Counseling*, 2, 115-120.
- Holmes, E. P. & River L.P. (1998). Individual strategies for coping with the stigma of severe mental illness. *Cognitive and Behavioural Practice*, 5, 231-239.
- Holmes, E. P., Corrigan, P. W., Williams, P., Canar, J., & Kubiak, M. (1999). Changing public attitudes about schizophrenia. *Schizophrenia Bulletin*, 25(3), 447-456.
- Hulin, C., Netemeyer, R., & Cudeck, R. (2001). Can a reliability coefficient be too high? *Journal of Consumer Psychology*, 10(1), 55-58.
- Jacobsson, L. (2002). The roots of stigmatization. *World Psychiatry*, 1(1), 25.
- Jahoda, A. & Markova, I. (2004). Coping with social stigma: people with intellectual disabilities moving from institutions and family home. *Journal of Intellectual Disability Research*, 48, 719– 729.

- Jones, E. E., Farina, A., Hastorf, A. H., Markus, H., Miller, D. T., & Scott, R. (1984). *Social stigma: the psychology of marked relationships*. New York: W.H. Freeman.
- Kadri, N., Manoudi, F., Berrada, S., & Moussaoui, D. (2004). Stigma impact on Moroccan families of patients with schizophrenia. *Canadian Journal of Psychiatry*, 49(9), 625-629.
- Kaiser, H. A. (1999). *The Health Law Institute State of Advocacy for People With Mental Disability in NS*. Accessed on November 3, 2009: <http://www.reachability.org/articles/The%20Health%20Law%20Institute%20State%20of%20Advocacy.pdf>
- Kanuk, L. & Berenson, C. (1975). Mail Surveys and Response Rates: A Literature Review. *Journal of Marketing Research*, 12(4), 440-453.
- Kearney, P. M. & Griffin, T. (2001). Between joy and sorrow: being a parent of a child with developmental disability. *Journal of Advanced Nursing*, 34, 582–92.
- Kim, S., Larson, S. A., & Lakin, K. C. (2001). Behavioral outcomes of deinstitutionalization for people with intellectual disability: A review of U.S. studies conducted between 1980 and 1999. *Journal of Intellectual and Developmental Disability*, 26(1), 35-50.
- Kirby, M. (2006). *Out of the Shadows at last: Transforming Mental Health, Mental Illness and Addiction Services in Canada*. Accessed on November 3, 2009 at: <http://www.parl.gc.ca/39/1/parlbus/commbus/senate/Com-e/SOCI-E/rep-e/rep02may06-e.htm>.
- Kirgiss, C. R. (2008). *Mental Retardation: Determining Eligibility for Social Security Benefits*. Washington, DC: National Academies Press.
- Lawton, M. P. (1991). A multidimensional view of quality of life. In: Birren, J.E., Lubben, J.E., Rowe, J.C., & Deutchman, D.E., editors. *The concept and measurement of quality of life in the frail elderly*. New York: Academic Press.
- Lefley, H. (1992). Expressed emotion: conceptual, clinical and social policy issues. *Hospital and Community Psychiatry*, 43, 591–598.
- Lemert, E. M. (1967). *Human deviance, social problems and social control*. Englewood cliffs: Prentice-Hall.
- Levinson, R. M. & Starling, D. M. (1981). Retardation and the burden of stigma. *Deviant Behavior*, 2, 371–390.

- Link, B. G. (1987). Understanding labeling effects in the area of mental disorders: An assessment of the effects of expectations of rejection. *American Sociological Review*, 52, 96-112.
- Link, B. G., Cullen, F. T., Struening, E., Shrout, P. E., & Dohrenwend, B. P. (1989). A Modified Labeling Theory Approach to Mental Disorders: An Empirical Assessment. *American Sociological Review*, 54, 400-423.
- Link, B. G., Phelan, J. C., Bresnahan, M., Stueve, A., & Pescosolido, B. A. (1999). Public conceptions of mental illness: Labels, causes, dangerousness and social distance. *American Journal of Public Health*, 89, 1328-1333.
- Link, B. & Phalen, J. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363-385.
- López-Ibor, Jr., J. J. (2002). The power of stigma. *World Psychiatry*, 1(1), 23-24.
- Luckasson, R., Coulter, D. L., Polloway, E. A., Reiss, S., Schalock, R. L., Snell, M. E., Spitalnik, D. M., & Stark, J. A. (2002). *Mental retardation: Definition, classification, and systems of supports* (10th ed). Washington, DC: American Association on Mental Retardation.
- Lunsky, Y., Garcin, N., Morin, D., Cobigo, D., & Bradley, E. (2007). Mental Health Services for Individuals with Intellectual Disabilities in Canada: Findings from a National Survey. *Journal of Applied Research in Intellectual Disabilities*, 20, 439-447.
- MacRae, H. (1999). Managing courtesy stigma: The case of alzheimer's disease. *Sociology of Health and Illness*, 21, 54-70.
- Mak, W. W. & Cheung, R. Y. M. (2008). Affiliate Stigma Among Caregivers of People with Intellectual Disability or Mental Illness. *Journal of Applied Research in Intellectual Disabilities*, 21 (6), 532-545.
- Mak, W. W. & Kwok, Y. T. (2010). Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong, *Social Science & Medicine*, in press: doi:10.1016/j.socscimed.2010.02.023
- Makimoto, K., Lida, Y., Hayashi, M., & Takasaki, F. (2001). Response bias by neuroblastoma screening participation status and social desirability bias in an anonymous postal survey, Ishikawa, Japan. *Journal of Epidemiology*, 11(2), 70-73.
- McCallion, P., & McCarron, M. (2004) Intellectual disabilities and dementia. In: Doka, K., editor. *Living with Grief: Alzheimer's disease* (pp. 67-84). Washington, DC: Hospice Foundation of America.

- McGuigan, S. M., Hollins, S., & Attard, M. (1995). Age-specific standardized mortality rates in people with learning disability. *Journal of Intellectual Disability Research*, 39(6), 527-531.
- McLaren, J. & Bryson, S. E. (1987). Review of recent epidemiological studies in mental retardation: Prevalence, associated disorders, and etiology. *American Journal of Mental Retardation*, 92, 243-254.
- Mehta, S. & Farina, A. (1988). Associative stigma: perceptions of the difficulties of college-aged children of stigmatized fathers. *Journal of Social Clinical Psychology*, 7, 192-202.
- Mental Health Commission of Canada. (2007). *Report to the Mental Health Commission of Canada, A Time for Action: Tackling Stigma and Discrimination*. Accessed online on January 17, 2010 at: [http://www.mentalhealthcommission.ca/SiteCollectionDocuments/Anti-Stigma/TimeforAction\\_Eng.pdf](http://www.mentalhealthcommission.ca/SiteCollectionDocuments/Anti-Stigma/TimeforAction_Eng.pdf)
- Miles, M. (2001). Martin Luther and Childhood Disability in 16<sup>th</sup> Century Germany: What did he write? What did he say? *Journal of Religion, Disability & Health*, 5 (4), 5-36.
- Miller, M. B. (1995). Coefficient alpha: A basic introduction from the perspectives of classical test theory and structural equation modeling. *Structural Equation Modeling*, 2, 255-273.
- Minns, R. A. (1997). Pre and perinatal conditions contributing to mental retardation. *Current Opinion in Psychiatry*, 10(5), 354-59.
- Nuehring, E. M. (1979). Stigma and state hospital patients. *American Journal of Orthopsychiatry*, 49, 626-633.
- Nunnally, J. (1978). *Psychometric theory*. New York: McGraw-Hill.
- O'Grady, J. (2007). Commentary on "Psychiatric Resident Education in Intellectual Disabilities". *Academic Psychiatry*, 31(6), 417-418.
- Ohaeri, J. U. & Fido, A. A. (2001). The opinion of caregivers on aspects of schizophrenia and major affective disorders in Nigerian setting. *Social Psychiatry Psychiatric Epidemiology*, 36, 493-499.
- Östman, M. & Kjellin, L. (2002) Stigma by association: psychological factors in relatives of people with mental illness. *British Journal of Psychiatry*, 181, 494-498.

- Ouellette-Kuntz, H., Minnes, P., Garcin, N., Martin, C., Lewis, M. E. S., & Holden, J. J. A. (2005). Addressing Health Disparities Through Promoting Equity for Individuals with Intellectual Disability. *Canadian Journal of Public Health*, 96(2), 8-22.
- Page, S. (1977). Effects of the mental illness label in attempts to obtain accommodation. *Canadian Journal of Behavioural Science*, 9, 85-90.
- Phelan, J. C., Bromet, E. J., & Link, B. G. (1998). Psychiatric illness and family stigma. *Schizophrenia Bulletin*, 24, 115–126.
- Payne, J. & Patton, J. (1981). *Mental retardation*. Columbus, Ohio: Charles E. Merrill.
- Polder, J. J., Meerding, W. J, Bonneux, L., & van dermas, P. J. (2002). Health care costs of intellectual disability in the Netherlands: A cost-of-illness perspective. *Journal of Intellectual Disability Research*, 46, 168-78.
- Radford, J. P. & Park, D. C. (1993). A convenient means of riddance: institutionalization of people diagnosed as mentally deficient in Ontario,1876-1934. *Health and Canadian Society*, 1(2), 369-392.
- Raghuram, R., Weiss, M. G., Channabasavanna, S. M., & Diop, M. (1996). Stigma, depression and somatization in South India. *American Journal of Psychiatry*, 153,1043-1049.
- Reiss, S. (1990). Prevalence of dual diagnosis in community-based programs in the Chicago metropolitan area. *American Journal on Mental Retardation*, 94, 578-584.
- Roeleveld, N., Zielhuis, G. A., & Gabreels, F. (1997). The prevalence of mental retardation: a critical review of recent literature. *Developmental Medicine and Child Neurology*, 39, 125-32.
- Royal College of Psychiatrists. (1999). *Patient Advocacy*. Council Report CR74. London: Royal College of Psychiatrists.
- Rubin, S. & Roessler, R. (1983). *Foundations of the vocational rehabilitation process*. Baltimore: University Park.
- Sartorius, N. (1999). One of the last obstacles to better mental health care: the stigma of mental illness. In: Guimon, J., Fischer, W., & Sartorius, N., editors. *The Image of Madness: The Public Facing Mental Illness and Psychiatric Treatment*. Basel, Switzerland: Karger.

- Sartorius, M. & Schulze, H. (2005). *Reducing the stigma of mental illness: a report from a global programme of the World Psychiatric Association*. Cambridge: Cambridge University Press.
- Scheerenberger, R. C. (1983). *A History of Mental Retardation*. Baltimore: P. H. Brooks Publishing Co.
- Scheff, T. J. [1966] (1984). *Being Mentally Ill: A Sociological Theory*. New York: Aldine.
- Schilling, R. F., Gilchrist, L. D., & Schinke, S. P. (1984). Coping and Social Support in Families of Developmentally Disabled Children. *Family Relations*, 33, (1), 47-54.
- Schilling, R. F. & Schinke, S. P. (1984). Maltreatment and mental retardation. *Mental Retardation*, 20, 201-209.
- Schulze, B. & Angermeyer, M. C. (2003). Subjective experiences of stigma: A focus group study of schizophrenic patients, their relatives and mental health professionals. *Social Science & Medicine*, 56, 299–312.
- Scorgie, K. & Sobsey, D. (2000). Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation*, 38, 195-206.
- Seltzer, M. M., Greenberg, J. S., Floyd, F. J., Pettee, Y., & Hong, J. (2001). Life course impacts of parenting a child with a disability. *American Journal on Mental Retardation*, 106, 265–286.
- Shibre, T., Negash, A., Kullgren, G., Kebede, D., Alem, A., Fekadu, A., Fekadu, D., Medhin, G., & Jacobsson, L. (2001). Perception of stigma among family members of individuals with schizophrenia and major affective disorders in rural Ethiopia. *Social Psychiatry & Psychiatric Epidemiology*, 36(6), 299–303.
- Sigelman, C. K., Howell, J. L., Cornell, D. P., Cutright, J. D., & Dewey, J. C. (1991). Courtesy stigma: The social implications of associating with a gay person. *Journal of Social Psychology*, 131, 45–56.
- Spangenberg, J. & Theron, J. (2000). Stress and coping in parents of children with Down syndrome, *Studia Psychologica*, 43,41–48.
- Stengler-Wenzke, K., Beck, M., Holzinger, A., & Angermeyer, M. C. (2004). Stigma Experiences of Patients with Obsessive Compulsive Disorders. *Fortschritte Der Neurologie Psychiatrie*, 72, 7-13.
- Strauss, D. & Eyman, R. K. (1996). Mortality of people with mental retardation in California with and without Down's syndrome, 1986-1991. *American Journal on Mental Retardation*, 100, 643-53.

- Streiner, D. L. & Norman, G. R. (2003). *Health Measurement Scales: a practical guide to their development and use* (3rd ed.). New York: Oxford University Press.
- Strohmer, D. C., Grand, S. A., & Purcell, M. J. (1984). Attitudes toward persons with a disability: An examination of demographic factors, social context, and specific disability. *Rehabilitation Psychology*, 29, 131-145.
- Struening, E. L., Perlick, D. A., Link, B. G., Hellman, F., Herman, J. D., & Sirey, J. A. (2001). The extent to which caregivers believe most people devalue consumers and their families. *Psychiatric Services*, 52, 1633 –1638.
- Stuart, H. & Arboleda-Flórez, J. (2001). Community Attitudes Toward People with Schizophrenia. *Canadian Journal of Psychiatry*, 46, 245-252.
- Stuart, H., Milev, R., & Koller, M. (2005). The inventory of stigma experiences: Development and reliability. *World Psychiatry*, 4(1), 33-37.
- Stuart, H. (2008). Building an evidence base for anti-stigma programming. In: Arboleda Florez, J., & Sartorius, N., editors. *Understanding the Stigma of Mental Illness – Theories and Interventions*. Toronto: Wiley & Sons.
- Stuart, H., Koller, M., & Milev, R. (2008). Inventories to Measure the Scope and Impact of Stigma Experiences From the Perspective of Those Who Are Stigmatized—Consumer and Family Versions. In: Arboleda Florez, J., & Sartorius, N., editors. *Understanding the Stigma of Mental Illness – Theories and Interventions*. Toronto: Wiley & Sons.
- Szymanski, L. & Wilska, M. (1997) Mental retardation. In: Tasman, A., editor. *Psychiatry*, 1<sup>st</sup> Ed., pg. 606. Philadelphia: WB Saunders.
- Szmukler, G. I., Burgess, P., Herrman, H., Benson, A., Colusa, S., & Bloch, S. (1996). Caring for relatives with serious mental illness: The development of the Experience of Caregiving Inventory. *Social Psychiatry and Psychiatric Epidemiology*, 31(3-4), 137-148.
- Tak-fai Lau, J. & Cheung, C. (1999). Discriminatory attitudes to people with intellectual disability or mental health difficulty. *International Social Work*, 42(4), 431-444.
- Thomas, A. (2000). Stability of Tringo's hierarchy of preference toward disability groups: 30 years later. *Psychological Reports*, 86, 1155-1156.
- Tossebro, J. (2004). Family Attitudes to Deinstitutionalization Before and After Resettlement: The Case of a Scandinavian Welfare State. *Journal of Developmental and Physical Disabilities*, 10(1), 55-72.
- Tringo, J. L. (1970). The Hierarchy of Preference toward Disability Groups. *The Journal of Special Education*, 4(3), 295-306.

- Turnbull, A. R. & Turnbull, H. R., editors. (1978). *Parents Speak Out*. Columbus, Ohio: Merrill/Prentice Hall.
- van Schrojenstein Lantman-de Valk, H. M. J., van den Akker, M., Maaskant, M. A., Haveman, M. J., Urlings, H. F. J., Kessels, A. G. H., & Crebolder., H. F. J. K. (1997). Prevalence and incidence of health problems in people with intellectual disability. *Journal of Intellectual Disability Research*, 41(1), 42-51.
- Wahl, O. F. & Harman, C. R. (1989). Family views of stigma. *Schizophrenia Bulletin*, 15, 131-139.
- WHO. ICD-10. (1992). *International Statistical Classification of Diseases and Related Health Problems, Tenth Revision*. Volumes 1-3. Geneva: World Health Organization.
- WHO. ICF. (2001). *International Classification of Functioning, Disability and Health*. Geneva: World Health Organization.
- Winzer, M. (2003). *The history of special education: from isolation to integration*. Washington, DC: Gallaudet University Press.
- Wolfensberger, W. (1972). *The principle of Normalization in human services*. Toronto: National Institute on Mental Retardation.
- Yu, D. & Atkinson, L. (1993). Intellectual disability with and without psychiatric involvement: Prevalence estimates for Ontario. *Journal on Intellectual Disabilities*, 2, 92-99.

# APPENDIX A: ETHICS APPROVAL

QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING  
HOSPITALS RESEARCH ETHICS BOARD



September 18, 2008

This Ethics Application was subject to:

- Full Board Review  
Meeting Date: July 14, 2008  
 Expedited Review

Ms. Ahana Sarkar  
Department of Community Health and Epidemiology  
c/o Ongwanada Resource Centre  
191 Portsmouth Avenue  
Kingston, ON K7M 8A6

Dear Ms. Sarkar,

**Study Title:** Stigma Experienced by Parents of Adults with Developmental Disabilities and Dual Diagnoses  
**Co-Investigators:** Ms. H. Ouellette-Kuntz and Dr. H. Stuart

The members of the Queen's University Health Sciences & Affiliated Teaching Hospitals Research Ethics Board have examined the protocol, questionnaire and the consent form for your project (as stated above) and consider it to be ethically acceptable. This approval is valid for one year from the date of the Chair's signature below. Please attend carefully to the following list of ethics requirements you must fulfill over the course of your study:

- **Reporting of Amendments:** If there are any changes to your study (e.g. consent, protocol, study procedures, etc.), you must submit an amendment to the Research Ethics Board for approval. (see <http://www.queensu.ca/vpr/reb.htm>).
- **Reporting of Serious Adverse Events:** Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information.
- **Reporting of Complaints:** Any complaints made by participants or persons acting on behalf of participants must be reported to the Research Ethics Board within 7 days of becoming aware of the complaint. Note: All documents supplied to participants must have the contact information for the Research Ethics Board.
- **Annual Renewal:** Prior to the expiration of your approval (which is one year from the date of the Chair's signature below), you will be reminded to submit your renewal form along with any new changes or amendments you wish to make to your study. If there have been no major changes to your protocol, your approval may be renewed for another year.

Yours sincerely,

Albert Clark  
Chair, Research Ethics Board

Sept 19, 2008  
Date

ORIGINAL TO INVESTIGATOR - COPY TO DEPARTMENT HEAD - COPY TO HOSPITAL(S) /P&T (if appropriate) - FILE COPY

Study Code: EPID-265-08

- **Investigators please note that if your trial is registered by the sponsor, you must take responsibility to ensure that the registration information is accurate and complete**

## **APPENDIX B: INITIAL LETTER OF INVITATION TO AGENCIES**

Date

Name of Executive Director

Address

Dear [Executive Director],

Title of Study: Stigma Experienced by Parents of Adults with Developmental Disabilities and Dual Diagnoses

As you know, raising a child with special needs can be both challenging and rewarding for parents. This SEO CURA in ID sponsored project will give parents of adults with developmental disabilities an opportunity to contribute to our understanding of stigma. The project is undertaken by one of my masters student, Ahana Sarkar. She is being supervised by both myself and Dr. Heather Stuart of the Department of Community Health & Epidemiology at Queen's University.

A total of 110 **parents** are needed. According to GRID records, your agency supports # adults with a developmental disability only, and # adults with a dual diagnosis. We recognize that not all will have parents who can be contacted. We are writing to ask for your agency's assistance in contacting those parents for whom you have addresses. This would require sending a survey (copy attached) to parents on our behalf. We would provide all self-addressed stamped survey packages.

If you can help us engage parents in this important project, please complete and fax back the attached response form. If you have any questions or concerns, do not hesitate to contact me (613-548-4417 x. 1198). You may also contact the Head of my Department at Queen's, Dr. Bill MacKillop (613-533-2901), or the Chair of the Queen's Research Ethics Board, Dr. Albert Clark (613-533-6081).

Sincerely,

Hélène Ouellette-Kuntz  
Director, SEO CURA in ID  
Associate Professor, Dept. Community Health & Epidemiology, Queens' University

Encl. cover letter and survey to parents, partner-agency response form.



## APPENDIX C: LETTER TO AGENCY CONTACT WITH LIST

### *(identification of potential participants)*

Date

Agency Contact, Title  
Address

Dear [name of agency contact],

Title of study: Stigma Experienced by Parents of Adults with Developmental Disabilities and Dual Diagnoses

Thank you for your interest in helping us with the above-noted study. There are two parts to the recruitment of participants for which we need your help.

For the first part, with this letter, we are sending you a list of all adult clients served by your agency. Please go through the attached list and check off all individuals for whom a **parent** (biological, adoptive, foster, step-parent) is available for participation in our study (i.e., eligibility for our study). Please use the enclosed self-addressed stamped envelope to mail the list back to us when completed.

Once we receive the list, we will be able to determine the number of survey packages to be sent to each agency. We will then send you a list of selected clients along with survey packages to send to their parents on our behalf.

Thank you for your time and involvement in helping us recruit participants for the study. If you have any questions, please feel free to contact us.

Ahana Sarkar, 6as34@queensu.ca (613-888-8971)  
Hélène Ouellette-Kuntz, oulette@queensu.ca (613-548-4417 x. 1198)  
Heather Stuart, heather.stuart@queensu.ca (613-533-6000 x. 77097)

If you have any worries about this project, you may contact Dr. Albert Clark, Chair of the Queen's University Research Ethics Board, (613) 533-6081 or our Department Head at Queen's University, Dr. Bill MacKillop (613-533-2901).

Thanking you in advance.

With regards,

Ahana Sarkar



## APPENDIX D: LETTER TO AGENCY - MAILING INSTRUCTIONS

Date  
Name, Title  
Address

Dear [name of staff with whom investigators had phone contact regarding study]

Title of study: Stigma Experienced by Parents of Adults with Developmental Disabilities and Dual Diagnoses

Investigators: Ahana Sarkar (student investigator), H el ene Ouellette-Kuntz and Heather Stuart

Thank you for your interest in helping us with the study. With this letter, we are including the list of parents of adults with special needs to whom we ask that you send the study information, along with a survey package, for each of them, in postage-paid envelopes.

Each survey package includes:

- (1) the survey (titled: Experiences of parents of adults with special needs) that the parent participant will fill out, which takes about 30 minutes to complete [an extra copy is attached for your records]
- (2) a postage-paid self-addressed envelope which the parent will use to mail the completed survey back to us at SEO CURA in ID
- (3) a postage-paid self-addressed postcard for the parent to mail back with their contact information if they are interested in the results of the study

### WHAT YOU NEED TO DO:

- Prepare the **cover letter**. A copy of the template to use is attached and has been emailed to you. If you need another copy to be sent to you, please send me a request at 6as34@queensu.ca as soon as possible.
  - a. In order to personalize the letter to the parents, we ask that you add the name of the parent, where indicated (i.e., “Dear [**add name of parent**]”)
  - b. In order for the parents to know which child the study is interested in knowing about, in terms of their experiences as a parent, you also need to fill out the first name of the adult child with special needs, where indicated (i.e., “You are invited to respond to this survey as [**add first name of child**]’s parent.”)
  - c. Finally, since the package is being sent by you, on our behalf, please print the letter on your agency’s letterhead, sign it and include your contact information at the **end** of the letter. The parents will then have your contact information in case they wish to speak to agency staff rather than us.
- Once you have filled out the necessary information in the cover letter, you can include the cover letter with the rest of the survey package, and use the postage-paid envelope provided to mail out the survey packages to the parents.
  - a. You will need to address each package to the respective participant taking care to match the envelope label to the name on the cover letter you have added.

Thank you for your time and involvement in helping us recruit participants for the study. We hope that this study will help us understand the nature of experiences with stigma among these parents. We also expect that this study can give us a valid tool that can measure stigma and its impact across different populations. The results of such inquiries may one day benefit future programs and actions aimed at targeting the needs and issues surrounding the primary caregivers of adults with special needs, their parents.

If you have any questions, please feel free to contact us.

Ahana Sarkar, 6as34@queensu.ca (613-888-8971)  
Hélène Ouellette-Kuntz, oulette@queensu.ca (613-548-4417 x. 1198)  
Heather Stuart, heather.stuart@queensu.ca (613-533-6000 x. 77097)

If you have any worries about this project, you may contact Dr. Albert Clark, Chair of the Queen's University Research Ethics Board, (613) 533-6081 or our Department Head at Queen's University, Dr. Bill MacKillop (613-533-2901).

Thanking you in advance.

With regards,

*Signed by student investigator*

Ahana Sarkar

## APPENDIX E: COVER LETTER FOR PARENT PARTICIPANTS

Date [Dear Agency staff: Please print this letter on your agency's letterhead]

Dear [Parent]:

Title of study: Stigma Experienced by Parents of Adults with Developmental Disabilities and  
Dual Diagnoses

As you know, raising a child with special needs can be both challenging and rewarding. We are working with researchers at Queen's University to better understand the experiences of families of **adult** children with either developmental disability or dual diagnoses. By the term dual diagnoses, we mean diagnoses of *both* a developmental disability (e.g., intellectual disability) and mental health/behaviour problems.

You are invited to respond to this survey as \_\_\_\_\_'s parent.

There are two parts to this survey. The first part of the survey will ask you information about your child, use of specialized services and yourself. The second part of the questionnaire will ask you about a range of experiences you, as a parent, have had. It takes approximately 30 minutes to finish the survey.

All of your answers will be kept strictly confidential. No names are collected so you will remain anonymous at all times. Your participation is entirely voluntary. Feel free to skip any questions that you do not wish to answer, or stop at any time. If you wish, you are free to discuss your participation in this study with your adult child.

Information from this project will be used to help us and researchers at Queen's University understand the nature of parents' experiences and develop programs to enhance public awareness and acceptance. Your participation or lack of participation in this study will not affect any services you may be receiving currently or in the future. However, you may ultimately benefit from actions that may be informed by this research.

If you choose to participate, your consent for participation in the study, and the consent for use of data collected from information in your survey, will be assumed by your completion and mailing back of the survey. There is a self-addressed stamped envelope provided for this purpose. Thank you.

A grant to support this research has been obtained from the South Eastern Ontario Community-University Research Alliance in Intellectual Disabilities (SEO CURA in ID).

If you would like to know the results of the study, you may fill out your contact information and mail back the self-addressed stamped postcard provided with the package, mailed **separately** from this survey, to maintain your anonymity.

### Contact People

If at any time you wish to talk to someone about this project, feel free to contact the investigators of the study.

Ahana Sarkar, 6as34@queensu.ca (613-888-8971)  
Hélène Ouellette-Kuntz, oullette@queensu.ca (613-548-4417 x. 1198)  
Heather Stuart, heather.stuart@queensu.ca

If you have any worries about this project, such as questions about your rights as a research subject, you may contact Dr. Albert Clark, Chair of the Queen's University Research Ethics Board, (613) 533-6081 or Dr. Bill MacKillop, Head of the Department of Community Health & Epidemiology at Queen's University, (613) 533-2901.

You may also contact me if you feel the need to talk to someone regarding some of the issues raised in the survey.

*Signed by agency contact*  
[Agency contact name, phone #]

KEEP THIS PAGE FOR YOUR RECORDS

**APPENDIX F: SURVEY**

**Experiences of parents  
of adults with special needs**



Caring • Inclusion • Commitment

Return survey by mail to:  
Ahana Sarkar  
191 Portsmouth Avenue  
Kingston, Ontario  
K7M 8A6

Information about your child

**1. What is your relationship to the adult with special needs named in the cover letter?**

- Biological parent
- Adoptive parent
- Step parent
- Other; specify : \_\_\_\_\_

**2. Does this adult child currently live with you?**

- Yes
- Yes, but currently in hospital
- No, specify: \_\_\_\_\_

**3. Has your child ever lived in a group home or institution?**

- Yes
- No

**3a) If yes, specify:**

- Group home
- Institution
- Both

**4. How old is your child?**

Age at last birthday: \_\_\_\_\_

**5. Is your child...?**

- Male
- Female

**6. Which of the following diagnoses apply to your adult child named in the cover letter? Check all that may apply.**

**6a) Developmental Disability:**

- Autism Spectrum Disorder
- Down Syndrome
- Fragile X Syndrome
- Developmental Delay
- Cerebral Palsy
- Other (specify): \_\_\_\_\_

**6b) Mental Health Problem:**

- Schizophrenia
- Manic Depression/Bipolar Disorder
- Depression
- Anxiety Disorder
- Behaviour Disorder
- Other (specify): \_\_\_\_\_

**6c) Any other disability?**

- Mobility (e.g., uses wheelchair)
- Epilepsy/Seizure Disorder
- Vision Impairment
- Hearing Impairment
- Other (specify): \_\_\_\_\_

Skip to Question 13 if your child does NOT have mental health problems and/or significant behaviour problems

**7. Compared to one year ago, would you say your child's mental health problem is...?**

- Better
- About the same
- Worse

**8. About how old was your child when he/she first had symptoms of mental health problems?**

\_\_\_\_\_

**9. Has your child ever received services for his/her mental health problems?**

- No
- Yes

**10. About how old was your child when he/she received treatment for their symptoms of mental health problems?**

\_\_\_\_\_

**11. In the last year, has your child attended an outpatient or community mental health program?**

- Don't know
- No
- Yes

**11 a) If yes, about how often does he/she attend?**

- Weekly or more often
- 2 or 3 times a month
- Once a month
- Once every 2 or 3 months
- Once every 6 months
- Only seen once in the year

**12. Have you ever been personally involved in having your child hospitalized against his/her will because of his/her mental health problems and/or behaviour problems (i.e., for reasons of safety)?**

- No
- Yes

**13. Was your child ever in conflict with the law (e.g., contact with the police)?**

- Don't know
- No
- Yes

**13 a) If yes, did it result in charges?**

- No
- Yes, specify: \_\_\_\_\_

**13 a i) If yes, what were the final legal consequences?**

---

---

**14. Has your child ever used any of the following specialized services? Check all that apply.**

- Occupational therapy
- Physiotherapy
- Speech therapy
- Psychology
- Social Work
- Community behaviour management services
- Other (specify): \_\_\_\_\_

Information about you

**15. Are you...?**

- Male
- Female

**16. What year were you born? \_\_\_\_\_**

**17. What is your highest level of education?**

- Public school or less (up to grade 8)
- Some high school
- Completed high school (grade 12 or 13)
- Some college or technical training
- Completed college or technical training
- Some university
- Completed university
- Graduate or professional degree

**18. What is your current living arrangement? Are you currently living...?**

- Alone
- With a Spouse/partner
- With another relative(s)
- With other unrelated person(s)
- Other, specify: \_\_\_\_\_

**19. Have you or your spouse been the primary caregiver of your child through most of his or her life?**

- No
- Yes (go to Question 20)

**19 a) If no, please explain.**

---

---

**20. Do you have any other child(ren) with special needs or mental health problems?**

- No
- Yes

**20a) If yes:**  
**How many?** \_\_\_\_\_

**20b) What is the primary diagnosis for each (mental health problems and/or developmental disability)?**

---

---

**21. Are you employed?**

- Employed full-time
- Employed part-time
- Not employed

**21a) If not employed, are you?**

- Looking for employment
- Not looking for employment,  
specify (e.g., homemaker, retired, student, etc):

---

### Experiences with Stigma

The next section asks about experiences with stigma you or your family as a whole has had.

By stigma we mean negative feelings people have towards persons with a developmental disability and/or mental health problems.

We include both psychiatric disorders and significant behaviour problems as mental health problems.

Family Experiences with Stigma © Heather Stuart

**22a. Do you think that people think less of those who have mental health problems?**

- Never
- Rarely
- Sometimes
- Often
- Always

**22b. Do you think that people think less of those who have a developmental disability?**

- Never
- Rarely
- Sometimes
- Often
- Always

**22c. Do you think that people think less of those who have both a developmental disability and a mental health problem?**

- Never
- Rarely
- Sometimes
- Often
- Always

**23a. Do you think that the average person is afraid of someone with a mental health problem?**

- Never
- Rarely
- Sometimes
- Often
- Always

**23b. Do you think that the average person is afraid of someone with a developmental disability?**

- Never
- Rarely
- Sometimes
- Often
- Always

**23c. Do you think that the average person is afraid of someone who has both a developmental disability and a mental health problem?**

- Never
- Rarely
- Sometimes
- Often
- Always

**24a. Has your child been stigmatized because of his/her mental health problem?**

- Not applicable, does not have mental health problems (go to Question 24b)
- Never
- Rarely
- Sometimes
- Often
- Always

**Please explain.**

---

---

**24b. Has your child been stigmatized because of his/her developmental disability?**

- Never
- Rarely
- Sometimes
- Often
- Always

**Please explain.**

---

---

**25a. Have you felt stigmatized because of your child's mental health problem?**

- Not applicable, does not have mental health problems (go to Question 25b)
- Never
- Rarely
- Sometimes
- Often
- Always

**Please explain.**

---

---

**25b. Have you felt stigmatized because of your child's developmental disability?**

- Never
- Rarely
- Sometimes
- Often
- Always

**Please explain.**

---

---

**26a. Have other members of your family been stigmatized because of your child's mental health problem?**

- Not applicable, does not have mental health problems (go to Question 26b)
- Never
- Rarely
- Sometimes
- Often
- Always

**Please explain.**

---

---

**26b. Have other members of your family been stigmatized because of your child's developmental disability?**

- Never
- Rarely
- Sometimes
- Often
- Always

**Please explain.**

---

---

**27. Could you give an example of a stigmatizing experience your family has had in the last year?**

---

---

**28. Was this the worst experience of stigma your family has had?**

- No
- Yes (go to Question 30)

**28a) If not, what is the worst stigmatizing experience you or your family have had?**

---

---

**29. When did this happen? \_\_\_\_\_**

**30. What impact has stigma had on your family?**

---

---

**31. Has stigma affected your family's ability to make or keep friends?**

- Not sure
- No
- Yes

**Please explain.**

---

---

**32. Has stigma affected your ability to interact with your other relatives?**

- Not sure
- No
- Yes

**Please explain.**

---

---

**33. Have your experiences with stigma affected your family's quality of life?**

- Not sure
- No
- Yes

**Please explain.**

---

---

**34. What does your family do to cope with stigma?**

---

---

---

**35. Do you try to avoid situations that may be stigmatizing to your family?**

- Not sure
- No
- Yes

**Please explain.**

---

---

**36a. Have you ever tried to reduce stigma by educating your family or relatives about mental health problems?**

- Not applicable to my situation (go to Question 36b)
- Not sure
- No
- Yes

**Please explain.**

---

---

**36b. Have you ever tried to reduce stigma by educating your family or relatives about developmental disability?**

- Not sure
- No
- Yes

**Please explain.**

---

---

**37a. Have your experiences with stigma motivated a member of your family to speak out about the rights of those with mental health problems?**

- Not applicable to my situation (go to Question 37b)
- Not sure
- No
- Yes

**Please explain.**

---

---

**37b. Have your experiences with stigma motivated a member of your family to speak out about the rights of those with a developmental disability?**

- Not sure
- No
- Yes

**Please explain.**

---

---

**38a. Have your experiences with stigma motivated a member of your family to participate in programs to educate the public about mental health problems?**

- Not applicable to my situation (go to Question 38b)
- Not sure
- No
- Yes

**Please explain.**

---

---

**38b. Have your experiences with stigma motivated a member of your family to participate in programs to educate the public about developmental disabilities?**

- Not sure
- No
- Yes

**Please explain.**

---

---

**39. On a ten-point scale, where 0 is the lowest possible amount, and 10 is the highest possible amount, how much has stigma affected you personally? Please circle the number that best quantifies this impact in the following areas.**

Quality of Life:    0    1    2    3    4    5    6    7    8    9    10

Social Contacts:    0    1    2    3    4    5    6    7    8    9    10

Family Relations: 0    1    2    3    4    5    6    7    8    9    10

Self Esteem:        0    1    2    3    4    5    6    7    8    9    10

---

**40. On a ten-point scale, where 0 is the lowest possible amount, and 10 is the highest possible amount, how much has stigma affected your family as a whole? Please circle the number that best quantifies this impact in the following areas.**

Quality of Life:    0    1    2    3    4    5    6    7    8    9    10

---

Social Contacts:    0    1    2    3    4    5    6    7    8    9    10

---

Family Relations:    0    1    2    3    4    5    6    7    8    9    10

---

**41. What do you think causes stigma?**

---

---

---

---

---

---

---

**42. What should we do to fight stigma?**

---



---



---



---



---



---

**Parental Changes Scale**  
Adapted from Life Management Survey (Scorgie & Sobsey, 2000)

This last section has statements that express how some parents feel they have been CHANGED through the experience of parenting a child with special needs. Circle the number that corresponds to your level of agreement with each statement.

	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Not sure</b>	<b>Agree</b>	<b>Strongly Agree</b>
1. I have learned to speak out for my child.	1	2	3	4	5
2. I have learned that I can achieve rather than feel powerless.	1	2	3	4	5
3. I am more compassionate toward others.	1	2	3	4	5
4. I have made a career change, which has led to greater vocational satisfaction.	1	2	3	4	5
5. I am a stronger person.	1	2	3	4	5
6. I am more confident.	1	2	3	4	5

	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Not sure</b>	<b>Agree</b>	<b>Strongly Agree</b>
7. I take better care of myself.	1	2	3	4	5
8. I have stronger spiritual convictions now (e.g., personal spirituality, faith).	1	2	3	4	5
9. I have made many close friends with people I would have never met otherwise.	1	2	3	4	5
10. I have learned to see life from a different perspective (learned what it is like to live in someone else's shoes).	1	2	3	4	5
11. I have made a difference in the lives of other people (through advocacy/promoting changes).	1	2	3	4	5
12. I make the most of each day rather than living for the future.	1	2	3	4	5
13. I celebrate life more now (rather than just merely surviving day to day).	1	2	3	4	5
14. I have a different and more authentic view of what it means to be successful in life.	1	2	3	4	5
15. I have learned what is really important and valuable in life.	1	2	3	4	5
16. I have developed new skills that have helped me do a better job in my career/vocation.	1	2	3	4	5
17. I have developed attitudes that have helped me to do a better job in my chosen career/vocation.	1	2	3	4	5
18. My marriage has emerged stronger. <b>NA*</b>	1	2	3	4	5

\* **NA** = Not applicable/Never been married



**APPENDIX G: POSTCARD FOR PARTICIPANTS**

**TO OBTAIN RESULTS OF THE STUDY...**



PLEASE FILL OUT YOUR CONTACT INFORMATION IF YOU WOULD LIKE TO RECEIVE A COPY OF THE RESULTS OF THE STUDY, ONCE COMPLETED:

[BACK OF POSTCARD]

---

---

---



[FRONT OF POSTCARD]

**AHANA SARKAR  
191 PORTSMOUTH AVENUE  
KINGSTON, ONTARIO  
K7M 8A6**

**APPENDIX H: COMPARISON OF RESPONDENTS WITH EITHER SOME OR COMPLETED PUBLIC SCHOOL EDUCATION VERSUS RESPONDENTS WHO EITHER HAD SOME OR COMPLETED HIGH SCHOOL**

Those respondents whose highest education level was either some public school or completing grade 8 were not significantly different (p-values were not less than 0.05) than those respondents whose highest education level were some high school or having had completed high school for any of the seven items in the *Stigma Experience Scale*. The contingency tables, with the Fisher’s exact test statistic and its accompanying p-values are presented. As such, these two groups were collapsed into one sub-group called “some or completed public school or some or completed high school” to increase sample size of the subgroup for further analysis in the study.

Descriptive characteristic of child	<i>Stigma Experience Scale</i> Item - Whether people think less of those with an intellectual disability			Fisher’s exact test, p-value
	Yes	No	Total	
Highest education level				<b>2.56,0.23</b>
Some or completed public school	1 (6%)	7 (23%)	8 (17%)	
Some or completed high school	17 (94%)	23 (77%)	40 (83%)	
<b>Total</b>	18 (38%)	30 (62%)	48 (100%)	

Descriptive characteristic of child	<i>Stigma Experience Scale</i> Item - Whether people are afraid of those with an intellectual disability			Fisher’s exact test, p-value
	Yes	No	Total	
Highest education level				<b>2.04,0.32</b>
Some or completed public school	0 (0%)	8 (21%)	8 (17%)	
Some or completed high school	8 (100%)	30 (79%)	38 (83%)	
<b>Total</b>	8 (17%)	38 (83%)	46 (100%)	

Descriptive characteristic of child	<i>Stigma Experience Scale</i> Item - Whether the adult child had been stigmatized because of his/her intellectual disability			Fisher’s exact test, p-value
	Yes	No	Total	
Highest education level				<b>0.93,0.64</b>
Some or completed public school	1 (8%)	6 (19%)	7 (16%)	
Some or completed high school	12 (92%)	25 (81%)	37 (84%)	
<b>Total</b>	13 (30%)	31 (70%)	44 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether the parent had felt stigmatized because of his/her child's intellectual disability			<b>Fisher's exact test, p-value</b>
<b>Highest education level</b>	Yes	No	<b>Total</b>	<b>1.12,0.57</b>
Some or completed public school	0 (0%)	8 (19%)	8 (17%)	
Some or completed high school	5 (100%)	35 (81%)	40 (83%)	
<b>Total</b>	5 (10%)	43 (90%)	48 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected family's ability to make or keep friends			<b>Fisher's exact test, p-value</b>
<b>Highest education level</b>	Yes	No	<b>Total</b>	<b>0.04,1.00</b>
Some or completed public school	1 (14%)	7 (18%)	8 (17%)	
Some or completed high school	6 (86%)	33 (82%)	39 (83%)	
<b>Total</b>	7 (15%)	40 (85%)	47 (100%)	

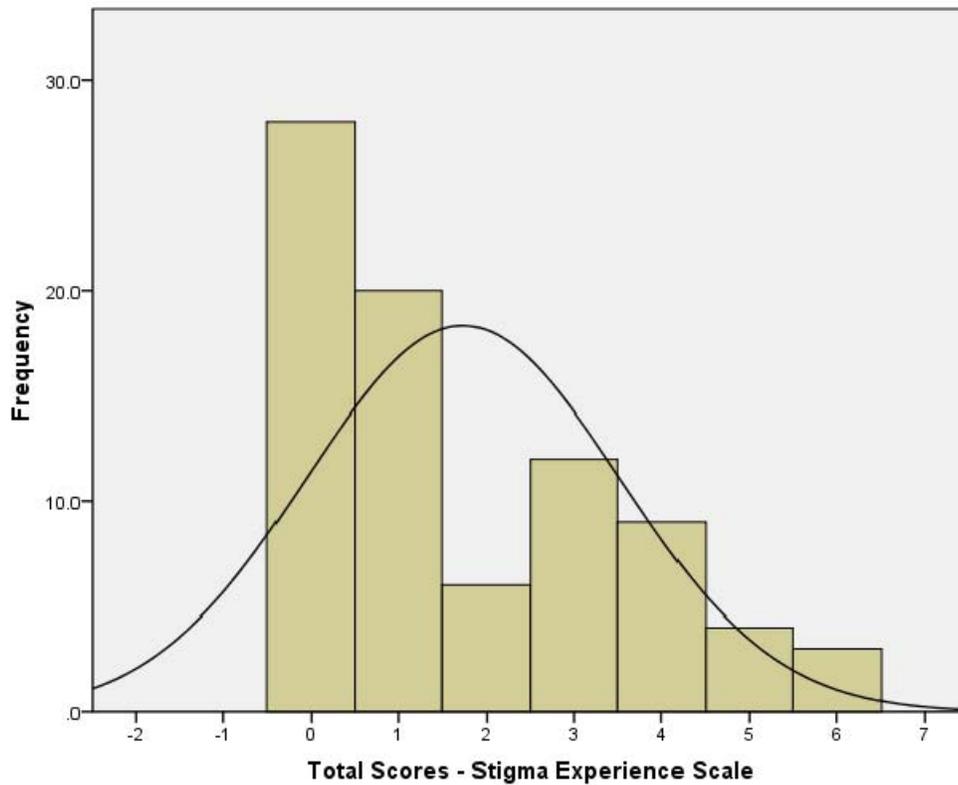
<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected parent's ability to interact with other relatives			<b>Fisher's exact test, p-value</b>
<b>Highest education level</b>	Yes	No	<b>Total</b>	<b>0.59,0.66</b>
Some or completed public school	1 (9%)	7 (19%)	8 (17%)	
Some or completed high school	10 (91%)	30 (81%)	40 (83%)	
<b>Total</b>	11 (23%)	37 (77%)	48 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected family's quality of life			<b>Fisher's exact test, p-value</b>
<b>Highest education level</b>	Yes	No	<b>Total</b>	<b>3.20,0.17</b>
Some or completed public school	0 (0%)	8 (22%)	8 (17%)	
Some or completed high school	12 (100%)	28 (78%)	40 (83%)	
<b>Total</b>	12 (25%)	36 (75%)	48 (100%)	

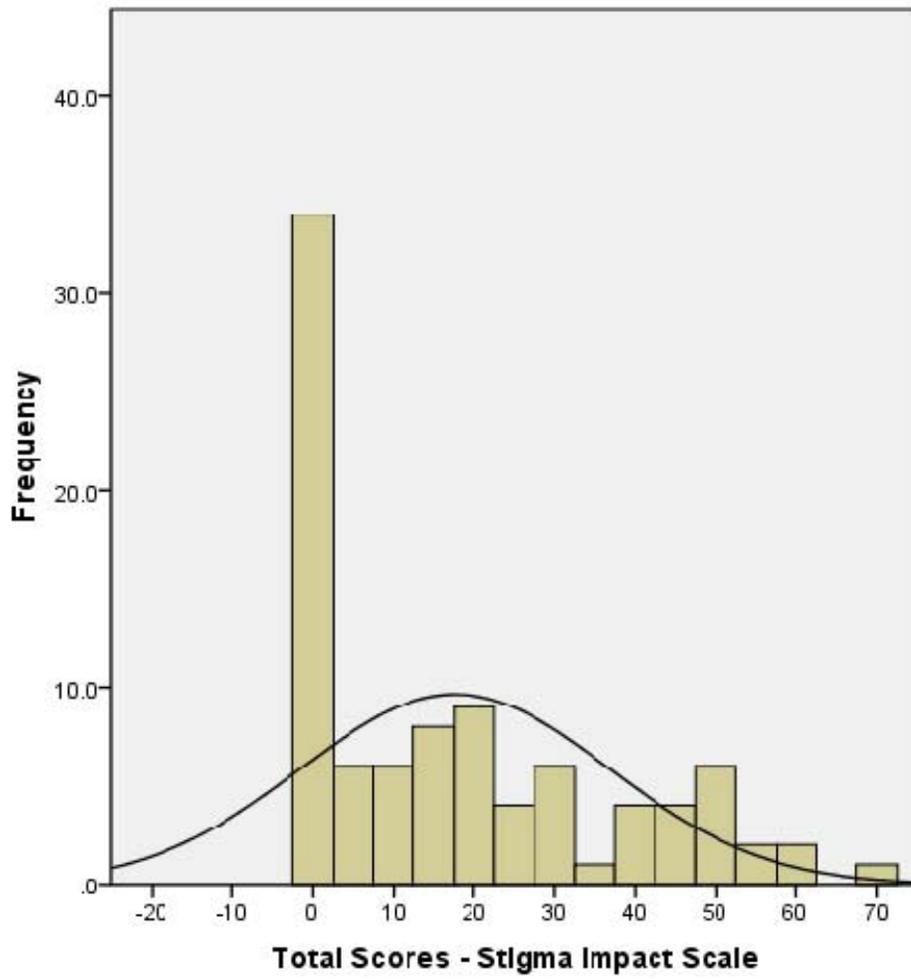
**APPENDIX I: DISTRIBUTION OF THE FREQUENCY OF THE TOTAL SCORES FOR EACH OF THE THREE SCALES**

The total scores are represented by histograms, with normal distribution curve fitted to the data.

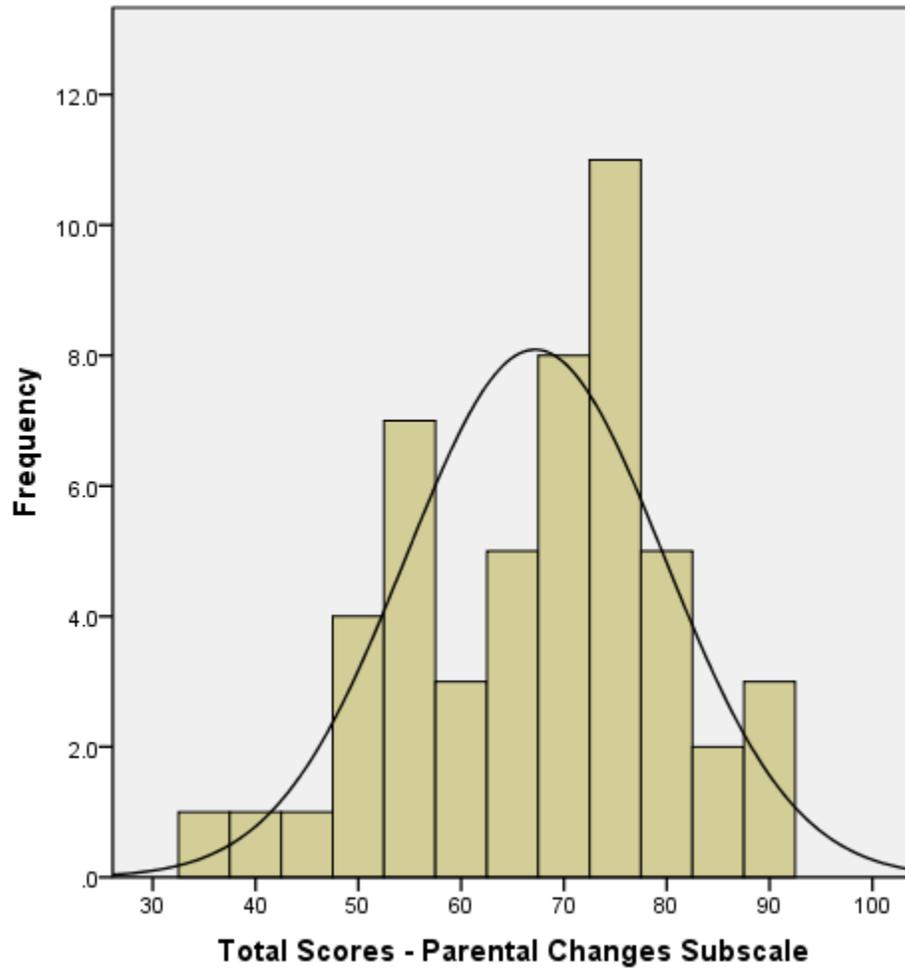
(A) Distribution of the frequency of total scores for the *Stigma Experience Scale* (N=82)



(B) Distribution of the frequency of total scores for the *Stigma Impact Scale* (N=93)

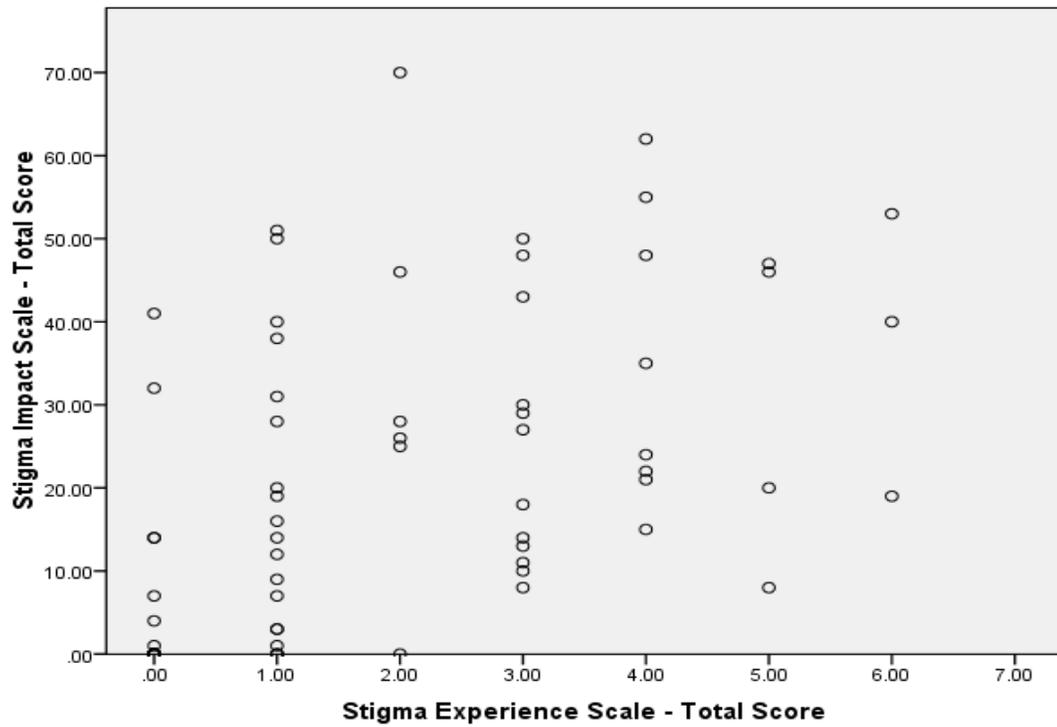


(C) Distribution of the frequency of total scores for the *Parental Changes Subscale* (N=51)

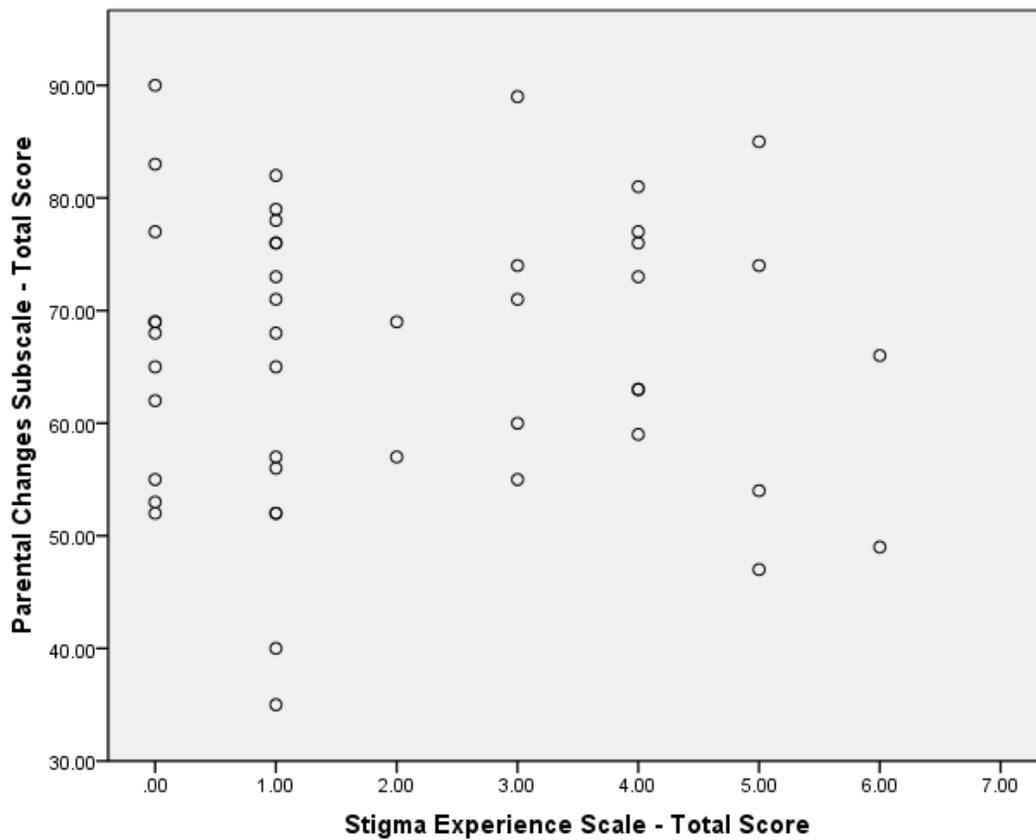


## APPENDIX J: GRAPHICAL REPRESENTATION OF CORRELATION BETWEEN SCALES

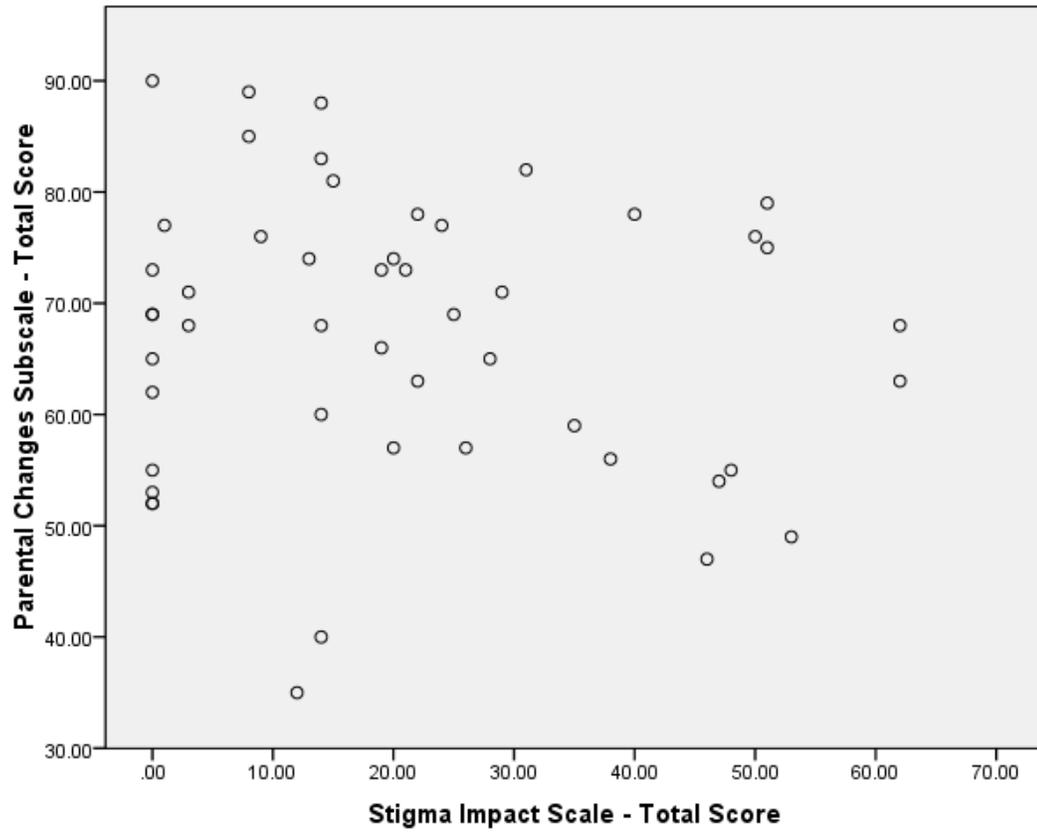
(A) Inter-correlation between *Stigma Experience Scale* and *Stigma Impact Scale* (N=79)



(B) Inter-correlation between the *Stigma Experience Scale* and the *Parental Changes Subscale* (N=46)



(C) Inter-correlation between the *Stigma Impact Scale* and the *Parental Changes Subscale* (N=49)



**APPENDIX K: ASSOCIATION BETWEEN DESCRIPTIVE CHARACTERISTICS AND ITEMS IN THE STIGMA EXPERIENCE SCALE**

Each of the thirteen descriptive characteristics was tested for its association with each of the seven items in the *Stigma Experience Scale*. All chi-square or Fisher’s exact test statistics which did not reach statistical significance (p-value less than 0.05) are presented here.

**1) Respondent’s relationship to adult child**

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale</i> Item - Whether people think less of those with an intellectual disability</b>			<b>Fisher’s exact test statistic, p-value</b>
<b>Relationship to child</b>	Yes	No	<b>Total</b>	<b>1.89, 0.26</b>
Biological	32 (87%)	53 (95%)	85 (91%)	
Other	5 (13%)	3 (5%)	8 (9%)	
<b>Total</b>	37 (40%)	56 (60%)	93 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale</i> Item - Whether people are afraid of those with an intellectual disability</b>			<b>Fisher’s exact test statistic, p-value</b>
<b>Relationship to child</b>	Yes	No	<b>Total</b>	<b>0.56, 0.34</b>
Biological	21 (88%)	62 (92%)	63 (91%)	
Other	3 (12%)	5 (8%)	8 (9%)	
<b>Total</b>	24 (26%)	67 (74%)	91 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether the adult child had been stigmatized because of his/her intellectual disability			<b>Fisher's exact test statistic, p-value</b>
<b>Relationship to child</b>	Yes	No	<b>Total</b>	<b>1.35, 0.26</b>
Biological	18 (82%)	60 (91%)	78 (89%)	
Other	4 (18%)	6 (9%)	10 (11%)	
<b>Total</b>	22 (25%)	66 (75%)	88 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether the parent had felt stigmatized because of his/her child's intellectual disability			<b>Fisher's exact test statistic, p-value</b>
<b>Relationship to child</b>	Yes	No	<b>Total</b>	<b>0.004, 1.00</b>
Biological	8 (89%)	77 (90%)	85 (89%)	
Other	1 (11%)	9 (10%)	10 (11%)	
<b>Total</b>	9 (10%)	86 (90%)	95 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected family's ability to make or keep friends			<b>Fisher's exact test statistic, p-value</b>
<b>Relationship to child</b>	Yes	No	<b>Total</b>	<b>0.26, 1.00</b>
Biological	15 (94%)	69 (90%)	84 (90%)	
Other	1 (6%)	8 (10%)	9 (10%)	
<b>Total</b>	16 (17%)	77 (83%)	93 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected parent's ability to interact with other relatives			<b>Fisher's exact test statistic, p-value</b>
<b>Relationship to child</b>	Yes	No	<b>Total</b>	<b>1.23, 0.27</b>
Biological	20 (83%)	64 (91%)	84 (89%)	
Other	4 (17%)	6 (9%)	10 (11%)	
<b>Total</b>	24 (25%)	70 (75%)	94 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected family's quality of life			<b>Fisher's exact test statistic, p-value</b>
<b>Relationship to child</b>	Yes	No	<b>Total</b>	<b>0.11, 1.00</b>
Biological	21 (91%)	64 (89%)	85 (90%)	
Other	2 (9%)	8 (11%)	10 (10%)	
<b>Total</b>	23 (24%)	72 (76%)	95 (100%)	

2) *Whether the adult child currently lives with parent respondent*

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether people think less of those with an intellectual disability			<b><math>\chi^2</math>, df, p-value</b>
<b>Currently live with parent?</b>	Yes	No	<b>Total</b>	<b>0.65, 1, 0.53</b>
Yes	19 (51%)	24 (43%)	43 (46%)	
No	18 (49%)	32 (57%)	50 (54%)	
<b>Total</b>	37 (40%)	56 (60%)	93 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether people are afraid of those with an intellectual disability			<b><i>X</i><sup>2</sup>, df, p-value</b>
<b>Currently live with parent?</b>	Yes	No	<b>Total</b>	<b>3.04, 1, 0.10</b>
Yes	15 (63%)	28 (42%)	43 (47%)	
No	9 (37%)	39 (58%)	48 (53%)	
<b>Total</b>	24 (26%)	67 (74%)	91 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether the adult child had been stigmatized because of his/her intellectual disability			<b><i>X</i><sup>2</sup>, df, p-value</b>
<b>Currently live with parent?</b>	Yes	No	<b>Total</b>	<b>0.06, 1, 1.00</b>
Yes	11 (50%)	31 (47%)	42 (48%)	
No	11 (50%)	35 (53%)	46 (52%)	
<b>Total</b>	22 (25%)	66 (75%)	88 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether the parent had felt stigmatized because of his/her child's intellectual disability			<b>Fisher's exact test statistic, p-value</b>
<b>Currently live with parent?</b>	Yes	No	<b>Total</b>	<b>0.27, 0.73</b>
Yes	5 (56%)	40 (46%)	45 (47%)	
No	4 (44%)	46 (54%)	50 (53%)	
<b>Total</b>	9 (10%)	86 (90%)	95 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected family's ability to make or keep friends			<b><i>X<sup>2</sup>, df, p-value</i></b>
<b>Currently live with parent?</b>	Yes	No	<b>Total</b>	<b>0.78, 1, 0.42</b>
Yes	9 (56%)	34 (44%)	43 (46%)	
No	7 (44%)	43 (56%)	50 (54%)	
<b>Total</b>	16 (17%)	77 (83%)	93 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected parent's ability to interact with other relatives			<b><i>X<sup>2</sup>, df, p-value</i></b>
<b>Currently live with parent?</b>	Yes	No	<b>Total</b>	<b>2.06, 1, 0.16</b>
Yes	14 (58%)	29 (41%)	43 (46%)	
No	10 (42%)	41 (59%)	51 (54%)	
<b>Total</b>	24 (26%)	70 (74%)	94 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected family's quality of life			<b><i>X<sup>2</sup>, df, p-value</i></b>
<b>Currently live with parent?</b>	Yes	No	<b>Total</b>	<b>0.10, 1, 0.81</b>
Yes	10 (44%)	34 (47%)	44 (46%)	
No	13 (56%)	38 (53%)	51 (54%)	
<b>Total</b>	23 (24%)	72 (76%)	95 (100%)	

3) Gender of respondent's adult child with intellectual disability

<b>Descriptive characteristic of child</b>	<b>Stigma Experience Scale Item - Whether people think less of those with an intellectual disability</b>			<b>X<sup>2</sup>, df, p-value</b>
<b>Gender</b>	Yes	No	<b>Total</b>	<b>0.53, 1, 0.52</b>
Male	21 (57%)	36 (64%)	57 (61%)	
Female	16 (43%)	20 (36%)	36 (39%)	
<b>Total</b>	37 (40%)	56 (60%)	93 (100%)	

<b>Descriptive characteristic of child</b>	<b>Stigma Experience Scale Item - Whether people are afraid of those with an intellectual disability</b>			<b>X<sup>2</sup>, df, p-value</b>
<b>Gender</b>	Yes	No	<b>Total</b>	<b>0.75, 1, 0.47</b>
Male	13 (54%)	43 (64%)	56 (62%)	
Female	11 (46%)	24 (36%)	35 (38%)	
<b>Total</b>	24 (26%)	67 (74%)	91 (100%)	

<b>Descriptive characteristic of child</b>	<b>Stigma Experience Scale Item - Whether the adult child had been stigmatized because of his/her intellectual disability</b>			<b>X<sup>2</sup>, df, p-value</b>
<b>Gender</b>	Yes	No	<b>Total</b>	<b>0.25, 1, 0.80</b>
Male	12 (55%)	40 (61%)	52 (59%)	
Female	10 (45%)	26 (39%)	36 (41%)	
<b>Total</b>	22 (25%)	66 (75%)	88 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether the parent had felt stigmatized because of his/her child's intellectual disability			<b>Fisher's exact test statistic, p-value</b>
<b>Gender</b>	Yes	No	<b>Total</b>	<b>0.13, 1.00</b>
Male	5 (56%)	53 (62%)	58 (61%)	
Female	4 (44%)	33 (38%)	37 (39%)	
<b>Total</b>	9 (10%)	86 (90%)	95 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected family's ability to make or keep friends			<b>X<sup>2</sup>, df, p-value</b>
<b>Gender</b>	Yes	No	<b>Total</b>	<b>0.21, 1, 0.78</b>
Male	9 (56%)	48 (62%)	57 (61%)	
Female	7 (44%)	29 (38%)	36 (39%)	
<b>Total</b>	16 (17%)	77 (83%)	93 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected parent's ability to interact with other relatives			<b>X<sup>2</sup>, df, p-value</b>
<b>Gender</b>	Yes	No	<b>Total</b>	<b>0.16, 1, 0.81</b>
Male	14 (58%)	44 (63%)	58 (62%)	
Female	10 (42%)	26 (37%)	36 (38%)	
<b>Total</b>	24 (26%)	70 (74%)	94 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected family's quality of life			<b>X<sup>2</sup>, df, p-value</b>
<b>Gender</b>	Yes	No	<b>Total</b>	<b>0.02, 1, 1.00</b>
Male	14 (61%)	45 (62%)	59 (62%)	
Female	9 (39%)	27 (38%)	36 (38%)	
<b>Total</b>	23 (24%)	72 (76%)	95 (100%)	

4) Whether the respondent's adult child has ever lived in a group home or institution

<b>Descriptive characteristic of child</b>	<b>Stigma Experience Scale Item - Whether people think less of those with an intellectual disability</b>			<b>X<sup>2</sup>, df, p-value</b>
<b>Ever lived in a group home or institution</b>	Yes	No	<b>Total</b>	<b>0.95, 1, 0.40</b>
Yes	16 (43%)	30 (54%)	46 (49%)	
No	21 (57%)	26 (46%)	47 (51%)	
<b>Total</b>	37 (40%)	56 (60%)	93 (100%)	

<b>Descriptive characteristic of child</b>	<b>Stigma Experience Scale Item - Whether people are afraid of those with an intellectual disability</b>			<b>X<sup>2</sup>, df, p-value</b>
<b>Ever lived in a group home or institution</b>	Yes	No	<b>Total</b>	<b>1.54, 1, 0.24</b>
Yes	9 (38%)	35 (52%)	44 (48%)	
No	15 (62%)	32 (48%)	47 (52%)	
<b>Total</b>	24 (26%)	67 (74%)	91 (100%)	

<b>Descriptive characteristic of child</b>	<b>Stigma Experience Scale Item - Whether the adult child had been stigmatized because of his/her intellectual disability</b>			<b>X<sup>2</sup>, df, p-value</b>
<b>Ever lived in a group home or institution</b>	Yes	No	<b>Total</b>	<b>0.06, 1, 1.00</b>
Yes	10 (46%)	32 (48%)	42 (48%)	
No	12 (54%)	34 (52%)	46 (52%)	
<b>Total</b>	22 (25%)	66 (75%)	88 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether the parent had felt stigmatized because of his/her child's intellectual disability			<b>Fisher's exact test statistic, p-value</b>
<b>Ever lived in a group home or institution</b>	Yes	No	<b>Total</b>	<b>0.06, 1.00</b>
Yes	4 (44%)	42 (49%)	46 (48%)	
No	5 (56%)	44 (51%)	49 (52%)	
<b>Total</b>	9 (10%)	86 (90%)	95 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected family's ability to make or keep friends			<b>X<sup>2</sup>, df, p-value</b>
<b>Ever lived in a group home or institution</b>	Yes	No	<b>Total</b>	<b>0.92, 1, 0.42</b>
Yes	6 (38%)	39 (51%)	45 (48%)	
No	10 (62%)	38 (49%)	48 (52%)	
<b>Total</b>	16 (17%)	77 (83%)	93 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected parent's ability to interact with other relatives			<b>X<sup>2</sup>, df, p-value</b>
<b>Ever lived in a group home or institution</b>	Yes	No	<b>Total</b>	<b>1.69, 1, 0.24</b>
Yes	9 (38%)	37 (53%)	46 (49%)	
No	15 (62%)	33 (47%)	48 (51%)	
<b>Total</b>	24 (26%)	70 (74%)	94 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected family's quality of life			<b><i>X</i><sup>2</sup>, df, p-value</b>
<b>Ever lived in a group home or institution</b>	Yes	No	<b>Total</b>	<b>0.17, 1, 0.81</b>
Yes	12 (52%)	34 (47%)	46 (48%)	
No	11 (48%)	38 (53%)	49 (52%)	
<b>Total</b>	23 (24%)	72 (76%)	95 (100%)	

**5) Whether the respondent is the primary caregiver of their adult child**

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether people think less of those with an intellectual disability			<b><i>X</i><sup>2</sup>, df, p-value</b>
<b>Primary caregiver</b>	Yes	No	<b>Total</b>	<b>0.47, 1, 0.63</b>
Yes	30 (79%)	40 (73%)	70 (75%)	
No	8 (21%)	15 (27%)	23 (25%)	
<b>Total</b>	38 (41%)	55 (59%)	93 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether people are afraid of those with an intellectual disability			<b>Fisher's exact test statistic, p-value</b>
<b>Primary caregiver</b>	Yes	No	<b>Total</b>	<b>0.33, 0.78</b>
Yes	20 (80%)	49 (74%)	69 (76%)	
No	5 (20%)	17 (26%)	22 (24%)	
<b>Total</b>	25 (28%)	66 (72%)	91 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item - Whether the adult child had been stigmatized because of his/her intellectual disability</i></b>			<b>X<sup>2</sup>, df, p-value</b>
<b>Primary caregiver</b>	Yes	No	<b>Total</b>	<b>0.03, 1,1.00</b>
Yes	17 (74%)	50 (76%)	67 (75%)	
No	6 (26%)	16 (24%)	22 (25%)	
<b>Total</b>	23 (26%)	66 (74%)	89 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item - Whether the parent had felt stigmatized because of his/her child's intellectual disability</i></b>			<b>Fisher's exact test statistic, p-value</b>
<b>Primary caregiver</b>	Yes	No	<b>Total</b>	<b>0.02, 1.00</b>
Yes	7 (78%)	65 (76%)	72 (76%)	
No	2 (22%)	21 (24%)	23 (24%)	
<b>Total</b>	9 (10%)	86 (90%)	95 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item - Whether stigma affected family's ability to make or keep friends</i></b>			<b>Fisher's exact test statistic, p-value</b>
<b>Primary caregiver</b>	Yes	No	<b>Total</b>	<b>1.55, 0.34</b>
Yes	14 (88%)	56 (73%)	70 (75%)	
No	2 (12%)	21 (27%)	23 (25%)	
<b>Total</b>	16 (17%)	77 (83%)	93 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected parent's ability to interact with other relatives			<b>Fisher's exact test statistic, p-value</b>
<b>Primary caregiver</b>	Yes	No	<b>Total</b>	<b>1.32, 0.29</b>
Yes	21 (84%)	50 (73%)	71 (76%)	
No	4 (16%)	19 (27%)	23 (25%)	
<b>Total</b>	25 (27%)	69 (73%)	94 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected family's quality of life			<b>Fisher's exact test statistic, p-value</b>
<b>Primary caregiver</b>	Yes	No	<b>Total</b>	<b>0.77, 0.57</b>
Yes	19 (83%)	53 (74%)	72 (76%)	
No	4 (17%)	19 (26%)	23 (24%)	
<b>Total</b>	23 (24%)	72 (76%)	95 (100%)	

**6) Whether the respondent's adult child had ever been in conflict with the law**

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether people think less of those with an intellectual disability			<b>X<sup>2</sup>, df, p-value</b>
<b>Conflict with the law</b>	Yes	No	<b>Total</b>	<b>0.93, 1, 0.40</b>
Yes	8 (23%)	8 (15%)	16 (18%)	
No	27 (77%)	46 (85%)	73 (82%)	
<b>Total</b>	35 (39%)	54 (61%)	89 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether people are afraid of those with an intellectual disability			<b>Fisher's exact test statistic, p-value</b>
<b>Conflict with the law</b>	Yes	No	<b>Total</b>	<b>0.23, 1, 0.75</b>
Yes	5 (22%)	11 (17%)	16 (18%)	
No	18 (78%)	53 (83%)	71 (82%)	
<b>Total</b>	23 (26%)	64 (74%)	87 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether the adult child had been stigmatized because of his/her intellectual disability			<b>Fisher's exact test statistic, p-value</b>
<b>Conflict with the law</b>	Yes	No	<b>Total</b>	<b>1.89, 0.20</b>
Yes	6 (27%)	9 (14%)	15 (18%)	
No	16 (23%)	54 (86%)	70 (82%)	
<b>Total</b>	22 (26%)	63 (74%)	85 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether the parent had felt stigmatized because of his/her child's intellectual disability			<b>Fisher's exact test statistic, p-value</b>
<b>Conflict with the law</b>	Yes	No	<b>Total</b>	<b>1.71, 0.35</b>
Yes	3 (33%)	13 (16%)	16 (18%)	
No	6 (67%)	69 (84%)	75 (82%)	
<b>Total</b>	9 (10%)	82 (90%)	91 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected family's ability to make or keep friends			<b>Fisher's exact test statistic, p-value</b>
<b>Conflict with the law</b>	Yes	No	<b>Total</b>	<b>0.29, 0.73</b>
Yes	2 (13%)	14 (19%)	16 (18%)	
No	13 (87%)	59 (81%)	72 (82%)	
<b>Total</b>	15 (17%)	73 (83%)	88 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected parent's ability to interact with other relatives			<b>Fisher's exact test statistic, p-value</b>
<b>Conflict with the law</b>	Yes	No	<b>Total</b>	<b>0.51, 0.75</b>
Yes	3 (13%)	13 (20%)	16 (18%)	
No	20 (87%)	53 (80%)	73 (82%)	
<b>Total</b>	23 (26%)	66 (74%)	89 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected family's quality of life			<b>X<sup>2</sup>, df, p-value</b>
<b>Conflict with the law</b>	Yes	No	<b>Total</b>	<b>3.93, 1, 0.06</b>
Yes	7 (32%)	9 (13%)	16 (18%)	
No	15 (68%)	59 (87%)	74 (82%)	
<b>Total</b>	22 (24%)	68 (76%)	90 (100%)	

7) Gender of the parent respondent

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether people think less of those with an intellectual disability			<b>X<sup>2</sup>, df, p-value</b>
<b>Gender</b>	Yes	No	<b>Total</b>	<b>0.71, 1, 0.46</b>
Male	7 (18%)	14 (26%)	21 (23%)	
Female	31 (82%)	40 (74%)	71 (77%)	
<b>Total</b>	38 (41%)	54 (59%)	92 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether people are afraid of those with an intellectual disability			<b>Fisher's exact test statistic, p-value</b>
<b>Gender</b>	Yes	No	<b>Total</b>	<b>0.10, 0.79</b>
Male	5 (20%)	15 (23%)	20 (22%)	
Female	20 (80%)	50 (77%)	70 (78%)	
<b>Total</b>	25 (28%)	65 (72%)	90 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether the adult child had been stigmatized because of his/her intellectual disability			<b>Fisher's exact test statistic, p-value</b>
<b>Gender</b>	Yes	No	<b>Total</b>	<b>1.42, 0.38</b>
Male	3 (13%)	16 (25%)	19 (22%)	
Female	20 (87%)	48 (75%)	68 (78%)	
<b>Total</b>	23 (26%)	64 (74%)	87 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether the parent had felt stigmatized because of his/her child's intellectual disability			<b>Fisher's exact test statistic, p-value</b>
<b>Gender</b>	Yes	No	<b>Total</b>	<b>0.00, 1.00</b>
Male	2 (10%)	19 (22%)	21 (22%)	
Female	7 (90%)	66 (78%)	73 (78%)	
<b>Total</b>	9 (10%)	85 (90%)	94 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected family's ability to make or keep friends			<b>Fisher's exact test statistic, p-value</b>
<b>Gender</b>	Yes	No	<b>Total</b>	<b>0.18, 1.00</b>
Male	3 (19%)	18 (24%)	21 (23%)	
Female	13 (81%)	58 (76%)	71 (77%)	
<b>Total</b>	16 (17%)	76 (83%)	92 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected family's quality of life			<b>Fisher's exact test statistic, p-value</b>
<b>Gender</b>	Yes	No	<b>Total</b>	<b>0.006, 1.00</b>
Male	5 (22%)	16 (22%)	21 (22%)	
Female	18 (78%)	55 (78%)	73 (78%)	
<b>Total</b>	23 (25%)	71 (76%)	94 (100%)	

8) Age (categorical) of parent respondent

<b>Descriptive characteristic of parent</b>	<b>Stigma Experience Scale Item - Whether the adult child had been stigmatized because of his/her intellectual disability</b>			<b>Fisher's exact test statistic, p-value</b>
<b>Age (years)</b>	<b>Yes</b>	<b>No</b>	<b>Total</b>	<b>0.47, 0.84</b>
<55	4 (20%)	16 (25%)	20 (24%)	
55-64	6 (30%)	15 (24%)	21 (25%)	
65+	10 (50%)	32 (51%)	42 (51%)	
<b>Total</b>	20 (24%)	63 (76%)	83 (100%)	

<b>Descriptive characteristic of parent</b>	<b>Stigma Experience Scale Item - Whether the parent had felt stigmatized because of his/her child's intellectual disability</b>			<b>Fisher's exact test statistic, p-value</b>
<b>Age (years)</b>	<b>Yes</b>	<b>No</b>	<b>Total</b>	<b>0.18, 1.00</b>
<55	2 (22%)	19 (23%)	21 (23%)	
55-64	2 (22%)	21 (26%)	23 (26%)	
65+	5 (56%)	41 (51%)	46 (51%)	
<b>Total</b>	9 (10%)	81 (90%)	90 (100%)	

<b>Descriptive characteristic of parent</b>	<b>Stigma Experience Scale Item - Whether stigma affected family's ability to make or keep friends</b>			<b>Fisher's exact test statistic, p-value</b>
<b>Age (years)</b>	<b>Yes</b>	<b>No</b>	<b>Total</b>	<b>4.98, 0.07</b>
<55	6 (40%)	15 (20%)	21 (23%)	
55-64	5 (33%)	17 (23%)	22 (25%)	
65+	4 (27%)	42 (57%)	46 (52%)	
<b>Total</b>	15 (17%)	74 (83%)	89 (100%)	

<b>Descriptive characteristic of parent</b>	<b>Stigma Experience Scale Item - Whether stigma affected family's quality of life</b>			<b>X<sup>2</sup>, df, p-value</b>
<b>Age (years)</b>	<b>Yes</b>	<b>No</b>	<b>Total</b>	<b>3.93, 2, 0.14</b>
<55	7 (33.3%)	14 (20%)	21 (23%)	
55-64	7 (33.3%)	15 (22%)	22 (25%)	
65+	7 (33.3%)	40 (58%)	47 (52%)	
<b>Total</b>	21 (23%)	69 (77%)	90 (100%)	

9) Respondent's employment status

<b>Descriptive characteristic of parent</b>	<b>Stigma Experience Scale Item - Whether the adult child had been stigmatized because of his/her intellectual disability</b>			<b>X<sup>2</sup>, df, p-value</b>
<b>Employment status</b>	Yes	No	<b>Total</b>	<b>1.87, 1, 0.19</b>
Employed	9 (39%)	16 (24%)	25 (28%)	
Not employed	14 (61%)	50 (76%)	64 (72%)	
<b>Total</b>	23 (26%)	66 (74%)	89 (100%)	

<b>Descriptive characteristic of parent</b>	<b>Stigma Experience Scale Item - Whether the parent had felt stigmatized because of his/her child's intellectual disability</b>			<b>Fisher's exact test statistic, p-value</b>
<b>Employment status</b>	Yes	No	<b>Total</b>	<b>0.17, 1.00</b>
Employed	2 (22%)	25 (29%)	27 (28%)	
Not employed	7 (78%)	62 (71%)	69 (72%)	
<b>Total</b>	9 (9%)	87 (91%)	96 (100%)	

<b>Descriptive characteristic of parent</b>	<b>Stigma Experience Scale Item - Whether stigma affected family's ability to make or keep friends</b>			<b>X<sup>2</sup>, df, p-value</b>
<b>Employment status</b>	Yes	No	<b>Total</b>	<b>2.03, 1, 0.22</b>
Employed	7 (44%)	20 (26%)	27 (29%)	
Not employed	9 (56%)	57 (74%)	66 (71%)	
<b>Total</b>	16 (17%)	77 (83%)	(100%)	

Descriptive characteristic of parent	Stigma Experience Scale Item - Whether stigma affected family's quality of life			X <sup>2</sup> , df, p-value
	Yes	No	Total	
<b>Employment status</b>				<b>1.71, 1, 0.29</b>
Employed	9 (39%)	18 (25%)	27 (28%)	
Not employed	14 (61%)	54 (75%)	68 (72%)	
<b>Total</b>	23 (24%)	72 (76%)	95 (100%)	

*10) Respondent's level of education*

Descriptive characteristic of parent	Stigma Experience Scale Item - Whether people think less of those with an intellectual disability			X <sup>2</sup> , df, p-value
	Yes	No	Total	
<b>Highest education level</b>				<b>0.63, 2, 0.75</b>
Some or completed public school or some or completed high school	18 (48%)	30 (55%)	48 (52%)	
Some or completed college or technical training	123 (34%)	15 (28%)	28 (31%)	
Some or completed university	7 (18%)	9 (17%)	16 (17%)	
<b>Total</b>	38 (41%)	54 (59%)	92 (100%)	

Descriptive characteristic of parent	Stigma Experience Scale Item - Whether people are afraid of those with an intellectual disability			Fisher's exact test statistic, p-value
	Yes	No	Total	
<b>Highest education level</b>				<b>5.73, 0.06</b>
Some or completed public school or some or completed high school	8 (32%)	38 (58%)	46 (51%)	
Some or completed college or technical training	12 (48%)	16 (25%)	28 (31%)	
Some or completed university	5 (20%)	11 (17%)	16 (18%)	
<b>Total</b>	25 (28%)	65 (72%)	90 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item - Whether the adult child had been stigmatized because of his/her intellectual disability</i></b>			<b>Fisher's exact test statistic, p-value</b>
<b>Highest education level</b>	Yes	No	<b>Total</b>	<b>0.48, 0.85</b>
Some or completed public school or some or completed high school	13 (57%)	31 (48%)	44 (51%)	
Some or completed college or technical training	6 (26%)	21 (33%)	27 (31%)	
Some or completed university	4 (17%)	12 (19%)	16 (18%)	
<b>Total</b>	23 (26%)	64 (74%)	87 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item - Whether the parent had felt stigmatized because of his/her child's intellectual disability</i></b>			<b>Fisher's exact test statistic, p-value</b>
<b>Highest education level</b>	Yes	No	<b>Total</b>	<b>0.23, 1.00</b>
Some or completed public school or some or completed high school	5 (56%)	43 (50%)	48 (51%)	
Some or completed college or technical training	3 (33%)	27 (32%)	30 (32%)	
Some or completed university	1 (11%)	15 (18%)	16 (17%)	
<b>Total</b>	9 (10%)	85 (90%)	94 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item - Whether stigma affected family's ability to make or keep friends</i></b>			<b>Fisher's exact test statistic, p-value</b>
<b>Highest education level</b>	Yes	No	<b>Total</b>	<b>1.08, 0.65</b>
Some or completed public school or some or completed high school	7 (44%)	40 (53%)	47 (51%)	
Some or completed college or technical training	7 (44%)	23 (30%)	30 (33%)	
Some or completed university	2 (12%)	13 (17%)	15 (16%)	
<b>Total</b>	16 (17%)	76 (83%)	92 (100%)	

Descriptive characteristic of parent	<i>Stigma Experience Scale Item - Whether stigma affected parent's ability to interact with other relatives</i>			Fisher's exact test statistic, p-value
	Yes	No	Total	
<b>Highest education level</b>				<b>1.09, 0.60</b>
Some or completed public school or some or completed high school	11 (44%)	37 (55%)	48 (52%)	
Some or completed college or technical training	10 (40%)	20 (29%)	30 (32%)	
Some or completed university	4 (16%)	11 (16%)	15 (16%)	
<b>Total</b>	25 (27%)	68 (73%)	93 (100%)	

Descriptive characteristic of parent	<i>Stigma Experience Scale Item - Whether stigma affected family's quality of life</i>			Fisher's exact test statistic, p-value
	Yes	No	Total	
<b>Highest education level</b>				<b>0.35, 0.90</b>
Some or completed public school or some or completed high school	12 (52%)	36 (51%)	48 (51%)	
Some or completed college or technical training	8 (35%)	22 (31%)	30 (32%)	
Some or completed university	3 (13%)	13 (18%)	16 (17%)	
<b>Total</b>	23 (25%)	71 (75%)	94 (100%)	

*11) Respondent's current living arrangement*

Descriptive characteristic of parent	<i>Stigma Experience Scale Item - Whether people think less of those with an intellectual disability</i>			X <sup>2</sup> , df, p-value
	Yes	No	Total	
<b>Living arrangement</b>				<b>0.20, 0.94</b>
Alone	8 (21%)	13 (24%)	21 (22%)	
Spouse/Partner	27 (71%)	37 (67%)	64 (69%)	
Other	3 (8%)	5 (9%)	8 (9%)	
<b>Total</b>	38 (41%)	55 (59%)	93 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether people are afraid of those with an intellectual disability			<b>Fisher's exact test statistic, p-value</b>
<b>Living arrangement</b>	Yes	No	<b>Total</b>	<b>1.31, 0.52</b>
Alone	4 (16%)	17 (26%)	21 (23%)	
Spouse/Partner	18 (72%)	44 (67%)	62 (68%)	
Other	3 (12%)	5 (7%)	8 (9%)	
<b>Total</b>	25 (27%)	66 (73%)	91 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether the adult child had been stigmatized because of his/her intellectual disability			<b>Fisher's exact test statistic, p-value</b>
<b>Living arrangement</b>	Yes	No	<b>Total</b>	<b>0.71, 0.72</b>
Alone	6 (26%)	13 (20%)	19 (22%)	
Spouse/Partner	16 (70%)	46 (71%)	62 (70%)	
Other	1 (4%)	6 (9%)	7 (8%)	
<b>Total</b>	23 (26%)	65 (74%)	88 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether the parent had felt stigmatized because of his/her child's intellectual disability			<b>Fisher's exact test statistic, p-value</b>
<b>Living arrangement</b>	Yes	No	<b>Total</b>	<b>0.87, 0.73</b>
Alone	1 (11%)	20 (23%)	21 (22%)	
Spouse/Partner	7 (78%)	59 (69%)	66 (70%)	
Other	1 (11%)	7 (8%)	8 (8%)	
<b>Total</b>	9 (10%)	86 (90%)	95 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected family's ability to make or keep friends			<b>Fisher's exact test statistic, p-value</b>
<b>Living arrangement</b>	Yes	No	<b>Total</b>	<b>1.38, 0.61</b>
Alone	4 (25%)	18 (23%)	22 (24%)	
Spouse/Partner	12 (75%)	51 (66%)	63 (68%)	
Other	0 (0%)	8 (11%)	8 (8%)	
<b>Total</b>	16 (17%)	77 (83%)	93 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected parent's ability to interact with other relatives			<b>Fisher's exact test statistic, p-value</b>
<b>Living arrangement</b>	Yes	No	<b>Total</b>	<b>0.70, 0.81</b>
Alone	6 (24%)	16 (23%)	22 (23%)	
Spouse/Partner	18 (72%)	46 (67%)	64 (68%)	
Other	1 (4%)	7 (10%)	8 (9%)	
<b>Total</b>	25 (27%)	69 (73%)	94 (100%)	

<b>Descriptive characteristic of parent</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected family's quality of life			<b>Fisher's exact test statistic, p-value</b>
<b>Living arrangement</b>	Yes	No	<b>Total</b>	<b>2.74, 0.25</b>
Alone	5 (22%)	17 (24%)	22 (23%)	
Spouse/Partner	18 (78%)	47 (65%)	65 (69%)	
Other	0 (0%)	8 (11%)	8 (8%)	
<b>Total</b>	23 (24%)	72 (76%)	95 (100%)	

12) Age (categorical) of respondent's adult child

<b>Descriptive characteristic of child</b>	<b>Stigma Experience Scale Item - Whether the adult child had been stigmatized because of his/her intellectual disability</b>			<b>Fisher's exact test statistic, p-value</b>
<b>Age (years)</b>	<b>Yes</b>	<b>No</b>	<b>Total</b>	<b>9.05, 0.06</b>
18-24	5 (23%)	13 (20%)	18 (21%)	
25-34	6 (27%)	17 (26%)	23 (26%)	
35-44	9 (41%)	11 (17%)	20 (23%)	
45+	2 (9%)	25 (37%)	23 (30%)	
<b>Total</b>	<b>22 (25%)</b>	<b>66 (75%)</b>	<b>88 (100%)</b>	

<b>Descriptive characteristic of child</b>	<b>Stigma Experience Scale Item - Whether the parent had felt stigmatized because of his/her child's intellectual disability</b>			<b>Fisher's exact test statistic, p-value</b>
<b>Age (years)</b>	<b>Yes</b>	<b>No</b>	<b>Total</b>	<b>2.94, 0.43</b>
18-24	3 (33.5%)	15 (17%)	18 (19%)	
25-34	1 (11%)	25 (29%)	26 (27.5%)	
35-44	3 (33.5%)	18 (21%)	21 (22%)	
45+	2 (22%)	28 (33%)	30 (31.5%)	
<b>Total</b>	<b>9 (10%)</b>	<b>86 (10%)</b>	<b>95 (100%)</b>	

<b>Descriptive characteristic of child</b>	<b>Stigma Experience Scale Item - Whether stigma affected family's ability to make or keep friends</b>			<b>Fisher's exact test statistic, p-value</b>
<b>Age (years)</b>	<b>Yes</b>	<b>No</b>	<b>Total</b>	<b>4.06, 0.24</b>
18-24	4 (25%)	14 (18%)	18 (19%)	
25-34	5 (31%)	20 (26%)	25 (27%)	
35-44	5 (31%)	15 (20%)	20 (22%)	
45+	2 (13%)	28 (36%)	30 (32%)	
<b>Total</b>	<b>16 (17%)</b>	<b>77 (83%)</b>	<b>93 (100%)</b>	

13) Whether the adult child had a dual diagnosis

<b>Descriptive characteristic of child</b>	<b>Stigma Experience Scale Item - Whether people think less of those with an intellectual disability</b>			<b>X<sup>2</sup>, df, p-value</b>
<b>Dual Diagnosis</b>	Yes	No	<b>Total</b>	<b>3.990, 1, 0.073</b>
Yes	17 (45%)	14 (25%)	31 (33%)	
No	21 (55%)	42 (75%)	63 (67%)	
<b>Total</b>	38 (40%)	56 (60%)	94 (100%)	

<b>Descriptive characteristic of child</b>	<b>Stigma Experience Scale Item - Whether people are afraid of those with an intellectual disability</b>			<b>X<sup>2</sup>, df, p-value</b>
<b>Dual Diagnosis</b>	Yes	No	<b>Total</b>	<b>0.611, 1, 0.465</b>
Yes	10 (40%)	21 (31%)	31 (34%)	
No	15 (60%)	46 (69%)	61 (66%)	
<b>Total</b>	25 (27%)	67 (73%)	92 (100%)	

<b>Descriptive characteristic of child</b>	<b>Stigma Experience Scale Item - Whether the adult child had been stigmatized because of his/her intellectual disability</b>			<b>X<sup>2</sup>, df, p-value</b>
<b>Dual Diagnosis</b>	Yes	No	<b>Total</b>	<b>3.280, 1, 0.078</b>
Yes	11 (48%)	18 (27%)	29 (33%)	
No	12 (52%)	48 (73%)	60 (67%)	
<b>Total</b>	23 (26%)	66 (74%)	89 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether the parent had felt stigmatized because of his/her child's intellectual disability			<b>Fisher's exact test statistic, p-value</b>
<b>Dual Diagnosis</b>	Yes	No	<b>Total</b>	<b>0.000, 1, 1.000</b>
Yes	3 (33%)	29 (33%)	32 (33%)	
No	6 (67%)	58 (67%)	64 (67%)	
<b>Total</b>	9 (9%)	87 (91%)	96 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected family's ability to make or keep friends			<b>X<sup>2</sup>, df, p-value</b>
<b>Dual Diagnosis</b>	Yes	No	<b>Total</b>	<b>2.902, 1, 0.139</b>
Yes	8 (50%)	22 (28%)	30 (32%)	
No	8 (50%)	56 (72%)	64 (68%)	
<b>Total</b>	16 (17%)	78 (83%)	94 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale Item -</i></b> Whether stigma affected parent's ability to interact with other relatives			<b>X<sup>2</sup>, df, p-value</b>
<b>Dual Diagnosis</b>	Yes	No	<b>Total</b>	<b>0.175, 1, 0.804</b>
Yes	9 (36%)	22 (31%)	31 (33%)	
No	16 (64%)	48 (69%)	64 (67%)	
<b>Total</b>	25 (26%)	70 (74%)	95 (100%)	

## APPENDIX L: SAMPLE SIZE CALCULATIONS FOR INTERNAL CONSISTENCY<sup>1</sup>

Using the equation below to obtain the upper limit and lower limit of interval estimation, we derived absolute precision estimate as the difference of the two limits.

$$1 - \exp[\ln(1 - \rho_k) \pm Z_{\alpha/2} (2k / \{(k-1)(n-2)\})^{1/2}]$$

(Bonett, 2002), where  $\rho_k$ =correlation coefficient,  $k$ = quantitative scored items= 7 (in each scale)

$\alpha$	N =	Absolute Precision	Fluctuations around $\alpha$ [% , {absolute precision/2}*100%]	Justification
0.6	55	0.3383	17% [(0.3383/2)*100%]	Marginally satisfactory
0.7	55	0.2538	13% [(0.2538/2)*100%]	Satisfactory
0.8	55	0.1692	8% [(0.1692/2)*100%]	Very satisfactory

The current study's total sample size was N=97, with sample sizes for the evaluation of internal consistency of each of the three scales being: n=82 for *Stigma Experience Scale*, n=93 for *Stigma Impact Scale* and n=51 for *Parental Changes Subscale*. The coefficients of reliability for each of the three scales ranged from 0.70 to 0.95, thus the sample sizes attained in our current study was satisfactory to meet our primary objective of evaluating the internal consistencies of the three scales.

### Reference:

Bonett, D.G. (2002). Sample Size Requirement for Testing and Estimating Coefficient Alpha. *Journal of Educational and Behavioral Statistics*, 27(4), 335-340.

<sup>1</sup> The sample size table was constructed with the assistance of Dr. Miu Lam, Department of Community Health and Epidemiology.

**APPENDIX M: COMPARISON OF RESPONDENTS AND NON-RESPONDENTS  
FOR THE STIGMA EXPERIENCE SCALE**

Testing the association between each of the thirteen key characteristics of the respondents (and their adult child) and whether they completed the *Stigma Experience Scale* (none reached statistical significance, i.e., p-value of less than 0.05):

Descriptive characteristic of child	<i>Stigma Experience Scale</i> – answered all 7 items?			X <sup>2</sup> , df, p-value
	Yes	No	Total	
<b>Dual Diagnosis</b>				<b>0.39, 1, 0.56</b>
Yes	26 (81%)	6 (19%)	32 (33%)	
No	56 (86%)	9 (14%)	65 (67%)	
<b>Total</b>	82 (85%)	15 (15%)	97 (100%)	

Descriptive characteristic of child	<i>Stigma Experience Scale</i> – answered all 7 items?			Fisher's exact test statistic, p-value
	Yes	No	Total	
<b>Age (years)</b>				<b>0.56, 0.98</b>
18-24	16 (89%)	2 (11%)	18 (19%)	
25-34	22 (85%)	4 (15%)	26 (27%)	
35-44	17 (81%)	4 (19%)	21 (22%)	
45+	26 (84%)	5 (16%)	31 (32%)	
<b>Total</b>	81 (84%)	15 (16%)	96 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale</i> – answered all 7 items?</b>			<b>Fisher’s exact test statistic, p-value</b>
<b>Conflict with the law</b>	Yes	No	<b>Total</b>	<b>1.02, 0.45</b>
Yes	15 (94%)	1 (6%)	16 (18%)	
No	63 (84%)	12 (16%)	75 (82%)	
<b>Total</b>	78 (86%)	13 (14%)	91 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale</i> – answered all 7 items?</b>			<b>Fisher’s exact test statistic, p-value</b>
<b>Gender</b>	Yes	No	<b>Total</b>	<b>1.06, 0.39</b>
Male	48 (81%)	11 (19%)	59 (62%)	
Female	33 (89%)	4 (11%)	37 (38%)	
<b>Total</b>	81 (84%)	15 (16%)	96 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale</i> – answered all 7 items?</b>			<b>X<sup>2</sup>, df, p-value</b>
<b>Ever lived in a group home or institution</b>	Yes	No	<b>Total</b>	<b>0.01, 1, 1.00</b>
Yes	39 (85%)	7 (15%)	46 (48%)	
No	42 (84%)	8 (16%)	50 (52%)	
<b>Total</b>	81 (84%)	15 (16%)	96 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Stigma Experience Scale</i> – answered all 7 items?</b>			<b>X<sup>2</sup>, df, p-value</b>
<b>Currently live with parent?</b>	Yes	No	<b>Total</b>	<b>0.00, 1, 1.00</b>
Yes	38 (84%)	7 (16%)	45 (47%)	
No	43 (84%)	8 (16%)	51 (53%)	
<b>Total</b>	81 (84%)	15 (16%)	96 (100%)	

Descriptive characteristic of parent	<i>Stigma Experience Scale</i> – answered all 7 items?			Fisher’s exact test statistic, p-value
	Yes	No	Total	
<b>Living arrangement</b>				<b>0.16, 1.00</b>
Alone	19 (86%)	3 (14%)	22 (23%)	
Spouse/Partner	55 (83%)	11 (17%)	66 (69%)	
Other	7 (88%)	1 (12%)	8 (8%)	
<b>Total</b>	81 (84%)	15 (16%)	96 (100%)	

Descriptive characteristic of parent	<i>Stigma Experience Scale</i> – answered all 7 items?			Fisher’s exact test statistic, p-value
	Yes	No	Total	
<b>Highest education level</b>				<b>1.98, 0.355</b>
Some or completed public school or some or completed high school	41 (85%)	7 (15%)	48 (50%)	
Some or completed college or technical training	24 (77%)	7 (23%)	31 (33%)	
Some or completed university	15 (94%)	1 (6%)	16 (17%)	
<b>Total</b>	80 (84%)	15 (16%)	95 (100%)	

Descriptive characteristic of parent	<i>Stigma Experience Scale</i> – answered all 7 items?			Fisher’s exact test statistic, p-value
	Yes	No	Total	
<b>Employment status</b>				<b>0.002, 0.60</b>
Employed	23 (85%)	4 (15%)	27 (28%)	
Not employed	59 (86%)	10 (14%)	69 (72%)	
<b>Total</b>	82 (85%)	14 (15%)	96 (100%)	

Descriptive characteristic of parent	<i>Stigma Experience Scale</i> – answered all 7 items?			Fisher’s exact test statistic, p-value
	Yes	No	Total	
<b>Age (years)</b>				<b>0.22, 1.00</b>
<55	18 (86%)	3 (14%)	21 (23%)	
55-64	20 (90%)	3 (10%)	23 (25%)	
65+	39 (83%)	8 (17%)	47 (52%)	
<b>Total</b>	77 (85%)	14 (15%)	91 (100%)	

Descriptive characteristic of parent	<i>Stigma Experience Scale</i> – answered all 7 items?			Fisher’s exact test statistic, p-value
	Yes	No	Total	
<b>Gender</b>				<b>0.05, 1.00</b>
Male	18 (86%)	3 (14%)	21 (22%)	
Female	62 (84%)	12 (16%)	74 (78%)	
<b>Total</b>	80 (84%)	15 (16%)	95 (100%)	

Descriptive characteristic of parent	<i>Stigma Experience Scale</i> – answered all 7 items?			Fisher’s exact test statistic, p-value
	Yes	No	Total	
<b>Primary caregiver</b>				<b>0.84, 0.51</b>
Yes	61 (84%)	12 (16%)	73 (76%)	
No	21 (91%)	2 (9%)	23 (24%)	
<b>Total</b>	82 (85%)	14 (15%)	96 (100%)	

Descriptive characteristic of parent	<i>Stigma Experience Scale</i> – answered all 7 items?			Fisher’s exact test statistic, p-value
	Yes	No	Total	
<b>Relationship to child</b>				<b>1.75, 0.19</b>
Biological	74 (86%)	12 (14%)	86 (90%)	
Other	7 (70%)	3 (30%)	10 (10%)	
<b>Total</b>	81 (84%)	15 (16%)	96 (100%)	

**APPENDIX N: COMPARISON OF RESPONDENTS AND NON-RESPONDENTS  
FOR THE PARENTAL CHANGES SUBSCALE**

Testing the association between each of the thirteen key characteristics of the respondents (and their adult child) and whether they completed the *Parental Changes Subscale*.

Respondents were significantly different than non-respondents (p-value less than 0.05), in terms of five key characteristics: age of adult child, respondent’s living arrangement, respondent’s level of education, respondent’s employment status, and the age of the parent respondent.

Descriptive characteristic of child	<i>Parental Changes Subscale – answered all 18 items?</i>			Fisher’s exact test statistic, p-value
	Yes	No	Total	
<b>Age (years)</b>				<b>17.9, 0.001</b>
18-24	3 (17%)	15 (83%)	18 (19%)	
25-34	9 (35%)	17 (65%)	26 (27%)	
35-44	11 (52%)	10 (48%)	21 (22%)	
45+	23 (74%)	8 (26%)	31 (32%)	
<b>Total</b>	46 (48%)	50 (52%)	96 (100%)	

Descriptive characteristic of parent	<i>Parental Changes Subscale – answered all 18 items?</i>			Fisher’s exact test statistic, p-value
	Yes	No	Total	
<b>Living arrangement</b>				<b>12.1, 0.002</b>
Alone	6 (27%)	16 (63%)	22 (23%)	
Spouse/Partner	43 (65%)	23 (35%)	66 (69%)	
Other	2 (25%)	6 (75%)	8 (8%)	
<b>Total</b>	51 (47%)	45 (53%)	96 (100%)	

Descriptive characteristic of parent	Parental Changes Subscale – answered all 18 items?			X <sup>2</sup> , df, p-value
	Yes	No	Total	
<b>Highest education level</b>				<b>12.1, 2, 0.002</b>
Some or completed public school or some or completed high school	18 (38%)	30 (62%)	48 (50%)	
Some or completed college or technical training	24 (77%)	7 (23%)	31 (33%)	
Some or completed university	9 (56%)	7 (44%)	16 (17%)	
<b>Total</b>	51 (54%)	44 (46%)	95 (100%)	

Descriptive characteristic of parent	Parental Changes Subscale – answered all 18 items?			X <sup>2</sup> , df, p-value
	Yes	No	Total	
<b>Employment status</b>				<b>4.5, 1, 0.03</b>
Employed	19 (70%)	8 (30%)	27 (28%)	
Not employed	32 (44%)	37 (56%)	69 (72%)	
<b>Total</b>	51 (53%)	45 (47%)	96 (100%)	

Descriptive characteristic of parent	Parental Changes Subscale – answered all 18 items?			X <sup>2</sup> , df, p-value
	Yes	No	Total	
<b>Age (years)</b>				<b>9.7, 2, 0.008</b>
<55	15 (71%)	6 (19%)	21 (23%)	
55-64	17 (74%)	6 (26%)	23 (25%)	
65+	19 (40%)	28 (60%)	47 (52%)	
<b>Total</b>	51 (56%)	40 (44%)	91 (100%)	

Descriptive characteristic of parent	<i>Parental Changes Subscale – answered all 18 items?</i>			<i>X<sup>2</sup>, df, p-value</i>
	Yes	No	Total	
<b>Primary caregiver</b>				<b>4.09, 1, 0.06</b>
Yes	43 (59%)	30 (41%)	73 (76%)	
No	8 (35%)	15 (65%)	23 (24%)	
<b>Total</b>	51 (53%)	45 (47%)	96 (100%)	

Descriptive characteristic of child	<i>Parental Changes Subscale – answered all 18 items?</i>			<i>X<sup>2</sup>, df, p-value</i>
	Yes	No	Total	
<b>Conflict with the law</b>				<b>0.10, 1, 0.79</b>
Yes	9 (56%)	7 (44%)	16 (18%)	
No	39 (52%)	36 (48%)	75 (82%)	
<b>Total</b>	48 (53%)	43 (47%)	91 (100%)	

Descriptive characteristic of child	<i>Parental Changes Subscale – answered all 18 items?</i>			<i>X<sup>2</sup>, df, p-value</i>
	Yes	No	Total	
<b>Gender</b>				<b>0.29, 1, 0.68</b>
Male	32 (54%)	27 (46%)	59 (62%)	
Female	18 (49%)	19 (51%)	37 (38%)	
<b>Total</b>	50 (52%)	46 (48%)	96 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Parental Changes Subscale – answered all 18 items?</i></b>			<b><math>X^2</math>, df, p-value</b>
<b>Ever lived in a group home or institution</b>	Yes	No	<b>Total</b>	<b>1.46, 1, 0.31</b>
Yes	21 (46%)	25 (54%)	46 (48%)	
No	29 (58%)	21 (46%)	50 (52%)	
<b>Total</b>	50 (52%)	46 (48%)	96 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Parental Changes Subscale – answered all 18 items?</i></b>			<b><math>X^2</math>, df, p-value</b>
<b>Currently live with parent?</b>	Yes	No	<b>Total</b>	<b>3.49, 1, 0.07</b>
Yes	28 (62%)	17 (38%)	45 (47%)	
No	22 (43%)	29 (57%)	51 (53%)	
<b>Total</b>	50 (52%)	46 (48%)	96 (100%)	

<b>Descriptive characteristic of child</b>	<b><i>Parental Changes Subscale – answered all 18 items?</i></b>			<b><math>X^2</math>, df, p-value</b>
<b>Dual Diagnosis</b>	Yes	No	<b>Total</b>	<b>0.26, 1, 0.61</b>
Yes	18 (56%)	14 (44%)	32 (33%)	
No	33 (51%)	32 (49%)	65 (67%)	
<b>Total</b>	51 (53%)	46 (47%)	97 (100%)	

Descriptive characteristic of parent	<i>Parental Changes Subscale – answered all 18 items?</i>			<i>X<sup>2</sup>, df, p-value</i>
	Yes	No	Total	
<b>Gender</b>				<b>0.40, 1, 0.62</b>
Male	10 (48%)	11 (52%)	21 (22%)	
Female	41 (55%)	33 (45%)	74 (78%)	
<b>Total</b>	51 (54%)	44 (46%)	95 (100%)	

Descriptive characteristic of parent	<i>Parental Changes Subscale – answered all 18 items?</i>			<i>Fisher's exact test statistic, p-value</i>
	Yes	No	Total	
<b>Relationship to child</b>				<b>1.44, 0.32</b>
Biological	43 (50%)	43 (50%)	86 (90%)	
Other	7 (70%)	3 (30%)	10 (10%)	
<b>Total</b>	50 (52%)	46 (48%)	96 (100%)	