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Family Caregiver Adaptation: Caring for an Individual with Intellectual Disability

Shivasangarey Kanthasamy

A thesis submitted in fulfilment of the requirements for the degree of

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Acknowledgements

I want to reflect on my entire Ph.D. journey, starting with my *tata* (grandfather), whom I lost when I was three years old. Though my memories of him are faint, his impact on my life remains vivid. My *tata* and parents firmly believed that education was the key to transforming lives, and they prioritized it for their children, especially my *amma* (mother). She has always been my first role model. Thank you for being the source of inspiration.

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Abstract

This thesis describes the results from three investigations focused on family caregivers caring for individuals diagnosed with intellectual disability (ID) in Singapore. The project aimed to study the caregiver's stress and coping mechanisms, and the impact on placement decisions for their family member with ID. The outcome of the scoping review, highlighted the multi-faceted nature of the adaptation process for caregivers, underscoring the complexity of their role. Study 1 was a series of five explanatory sequential case studies examining family caregivers' adaptation over a one to two-year period. It was hypothesised that caregivers who coped with the caregiving demands keep their child in the family home longer. The measures completed by the caregivers' assessed stressors, coping resources, stress response, and adaptation outcomes related to placement. The qualitative data analysis highlighted that decision-making for the out-of-home placement can be "fluid", a concept that acknowledges the dynamic nature of caregiving. Study 2 was a quantitative cross-sectional study and used the same assessment framework as Study 1. Study 2 aimed to understand caregivers' current perspectives on caring for an adult with ID in a clinical setting. A group of 41 caregivers completed the measures. The outcome from this study was an understanding of the combination of the coping resources that best predicted the placement tendency scores. In conclusion, the results from both studies gave an indication of the coping factors that can best reduce the impact of stressors on caregivers. A more personalised approach to caregiver profiling is proposed, including the recommendation of a policy framework that promotes early identification of high-risk profiles among family caregivers of people with ID.

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Chapter 1

General Introduction

Being the primary caregiver of a family member diagnosed with intellectual disability (ID) is a distinctive journey. Primary caregivers may need to undergo adjustment across their caregiving journey to meet their individual and family's changing needs. The overarching aim of this research project was to study the primary caregiver's adaptation to caring for adults with ID who were living in the community and the factors that impacted on the decision-making related to long-term placement (home or out-of-home placement). Chapter 1 covers the definition and characteristics of individuals with ID and their family caregivers based on the current mental healthcare approach that advocates for social inclusion and community living in Singapore. Different models of family stress and adaptation are considered. Lazarus and Folkman's (1984) Transactional Model of Stress and Coping is proposed as a useful framework, with a focus on placement tendency as an objective marker of successful and unsuccessful adaption.

Some extreme examples of caregivers' coping illustrate the seriousness of the issues faced by family caregivers caring for a child with a disability. For example, a documented incident known as the Latimer Case that got public attention in 1993, related to "mercy killing" and how the particular caregiver coped with ending the "suffering" of his daughter (Schwartz & Lutfiyya, 2009). Tracy Latimer was born with cerebral palsy and severe ID. She required multiple surgeries related to her physical disability. The father, Robert William Latimer, decided to kill his daughter with carbon monoxide poisoning. His justification was that he was motivated by his love for his daughter and wanted to end her 13 years of suffering and pain. Another documented case in the past two decades is that of Marielle Houle, a mother of a son with a physical disability (Schwartz & Lutfiyya, 2009). She assisted her son

in committing suicide, according to the son's plan, and pleaded guilty immediately after.

Similarly, in Singapore, a father committed suicide by jumping from the eighth storey of a building after stabbing his 27-year-old daughter, who had been diagnosed with moderately severe ID and autism spectrum disorder (ASD; Tang, September 2018). The State Coroner concluded the investigation by stating that the father had been diagnosed with depression and insomnia, which may have been triggered by the relapse of the daughter's challenging behaviour, such as repetitive requests to go to the toilet even if there were no toileting needs and aggressive behaviours (throwing items, hitting, and pushing others). The father, the primary caregiver, was assessed to have become physically weak and unable to attend to the daughter's needs. The father may have had difficulty coping with the increased caregiving demands and the consequences of his deteriorating mental health, so he opted to end their lives together.

The primary caregivers may want to "end the suffering" to the extent that it can be fatal to their loved ones, instead of taking steps to hand over the caregiving needs. Therefore, being a primary caregiver for a child with a disability can be unique, emotionally and physically, and the caregiving journey is incomparable, requiring multipart coping mechanisms (Mak & Ho, 2006; Panicker & Ramesh, 2019). An article by Tan (2022) documenting the journey of Dr Lim Hong Huay, a former developmental and behavioural paediatrician and mother of two children with ASD, exemplified caregivers' needs in Singapore. Dr Lim expressed that her marriage started straining when her first child displayed behaviours related to autism traits, and she had to let go of her career when her second child was diagnosed with autism. She explicitly shared, "emotionally and mentally, having no job is really, really, really tough for me". Later, she coped by advocating for caregivers through being a steering committee member for Singapore's Enabling Masterplan 2030, a founder of CaringSG and co-leader of Singapore Together Alliance for Action (AfA). These

organisations cater to caregivers caring for individuals with special needs. Dr Lim emphasised the need for extensive support for the primary caregiver, such as knowledge and resources in supporting their child: "If I, as a professional, can't even muster the courage to face these issues, how do I expect the caregivers to do so?". Dr Lim's sharing as a medical professional and caregiver highlighted the complex needs of the primary caregivers, who shoulder the responsibility of caring for their child with a disability over the long term. Understanding the definition and factors related to ID is a first step in understanding the possible demands and support the family caregivers are expected to provide to care for an individual with ID.

Intellectual Disability (ID)

Definition of ID

The American Association on Intellectual and Developmental Disabilities (AAIDD) defines individuals diagnosed with ID as having significant limitations in intellectual functioning and adaptive behaviour in their day-to-day functioning (Schalock et al., 2010). Due to improved understanding of neurodevelopment disorder and increased sensitivity to the terms used at a societal level, the terminology used to describe individuals with these significant impairments has evolved from idiocy, moron or imbecile, to mental retardation, and currently to "intellectual disability" or "disorder of intellectual development" (Maulik et al., 2011).

ID is classified as a neurodevelopmental disorder (interference with brain development), which results in significant limitations in intellectual and adaptive functioning, such as conceptual, social and practical skills, and it is irreversible (Patel et al., 2020; Thapar et al., 2017).

- Conceptual skills consist of academic related skills such as reading, writing, memory,

language, math reading, problem solving and judgment in new situations.

- Social skills consist of communication skills (expressive and receptive language), empathy, social judgement, awareness of others' thought and feelings.
- Practical skills consist of self-management of personal hygiene care, money and time management, job related task organization, and recreation.

Diagnostic manuals such as the American Psychiatric Association's (2022) *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; text rev.; *DSM-5-TR*) and the World Health Organisation's (2021) *International Statistical Classification of Diseases and Related Health Problems* (11th ed.; *ICD-11*) are used by clinicians for the diagnosis criteria. There are three diagnostic criteria, which would be measured using standardised tests on (a) cognitive functioning assessment (intelligence quotient [IQ]) assessment) which shows a significant deficit in intellectual functioning, (b) adaptive functioning assessment showing a significant impairment in the conceptual, social and practical skills, and (c) the onset should occur during the early developmental milestone period, before 18 years old (American Psychiatric Association, 2022; World Health Organisation, 2021; Girimaji et al., 2018; Greenspan & Woods, 2014; Papazoglou et al., 2014; Katz & Lazcano-Ponce, 2008; Emerson et al., 2008). The limitations in cognitive and adaptive functioning also affect the ability of the individual to develop and meet personal independence across various settings such as home, school, work, and community (Patel et al., 2020).

Healthcare professionals usually suggest an IQ and adaptive functioning assessment to the family caregivers if there is any significant delay in the milestone development of the child. Despite the cutoff scores on the assessment tools, the clinician's clinical judgment in assessing the individual's ability to learn and adapt across conceptual, social, and practical skills domains, compared to typical milestone development, is crucial as it may mitigate influencing factors on the interpretation of the cognitive and adaptive functioning

standardised test scores. These influencing factors include socio-cultural background, sensory and motor impairments, communication ability, behavioural factors, associated medical and mental disorders, and the test environment (Patel et al., 2020).

Severity Level of ID

The assessment and diagnosis of ID also includes determining the severity level of ID, such as mild, moderate, severe, or profound. The expected functioning level in each conceptual, social, and practical domain for each severity level is outlined in DSM-5-TR (American Psychiatric Association, 2022). The expected functioning level according to the classification of ID based on the severity of ID, proportion of individuals with ID in each severity level, IQ score range, and estimated mental age in adulthood are summarised in Table 1.1 (American Psychiatric Association, 2022; Patel et al., 2020; Boat et al., 2015).

Table 1.1

Classification of ID Based on Severity of ID, IQ Score and Estimated Mental Age

Severity level of ID	Proportion	IQ score range	Estimated mental age as adults
Mild	85%	50-55 to ~70	9 to 11 years old
Moderate	10%	35-49 to 50-55	6 to 8 years old
Severe	4%	20-25 to 35-49	3 to 5 years old
Profound	1%	<20-25	3 years old

Individuals diagnosed with mild ID score around ~50 to ~70 in IQ assessment and have an estimated mental age of nine to eleven years old as an adult. They comprise 85% of the ID population. They would have difficulty learning and understanding primary school academic materials regarding reading, writing, arithmetic, time and money. As adults, they have difficulty with abstract reasoning and executive functioning, such as planning, prioritising

and cognitive flexibility. They need help assessing risk related to the context, have limited social judgment and hence are at risk of being gullible (easily manipulated). Their language use during communication is more concrete compared to their same-age peers. In terms of the practical domain, they can complete their daily self-care routine and have community skills such as independent travelling to familiar places, preparing simple food, daily money management, recreational activities, and home chores. However, they require support to learn vocational skills for employment, legal decisions, and health care matters.

Individuals diagnosed with a moderate severity of ID score around ~35 to ~55 in IQ assessment and have an estimated mental age of six to eight years old as an adult. They comprise 10% of the ID population. Preschool academics would be challenging, requiring a repetitive approach and a significantly slower pace of learning. As an adult, they require caregivers to support their day-to-day living, for activities that require problem-solving and judgement. They need help with social and communication skills; hence, their social circle is limited to people they are familiar with, such as family members, teachers, and friends in school. Social judgment and decision-making are limited, thus requiring caregivers to provide support and make decisions on their behalf. Ongoing support and supervision are needed to sustain them in work settings. They can function independently for eating, dressing, toileting, and hygiene care, but only with prolonged teaching. They also need support for transportation and money management. There is a higher risk of maladaptive behaviour, which could lead to social problems.

Individuals diagnosed with severe ID score around ~20 to ~49 in IQ assessment and have an estimated mental age of three to five years old as an adult. They comprise 4% of the ID population. Learning academic skills is limited and they require extensive support in community living. Their communication may range to a few words or phrases. They can understand short-sentence communication. Support is needed for all activities of daily living,

such as showering, toileting, meals, and dressing. Long-term teaching coupled with supervision is needed for any simple skill learning. Due to their limitations in communication skills, there is a higher risk of maladaptive behaviour such as self-injury.

Finally, those diagnosed with profound severity of ID score less than 20 in IQ assessment and have an estimated mental age of three years old as an adult. They comprise 1% of the ID population and have limited conceptual, social, and practical skills. The motor and sensory impairments inhibit the individual from understanding the functional use of objects and reduces their ability to participate in social activities. They may understand simple gestures, such as “bye”, but may not understand the association of language used in communication and gestures. They express their needs and emotions via gestures. They are dependent in all areas of their daily self-care activities and require support from caregivers. Their sensory and motor impairments and physical health problems require adequate care and support from their caregivers.

Various forms of support would be needed for each individual with different levels of ID severity. For example, family caregivers will need to provide more support related to self-care and hygiene (such as toileting, showering, putting on clothes, and feeding) for individuals in the greater severity level. On the other hand, individuals with lower severity levels require more support in community skills (such as providing them with training and supervision for money management, withdrawing money from banks and independent travelling) than individuals with higher severity levels.

Aetiology of ID

Schalock (2010) conceptualised the aetiology of ID as multifactorial based on four risk factors, unlike previously, when only the biological and psychosocial factors were emphasised. The four risk factors, biomedical, social, behavioural, and educational, may affect the brain's neurodevelopment across three time factors: pre-, peri-, and post-natal

(Schalock, 2010). Biomedical factors are biologically driven, such as genetic abnormalities, transplacental infection, parental age and maternal illness, premature delivery, birth injury, degenerative/seizure disorders, and exposure to toxins. The social factors may range from social and family circumstances such as lack of prenatal care, maternal malnutrition, domestic violence, insufficient birth care, lack of stimulation for the child, institutionalisation, chronic illness, and family poverty. Thirdly, behavioural factors are associated with the consequences of risky activities such as parental drug use, child abandonment, and child abuse. The educational factors are the availability of support for adequate cognitive and adaptive skills development, such as support for parents who themselves have been diagnosed with a disability, lack of follow-up for early intervention, late diagnosis, lack of family support and special education services. The education factor could affect maximising the individual's cognitive and adaptive skills learning.

Prevalence and Life Expectancy of Individuals with ID

It is estimated that the prevalence of ID ranges from 0.05 to 1.55% of the population, based on a meta-analysis of 20 relevant articles conducted in different countries (McKenzie et al., 2016). Another meta-analysis across 52 studies in 2011 indicated a possibility of 10 individuals diagnosed with ID in every 1000 individuals, which accounts for 1% of the population. The estimated prevalence was higher in child and adolescent populations compared to adult populations and in low and middle-income countries compared to high-income countries (Maulik et al., 2011). In Singapore, no formal studies have reported on the prevalence of individuals with ID to date (Poon, 2015), even though comprehensive child development programs have been conducted over the last 30 years (Ho, 2007). The prevalence of individuals with ID across Asia is estimated to be consistent with the Western estimated prevalence (Jeevanandam, 2009), which ranges between 0.05 to 1.55% of the population (McKenzie et al., 2016; Maulik et al., 2011).

Apart from the prevalence of ID, it is estimated that the life expectancy of individuals with ID has increased, and there is a higher possibility for individuals with ID to outlive their caregivers. A 35-year population-based follow-up study was conducted in Finland to analyse the life expectancy of individuals with ID (Patja et al., 2000). The analysis consisted of 60,969 person-years for each severity level of ID (unknown, mild, moderate, severe and profound) and age groups (2-9, 10-19, 20-29, 30-39, 40-49, 50-59, 60-69, 70-79, and 80 - 99). The results indicated that the life expectancy of individuals with mild ID is equivalent to the general population, and ageing for individuals with mild ID has generally begun to be similar to the general population. In contrast, the expected life loss of the individual with profound ID was more than 20% for most age groups. Comorbidities such as epilepsy and the negative effect of hearing impairment heighten the risk of life loss for all severity levels of ID. This is due to the possibility of the severity being related to the neurological impairment instead of the risk factor related to the epilepsy and hearing impairment alone. Generally, the life span for individuals with ID has increased more than in previous generations, indicating that the healthcare of children with ID is being improved. At the same time, there may also be an increase in the demand for public healthcare to provide care for this population for an extended period.

Transition to Adulthood for Individuals with ID

The transition from adolescence to young adulthood, including graduating from secondary education, differs between adolescents with ID and adolescents with neurotypical development (Floyd et al., 2009; Biggs & Carter, 2016). Forte et al. (2011) conducted a study to explore the nature and intensity of worries an adolescent with ID faced during the transition compared to typical developing (TD) adolescents. A total of 52 participants with equal numbers of individuals in both groups were recruited: One group of adolescents with mild ID and another group of TD adolescents. The participants with ID were selected based

on having sufficient ability to understand and complete the questionnaire used in this study. The measures included participants' socio-economic status, Wechsler Abbreviated Scale of Intelligence (WASI; a brief formal measure of cognitive ability), semi-structured "worry" interview, General Self-Efficacy Scale-12 (GSES-12; assess persistence, effort and initiative), and Glasgow Anxiety Scale-ID (GAS-ID; measures worries, specific fears and physiological symptoms). The differences in language ability between the groups of participants were mitigated with pictorial clues. The questions in the self-report measures were read to the participants, and the interviewer recorded the responses. The study's outcome was that the participants with mild ID had completely different worries and significantly more rumination than those without ID. The adolescents with ID were more worried about their future, gaining and sustaining friends, being bullied, losing the person they depended on, and not being successful in life. Although this study only recruited adolescents with mild ID due to the language comprehension requirements and cannot be generalised to the rest of the population of adolescents with ID, the strength of this study is that it highlighted the importance of obtaining first-hand information from adolescents with ID regarding their future concerns related to this transition. By understanding the adolescents with IDs' particular challenges related to the uncertainties during the transition, the impact on their mental health needs can be examined.

Mental Health Co-Morbidities for Individuals with ID

One by-product of significant cognitive impairment is that it potentially affects the social functioning skills required for daily adaptive functioning especially for individuals diagnosed with mild to moderate severity of ID. As the demands for social functioning increase as the individual with ID ages and they may struggle to cope with these demands, it may affect their self-esteem and confidence to perform in social and work settings. Low self-esteem can trigger more challenging behaviours, emotional dysregulation, loneliness, mood

and anxiety-related symptoms (Buckley et al., 2020). Buckley et al. (2020) conducted a systematic review to assess the prevalence of both psychiatric disorders and their symptoms in children and adolescents with ID, for ages ranging from 6 to 21 years old. The strength of this review was that the definition of mental health terms was broadly explored by capturing two types of information: symptomology scores from standardised rating scales and formal diagnosis based on psychiatric interviews. Nineteen studies were extracted, which included 6151 children and adolescents with ID. It was highlighted that there were no studies that provided data on the specific prevalence of psychiatric diagnoses during the transition to adulthood period, ages from 18 to 21 years old. Hence, the prevalence in children and adolescents aged 6 to 21 was reviewed. The standard assessment tools used were the Developmental Behaviour Checklist (DBC) and Child Behaviour Checklist (CBCL) for symptom rating scales. The meta-analysis of the pooled prevalence for psychiatric symptoms in children and adolescents with ID was 38% and 49% based on the DBC and CBCL rating scales, accordingly. The estimated prevalence based on the DBC and CBCL was higher in children and adolescents with ID compared to the 14% found in TD children and adolescents using the CBCL (Sawyer et al., 2001).

The prevalence of the psychiatric diagnoses that were assessed via formal assessment in children and adolescents with ID were attention deficit hyperactive disorder (ADHD) at 39%, anxiety disorder ranging from 7 to 34%, conduct and externalising disorders at 3 to 21% and depression disorder at 3 to 5%. The ID behavioural traits can overshadow the mental health symptoms, and it is more challenging with poor communication skills for an individual with ID to express their emotional and mental health needs. Therefore, the risk of developing mental health problems is higher and requires the family caregivers to be more mindful in order to provide the needed support to monitor the mental health of the individual with ID.

Support for Individuals with ID

The understanding of disability has evolved, with the research and policy model shifting from a medical-based to a social contexts model (Emerson et al., 2008; Vehmas & Taylor, 2004). Emerson et al. (2008) emphasised the social contexts model, which consists of four themes. Firstly, the social contexts redefine the opportunities and life experiences that an individual with ID might be able to attain despite having a biological impairment. Secondly, family members and society can impact the lives of individuals with ID by curating services tailored to their needs, functioning, and cultural sensitivity. Thirdly, to modify medical-based specialised disability services to a service that would encourage and enable mainstream providers to serve individuals with disabilities needs. The shift in the understanding of disability initiated the efforts for social inclusion. The policymakers would need to prepare the community members and build more facilities to cater to the needs of individuals with disabilities. For example, making sure all public places are wheelchair accessible, teachers in preschool are being supported and trained to educate children with disability and employing individuals with ID in restaurants as service crew. The fourth theme that was discussed was the minimisation of poverty. It was argued that financial factors predict the quality of life of individuals with ID. However, this factor was least researched (Emerson et al., 2005). Supporting individuals with ID and their families by initiating strategies that minimise poverty by providing more supported employment opportunities could improve their quality of life. All these four themes drive the distinctive perspective of disability in general and incorporate social factors such as quality of life, family and societal circumstances, resources in the community, and community members' readiness to accept and form an inclusive society.

In Singapore government policies were reviewed to understand how individuals with disabilities are explicitly supported. The fourth Enabling Masterplan 2030 (2022 - 2030) was

drafted based on a longer-term vision of forming and supporting a more inclusive Singapore by 2030 (Ministry of Social and Family Development, n.d.). The masterplan was categorised based on three strategic themes:

- “Strategic Theme I: Strengthen Support for Lifelong Learning in a Fast-Changing Economy". This theme comprises three areas: (a) early years, (b) schooling years, and (c) beyond schooling years.
- "Strategic Theme II: Enable Persons with Disabilities to Live Independently". Independent living is supported by looking into: (a) inclusive employment, (b) inclusive living, (c) assistive technology, and (d) caregiver support.
- "Strategic Theme III: Create Inclusive Physical and Social Environments that are Inclusive to Persons with Disabilities". This theme comprises: (a) inclusive communications, (b) inclusive transport, (c) inclusive public spaces, (d) inclusive healthcare, (e) inclusive sports, (f) inclusive arts and heritage, and (g) inclusive communities.

Singapore's approach, rather than focusing on the limitations of individuals with ID, was geared to empower the individual with ID and the social counterpart, which aligns with Emerson’s et al. (2008) proposed themes of the social context and disability. The approach inspires social players to work together, support, and enable individuals with ID to maximise their potential and strength, fostering a sense of hope and optimism in society.

Stigmatisation of ID

As the effort to support the individual with ID is to build an inclusive community, the potential barrier could be stigmatisation. *Stigmatisation* is an experience and perception due to others’ differences in characteristics that were not recognised or undervalued (Pelleboer-Gunnink et al., 2019). For instance, due to the limitation in cognitive and adaptive functioning ability, individuals with ID might be stigmatised as slow learners or childlike,

which can lead to their exclusion from certain social activities and job opportunities. ID is a highly stigmatised condition, which requires sizeable public health resources to provide specialised support for individuals with ID instead of utilising existing support from community resources (Maulik et al., 2011).

Pelleboer-Gunnink et al. (2019) conducted a mixed-method cross-sectional study to examine the general public's perception of individuals with ID and how it relates to the stereotypes of discriminatory intentions and the level of familiarity/closeness. The study consisted of 892 participants from the Dutch population. Four different stereotype factors were categorised: "friendly", "in need of help", "unintelligent", and "nuisance". The stereotypes related to "nuisance" were the least reported factor in the open-ended interview. The "in need of help" factor was the most commonly reported. However, it was reported that the stereotypes were not related to the high probability of explicit discrimination but may result in other forms of discrimination as the individual with ID was perceived to have limited choices and self-determination. Regarding familiarity/closeness, participants unfamiliar with individuals with ID reported more of a "nuisance" factor and less of "in need of help" than those familiar with individuals with ID. The strength of this study was that it was one of the latest studies to understand the public's perception of individuals with ID and possible solutions to overcome the barriers to forming an inclusive society.

Family Caregivers

For people with ID, because of the recent shift in mental health approaches emphasising social inclusion (Louw et al., 2019; Bigby, 2012) and a community-based care approach (Keet et al., 2019), family caregivers are one of their central support systems. The family, especially the parents, likely did not anticipate raising a child with a disability, unlike paid caregivers with some choice and anticipation about their role as paid/professional

caregivers.

A systematic review was conducted to study the stigma experienced by families of individuals with ID and autism (Mitter et al., 2019). Based on the 10 included articles, the results indicated that family caregivers experienced stigma, there were consequences related to it (e.g. negatively affecting the caregiver's mental health and burden of care), and it was sensitive to each family's culture. The circle of stigma was discussed. *Courtesy stigma* consists of family caregivers' awareness of others' perception of their child diagnosed with ID/ASD and the unpleasant experiences and emotions associated with it. Then, there is an increase in self-internalisation due to social comparison and negative self-evaluations. The cycle continues with the fear of future discrimination and stigma due to unpleasant experiences in the past. The consequences are the emotional impact on the family caregivers' mental health as well as the behavioural consequences of coping with avoiding any social encounters (social isolation). Hence, the circle of stigma emphasises social isolation related to stigma management and the steps needed to work with the family caregivers in coping with stigma.

Apart from stigma, early family caregiver wellbeing research was based on the pathogenic paradigm of illness-focused behaviour (Laffrey et al., 1986). The pathogenic paradigm emphasised adverse outcomes, such as caregiver stress (Park & Kim, 2019) and stigma (Werner & Shulman, 2013) and their impact on caregivers' mental health (Singer, 2006), physical health (Grey, Totsika & Hastings, 2018) and overall quality of life (Jenaro et al., 2020; Chou et al., 2007). Similarly, in recent decades, various studies have continued to focus on the family caregivers of individuals with ID based on the pathogenic paradigm (Momtgomery & Kosloski, 2009; Shahrier et al., 2016; Fisher & Goodley, 2007). The psychological interventions suggested based on the outcomes of these studies are equally geared towards reducing adverse consequences (Rayan & Ahmad, 2018).

However, current researchers are taking steps to promote health by understanding the journey of caregiving based on a health paradigm rather than emphasising the negative aspects of caregiver stress (Young et al., 2020; Marino et al., 2017) while still acknowledging the family caregivers' struggle. The health paradigm focuses on actualising the capacity of the caregivers and increasing the caregivers' health and wellbeing (Laffrey et al.,1986) by focusing on themes associated with personal growth and reward for caregivers in raising a child with a developmental disorder (Young et al., 2020).

Young et al. (2020) conducted a longitudinal qualitative study for one year into the impact of raising a child with various disabilities, using a "salutogenic framework" (focusing on the factors that support wellbeing and not on identifying factors that cause disease). Thirty-three parents were interviewed twice to understand the progression of their journey of caregiving, with open-ended questions (e.g., Time 1: "Can you take me back to the beginning, and tell me how you were impacted by the diagnosis of [child]?"; Time 2: "It has been a year [since the first interview], how have things been since we last met?"). Interpretative phenomenological analysis was applied, and five themes were generated: distress and grief, personal growth, challenges, rewards and coping strategies, and resources for the parents. A mixture of pleasant and unpleasant caregiving experiences were associated with grief and distress. It was highlighted that both the themes, personal growth and rewards, were theorised to correspond with the model of post-traumatic growth (PTG; Tedeschi & Calhoun, 2004; Tedeschi et al., 2018). Thus, the salutogenic framework recognised the family caregivers' struggle while emphasising the themes associated with personal growth and reward for caregivers in raising a child with a developmental disorder.

Based on the current shift in the healthcare perspective from a pathogenic to a salutogenic framework, a revision of theories mapping caregiver wellbeing when managing an adult with ID is required. Theory is critical in conducting research and results should be

used to revise the theory accordingly (Raina et al., 2004). There are two primary schools of thought that influence the theoretical background for research related to caregiver wellbeing resulting from managing adults with ID: Hill's (1949) Family Stress Model (FSM) and Lazarus and Folkman's (1984) Transactional Model of Stress and Coping.

Family Stress Model (FSM)

The FSM defines *family stress* as an impact from any form of stress that affects the family's equilibrium and examines how the family, as a collective unit, copes with the stressors by incorporating factors such as family resilience (Lustig, 1999). Focusing specifically on studies that outlined the impact of managing adults with ID on families, most family studies adapted Hill's (1949) ABCX model with some variation and modification (Blacher, 2001; McCubbin & McCubbin, 1996).

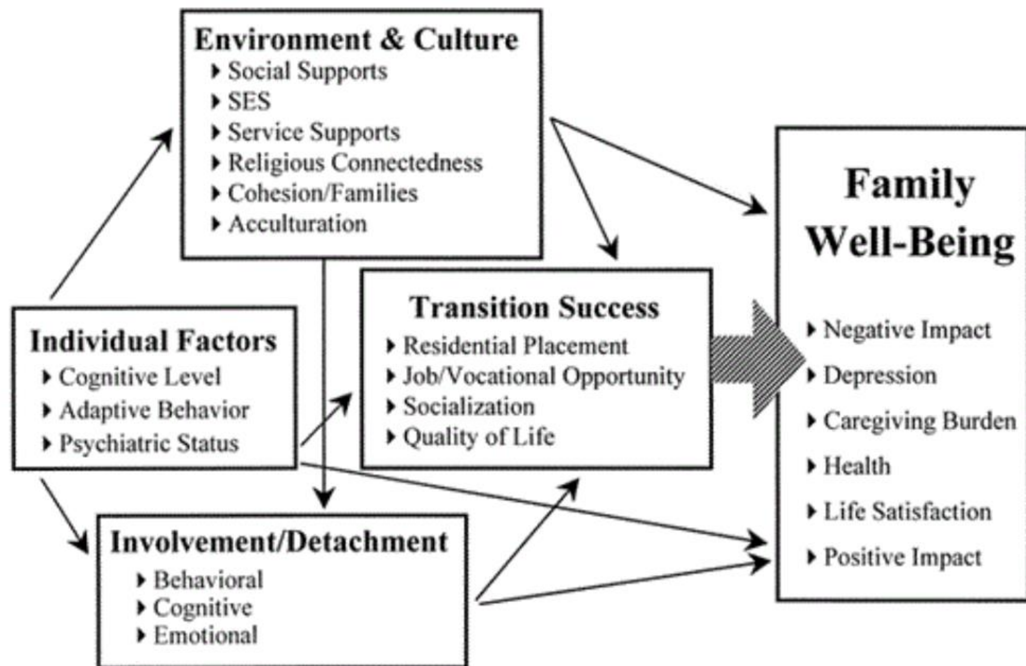
Blacher (2001) proposed a conceptual model of the factors contributing to the transition into adulthood and family wellbeing (Figure 1.1). Adolescents' functioning level was clustered as the stressors ("A"), which consisted of adolescent cognitive level, adaptive behaviour, and any comorbidity of psychiatric illness. The conceptualisation of family resources ("B") was broadened with the inclusion of environmental and cultural factors such as social supports, social and economic status (SES), service supports, religious connectedness, cohesion within the family and acculturation (the process of learning and adaptation to the new norm). The model conceptualised the coping strategies ("C") as only one type of family coping, either involvement with, or detachment from, the adolescent with ID, based on the caregiver's involvement behaviourally, cognitively, or emotionally. The primary outcome domain ("X") was the family's wellbeing, comprising the negative impact, depression, caregiving burden, health, life satisfaction, and positive impact. Blacher included another outcome domain, which comprised transition success, by assessing factors such as

residential placement, job or vocational engagement, socialisation, and quality of life of adolescents.

Blacher (2001) also discussed three potential issues related to this model specification. Firstly, the methodological specificity of how to incorporate different family members' responses to have a consensus score as a family rather than an individual representing the family. Secondly, there is a possibility of different combinations of direct and indirect effects of the variables within the model, which affects the transition and wellbeing of the family at different times of the adolescent's life stage. Therefore, he proposed to conduct a panel observational design, which would consist of a longitudinal study to understand the changes in the variables and their impact. Thirdly, the model was not explicitly tested. Thus, it was noted that the model was in an exploratory state. Overall, this model does represent an inclusive view of the representation in the natural environment, but the feasibility of it being tested is questionable. Testing is questionable due to the large number of variables, the need to include the family consensus, and the requirement for it to be a longitudinal study.

Figure 1.1

Conceptual model of family wellbeing and transition success with an adult with ID based on the ABCX Model



Note. Adapted from Blacher (2001).

Based on the understanding and rationale of Blacher's (2001) ABCX model, Neece et al. (2009) conducted a study to assess transitional satisfaction and family wellbeing among parents of individuals with ID and examined the best transition success predictors. A total of 128 parents of young adults (graduated from school and age range from 19 to 28 years old) with severe ID were recruited. The study was a cross-sectional study which comprised both qualitative and quantitative measures. The independent variables were collected using questionnaires assessing transition and family constructs such as demographic information, the Transition Experiences Survey interview protocol (TES, to assess transition experiences), Parent Involvement in Transition Planning form (to assess how much parents are involved in the transition), Center for Epidemiologic Studies –Depression Scale (CES-D; to assess

parental depression) and Family Impact Questionnaire (FIQ; to assess family impact). The individuals with ID were assessed using the Vineland Adaptive Behaviour Scales (VABS; for adaptive behaviour), Reiss Screen for Maladaptive Behaviour (for mental health) and Quality of Life Questionnaire (QOL-Q; for quality of life). It is worth noting that the constructs mentioned above are only a fractional representation of Blacher's (2001) model. Subsequently, these constructs were grouped into three domains: young adult, family, and environmental characteristics. The dependent variables were derived by using a coding system from the narrative information of the Transition Satisfaction Index and Family Wellbeing Index.

The interviewers conducted home visits to interview one of the parents. The interviewer followed a template which focused on the parents' views on how the school had prepared their child for the transition, community and future living, and also on the interviewer's perception of the family characteristics, parent-child attachment, amount and types of support the family received, as well as an observation about the home and physical environment. The responses and observations were collectively coded using a nominal scale to categorise the Transition Satisfaction Index into one of three groups: transition satisfaction and transition dissatisfaction, or they cannot be classified due to lack of information. A similar method was used for the Family Wellbeing Index; the groups were high, low, and unable to be classified as wellbeing groups. The transition satisfaction and dissatisfaction groups were then compared with the outcome variables. Some variables from each domain indicated significant differences between these two groups: young adult (young adult's quality of life), family (parent's depression level and effect of parent worrying about the family) and environment (parent's involvement in transition and the young adults' engagement in work). Overall, the environmental characteristics (service quality and transition plan, social, residential and vocational domains) were the strongest predictors of transition satisfaction. In addition,

transition satisfaction was also related to some measures of the family's wellbeing. This study's strengths are the inclusion of the qualitative approach and the robust method used to ensure the validity of the classifying indexes. However, the study was cross-sectional and only included the views of one parent (typically the mother), both of which were deviations from Blacher's (2001) recommendations on the ABCX Model.

Wong et al., (2020) conducted another study to examine parents' perspectives and experiences to enhance family-centred transition planning for adolescents with Autism Spectrum Disorder (ASD) using the ABCX Model (McCubbin et al., 1996). A total of 226 caregivers of individuals with ASD, ages ranging from 16 to 24 years old, were recruited online in the United States of America. The study was also a cross-sectional study. The research focused on family adaptation and adjustment (X) based on stressors (A), resources (B), and coping (C). This study incorporated 15 variables measuring the stressors, resources, and family coping and mapping them onto four outcome predictors: parent burden, parent-perceived transition experience, parent-perceived family quality of life, and parent subjective health. The model was confirmed using Confirmatory Factor Analyses (CFAs) and Structural Equation Modeling (SEM). Due to many variables and overloading, this study omitted some essential variables such as repetitive/rigid behaviours, psychotropic medication use, comorbid conditions, and marital relationship status during the statistical analysis. Nevertheless, it was concluded that the stressors (autism severity, mental health crisis/challenging behaviours and filial obligation), resources (parents' general social support, transition planning quality, parent-teacher relationship and parenting efficacy) and family coping (problem-focused, passive-avoidance coping and parental optimism) predicted the four outcome variables; parent burden, parent-perceived transition experience, parent-perceived family quality of life and parent subjective health. Although the study's strength was that it included multiple possible predictors as in a real-life situation, there were limitations in the statistical analysis

mapping the variables on the ABCX Model.

There are strengths and weaknesses to using the FSM in research design. The main strength is that this model represents the complex and natural phenomenon of the living arrangement of an adult in the community whose substantial needs vary along with the extent of the family support. However, there are challenges in applying and assessing the FSM in research design. There are significant limitations in conceptualising the term “family” with the type of participants recruited to study the impact on family caregivers’ wellbeing. Although Blacher (2001) acknowledged this methodological weakness and ultimately proposed using a family collective composite score, no published research appears to have adopted this suggestion. The fundamental concern is in using the term “family” wellbeing or quality of life when the responses were based on a particular parent’s or interviewer’s perspective in representing the collective family. The query is how accurately an individual perspective can represent the “family” situation when determining family adaptation and wellbeing. Secondly, it is noted that both studies (Neece et al., 2009; Wong et al., 2020) are cross-sectional studies. Referring to Blacher’s suggestions, the transition and adaptation of individuals with ID is complex and involves processes that evolve due to the fluidity of the demands and the caregiver’s resources in managing the demands (Mitchell, 1999). Thus, a cross-sectional study may not adequately represent the nature of the transition process. The cross-sectional design of the studies that adapted the FSM is a significant drawback in drawing any conclusions about the transition adaption and family wellbeing.

Transactional Model of Stress and Coping

Due to the methodological limitations of using the ABCX model, an alternative approach is proposed to understand caregiver adaption caring for an individual with ID. Firstly, working backwards, there is a need to understand the least preferred option for the

future care planning of an individual with ID. Based on the current community model of care and healthcare practitioners' emphasis on social inclusion and to maximise the potential strength of the individual with ID, out-of-home placement would be the least preferred option. So, understanding the occurrence of out-of-home placement would possibly provide insight into successful and unsuccessful adaptation.

Grey et al. (2020) conducted a longitudinal study examining placement decisions and associated factors. Their study aimed to examine the changes in the placement tendencies across one-year follow-up using the Placement Tendency Index (PTI) and subsequently to identify possible factors such as the demographic, social, or psychological characteristics of the family and/or individual with ID (age range from 18 to 67 years) that may lead to the change in the PTI score. A total of 75 primary caregivers completed the one-year follow-up study. The measures consisted of the PTI to assess the thoughts and actions related to the out-of-home placement for the adult with ID, socio-economic position (SEP) to assess the mean of the weekly family household income, Family Resource Scales (FRS) to assess which resources are adequate in the family household, EQ-5D-3L to assess the health-related quality of life for both caregiver and adult with ID, the Questionnaire on Resource and Stress-short form (QRS-F) to assess the general stress associated with caring for a family member with disability, Family Support Scale (FSS) to assess the possible support available with the degree of perceived helpfulness, Family Crisis Oriented Personal Scale (F-Copes) to assess the family coping mechanism (problem-focused and passive coping strategies), Kessler 6 (K6) to assess the non-specific psychological distress, and the Zarit Burden Index (ZBI) to assess subjective caregiving burden. The PTI was the only measure that was re-administered at one year follow-up, while the rest of the measures were administered once at the beginning of the study. The study's outcome was that over one year, 30 families moved closer to considering out-of-home placement. Of these 30 families, 14 placed the adult with ID in an

out-of-home placement. There was a significant association between the use of proactive coping styles and reduced likelihood of caregivers seeking to move the adult with ID out of their family home. Longitudinal follow-up helped track the changes in placement tendency across one year. Therefore, there is a need to understand why more caregivers are leaning towards out-of-home placement and the positive and negative factors that lead to the breakdown of this family care model. Furthermore, the life expectancy of individuals with ID has increased in line with the general population (Bittles et al., 2002; Patja et al., 2000), leading to the increased possibility that the individual with ID outlives the family caregivers, increasing the need for the caregivers to plan for their child's future care placement.

Taking into consideration the complexity of adapting the ABCX model for research design and understanding the need to assess the breakdown of family care as the least preferred outcome, the Lazarus and Folkman (1984) Transactional Model of Stress and Coping (TMSC) is proposed here as the preferred conceptual model for this research project. This model is based on the standard conceptualisation of stress that defines *perceived stress* as the outcome of a cognitive imbalance between the interpretation of the stressors and the available resources that an individual considers they have to cope with the stress (Hastings & Johnson, 2001; Dunn et al., 2001).

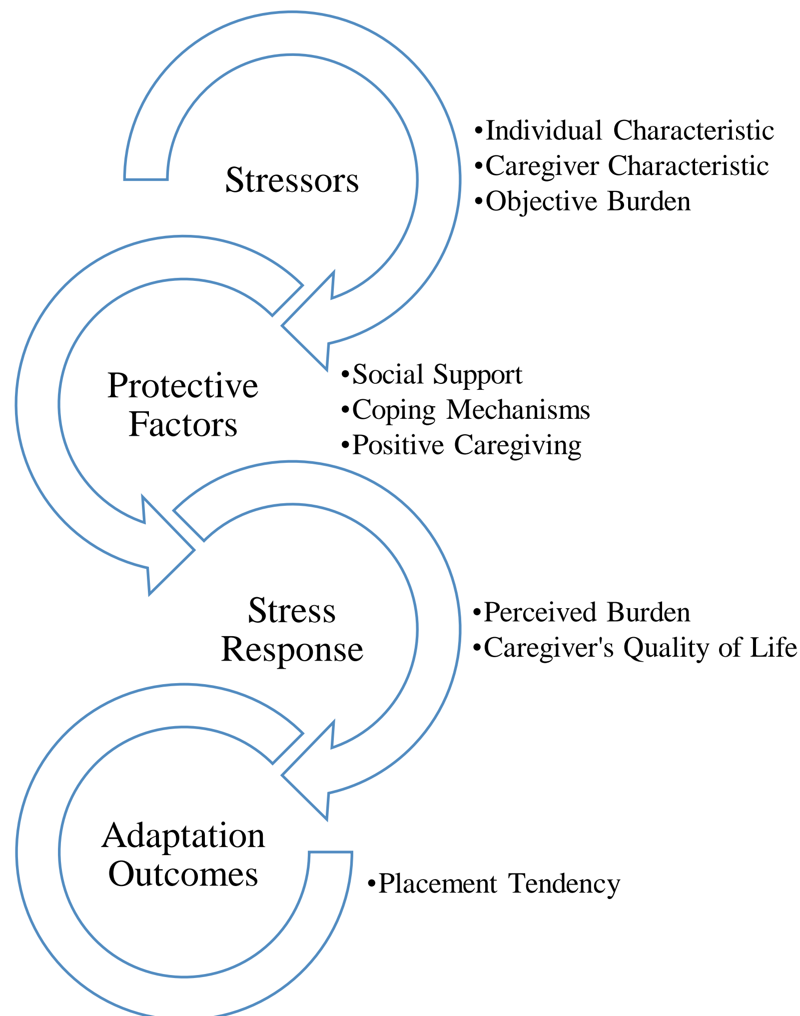
In a recent study, Lee and Shivers (2019) conceptualised their study based on Lazarus and Folkman's (1984) TMSC to investigate differences in the quality of life of caregivers of school aged children compared to young adults, both with a diagnosis of Autism Spectrum Disorder (ASD). A total of 132 caregivers of school aged children (mean age of the child with ASD was 11.35 years) and 61 caregivers of young adults, undergoing transition into adulthood (mean age of the adult with ASD was 24.57 years) were recruited. The measures that were used for each construct were the Caregiver Strain Questionnaire to assess strain, Adult Sibling Questionnaire to assess the support provided by the caregivers to the individual

with ASD, Family Needs Questionnaire to assess how the family needs in terms of the support were being met, brief COPE to assess coping behaviours and the outcome variable, Quality of Life (QOL), was measured using the Short Form 12-item Health Survey. The results of the study indicated that overall, there were no significant differences in the caregiver's QOL for both the groups. However, the differences that were noted between these two groups of caregivers were objective externalized strain, level of involvement and instrumental support needed, where the young children with ASD needed more support than the young adult with ASD. The outcomes of this study should be interpreted with caution as the sample size of the young adult's caregivers is comparatively smaller (n = 61) than the caregivers of school aged children (n = 132). Lee and Shivers (2019) concluded that future research should incorporate the potential moderating and mediating effects of specific caregiving needs, positive attributes and the longitudinal effect of the caregiving demands and its impact on the caregivers using the TMSC.

The TMSC is being widely used in caregiver studies related to older adults with dementia and brain injuries (Chwalisz, 1996; Pearlin et al., 1990; Haley et al., 1987) and in one study on professional caregivers working with individuals with ID (O'Connor, 2015). However, there does not appear to be any published research and theory to date that uses the TMSC in assessing family caregivers' adaptation to caring for individual with ID. The TMSC was adapted accordingly for this research project by including stressors, protective factors, stress response and adaptation outcome as shown in Figure 1.2.

Figure 1.2

Adapted Lazarus & Folkman's 1984 Transactional Model of Stress and Coping (TMSC) for caregivers caring for individuals with ID.



There are similarities and differences between the proposed TMSC and ABCX models. In terms of overall similarity, both models emphasise the dynamic psychosocial factors (Hawken et al., 2018) by incorporating the main domains of individual factors (individuals with ID and caregivers), social factors, and coping mechanisms. Both models attempt to represent the natural living environment of the caregiver as much as possible in managing the demands of caregiving. The proposed TMSC constructs were carefully selected, considering the feasibility of the research design and statistical analysis. Regarding the differences, the

proposed TMSC assumes that placement tendency could be the adaptation outcome of the particular caregiver response. In contrast, the ABCX model included placement tendency as part of transition success, which was proposed to influence family wellbeing. However, there is a lack of understanding of why the caregiver decides to move the individual with ID out of their family home. Is it because the caregivers are feeling overwhelmed in managing an individual with ID after they have left the special education school, is it because the caregivers are naturally planning for future care planning because the caregiver is ageing, or is there something else that predominantly influences the caregivers to opt for out-of-home placement? Past research on the factors affecting the decision-making for out-of-home placement (e.g., McConnell et al., 2016) overemphasised the stress response. No published study appears to have looked into caregivers who experienced high caregiver stress but did not consider out-of-home placement. Therefore, until this model is tested, it is reasonable to assume that the placement tendency variable can be considered as an adaptation outcome of the caregiver journey.

Summary

ID is a diagnosis given due to interference in the brain's neurodevelopment during the early developmental period, causing a significantly lowered ability to understand complex information across conceptual, social, and practical demands compared to individuals of the same age and culture. There are potential challenges for the individual with ID apart from the lack of intellectual and adaptative skills, such as mental health co-morbidity, stigmatisation and transition to adulthood. As ID is an irreversible condition with no "cure" or effective treatment (Shree & Shukla, 2016), individuals with ID require ongoing support and resources, depending on the severity level of their ID, to live at their best potential. The community, including the family caregivers and the resources in the community, are expected

to provide the needed support to form an inclusive society, as there is always a limit to maximising the cognitive and adaptive functioning of each adult with ID.

There are two main schools of thought that influence the theoretical background for research related to caregiver stress resulting from managing individuals diagnosed with ID: family stress theory (Blacher, 2001; McCubbin & McCubbin, 1996) and the transactional theory of stress and coping (Lazarus & Folkman, 1984). For this research project, Lazarus and Folkman's (1984) TMSC is adopted, instead of the Family Stress Model (ABCX model), as the most appropriate model to investigate the family caregiver adaptation, assuming that placement tendency is an adaptation outcome.

Government agencies and service providers may be able to apply the insights obtained in this research project on the factors affecting caregiver adaptation in Singapore. The insights could facilitate caregivers' long-term placement planning and prolong the stay of individuals with ID in their family homes for as long as possible by suggesting specific strategies that may improve the caregivers' coping and adaptation. In line with the fourth Enabling Masterplan 2030, the resources and support for individuals with ID and their caregivers can be further equipped to support lifelong learning in an inclusive environment. The direction should be a focus on equipping caregivers to empower their adult children with ID.

Thesis Structure

Following the general introduction presented in Chapter 1, Chapter 2 summarises a scoping review conducted based on the research literature on family caregiver adaption, specifically during the transition to adulthood of individuals with ID. The scoping review was designed to examine the past literature on the sources of the caregiver's objective burden, support, coping mechanisms, positive caregiving, and quality of life. Understanding the

findings from past literature on the caregiver's adaptation process when their son or daughter with ID transitions to adulthood would help map the factors that impact the adaptation process as holistic as possible.

Chapter 3 presents the Methods used in the two studies conducted following the findings of the scoping review. The measures used in the case series (Study 1) and the cross-sectional group study (Study 2) were the same.

Chapter 4 presents the findings from a series of explanatory sequential case studies (quantitative data collected first followed by qualitative data) conducted over two years assessing the family caregivers' adaptation in managing adolescents with ID who had graduated from special education school in Singapore (Study 1). The design of this study was based on the proposed adaptation of Lazarus and Folkman's (1984) TMSC model, assessing the decision-making process related to long-term placement and the factors related to caregiver adaptation.

Chapter 5 reports the results from a quantitative cross-sectional study assessing the factors that may impact on the current perspective of family caregivers', who are managing adults with ID, to placement options for their family member with ID (Study 2). This study focused on the family caregivers of an adult ID population recruited from a clinical service, the Institute of Mental Health (IMH), instead of the adolescent population with ID. The purpose was to assess the variation and impact of prolonged caregiving in caring for individuals with ID.

Chapter 6 is a concluding chapter that compares and outlines the factors that impact family caregiver adaptation in managing individuals with ID in Singapore. It incorporates the findings from the scoping review (Chapter 2), longitudinal case series (Chapter 4), and cross-sectional group study (Chapter 5), and, based on the totality of the findings from this research, presents a model for understanding the different approaches taken by family

caregivers. The general limitations and the future directions related to caregiver adaptation and placement tendency are discussed.

Project Aims

This project aimed to report the findings from three related research investigations that sought to understand family caregivers' adaption in managing adults with ID living in their family home in Singapore. The first investigation was a scoping review, the second was a series of case studies with primary family caregivers of adolescents with ID who just left special school and were staying in the family home, and the third investigation was a cross-sectional study of primary family caregivers of adults with ID who were living in the family home and receiving outpatient treatment from IMH. The results are presented to understand the following issues:

1) The overall factors that impact the family caregiver adaptation in managing individuals with ID, specifically during the transition to adulthood (Chapter 2).
2) The family caregiver adaptation over time and the impact on placement decisions for family caregivers managing adolescents who recently graduated from special education school (Chapter 4).
3) The factors related to family caregivers’ current stance on placement decisions for managing adults with ID who are receiving treatment from a specialised mental health service, IMH (Chapter 5).

Positionality Statement

As a clinical psychologist in an ID specialist service setting, the author had to apply a holistic approach to managing individuals with ID over 18 years old. This approach, honed in an acute setting in Singapore, addressed the concerns related to challenging behaviours,

emotion regulation, risk management, mental health-related symptoms, and caregiver support.

The assessment phase usually requires information from the individual with ID (if possible), the caregivers and the community partners (if present) to understand the individual with ID's needs. The assessment outcome will provide information regarding the individual with ID's strengths and weaknesses, the type of support needed and the function of the challenging behaviour. If the individual with ID were assessed to be unable to learn new skills to replace the challenging behaviour(s), an alternative approach would be considered. Alternative approaches include environmental management and working closely with the caregiver as a co-regulator or co-therapist in the home setting.

Depending on the presenting concerns and the individual with ID's ability level, ongoing work with the caregiver is needed. For example, to provide psychoeducation about ID, the strengths and weaknesses of the individual with ID, case formulation and the proposed management plan, psychosexual health education, expectation management (reasonable and concrete expectation and long-term planning) and developing the understanding of the caregivers that their adult child has "mind of their own" (wants and needs) as part of the transitioning to adulthood.

Based on the author's clinical experience, those caregivers who have the "energy" to cope with the demands may be defined as those caregivers who can approach the adult services asking for regular updates and seeking out more resources to support the individual with ID's hobbies such as baking, sports, yoga and performing arts (playing musical instruments and singing). On the other hand, caregivers who were assessed as being helpless and not coping with the caregiving demands (for various reasons) would be emotionally reactive, wanting to place the adult with ID out of their family home, expressing their dissatisfaction that the health or social support system are not supporting the caregivers and

individuals with ID. These caregivers are usually perceived as wanting a "quick fix". These are the possible indicators that caregivers are not coping with the caregiving demands.

For those caregivers who want the "quick fix", implementing a management plan that requires the caregiver to be the co-therapist in the home setting can also be difficult. The author cannot tap on the caregivers' resources to be the co-therapist in the home environment. Then, the significant need for community support arises, and case management should be redirected to the community support team. The community support team is crucial in providing ongoing care and support for individuals with ID and their caregivers in the community. However, one of the barriers in the Singapore context is the lack of a robust community support team, and the acute hospitals have to hold on to these cases until the community support team takes over.

The acute setting for individuals with ID in Singapore acts more as a "containment" strategy in holding on to individuals with ID, especially in the inpatient settings, while waiting to transfer to the community support team. This cycle of frequent re-admission is vicious due to the absence of a robust adult community support team and the lack of caregiver resources to manage the individual with ID's needs. Caregivers expressed dissatisfaction and frustration with the adult service compared to the child services or, in general, caregiving needs. Although caregivers at times show their appreciation of the professional in the hospital service and acknowledge the effort shown by their child, the frustration will continue to be reinforced when the individual cannot fit into any adult services, needs repeated paperwork, and there is a long waiting time to access community support.

Apart from these factors, based on this author's reflection, a consistent theme observed in the outpatient clinical setting is that once the psychoeducation about the transition to adulthood is conducted, caregivers usually respond by expressing their disappointment. The

possible themes related to the disappointment would be the need to continue supporting the child when they thought the child should be able to cope independently since he/she was coping "fine" in the special education school system. It could be argued that there is a second grief cycle, especially during the transition to adulthood stage. The grief may be more intense as the demands could be increasing, and caregivers are becoming more vulnerable due to ageing and the need for long-term planning.

Chapter 2

Family Caregiver Adaptation during the Transition to Adulthood of Individuals with Intellectual Disability: A Scoping Review

A scoping review was conducted as part of this project and was subsequently published (Kanthasamy et al., 2024; https://doi.org/10.3390/healthcare12010116; Appendix A). However, to aid the reader and give continuity to the thesis, a summary of the findings from the scoping review is presented here.

The scoping review aimed to study the sources of the caregiver's objective burden, support, coping mechanisms, positive caregiving, and quality of life to understand the caregiver's adaptation process when the individual with ID transits to adulthood. It followed the Joanna Briggs Institute (JBI) Scoping Review methodology guidelines. The inclusion criteria included studies of family caregivers of any age who provide unpaid care and lived with individuals diagnosed with ID who were transitioning to adulthood. Of 2875 articles identified, 12 published studies were included in the review. There was one quantitative study and eleven qualitative exploration studies. Most of the studies were designed based on the explorative qualitative method to gain a broad and deeper understanding of the caregivers' needs during the transition via open-ended questions.

Objective Burden

The objective burden factors have been categorised based on the needs of the individual with ID and the needs of the caregivers. Regarding the caregiving demands related to individuals with ID, stressful events were divided into young adult behaviour/conduct (Rapanaro et al., 2008; Gauthier-Boudreault et al., 2017) and incongruency between the physical and cognitive-emotional development of an individual with ID (Nucifora et al., 2024). In other words, caring for an individual with ID who is physically growing stronger

and bigger with challenging behaviours (Hubert, 2011) and psychosexual development needs (Biswas et al., 2017) was reported to be stressful. The prevalence of challenging behaviour in a study conducted with 265 adults with ID was 18.1% (about one-fifth of the adult population with ID, Bowring et al., 2017). The challenging behaviours in adults with ID are more persistent and stable over time. In contrast, there is a tendency for the challenging behaviours in typical development children to decrease over time (Totsika & Hastings, 2009). No comparison studies have yet been conducted on the prevalence of challenging behaviour in individuals with ID pre-, during, and post-transition to adulthood. In addition, three studies discussed the caregivers' objective burden related to independence issues (either individuals with ID had a lack of independence skills or were seeking independence) and the need for ongoing involvement even when the child moved out of the family home (Rapanaro et al., 2008; Issacson et al., 2014; Nucifora et al., 2024). Two studies reported caregiving demands related to young adult vulnerability and safety concerns (Rapanaro et al., 2008; Biswas et al., 2017). Lastly, one study discussed the stress related to health problems, especially when the child had a physical disability (Rapanaro et al., 2008).

For the caregivers' objective burden factor, there was a mixed report on the effect on caregiver employment; not all caregivers reported needing to be out of the workforce due to their caregiving responsibilities (Roos & Søndenaa, 2020; Gur et al., 2020). When a comparison was made among caregiver needs for three different age groups (under 21, 21 to 30 and above 31 years old) of the individual with ID, there were significantly higher needs for caregivers caring for individuals with ID above 21 years of age. Caregivers reported spending 15 out of 24 hours on caregiving needs (Gur et al., 2020). One study highlighted the financial burden and the need to manage practical household arrangements during the transition (Ellman et al., 2020). In summary, only one study indicated a significant difference

between the caregiving hours before, during and after the transition period, and few studies reported the specific factors contributing to the caregiving demands.

Social Support

Two categories of support were reported, formal and informal. Regarding formal support, a consistent theme emerged in all 12 studies regarding the overall caregiver's perceived dissatisfaction with the adult, compared to child, services, even though some caregivers in each study reported being satisfied with individual service providers. The subthemes related to the dissatisfaction were lack of information and late planning provided related to transition (six studies), lack of fit or accommodation to individual needs for adult services (five studies), caregivers needing to manage the transition on their own (three studies), lack of support services compared to child services (three studies), lack of parental involvement (two studies), long waiting list for adult services (two studies), staff not adequately communicating (two studies), paperwork stress for the caregivers (two studies), possible incongruency between the professional and caregivers' understanding and expectations related to the transition (two studies) and one study each identifying concerns such as lack of "real" alternatives for vocational training provider, the application for accommodation service not being approved, lack of coordination between child and adult services, professionals "not listening" to caregivers, negative experiences related to the environment and training in the employment service setting, requiring professional support for psychosexual development, absence of respite care during the waiting period, service providers mistreating the caregivers or the child with ID, and the service workers being overworked with high turnover of staff.

Regarding informal support, there were mixed results regarding its effectiveness. Four studies reported that caregivers benefited from informal support from extended family

members and friends, supportive networks, parent-child relationships, and parent groups. On the other hand, two studies reported that caregivers were reluctant to reach out and isolated themselves to avoid being burdensome to others and perceiving others to be fearful of their adult child, respectively.

Gauthier-Boudreault et al. (2017) labelled the caregivers' needs for formal and informal support into four categories: material, information, affective and cognitive support. Material support is the need for resources to cater to practical needs related to transition planning during the transition. Specific to the caregiver's needs, caregivers expressed the need for information support. It is necessary to have information related to the transition, such as legal services, long-term planning, and service availability, so that the caregivers can be more informed and aid with decision-making. Affective support would allow the caregivers to share and socialise with other caregivers to cope emotionally. Lastly, caregivers reported the need for a proper fit of adult services to keep their child occupied and maximise their child's ability through cognitive support. Due to the prolonged responsibility related to the caregiving demands, all these forms of support may be needed concurrently for a "successful transition", even after the transition period.

Coping Mechanisms

The coping mechanisms reported may be explicitly related to the transition period or overlap with formal and informal supports such as material, information, affective and cognitive support (Gauthier-Boudreault et al., 2017). Only five of the twelve studies reported specifically on the coping mechanisms. Caregivers from three studies reported that they coped by gaining information related to the transition (information support; Gillan & Coughlan, 2010; Biswas et al., 2017; Roos et al., 2020). Three studies highlighted the coping mechanism of needing to get access and taking a proactive role to reach for the support

system even though some caregivers reported hesitance (material support; Ellman et al., 2020; Gillan et al., 2010; Nucifora et al., 2024). One study reported that setting up a routine for the caregivers to volunteer in Non-Government Organisations (NGOs) while the child attends the centre helped the caregivers to watch over their child and, at the same time, secure the child's placement (Ellman et al., 2020). Lastly, another study reported that when caregivers had lower expectations, they could manage their worries better (Biswas et al., 2017).

Positive Caregiving

Based on the health approach, there has recently been more emphasis on the positive aspects of caregiving (Laffrey et al., 1986). However, only four of the twelve studies reported the positive aspects of caregiving factors. Two studies reported mixed feelings related to caregiving needs during the transition (Rapanaro et al., 2008; Ellman et al., 2020). Not all caregivers reported only positive or negative experiences related to caregiving needs. The positive and negative experiences are likely due to the fluctuation in the physical and social environmental factors and the intensity of the caregiving demands that the caregivers have to cope with (Ellman et al., 2020). The possible themes that had been highlighted were the sense of fulfilment and pride in their child and themselves (Rapanaro et al., 2008; Hubert, 2011), gratitude towards at least one of the multiple service providers (Gillan et al., 2010), benefits for the caregivers (to be more assertive and determined in achieving the transition needs, enhanced caregiver resources and growth and ability to seek more formal and informal support; Rapanaro et al., 2008) and benefits for the individual with ID (increased confidence and maturity, learning new coping skills, improvements in challenging behaviours, possible positive adjustment; Rapanaro et al., 2008; Gillan et al., 2010).

Quality of Life

Although possible positive aspects of caregiving were reported during the transition period, perceived burden was reported in eight of the 12 studies. Most of the studies reported negative emotions such as feeling physically and mentally tired of being the "fighter and advocate for their child" (Isaacson et al., 2014; Hubert, 2011; Codd & Hewitt, 2021; Rapanaro et al., 2008), feeling helplessness or hopelessness such as "feeling uncertain and confused" (Gillan et al., 2010; Ellman et al., 2020; Rapanaro et al., 2008), frustrated "dealing with the inflexible and unresponsive service" (Gillan et al., 2010) and having an "unsustainable burden of care" (Roos et al., 2020). The caregivers reported that decision-making was complex, and their daily activities felt restricted during the transition period. There was much uncertainty and a need to know what to expect (Ellman et al., 2020). Caregivers caring for their children above 31 years old reported more negative feelings, such as lower scores of well-being, higher frustration, lower life satisfaction, and higher sadness, compared to other caregiver groups caring for a child who was below 30 years old (Gur et al., 2020). Other reported feelings were guilt, resentment, anger, fear of repeat events and the future, depression, low self-worth, mistrust and wishing that they do not have a child with a disability (Rapanaro et al., 2008). The caregiver could spend more time with the spouse only when the child leaves the family home (Issacson et al., 2014).

The consistent themes linked to these negative feelings were the lack of support and dissatisfaction with the service system. It may have been a vicious cycle that made the caregivers feel physically and mentally tired, hopeless/helpless, and confused about what they could do during the transition period.

Other Factors

Some studies reported other factors that influenced the caregiver's quality of life during

the transition. Four studies highlighted the caregivers' concerns related to independence and vulnerability risk, such as the dilemma of letting go and separation (Gillan et al., 2010; Isaacson et al., 2014; Codd et al., 2021; Nucifora et al., 2024). Three studies also highlighted caregivers' anxiety. Anxious caregivers tended to be overprotective in managing their high-needs child as the caregivers perceived that there was a lack of adequate support for the child (Codd et al., 2021; Hubert, 2011; Gur et al., 2020).

The findings of this scoping review highlighted that the situation for caregivers of individuals with ID who are transitioning to adulthood is multi-faceted. They are faced with the challenge of nurturing a child who neuropathologically has had potential ceiling effects on their cognitive ability since birth and who may also have multiple physical disabilities and health problems. Transitioning to adulthood adds more demands when there is a combination of biopsychosocial factors, possibly due to their physical development, psychological needs, and social and environmental settings. From the caregiver's aspect, the caregivers are most probably in their stage of life where they are more vulnerable to health and mental issues and more fragile than they used to be due to progressive ageing, interrupted career progression, possible retirement planning, financial needs, family dynamics and other parenting needs. Due to the possibility of the incongruency between the service expected by the caregivers (since there might generally be an increase in the care demands during the transition and based on caregivers' expectation or understanding of "adulthood") and the actual service that the system and professionals have offered, the caregivers are constantly reporting on their overall dissatisfaction with adult services. Especially when the comparison with the child service system is made, the caregivers may feel that they are left alone, and responsibility for their child ultimately rests with them. Therefore, practical coping mechanisms such as information gaining, setting up a routine, taking a proactive role, accessing the support system, and managing their expectations are reported to help deal with the transition phase.

There are also mixed feelings reported depending on the situation and the demands of care that the situation requires, even though most of the research studies emphasised the caregiver's negative emotions and exhaustion of being a caregiver compared to the positive aspects of caregiving. The vicious cycle of the increased demand during the transition, caregivers most probably not being ready and hence unable to cope with the demands, concurrently with the perceived dissatisfaction with the service offered by the adult service system, leads the caregivers to develop helplessness (Kerr et al., 2023). This cycle may be reinforced by the long waiting period to access the expected adult services, and caregivers continue to be overprotective and anxious due to the risk of vulnerability for their child.

In summary, most of the studies reviewed were based on qualitative findings. The explorative nature of the study design did capture as broadly as possible the factors that affected the caregivers' adaptation process in caring for an individual with ID during the transition to adulthood. Although there were no studies on the significance of the increase in caregiving demands, specifically during the transition to adulthood, one study highlighted the significant need to spend more hours on caregiving during the transition period. However, the theme regarding caregivers' dissatisfaction with formal adult services was consistent and, in a vicious cycle, affected caregivers' negative emotions related to caregiving needs, increasing their dissatisfaction. Some studies highlighted the "mixed feelings" of the positive factors related to the caregiving experience, depending on the setting factors. This review’s findings emphasised caregivers' apprehensiveness regarding the vulnerability risk and definition of independence for their child. The coping mechanisms discussed in this review need to be studied in more detail but provide direction for a practical approach to meeting the demands of this particular caregiving role. The findings in this review suggest the importance of preparing and educating caregivers before their child graduates from child services about the possible change in caregiving demands, increased vulnerability risk, and dealing with adult

services during the transition period. The preparation and education aid the caregivers in forming their definition of independence with possible shifts in expectations and comparison with the typical definition of adulthood. Hence, further understanding the different transition types would help identify the possible different layers of players involved and their roles, empowering caregivers and other stakeholders to support adolescents with ID.

Transition Types

Based on an interview with parents, Ferguson et al. (1988) highlighted three different types of transition that coincide as the individual with ID turns 21: (a) bureaucratic transition, (b) family life transition, and (c) status transition. Based on this review's findings, the formal and informal support systems, including professionals who work in the adult service centres, the expectations and contributions from the caregivers, and the functional ability and needs of the adolescent with ID, are expected to be interlinked during the transition to adulthood.

Bureaucratic Transition

Bureaucratic transition is the change that occurs between the professional and agency services that support the individual with ID and their family. In this case, the transition is from special education school to community-based adult services. Regarding the caregivers' relationship with the professionals in adult services, four continuum types of patterns were categorised: abandonment, surrender, assimilation, and engagement. Thus, the bureaucratic transition, change between the professional and agency service, and the relationship formed with the caregiver during the transition may differ for each caregiver based on their circumstances. Those caregivers who gain sufficient information and can take a proactive role during the transition (Kraemer & Blacher, 2001; Ellman et al., 2020; Beresford, 2004) may benefit more when they collaborate with the professionals (engagement with professionals) or provide the needed service for their child (assimilation with professionals).

On the other hand, those caregivers who experience a high burden of care due to other stressors may not be able to meet the commitment needed for the transition and hence may perceive less benefit from the relationship with the professionals (Raghavan et al., 2013; Leonard et al., 2016). The outcome of the bureaucratic transition and the relationship with the professionals may spill over into the family life transition.

Family Life Transition

Family life transition describes the changes within the family system, such as daily routine and responsibilities (family role) when the son or daughter completes their special education program. Individuals with ID and their family members transit from six hours of structured engagement to new, unforeseeable adult services. Based on the adult service placement outcome, the caregiver and the family must accommodate their routines and roles within the family. The caregivers and other family members are expected to cope with the changes and make any alternative arrangements needed in their family home setting if the adult service placement is inaccessible or unsuitable. Based on the outcome of this review, it is a possible theme, as reported by the caregivers, that they were not prepared for the transition (to manage the demands) and felt hopeless when the cycle was reinforced by the prolonged waiting period (Caldwell & Heller, 2007) and the support from the caregiver needed even after the child leaves the family home.

Status Transition

Status transition is the status change from child to adult. This review's findings on the caregiver's apprehensiveness related to independence and risk of vulnerability align with Ferguson et al.'s (1988) study that the status transition could be more related to how much more or less supervision their adolescent with ID needs rather than expecting that the adolescent will be able to gain total independence as they reach the age of 21 years. Some caregivers viewed the individual with ID as a "little child," not a teenager. Hence, it may be

more helpful for the caregivers to view the transition from a more constructive perspective, which includes all stakeholders and deciding the "right thing to do", rather than categorising what is "right" and "wrong" with reference to what an adult would do (Murphy et al., 2011; Nucifora et al., 2024).

The Singaporean Context

Generalising the findings of this review and the transition types to the local context for this research project would aid in proposing policy changes and clinical implications in empowering caregivers of adolescents with ID in Singapore. Even though various service providers are trying to adapt to the continuous needs of individuals with ID, Singapore's vision of having an inclusive society for people with disabilities is still lacking (Zhuang, 2016; Poon, 2015). Wee et al. (2013) reviewed some of the possible factors that may be barriers to forming an inclusive society, the needs of adolescents with ID (demand) and the available service facilities in Singapore (supply). Generally, adolescents with ID in the transition age group of 16 to 22 reported having the highest need for support compared to other age groups (Shogren et al., 2016).

On the other hand, in terms of resource allocation, adult services in Singapore were relatively less developed than child services, which comprised early intervention programs and special schools. Adolescents with ID in Singapore transition from the special education system to open or supported employment, vocational training, day activity centres or engaged in the home. Their placement would be based on their functioning, adaptive skills level, and suitable service availability (Wei et al., 2012). A study conducted in Singapore by Poon et al. (2013) examined caregivers' perspectives on the likelihood of their child, who had been diagnosed with a neurodevelopmental disorder, transitioning into adult services. The study's outcome was that the parents in Singapore perceived that the likelihood of them achieving the

desired outcome for their child transitioning into adult services was low. This result suggested that the parents anticipate that there would be service gaps based on their experiences and knowledge of the adult services available in Singapore.

With the changing physical, psychological and social needs of adolescents with ID and the relatively less developed adult services in Singapore, family caregivers, by default, carry more responsibility in managing adolescents with ID in their home environment. Generally, family caregivers reported higher stress managing a child with ID than managing a child without ID (Cuzzocrea et al., 2013; Grey et al., 2018; Olsson & Hwang, 2003). One possible reason could be that the purpose of caregiving for a child with ID differs from caregiving for a child with typical development (TD), which influences parenting style (Cuzzocrea et al., 2013). The demands of caregiving for a child with TD will progressively change due to the child's ability to develop independence. However, for caregivers of a child with ID, the demands to provide care and support would continue as the child progresses through different stages of physical development and the social demands and expectations would increase as well. The caregiver role for their child with ID integrates various aspects; for example, the need to be actively involved as a decision-maker and support the child across the lifespan, which includes daily activity engagement, financial/legal matters, medical care, social support, and co-regulating emotions, while the levels of support required would be based on the child's functional ability (Kim & Shaffer, 2020). Thus, the caregiving for an individual with ID can be perceived to have different needs than other forms of caregiving, as the caregivers of an individual with ID must continuously provide prolonged caregiver duties and the possibility of uncertainties about the future management plan.

It is still unclear what specific factors related to caregiver stress affect and moderate the process of a successful transition from the special education school system and assist the caregiver in adapting to the new circumstances within the family home in Singapore. This

uncertainty underscores the need for further research and understanding in this area. However, it is clear that with the failure of the caregiver to cope with the adolescent's needs, the least preferred scenario would result in a decision for the adolescent with ID to be placed outside of the family home (McIntyre et al., 2002). Families who emphasised using proactive or problem-focused coping strategies were more able to continue to care for the adults with ID in their own homes (Grey et al., 2020), consistent with the understanding that there are possible chances of moving young adults or adults out of the family home due to poor coping and increased caregiver stress.

Hence, the factors discussed, such as objective burden, support, coping mechanisms, positive caregiving, and quality of life, and subsequently, the impact on the placement decision, were considered in this project, based on the proposed adaptation of Lazarus and Folkman's (1984) TMSC. For example, factors related to demands, such as the demographic characteristics of the caregivers (Grey et al., 2018) and the level of care required, as caregiver burden can increase depending on the nature, severity and course of the disability (Park et al., 2019; Barrio et al., 2016) and the perceived ongoing caregiver stress related to caregiving (Momtgomery et al., 2009; Shahrier et al., 2016) were considered. In terms of stress moderators (protective factors), coping (Hawken et al., 2018; Elliott et al., 2001), social support (Vernhet et al., 2019), and positive aspects (Folkman, 1997) were constructs that have been found to affect the perception of stress, and these were evaluated too. Previous studies, which included coping responses, social support, and appraisal models, were conducted with caregivers of older adults with dementia and brain injuries, among other care groups (e.g., Pearlin et al., 1990; Haley et al., 1987; Chwalisz, 1996; Grey et al., 2020) and these informed the approach adopted in this project. But, while past research has examined the individual factors that trigger and moderate caregiver stress, very few have conducted a longitudinal follow-up of caregiver stress and coping and its implication for the adolescent

with ID's future care management, specifically for adolescents transitioning from the special education school system.

Therefore, Study 1 and 2 (Chapters 4 and 5) aimed to assess how family caregivers adapted over two years of caring for an adolescent with ID and the primary caregivers' current stance on the placement decision of caring for an adult with ID in Singapore, respectively. The measures used in Studies 1 and 2 were similar and are outlined in Chapter 3.

Chapter 3

Method

Research Setting

Study 1

This study was conducted in the community setting and recruited primary caregivers of students in their final year of leaving Singapore's special education school system. The study design was based on convenience sampling; the primary caregivers were approached via the special education school system with the assistance of the school management staff. This study used pseudonyms to identify the participants and the adolescents with ID.

Study 2

This study was conducted in an acute hospital setting, the Institute of Mental Health (IMH) in Singapore, and recruited primary caregivers of adults diagnosed with ID who were receiving treatment under the Adult Neurodevelopmental Service (ANDS). The study design was based on convenience sampling; the primary caregivers of adults diagnosed with ID under ANDS were approached when they visited IMH for medical review.

Participants

Study 1

The participants were the primary caregivers of adolescents diagnosed with ID who had recently graduated from the special education school system. The primary caregiver was identified through discussions with the person who replied to the researcher's email indicating their interest in participating in the research. The email was sent to the parent, usually the contact person related to school matters. Hence, the researcher further understood their role as caregivers. The goal was to determine the key person who plays a significant role in the daily caregiving of the adolescent with ID, makes major decisions related to caregiving needs, not being paid for their caregiving role, and lives in the same household as the adolescent. All

five participants were identified as the primary caregivers based on the definition above. The participants claimed they make significant decisions and spend most of their time caring for the adolescents. The inclusion criteria were being a primary caregiver of an adolescent diagnosed with ID who had recently graduated from special school. Exclusion criteria were primary caregivers who could not read and write English or who were not Singapore citizens or Permanent Residents.

Study 2

The participants were the primary caregivers of adults diagnosed with ID who were currently receiving treatment from IMH. The primary caregiver was identified through discussions with the person who attended the consultation review in IMH with the adult with ID. The researcher further understood their role as caregivers when they indicated their interest in participating in this study. The goal was to determine the key person who plays a significant role in the daily caregiving of the adult with ID, makes major decisions related to caregiving needs, is not being paid for their caregiving role, and lives in the same household as the adult with ID. Therefore, care staff or primary caregivers of adults living in the adult residential homes were not approached to participate. The inclusion criteria were the primary family caregivers of adults diagnosed with ID receiving treatment from IMH. Exclusion criteria were primary caregivers who could not read and write English or who were not Singapore citizens or Permanent Residents.

In both studies, the participants were expected to be predominantly female, as recruitment was conducted in a natural setting (Sharma et al., 2016). Any potential gender bias in the sample should not be viewed as a methodological issue, as the study was designed to explore family caregivers' adaptation and their current perspectives on the placement decision in a real-life context. In everyday situations, most primary caregivers are indeed female.

Measures

All the measures were administered in English. Copies of those measures that are in the public domain are presented in Appendix B.

Demographic Information

The demographic information of the primary caregivers and individuals with ID was collected to understand the nature of the sample population of family caregivers living in the Singapore community. The primary caregiver's demographic information, such as the age, gender, ethnicity, religion, marital status, highest education, employment status, household income (per month), people living in the same family home (relationship and age), whether the caregivers have domestic helper or not, caregiving relationship (for example, mother, father), years of caregiving and other caregiving responsibilities were obtained. The individual with ID's demographic information, such as age, gender, current service engagement, mental and physical health diagnosis and epileptic episodes, were obtained.

Preliminary Measures (Study 1 only)

The validity of the ID diagnosis was confirmed in the intake assessment by administering the measures of intelligence and adaptive behaviour only for face-to-face sessions and omitted for online Zoom sessions. The Wechsler Abbreviated Scale of Intelligence—Second Edition (WASI-II; Wechsler, 2011) is a measure of general intelligence and was used to assess the cognitive ability of the adolescents with ID. The test has four subtests: vocabulary, block design, similarities, and matrix reasoning, and it generates a composite score. The Vineland Adaptive Behaviour Scales, Third Edition (Vineland-3; Sparrow et al., 2016) is a standardised measure of adaptive behaviour and was completed by the caregiver of the adolescents with ID. The Vineland-3 assesses three core adaptive behaviour domains: communication, daily living skills, and socialisation, and provides an overall adaptive behaviour composite standard score.

Resilience

The Brief Resilience Scale (BRS; Smith et al., 2008) is a self-report measure used to assess resilience, defined as an individual's ability to bounce back or recover from stress. It consisted of six items; items 1, 3 and 5 were positively worded, and items 2, 4 and 6 were negatively worded. The items are rated on a 5-point Likert scale, from 1 (*strongly disagree*) to 5 (*strongly agree*), with items 2, 4, and 6 being reverse coded in the questionnaire. The score ranges from 6 to 30. The total score was averaged (average score range from 1.00 to 5.00) and categorised into three groups: low (1.00 to 2.99), normal (3.00 to 4.30) and high (4.31 to 5.00) resilience. The mean of the sample (undergraduate students and primarily female participants in the Southwestern United States) was 3.53 (n = 128, SD = 0.68). The internal consistency across students, cardiac rehabilitation patients, women with fibromyalgia, and healthy samples ranges from 0.80 to 0.91, demonstrating good reliability (Smith et al., 2008). There were evidences of both convergent and discriminant validity (Smith et al., 2008). This study's Cronbach’s alpha reliability coefficient for BRS was excellent, α = .90. The BRS was selected because it has the shortest number of items and has strong psychometric properties compared to the other 19 resilience measures reviewed (Windle et al., 2011).

Future Anxiety

The Dark Future Scale (DFS; Zaleski et al., 2017) is a self-report measure of future anxiety, which refers to negative thoughts and emotions towards the future, where fear is more evident than hope. In this study, the DFS measured the primary caregiver’s general anxiety or fear regarding the plan related to caregiving for an individual with ID. The DFS consists of five items and is a shorter version of the Future Anxiety Scale (FAS; Zaleski, 1996). The items were rated on a 7-point Likert scale, from 0 (*decidedly false*) to 6 (*decidedly true*). The total score ranged from 0 to 30. Higher scores indicated that the caregiver felt more

anxious about the future. The mean DFS score for mothers who are the caregivers of their children with ID in Iran was 24.97 (n = 196, SD = 4.45; Torfayeh et al., 2020). The internal consistency reliability of the DFS was 0.90, fair convergent and discriminant validity was reported for a general adult sample of 1,000 Polish residents, and the test-retest reliability, r = 0.618, was adequate over a one-month interval (Zaleski et al., 2017). This study's Cronbach's alpha reliability coefficient for DFS was excellent, α = .96. Parents of children with developmental disabilities have completed the FAS1 to assess their views related to the uncertainties and fear of the future (Bujnowska et al., 2019). This study selected the shortest version of the FAS, the DFS.

Objective Burden 1 (symptom appraisal of individual with ID)

The Developmental Behaviour Checklist-P24 (DBC-P24; Taffe et al., 2007) is the short version form of the Developmental Behaviour Checklist (DBC; Einfeld & Tonge, 1992). The DBC-P24 is a self-report measure completed by caregivers that briefly measures the individual with ID's challenging behaviours for the past six months. The DBC-P24 was proposed for research use only, as the DBC has more information and subscales for clinical interpretation. The DBC-P24 consisted of 24 items, and the items were rated as 0 (*not true as far as you know*), 1 (*somewhat or sometimes true*), or 2 (*very true or often true*). The total Behaviour Problem Score ranges from 0 to 48. Higher scores indicated a higher prevalence of problem behaviours. The DBC-P24 had low bias and high precision when cross-validated with autism, fragile X, William and Prader-Willi samples in a longitudinal study and individuals with ID in a cross-sectional study (Taffe et al., 2007).

Modified Objective Burden 2 (caregiver)

The Objective Burden Scale (OBS; Montgomery et al., 1985) is a self-report measure and part of the Objective and Subjective Burden Scales. The OBS was designed for caregivers caring for their older relatives, with nine items assessing the extent of changes in

their day-to-day routine tasks due to caregiving needs. In this study, the OBS was used to measure the extent of day-to-day changes the primary caregivers undergo due to the need to care for an individual with ID. The items of the OBS consisted of personal freedom, amount of privacy, time, and energy. An additional item was added, "Your work/job (e.g. because of having to take time off)", giving 10 items in the modified OBS. The items were rated on a 5-point Likert scale from 1 (*a lot more (better)*) to 5 (*a lot less (worse)*). The total scores ranged from 10 to 50. Higher scores indicated more changes in the primary caregiver's day-to-day activities due to the caregiving needs. The internal consistency (Cronbach's alpha) reliability for the original (9-item) version was 0.85 (Montgomery et al., 1985). This study's Cronbach’s alpha reliability coefficient for modified OBS was excellent, $\alpha = .90$ (10-item). No normative or validity are available on the OBS.

Social Support

The Questionnaire on the Frequency of and Satisfaction with Social Support (QFSSS; Garcia-Martin et al., 2016) is a self-report questionnaire that measures the frequency and degree of satisfaction with social support based on the three types of support (emotional, informational, and instrumental), received from four different sources (partner, family, friends, and community). *Emotional support* was defined as listening support when participants wanted to talk and express their feelings. *Instrumental support* was practical support in finance, transportation, and practical help. Lastly, *informational support* was the support for receiving advice and information related to caregiving. The sources of support from the community are the support received from neighbours, parishes, caregiver groups or clubs, and the community in general.

There are a total of 24 items. The frequency and satisfaction items were rated on a 5-point Likert scale, from 1 (*rarely*) to 5 (*always*) and from 1 (*dissatisfied*) to 5 (*very satisfied*), respectively. The total frequency and satisfaction for each source (partner, family, friends,

and community) ranged from 3 to 15 and for each type of support (emotional, instrumental, and informational) ranged from 4 to 20. The total score on the frequency and satisfaction across four sources and three types of support ranged from 12 to 60. A higher score indicated more frequent support received and feeling highly satisfied with the support received from each source. The psychometric evaluation of the QFSSS was conducted on a general resident sample in Spain (Garcia-Martin et al., 2016). The mean for the frequency was 37.28 (*SD* = 9.73; range = 12 to 60), and for the satisfaction was 41.00 (*SD* = 10.10), with a sample size of *n* = 2042. Specifically, the mean scores for each support type (frequency and satisfaction) were about the same: emotional support (*M* = 28.09, *SD* = 6.03), instrumental support (*M* = 26.77, *SD* = 6.04) and informational support (*M* = 27.12, *SD* = 6.34). The means scores for each type of source (frequency and satisfaction) were highest for the family and lowest for the community; family (*M* = 24.29, *SD* = 5.45); partner (*M* = 23.25, *SD* = 7.11); friends (*M* = 20.94, *SD* = 6.01) and followed by community (*M* = 13.98, *SD* = 6.51). The structural validity based on the social support frequency and satisfaction models was positive and statistically significant. The Cronbach's alpha of the reliability analyses related to the frequency and satisfaction (across different types of sources and support) were 0.84 and 0.87 (good internal consistency). This study's Cronbach alpha reliability coefficient for QFSSS frequency and satisfaction (across different types of sources and support) were 0.84 and 0.91 (range from good to excellent internal consistency). The QFSSS was chosen for this study as it comprised a detailed breakdown of the formal and non-formal support sources and the different types of support with the support quality (Gottlieb & Bergen, 2010).

Coping

The Brief COPE (Carver, 1997) is a self-report shorter version of the COPE inventory (Carver, 1989). It measures an individual's coping behaviours associated with stressful life events. In this study, the caregivers were reminded of the coping strategies related to the

caregiving situation used to manage individuals with ID. The 28 items were classified into three domains (with two items for each subscale): eight items for the problem-focused domain (two items for each of: active coping, use of instrumental support, positive reframing and planning subscales, item numbers 2, 7, 10, 12, 14, 17, 23 and 25); 12 items for the emotion-focused domain (two items for each of: emotional support, venting, humour, acceptance, religion and self-blame subscales, item numbers 5, 9, 13, 15, 18, 20, 21, 22, 24, 26, 27 and 28); and eight items for the avoidant coping domain (two items for each of: self-distraction, denial, substance use and behavioural disengagement subscales, item numbers 1, 3, 4, 6, 8, 11, 16 and 19).

The items were rated on a 4-point Likert-type from 1 (*I haven't been doing this at all*) to 4 (*I've been doing this a lot*). The total score of each category was divided by the number of items and the average range is from one to four. There was no set clinical cutoff score. A higher average domain score indicated the more frequent use of the particular coping strategies (average domain score was used in Study 1). Problem-focused coping was described as active coping, which comprised informational support, planning, and having a positive outlook on the situation. The higher the scores in the problem-focused domain, the more likely the primary caregivers were to take a practical approach to cope with stressful events. Emotion-focused coping was described as emotional support, emotional expression, humour, acceptance, religion-focused and self-blaming. The higher the scores for emotion-focused coping, the more the primary caregivers would likely aim to regulate their emotions to cope with stressful events. Avoidant coping was described as the use of self-distraction, denial, substance use and behavioural disengagement. The higher the scores for avoidant coping, the more likely the primary caregivers were to physically and mentally disengage from the situation.

The initial study on the Brief COPE was conducted on a sample affected by a hurricane, and the Cronbach's alpha (reliability) ranged from 0.5 to 0.9 (Carver, 1997). Lee et al. (2019) adapted the Brief COPE into adaptive (16 items, item 2, 5, 7, 10, 12, 14, 15, 17, 18, 20, 22, 23, 24, 25, 27, and 28, scores ranging from 16 to 64) and maladaptive (12 items, item 1, 3, 4, 6, 8, 9, 11, 13, 16, 19, 21, and 26, scores ranging from 12 to 48) domains in assessing the physical and mental health of caregivers caring for school-age children and young adults transitioning into adulthood who were diagnosed with ASD in United States. Lee's et al. (2019) adaptative and maladaptive domains mean scores were used in Study 2. The mean score of the caregivers caring for adolescents transitioning into adulthood regarding adaptative coping was 40.30 (SD = 9.43), and maladaptive coping was 18.98 (SD = 4.63), with a sample size of n = 61. The internal consistency for the adaptive and maladaptive coping subscale was 0.83 and 0.73, respectively. This study's Cronbach's alpha reliability coefficients for Brief COPE adaptive was excellent, α = .90 and maladaptive was adequate, α = .72.

Positive Aspects of Caregiving

The Positive Aspects of Caregiving Scale (PACS; Tarlow et al., 2004) is a self-report measure that assessed the perceived sense of satisfaction and reward that was gained from the caregiving experience for caregivers caring for individuals with Alzheimer's Disease or cognitive impairment. The PACS is a 9-item measure rated on a 5-point Likert scale, from 1 (*disagree a lot*) to 5 (*agree a lot*), with higher scores indicating more positive caregiving appraisals. The total score ranges from 9 to 45. The overall reliability of the nine items was 0.89 (good internal consistency) and there were evidences for moderate convergent and discriminant validity (Tarlow et al., 2004). This study's Cronbach's alpha reliability coefficient for PACS was excellent, α = .92. The PACS total mean score based on a sample

of a family caregiver who lived and provided caregiving for their relatives was 34.0 (n = 1219, SD = 9), specifically female participants, was 33.5 (n = 992, SD = 9.2). The items were also analysed using subgroup analysis of Self-affirmation (items one to six), and Outlook on Life (items seven to nine; Tarlow et al., 2004). The PACS Self-affirmation mean score was 22.5 (n = 1219, SD = 6.3) and PACS Outlook on Life was 11.5 (n = 1219, SD = 3.5; Tarlow et al., 2004). This study used the two subscales of Self-affirmation and Outlook on Life. A systematic review based on 52 studies of the PACS highlighted that this scale can be used as a moderator variable in caregiving outcomes (Lee & Li, 2022).

Resources Checklist

The resources checklist was designed for this study to understand the resources available and used frequently by the primary caregivers of an individual with ID in Singapore. It is a self-report measure and consists of four open-ended questions:

1. What form of service(s) do you receive for the individual with ID currently?
2. What form of service(s) do you currently receive from yourself as a caregiver?
3. Do you receive any form of financial assistance? Yes/No
4. Have you used the respite care service? If yes, how many times?

Perceived Burden 1 (DBC-P24) and 2 (modified OBS)

The perceived burden scales were designed for this study to assess the perceived burden for each objective burden measure in managing the individual with ID and the primary caregivers' day-to-day needs. These are self-report measures with a 7-point scale, assessed at the end of the DBC-P24 and modified OBS. The primary caregivers rated the items as below:

- Perceived Burden 1 (DBC-P24): "Overall, how do you feel managing the individual with ID for their day-to-day needs?"
- Perceived Burden 2 (modified OBS): "Overall, how do you feel about managing your own day-to-day needs?

The items were rated from 1 (*completely stress-free (no stress at all)*)," to 7 (*completely stressful (could not be more stressed)*). The higher the number on the scale, the greater the perceived burden of managing the individuals with ID and the caregivers' day-to-day needs, respectively.

Quality of Life

The World Health Organisation Quality of Life-BREF (WHOQOL-BREF; Skevington et al., 2004) is a self-report and shorter version of the WHOQOL-100 comprising 26 items. Quality of Life was defined as the individual's perceptions of the level of satisfaction regarding essential aspects of life. The first two items were based on the overall quality of life and satisfaction with general health. The rest of the items of essential aspects of life are divided into four domains: physical health (7 items; item number 3, 4, 10, 15, 16, 17 and 18), psychological health (6 items; 5, 6, 7, 11, 19 and 26), social relationships (3 items; 20, 21 and 22), and environment (8 items; 8, 9, 12, 13, 14, 23, 24 and 25). The items were rated on a 5-point Likert scale, from 1 (*the lowest*) to 5 (*the highest*). Items 3, 4 and 26 were negatively worded and reverse-scored during the data analysis.

The raw scores were converted to a transformed score (0 to 100) based on the manual (Skevington et al., 2004). The higher transformed score indicates a higher quality of life in the particular domain. The WHOQOL-BREF was selected because it has good to excellent reliability and validity and was evaluated with clinical and healthy samples (Skevington et al., 2004). The WHOQOL-BREF English version has been validated and assessed as reliable in Singapore. The Singapore participants were recruited from the general population and two clinic samples. The mean score of participants who completed the English language survey form for physical health domain was 74.9 (SD = 15.5), psychological health domain was 72.5 (SD = 14.1), social relationship domain was 74.0 (SD = 16.1), and environment domain was 72.0 (SD = 14.1), sample size of n = 454 (Cheung et al., 2017). These norms were used in

interpreting the scores in these studies. Cronbach's alpha values ranging from 0.82 to 0.86, with good reliability across the four domains and good known-group validity (Cheung et al., 2017). This study's Cronbach's alpha reliability coefficient for physical domain was unacceptable, $\alpha = .34$; psychological domain was acceptable, $\alpha = .76$; social domain was acceptable, $\alpha = .72$; and environmental domain was good, $\alpha = .82$. Some previous studies have used the WHOQOL-BREF in assessing caregivers' quality of life when caring for individuals with ID (Lin et al., 2009; Barros et al., 2019).

Modified Placement Tendency Index

The Placement Tendency Index (PTI; Blacher, 1990) is a self-report measure that has six items on the step-by-step placement tendency process for moving an individual with a developmental disability from the family home into an adult home from 1 (*No, we have never thought about it*) to 6 (*We have placed our child*). The primary caregivers score based on their current thought processes and the action taken to move the individuals with ID out of their family home. In this study, the PTI was modified accordingly to meet the service procedure in Singapore. A new item, "The individual with ID is on the waiting list for the adult home", was added between item five and six, resulting in a total of seven items. All the items were reworded from "we" to "I" as this study was based on a primary caregiver input. A higher score on PTI indicated that the primary caregiver was moving towards placing the individual with ID out of the family home.

Additional questions were focused on understanding the decision-making process related to the placement tendency, whether the decision-making had changed over the past six months, and the degree of consensus with the other family members:

- Has your decision-making regarding the out-of-home placement changed over the past 6 months? Response: Yes/No. If yes, what caused the change? (open-ended question).
- My family members and I agree on the future management plan. This item was rated based on a 7-point Likert scale, from 1 (*strongly disagree*) to 7 (*strongly agree*).

Procedure

Study 1

All the documents for Study 1 were included in Appendix C. All the special schools under the Ministry of Education in Singapore were listed based on information from the website (https://www.moe.gov.sg/special-educational-needs/sped-schools). Three categories of schools of mild ID, moderate to severe ID and autism spectrum disorder with ID were selected. Eight organisations (MINDS, Rainbow Centre, APSN, Metta School, Grace Orchard School, St. Andrew's Autism School, AWWA School and Eden School) were approached. All the organisations were contacted to enquire about the recruitment support for external research, and the representatives suggested emailing the organisations instead.

Therefore, an email invitation was sent to all organisations in July 2021, before the application for ethics, to obtain the support letters. Concurrently, a social worker was approached to connect with school principals for their support. Three organisations responded by asking to provide the study details to apply for the organisations' approval. Out of the three organisations, one rejected the application and did not share the reason for rejection. Two organisations agreed to distribute the research invitation to families of graduating students in 2021 and provided support letters for ethics application. There was no response from the other five organisations despite two follow-up emails and calls.

The two organisations committed to advertising the study in their school community network and informing the parents via email by distributing copies of the Participant

Information Sheet. Due to the COVID-19 movement restriction period, a face-to-face recruitment method (the initial proposed strategy for recruitment) was prohibited. This study was approved by the James Cook University Human Research Ethics Committee (JCU HREC application number H8566) in October 2021.

The organisation's research department representative forwarded the email to the school principals and the school principals emailed the parents of the graduating class. Five participants responded and indicated their interest. Based on the feedback from one of the school principals, the caregivers would respond more positively, and it is the usual practice to provide tokens of appreciation for their participation in the research study. Therefore, an amendment form was applied to JCUS HREC to include SGD 5 Grabfood vouchers each after the participants completed Time 2 and 4 assessments. The organisations were approached again with the inclusion of a token of appreciation in November 2021. The organisations rejected the request to resend the emails as the students had graduated from their school and the research was advised to approach the organisations again in July 2022.

The above recruitment process with the token of appreciation inclusion was repeated in July 2022. Only one organisation agreed to advertise the study online in 2022 and refused face-to-face recruitment due to the COVID-19 pandemic restrictions. Despite the school organisation being approached earlier in 2022, no caregivers indicated their interest in participating. The organisations shared no details on the number of caregivers approached via email; hence, the response rate was not obtained. When clarification was asked about the low response rate, the representative shared that the caregivers were asked to participate in the school survey and questionnaires every year. Hence, caregivers may not be interested in completing additional questionnaires, contributing to the low response rate. The school management shared that they could only advertise the study on their platform, and no additional support could be given for external research.

The five participants who agreed to participate were contacted via email in November 2021, and an online session was conducted based on the participants' indicated availability. During the recruitment phase, the primary caregivers were identified based on the consensus of other family members. The participants were briefed on the aim, method, and two-year time commitment with four data collection points. Information on the consent form was explained to the participants, who were given a choice of whether to participate in this study. The participants were given a choice of interview mode (via Zoom or face-to-face). All participants opted for Zoom. Therefore, despite the intention to administer the preliminary measures of the WAIS-II and the Vineland-3, the validity of the ID diagnosis was not confirmed, and the adolescents with ID were not interviewed in this study.

Quantitative data collection. Following recruitment, the participants were asked to complete the measures after the adolescents had left secondary school for three months (Time 1; March 2022), six months (Time 2; September 2022), 18 months (Time 3; March 2023), and 24 months (Time 4; September 2023). The sessions were conducted in English. The participants were not told to reflect on their prior responses from Time 2 to 4.

Qualitative data collection. A follow-up study using qualitative interviews was conducted to understand further the family caregivers' adaptation process and how this affects decisions on the future possibility of care arrangements (home vs. out-of-home). An amendment form was applied to JCU HREC indicating the rationale for the qualitative data, and the Semi-Structured Interview Schedule Form was developed. The questions were drafted based on the trend of the collected quantitative data and detailed discussion with supervisors. The JCU HREC approved the qualitative study in July 2023. After completing the questionnaires at Time 4 (September 2023), the three participants were invited to participate in the qualitative study. The participants were briefed on the aim, method and time commitment and given a choice of whether to participate in this additional qualitative

interview. Information on confidentiality and publication was explained to the participants. Two of the three participants agreed to take part in this qualitative interview. The participants were given a choice of interview mode (via Zoom or face-to-face) and a mutually agreed date and time with the principal investigator. The interviews were completed in February 2024 via Zoom. Consent was obtained before the start of the interview. Participants were briefed that all identifiable information would be replaced with generic descriptors; hence, no identifiable information would be included in the transcript. The interview duration was 45 to 60 minutes based on the questions in the Semi-Structured Interview Schedule Form. The interview was audiotaped and transcribed verbatim using the TurboScribe application. The transcripts were checked for accuracy, and identified information was removed and revised accordingly.

Study 2

All the documents relevant to Study 2 are included in Appendix D. The Domain Specific Review Board (DSRB) approval was obtained in February 2023 (application number H8566). DSRB provides ethical approvals for research conducted under the National Health Group (NHG) institutes in Singapore, and different review board from Study 1. Recruitment began in March 2023 and ended in March 2024, covering a one-year period. The researcher engaged caregivers who met specific criteria and had visited IMH for medical review. Participants were briefed on the study's objective, methodology, and time commitment, which ranged from 45 minutes to one hour. They were also informed about the consent form and the confidentiality of their data. Those who agreed to participate signed the consent form and received a copy of the Participation Information Sheet and the Informed Consent Form for their records. Primary caregivers were identified with the consensus of other family members when necessary. Participants were given the choice of interview mode via Zoom or face-to-face. Of 41 participants, 35 chose Zoom, and six preferred a face-to-face interview at

one of IMH's consultation rooms. The sessions took place at mutually agreed times between the researcher and participants, and all were conducted in English. The questionnaires were given to the participants, clarification was given when needed, and their responses were recorded.

Follow-up phone calls were made six to nine months after the questionnaire's completion. Thirty-three participants were contacted, while seven required a more extended period to meet the minimum six-month criterion. During the phone calls, the primary investigator introduced and summarised the purpose of the call, which was to assess the current placement tendency score on the PTI. Participants were thanked and informed that no further follow-ups were necessary.

Data Analysis

Different data analysis methods were employed for the data gathered in Study 1 and Study 2 to account for the distinct designs used. To ensure clarity for the reader, these methods are detailed in the respective chapters: Chapter 4 for Study 1 and Chapter 5 for Study 2.

Chapter 4

Family Caregiver Adaptation After Adolescents with Intellectual Disability Leave Special Education School: Five Case Studies

This study aimed to understand the caregiver adaption process during the first two years of caring for adolescents with ID who had recently graduated from the special education school and the decisions on the future possibility of care arrangements (home vs out-of-home). In general, Lazarus and Folkman's (1984) TMSC informed the selection of the possible factors to be examined. Factors such as the caregivers' appraisal, coping styles, perceived social support and outcomes related to the caregivers' stress and their implications for future possible of the care arrangements, which were identified by using the modified Placement Tendency Index (PTI; Blacher, 1990).

Building on the findings of Grey et al. (2020), it was hypothesised that the caregivers who use passive coping styles would move towards the direction of the placement index of wanting the adolescents with ID to be placed out-of-the-home over the 24 months. The PTI score change would give insight into the caregivers' profiles and adaptation outcomes in managing adolescents with ID after graduating from the special school. It was anticipated that caregivers with higher PTI scores would be associated with factors that cause difficulty using proactive coping mechanism to cope with the perceived demands and a deterioration in the caregivers' quality of life, and vice-versa. These findings would improve the understanding of the adolescents with ID needs in Singapore and how the caregivers were managing the adolescents with ID with the perceived limited resources of adult services.

Lazarus and Folkman's (1984) TMSC would provide insights into the crucial variables that result in successful adaptation. Understanding the factors related to perceived stress could be instrumental in guiding the actions of healthcare professionals, policymakers, and support services in the community. These stakeholders would be able to identify possible risk

based on the caregivers' demographic information (such as low household income, lack of actual or perceived support from family, friends or community support and caregivers' physical and mental health) and tap on the protective factors (such as educating and encouraging caregivers about adaptive or proactive coping mechanism based on their reliance in managing their day-to-day stress level) by planning for early follow-up to support caregivers substantially during the transition period. By empowering the needed support to the caregivers, such interventions could decrease the need for adolescents to be placed in out-of-home care. Empowering the caregiver could increase the opportunities for adolescents with ID to be socially included rather than stigmatized.

Participants

The participants were the primary caregivers of adolescents diagnosed with ID who had recently graduated from the special education school system. Initially, this study aimed to recruit a large group of 150 participants. However, due to barriers in the recruitment process, only five participants were recruited and a case study approach was adopted. Two of the five participants dropped out after Time 2, and three completed Time 4. Out of the three participants who completed Time 4, two participated in the semi-structured qualitative interview.

The demographic information of all the participants is summarised in Table 4.1. All the participants were mothers, caring for their daughter (n = 2) or son (n = 3) who has been diagnosed with ID comorbid with autism spectrum disorder (ASD, n = 3), ID comorbid with attention deficit hyperactive disorder (ADHD, n = 1) and ID comorbid with anxiety (n = 1). The primary caregivers age ranged from 53 to 60 (M = 56, SD = 2.65). All the participants had been the primary caregiver for 19 years, since the birth of the child. They were all Chinese, with different religions; Buddhist (n = 2), Roman Catholic (n = 1), Christian (n = 1)

and not associated to any religion (*n* =1). There were participants who were divorced (*n* = 2) and married (*n* = 3). Most of the participants achieved highest education of secondary level (*n* = 3), followed by post-secondary (non-tertiary level, *n* = 1) and university (*n* = 1). The participants were working full time employment at office hours (*n* = 1); unemployed (*n* = 1); retired (*n* = 1) and homemaker (*n* = 2). The reported household income was $2,500 to $3,500 (*n* = 1), $3,501 to $4,500 (*n* = 1), $4,501 to $7, 500 (*n* = 2) and above $7,501 (*n* = 1). Most of the participants did not have foreign domestic helper (*n* = 3) and the others had helper (*n* = 2). All the participants did not have any other caregiving responsibility. The people living in the same household (excluding the participant and adolescent with ID) were with no one else (*n* = 2), an elder son (*n* = 1), husband (*n* = 1), and husband and elder daughter (*n* = 1). The adolescents with ID were all 19 years old at the year of recruitment. None of the adolescents had epilepsy and only one adolescent had physical health diagnosis of Eczema.

Table 4.1

Demographic information of participants and adolescents with ID

Caregiver	X	Y	Z	AB	CD
Age	53	55	60	55	57
Gender	Female	Female	Female	Female	Female
Ethnicity	Chinese	Chinese	Chinese	Chinese	Chinese
Religion	Buddhist	Roman Catholic	Buddhist	No religion	Christian
Marital status	Divorced	Divorced	Married	Married	Married
Highest Education	Post-secondary	Secondary	Secondary	Secondary	University
Employment status	Unemployed	Homemaker	Retired	Full time employment (office hours)	Homemaker
Household Income	$4,501 to $7,500	$3,501 to $4,500	$2,500 to $3,500	$4,501 to $7,500	Above $ 7,501
People living in the same household	Elder son, 19 years	No	No	Husband, 56 years	Husband, 58 Elder daughter,22
Do you have helper?	No	Yes	No	No	Yes
Caregiving relationship	Mother	Mother	Mother	Mother	Mother
Years of caregiving	19	19	19	19	19
Other caregiving responsibility	No	No	No	No	No
Adolescent with ID					
Age	19	19	19	19	19
Gender	Male	Male	Male	Female	Female

Current engagement	Social Club – only on Saturday	Day Activity Centre	On waiting list for adult service placement	Social clubs	Home based program
Diagnosis	ID and ASD	ID and ASD	ID and ADHD	ID and ASD	ID and anxiety
Epilepsy	No	No	No	No	No
Physical health related diagnosis	No	Eczema	No	No	No

Measures and Procedure

The self-report measures administered, and procedures followed were as described in Chapter 3.

Data Analysis

The findings of this study are reported using the following presentation formats: one year of follow-up quantitative data (two participants, X and Y), two years of follow-up quantitative data (one participant, Z) and two case studies including both quantitative and qualitative data (two participants, AB and CD).

The Reliable Change Index (RCI) was calculated in this study to assess the statistical reliability of the change in the score between the first and last point of the measures (Jacobson & Truax, 1991; Mata et al., 2018). RC calculation used in this study was as follows:

$$RCI = \frac{X_2 - X_1}{\sqrt{2S_E{}^2}}$$

where X_2 defines the participant's last point measures scores, and X_1, the first point measures scores of the same participant. The Standard Error (S_E) can be calculated based on the standard deviation (*SD*) and coefficient alpha (r_{xx}) of the normative sample for each measure as follow:

$$S_E = SD\sqrt{1 - r_{xx}}$$

The change in the scores between Time 1 and 2 (for one-year follow-up) and Time 1 and 4 (for two-year follow-up) was visually checked to identify score trends. The questionnaires for DBC-P24, modified OBS, and PACS were chosen as there were trends across the time points. However, the required information to calculate the S_E for DBC-P24 and modified OBS was not available in the published literature. The necessary psychometric

data was available to calculate RCI for PACS. Hence, the RCI was calculated for PACS only. The S_E for PACS was 2.98 (SD = 9, $r_{xx} = 0.89$).

The case study presentation format utilised here is similar to that of Katherndahl et al. (2012). The explanatory sequential design was implemented whereby the quantitative data was analysed and presented as a case series, tracking individual changes. The follow up qualitative interview was incorporated to explore other possible factors or themes that anchored the quantitative changes. The explanatory sequential design further strengthened the understanding of the caregivers' adaptation caring for an adolescent with ID (Creswell, 2003). The qualitative interview explored the caregivers' unique experiences and factors (for example, psychological, environmental, and personal values) that were not assessed in the quantitative study but were important drivers of their decision-making regarding placement decisions.

The principal investigator has eight years of experience as a clinical psychologist working with individuals with ID and their caregivers. The supervisors have research expertise in both quantitative and qualitative study design. Hence the research team had the necessary experience and expertise to effectively use the explanatory sequential design adopted here.

Results

Case Study 1 and 2: One-year follow-up quantitative data

Two participants, X and Y, completed the one-year follow-up, Time 1 and 2, and dropped out thereafter. Both participants did not reply to two follow-up emails to indicate their availability to complete Time 3 data collection. Hence, the reason for withdrawal was unknown. The scores for both participants, X and Y, across Time 1 and 2 are presented in Table 4.2.

Table 4.2

Scores for each measure for Participant X and Y across Time 1 and 2

Measure	**X**				**Y**			
	Time 1		Time 2		Time 1		Time 2	
BRS	2.5 (low)				3.83 (normal)			
DFS	20				23			
DBC-P24	16		19		20		23	
Modified OBS	36		36		40		42	
QFSSS:	F	S	F	S	F	S	F	S
Total	23	35	24	36	25	27	24	29
Support Type:								
Emotional support	8	11	8	12	9	10	8	10
Instrumental support	9	12	8	12	8	9	8	9
Informational support	6	12	8	12	8	8	8	10
Support Source:								
Partner	7	9	7	10	5	5	4	5
Family	6	10	7	10	7	7	7	8
Friends	3	6	3	6	7	9	7	9
Community	7	10	7	10	6	6	6	7
Brief COPE:								
Problem-focused domain	2.5		2.63		3.5		3.25	
Emotion-focused domain	1.75		1.58		2.58		2.58	
Avoidant domain	1.375		1.25		1.63		1.63	
PACS	37		38		41		43	
Perceived Burden 1 (DBC-P24)	5		5		4		5	
Perceived Burden 2 (modified OBS)	4		4		4		5	
WHOQOL-BREF (Tabulated Score)								
Physical Health Domain	69		69		63		63	
Psychological Domain	56		56		63		56	
Social Relationships Domain	44		31		50		56	
Environment Domain	56		56		63		63	
Modified PTI	4		4		4		4	

Note. BRS = Brief Resilience Scale; DFS = Dark Future Scale; DBC-P24 = Developmental Behavior Checklist P24; modified OBS = modified Objective Burden Scale; QFSSS = Questionnaire on the Frequency of and Satisfaction with Social Support (F = Frequency, S = Satisfaction); PACS = Positive Aspects of Caregiving Scale; modified PTI = modified Placement Tendency Index. Brief COPE is the short version of a coping mechanism scale; WHOQOL-BREF is the short version of quality-of-life scale.

Participant X. The BRS and DFS were used to understand X's resilience and anxiety about the future as a caregiver. The BRS score of 15 (an average of 2.5) falls within the low resilience range, indicating that X may struggle to bounce back from stressful situations. The DFS score of 20 out of 30 reflects moderately high level of anxiety about the future.

The DBC-P24 scores, which were 16 and 19 out of 48 total scores at Time 1 and 2, demonstrate an increase in the prevalence of challenging behaviour over the six months. This upward trend in scores underscores the evolving nature of X's caregiving challenges and the need for continuous support to manage the challenging behaviour. Despite this, the perceived burden 1 (DBC-P24) scores remained the same, with X scoring 5 (somewhat feeling stressed) at Times 1 and 2 in managing her son's day-to-day needs.

The modified OBS scores were 36 out of 50; the scores were the same at Time 1 and 2. These scores may indicate that the caregiving needs have impacted X's day-to-day activities, leaving her with less time for herself. X scored 4 (a little less, worse) on seven items (out of ten items), except for item number 8 (your relationship with other people). On this item, she scored 2 (a little better) at Time 1 and 2, indicating that comparatively, she had developed better relationships with the others since she became a caregiver. Although X reported having less time to manage her day-to-day needs, she scored 4 (neither feeling stress nor stress-free) at Time 1 and 2 for the perceived burden 2 (modified OBS). Overall, despite the increased prevalence of the challenging behaviour and having a little less time for her day-to-day needs since the adolescent with ID left special school, the perceived burden scores do not align with the reported objective burden scores.

Hence, the protective factors, such as the support, coping mechanisms and positive aspects of caregiving, were considered. The QFSSS measures the frequency and satisfaction of the received support. The total support frequency reported was 23 and 24 (lower than the mean frequency of 37.28), indicating that X received support less frequently than the average

caregiver. The total support satisfaction was 35 and 36 (lower than the mean of 41.00), suggesting that X was somewhat dissatisfied with the support that she received. Specifically, the frequency scores for each support type, such as emotional (support that addresses emotional needs), were 8 and 8; instruments (support that involves the use of tools or resources) were 9 and 8; and information (support that provides knowledge or advice) were 6 and 8, respectively, for Time 1 and 2. The satisfaction scores for each emotional support group were 11 and 12, instruments were 12 and 12, and information was 12 and 12, respectively, for Time 1 and 2. On the other hand, the frequency for each support source for partner (support from a romantic partner), family (support from family members), friends (support from friends), and community (support from the community) were 7 and 7; 6 and 7; 3 and 3; and 7 and 7, respectively for Time 1 and 2. The satisfaction scores for each support source for the partner were 9 and 10; family were 10 and 10; friends were 6 and 6; and community were 10 and 10, respectively, for Time 1 and 2. Overall, X received equal support from the partner, family and community and the lowest from friends.

The average scores in BRIEF COPE for each coping domain across Time 1 and 2 were reported. X demonstrated a strong problem-focused coping strategy, with average scores of 2.5 and 2.63 (around 44% and 48% of the total coping strategy). This was followed by emotion-focused coping, with average scores of 1.75 and 1.58 (31% and 30% of the total coping strategy), and avoidant coping, with average scores of 1.38 and 1.25 (25% and 22% of the total coping strategy). X mostly applied adaptive problem-solving skills to cope with caregiving demands.

The total scores for the positive aspects (PACS) were 37 and 38 out of a total score of 45 for Time 1 and 2, respectively. Both the scores were higher than the female population mean score of 33.5, indicating that X perceived several positive aspects of her caregiving role. These positive aspects include a sense of purpose, personal growth, and improved

relationships, which can contribute to X's overall well-being. The difference in score between Time 1 and 2 was one, and the RCI score was -0.24 (less than 1.96). Hence, there is no reliable change between the scores.

Even though X reported a lower frequency and satisfaction of the support that she received, compared to the mean population scores, X may have applied adaptive coping mechanisms and developed a positive caregiving perspective. X’s overall quality of life and satisfaction with her health scores were 3 (neither poor nor good quality of life and neither satisfied nor dissatisfied with her health) and consistent over the two time points. X consistently scored highest on the physical health domain across Time 1 and 2; the score was 69 (similar to the general norm mean, 70.6). Then, followed by the scores on the psychological health domains (56 and 56; lower than the general norm mean, 71.5), environment domains scores (56 and 56; lower than the general norm mean, 75.1), and the lowest were social relationship domain scores (44 and 31; lower than the general norm mean, 75.1) at Time 1 and 2. Even with the increasing prevalence of challenging behaviour and caregiving demands, there were no changes to the modified PTI score across the six months. With the family members’ agreement, X scored 4 (I have thought about it and enquired but have not done anything yet) at Time 1 and 2. X had thoughts about the residential home but had not initiated any action related to the thought, even though there was an increase in challenging behaviour after graduating from school.

Despite an upward trend in the objective burden scores, there was no increase in the reported perceived burden scores. The perceived burden scores could be explained by the fact that X coped mainly with problem-focused coping strategies, which involve actively addressing the source of stress and developing a positive perspective on caregiving. This may have helped her to maintain a balanced view of her situation. These coping strategies and the positive perspective likely contributed to the stability of her quality of life and PTI scores and

indicated that her thoughts about residential care did not translate into action; even though X reported falling within the low resilience range score, some level of anxiety about the future, and lesser reported frequency and satisfaction with the support received.

Participant Y. The BRS and DFS were used to understand Y's resilience and anxiety about the future as a caregiver. The BRS score of 23 (an average of 3.83) falls within the normal resilience range, indicating that Y can bounce back from stressful situations. The DFS score of 23 out of 30 reflects moderately high anxiety about the future.

The DBC-P24 scores were 20 and 23 out of 48 at Time 1 and 2, respectively. These scores indicated an increase in the prevalence of challenging behaviour over the six months. The perceived burden 1 (DBC-P24) scores increased, with Y scoring 4 (neither feeling stress nor stress-free) to 5 (somewhat feeling stressed) at Times 1 and 2 in managing her son’s day-to-day needs.

The modified OBS scores were 40 and 42 out of 50, increasing from Time 1 and 2. These scores indicate that the caregiving needs have impacted Y's day-to-day activities, leaving her less time for herself. Y scored 4 (a little less, worse) on eight items (out of ten items). For items number 5 (amount of energy you have) and 6 (amount of time you spend in recreational and/or social activities), Y scored 5 (a lot less, worse) at Time 2, indicating that, comparatively, she had less energy and time for social activities, especially after the son left the special school. Y reported having less time for herself to manage her day-to-day needs, she scored 4 (neither feeling stress nor stress-free) at Time 1 and increased to score 5 (somewhat feeling stress) at Time 2 for the perceived burden 2 (modified OBS). Overall, the perceived burden scores increase was aligned with the upward trend in the prevalence of the challenging behaviour and the amount of time Y left to manage her day-to-day needs.

The protective factors, such as Y’s support system, coping mechanism and positive aspects of caregiving, were analysed. The total support frequency received was 25 and 24

(lower than the population mean frequency of 37.28), indicating that Y receives support less frequently than the average caregiver. The total support satisfaction was 27 and 29 (lower than the population mean of 41.00), suggesting Y was somewhat dissatisfied with her support. Specifically, the frequency scores for each support type, such as emotional (support that addresses emotional needs), were 9 and 8; instruments (support that involves the use of tools or resources) were 8 and 8; and information (support that provides knowledge or advice) were 8 and 8, respectively, for Time 1 and 2. The satisfaction scores for each emotional support group were 10 and 10, instruments were 9 and 9, and information was 8 and 10, respectively, for Time 1 and 2. On the other hand, the frequency for each support source for partner (support from a romantic partner), family (support from family members), friends (support from friends), and community (support from the community) were 5 and 4; 7 and 7; 7 and 7; and 6 and 6, respectively for Time 1 and 2. The satisfaction scores for each support source for the partner were 5 and 5; family were 7 and 8; friends were 9 and 9; and community were 6 and 7, respectively, for Time 1 and 2. Overall, Y received more support from her family, friends, and community than her partner.

Y's averaged score on her coping mechanism (Brief COPE) in each domain across Time 1 and 2 was reported. The average score on problem-focused coping was 3.5 and 3.25 (around 45% and 44%), followed by emotion-focused coping, 2.58 and 2.58 (34%), and avoidant coping, 1.63 and 1.63 (21% and 22%). Y mostly applied problem-focused coping skills to cope with caregiving demands.

The total scores for the positive aspects (PACS) were 41 and 43 out of a total score of 45 for Time 1 and 2, respectively. Both scores were higher than the female mean score of 33.5, emphasizing that Y perceives several positive aspects in her caregiving role. These positive aspects, such as a sense of purpose, personal growth, improved relationships, and a more positive attitude towards life, underscore Y's ability to find joy in her responsibilities

despite the challenges. The score difference between Time 1 and 2 was 2. Hence, the RCI score was -0.47 (lesser than 1.96). There was no reliable change between the scores.

Even though Y reported a lower frequency and satisfaction with the support that she received, compared to the mean population scores, Y had actively used problem-focused coping skills and developed a positive caregiving perspective. Y’s overall quality of life and satisfaction with her health scores were 3 (neither poor nor good quality of life) and 2 (dissatisfied with her health), and were consistent over the two time points. Y consistently scored highest on the physical health and environmental domains across Time 1 and 2; the score was 63, but lower than the general norm means, 74.9 (physical health) and 72.0 (environmental). Then, followed by the scores on the psychological health domains (63 and 56; lower than the general norm mean, 72.5), and the lowest were social relationship domain scores (50 and 56; lower than the general norm mean, 74.0) at Time 1 and 2. Despite the increase in the objective and perceived burden scores, the modified Placement Tendency Index (PTI) score did not change across the six months. With the family member's agreement, Y scored 4 (I have thought about it and enquired but have not done anything yet) at Time 1 and 2. Y had thoughts about the residential home but had not initiated any action related to the thought.

In summary, Y reported an upward trend in both the objective and perceived burden scores. Y coped mainly using problem-focused coping strategies, which involve actively addressing the source of stress, developed a positive perspective of caregiving and her resilience level fell within the normal range. The adaptive coping strategies and positive perspectives may not be adequate to cope with the increased objective caregiver burden, which could have increased subjective burden scores. However, the quality of life and PTI scores were the same across the six months, even though she reported having some anxiety about the future and lesser reported frequency and satisfaction with the support received.

Case Study 3: Two years follow up quantitative data (Participant Z)

Participant Z completed all four assessment sessions across the two years but not the qualitative (semi-structured interview) component (Table 4.3). When the invitation was extended for the qualitative interview, Z indicated that she was interested but rescheduled two times and did not indicate her availability thereafter via the follow-up emails.

Table 4.3

Scores for each variable for Participants Z across four Timepoints

Variables	Time 1		Time 2		Time 3		Time 4	
BRS	3.5 (normal)							
DFS	15							
DBC-P24	15		16		16		17	
Modified OBS	32		30		32		32	
QFSSS:	F	S	F	S	F	S	F	S
Total	41	40	42	43	42	43	42	43
Support Type:								
Emotional support	14	13	14	13	16	15	16	15
Instrumental support	13	15	14	15	13	14	13	14
Informational support	14	12	14	15	13	14	13	14
Support Source:								
Partner	14	9	12	13	13	13	13	13
Family	10	10	10	10	10	11	10	11
Friends	8	6	10	10	8	9	8	9
Community	9	10	10	10	11	10	11	10
Brief COPE:								
Problem-focused domain	4.00		3.75		3.88		3.75	
Emotion-focused domain	2.67		2.5		2.58		2.67	
Avoidant domain	1.25		1.25		1.38		1.38	
PACS	44		44		43		44	
Perceived Burden 1 (DBC-P24)	5		5		5		5	
Perceived Burden 2 (modified OBS)	5		5		5		5	
WHOQOL-BREF (Tabulated Score)								
Physical Health Domain	63		69		63		63	
Psychological Domain	81		75		75		81	
Social Relationships Domain	69		69		75		75	
Environment Domain	84		84		81		88	
Modified PTI	2		2		2		2	

Note. BRS = Brief Resilience Scale; DFS = Dark Future Scale; DBC-P24 = Developmental Behavior Checklist P24; modified OBS = modified Objective Burden Scale; QFSSS = Questionnaire on the Frequency of and Satisfaction with Social Support (F = Frequency, S = Satisfaction); PACS = Positive Aspects of Caregiving Scale; modified PTI = modified Placement Tendency Index. Brief COPE is the short version of a coping mechanism scale; WHOQOL-BREF is the short version of quality-of-life scale.

The BRS and DFS were administered to assess Z's resilience and anxiety about the future as a caregiver. The BRS score of 21 (an average of 3.5) falls within the normal resilience range, indicating that Z has the ability to bounce back from stressful situations. The DFS score of 15 out of 30 reflects some level of anxiety about the future.

The DBC-P24 scores were 15, 16, 16, and 17 out of 48 at Time 1, 2, 3, and 4, respectively. These scores indicate an upward trend in the prevalence of challenging behaviour over the two years of leaving school. Although there was an increase in the prevalence of challenging behaviour, the perceived burden 1 (DBC-P24) scores remained the same. Z scored 5 (somewhat feeling stress) across all the time points in managing her son's day-to-day needs.

The modified OBS scores were 32, 30, 32 and 32 out of 48 at Time 1, 2, 3 and 4. The scores mostly remained constant across the two years. These scores indicate that the caregiving needs were roughly the same, leaving her the same amount of time for herself. Z scored 3 (the same) on eight items (out of ten items). Except for item number 5 (amount of energy you have) and 6 (amount of time you spend in recreational and/or social activities), Z scored 4 (a little less, worse) at Time 1, 2,3 and 4. Similarly, the perceived burden 2 (modified OBS) remained constant. Z scored 5 (somewhat feeling stress) at all the time points for managing her day-to-day needs. Despite an upward trend in the prevalence of the challenging behaviour, there was no increase in the perceived burden scores (for managing the son's challenging behaviour and her day-to-day needs).

The protective factors, such as Z's support system, coping mechanism and positive aspects of caregiving, were analysed. The total support frequency received was 41, 42, 42 and 42 (higher than the mean frequency of 37.28), indicating that Z receives support more frequently than the average caregiver. The total support satisfaction felt was 40, 43, 43 and 43 (mostly the same as the mean of 41.00), suggesting Z is somewhat satisfied compared to the

average score. Specifically, the frequency scores for each support type, such as emotional (support that addresses emotional needs), were 14, 14, 16 and 16 (increasing trend across the four time points); instruments (support that involves the use of tools or resources) were 13, 14, 13 and 13 (remained constant across the four time points); and information (support that provides knowledge or advice) were 14, 14, 13 and 13 (decreasing trend across the four time points) respectively, for Time 1, 2, 3 and 4. The satisfaction scores for each emotional support group were 13, 13, 15 and 15, instruments were 15, 15, 14 and 14, and information was 12, 15, 14 and 14, respectively, for Time 1, 2, 3 and 4. On the other hand, the frequency for each support source for partner (support from a romantic partner), family (support from family members), friends (support from friends), and community (support from the community) were 14, 12, 13 and 13; 10, 10, 10 and 10; 8, 10, 8 and 8; 9, 10, 11 and 11 for Time 1, 2, 3 and 4 respectively. The satisfaction scores for each support source; partner were 9, 13, 13 and 13; family were 10, 10, 11 and 11; friends were 6, 10, 9 and 9; and community were 10, 10, 10 and 10, respectively, for Time 1, 2, 3 and 4. Overall, Z received the most support from her partner, followed by the family and community and the least from the community.

Z’s averaged score on her coping mechanism (Brief COPE) in each domain across Time 1, 2, 3 and 4 was reported. The average score on problem-focused coping was 4.00, 3.75, 3.88 and 3.75 (ranging from 48% to 50%), indicating a predominance of problem-focused coping skills in Z's coping mechanism. This suggests a proactive approach to managing caregiving demands. Z also applied emotion-focused coping, 2.67, 2.5, 2.58 and 2.67 (ranging from 33% to 34%), and avoidant coping, 1.25, 1.25, 1.38 and 1.38 (16% to 18%).

The total scores for the PACS were 44, 44, 43 and 44 out of a total score of 45 for Time 1 and 2, respectively. All the scores were higher than the female mean score of 33.5,

indicating that Z perceived several positive aspects in her caregiving role. These positive aspects may include a sense of purpose, personal growth, and improved relationships, which can contribute to Z's overall well-being despite her caregiver duties. This high score on the PACS suggested that Z was able to find meaning and satisfaction in her caregiving role, which was a positive indicator of her well-being.

Z scored higher than the mean frequency and satisfaction of the support received. She actively uses problem-focused coping skills and developed a positive caregiving perspective in providing care and support for managing her son after he graduated from a special school. Overall, Z’s scores on the quality of life and satisfaction with her health were 4 (good quality of life) and 3 (neither satisfied nor dissatisfied with her health), consistently across the four time points. Z consistently scored highest on the environment domain across Time 1, 2, 3 and 4; the score was 84, 84, 81 and 88 (higher than the environmental general norm mean of 72.0), followed by the psychological health domain (81, 75, 75 and 81; generally higher than the psychological general norm mean, 72.5). The lowest domain scores were for the social relationship domain (69, 69, 75 and 75; initially lower, but the score increased and was generally similar to the social general norm mean, 74.0) and physical health domain (63, 69, 63 and 63; generally lower than the physical health general norm mean, 74.9). Despite the increase in the challenging behaviour, the modified PTI score did not change across the two years. With the family member’s agreement, Z scored 2 (Occasionally, I have given it a thought) at Time 1, 2, 3, and 4.

In summary, Z reported an upward trend in challenging behaviours across the two years. However, the time left to manage her own day-to-day needs remained the same, despite the increase in the challenging behaviours. There were no changes to the perceived burden scores across the two years. Z has received support from various sources and types, and she feels satisfied with the support received. Factors such as problem-focused coping

strategies, developing a positive perspective of caregiving, ability to bounce back from stressful situations and not much anxiety about the future could have contributed to the reported good quality of life and lower PTI score. She had only thought about out of placement occasionally, even though there was an upward trend in challenging behaviour across the two years of leaving school.

Case Study 4: Explanatory sequential design (Participant AB)

AB is a 55-year-old mother who takes care of her daughter, Deby. Deby is 20-years-old and diagnosed with moderate ID and Autism Spectrum Disorder (ASD). Deby has never experienced any seizure episodes or physical health problems. AB is a full-time employee who started working from home in 2020 due to the COVID-19 pandemic. AB lives with her retired husband and Deby, her only child. They do not have a domestic helper, and AB has no additional caregiving responsibilities. The household income ranges between $4,500 and $7,500 per month, and AB does not associate herself with any religion. AB had completed her secondary school education and had never participated in any caregiver groups or utilized any caregiver support services. She had also not received any form of financial assistance or used any respite care services. Deby mainly stays at home and attends an activity centre once a week. However, AB believes Deby's quality of life is unsatisfactory due to the lack of community engagement. During Deby's schooling, AB's sister took care of her on weekdays, and AB took care of her on weekends. Since the start of the COVID-19 pandemic, Deby has been staying with AB while AB manages her work-from-home routine.

With her husband's agreement, AB had considered and developed a working plan to place Deby in the adult home in the future but had not initiated any action. AB scored 3 in the modified Placement Tendency Index (PTI; Yes, I have thought about it a lot, but have done nothing) and there were no changes to the response across the four time points. During the

interview, it was clarified that AB and her husband would only consider placing Deby in an adult home when they can no longer care for Deby due to their health or when they die.

AB clarified at the interview that Deby is increasingly having difficulty with waiting, has started hitting the parents, is not listening to instructions compared to previously, and mostly refusing to allow AB to leave the home without her, since she have left school. The information shared at the interview was consistent with the scores on the Development Behaviour Checklist (DBC-P24). The DBC-P24 scores were 22, 24, 26 and 26 out of total scores of 48 for Time 1, 2, 3 and 4, respectively (see Figure 4.1). Higher scores indicated that there was higher prevalence of the challenging behaviour. The scoring for each item was the same across the four time points except that the scores on items number 7 (impatient), 10 (kicks, hits others), 17 (stubborn, disobedient or uncooperative) and 23 (upset or distressed over small changes in routine or environment) increased across the time points over the two years. On the other hand, the perceived burden of managing Deby's day-to-day needs was 4 (neither feeling stress nor stress-free) at Time 1. The score increased to 5 (somewhat feeling stressed) and were constant at Time 2, 3 and 4 (see Figure 4.2). During the interview, even though AB clarified that it is more challenging to manage Deby's behaviour since she left school due to the increase in the problem behaviour, AB denied feeling significantly overwhelmed in managing Deby's day-to-day needs and it did not trigger the initiation for the out of home placement plan; "*It's still the same. It's still like more or less the same*". AB expressed that she occasionally felt overwhelmed when she was unable to manage Deby, *"Sometimes, of course, I would just have temper. If you just cannot take it, you just blow out.*"

Figure 4.1

Developmental Behavioural Checklist-P24 for AB

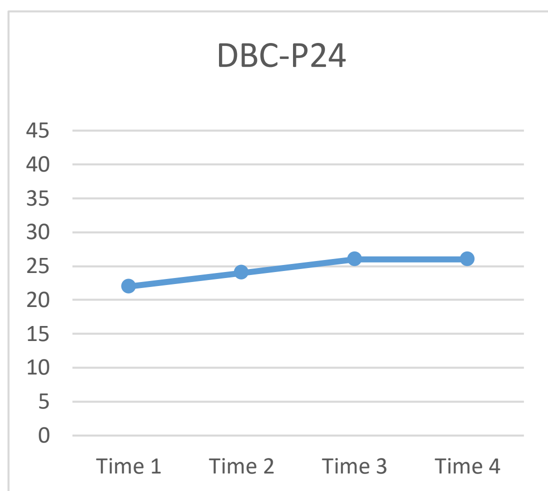
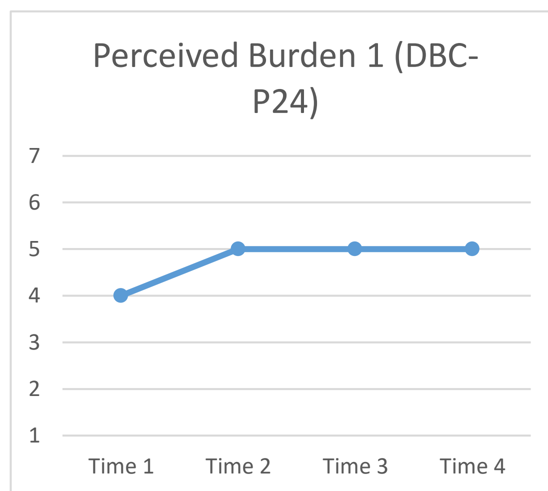


Figure 4.2

Perceived burden 1 (DBC-P24), managing Deby's behaviour for AB



The modified Objective Burden Scale (OBS) scores were 37, 38, 40 and 40 out of a total of 50 for Time 1, 2, 3 and 4, respectively (see Figure 4.3). Higher scores indicate more changes in the primary caregiver's day-to-day activities due to the caregiving needs. Hence, the scores of modified OBS indicated that the caregiving needs have occupied Deby and she has less time for herself. Specifically, at Time 4, AB scored 5 (a lot less time for herself) for items number 1 (amount of time you have to yourself), 4 (amount of personal freedom you have), 7 (amount of vacation activities and trips you take) and 8 (your relationship with other family members). Although AB reported a little less time that she spends on her day-to-day needs (especially time for herself, personal freedom, vacation activities and relationship with other family members), AB shared that she perceived feeling neutral (neither stress nor stress-free; Figure 4.4) in managing her time for her own day-to-day needs, and it did not trigger the initiation for the out-of-home placement plan. The perceived burden score of managing AB's own day-to-day needs was 4 (neither feeling stress nor stress-free) consistently across all timepoints.

Figure 4.3

Modified Objective Burden Scale (OBS) for AB

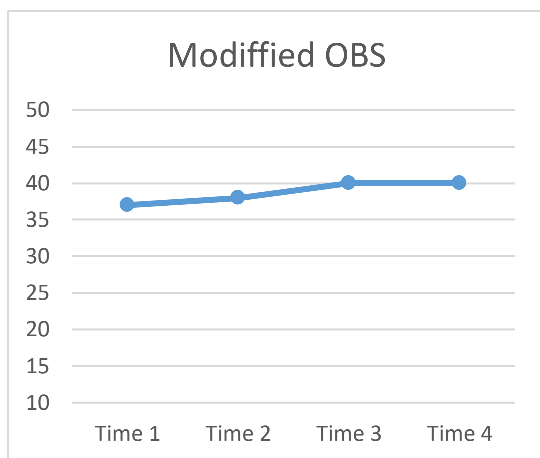
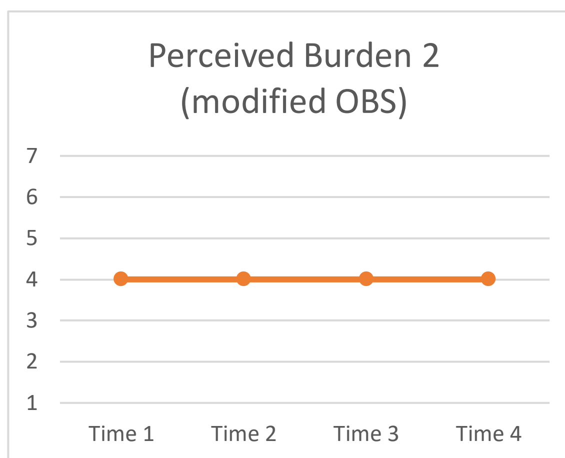


Figure 4.4

Perceived burden 2 (modified OBS), managing AB's day-to-day needs



The QFSSS measures the frequency and satisfaction of the support received. The total frequency of support received were 19, 18, 19 and 19 (lower than the mean frequency of 37.28), while the total satisfaction based on the support received were 42, 44, 44 and 44 (around the mean satisfaction of 41.00) across Time 1, 2, 3 and 4. Specifically, the frequency scores for each support type, such as emotional (support that addresses emotional needs), were 5, 5, 5 and 5; instruments (support that involves the use of tools or resources) were 7, 6, 7 and 7; and information (support that provides knowledge or advice) were 7, 7, 7 and 7, respectively, for Time 1, 2, 3 and 4 (Figure 4.5). Whereas the satisfaction scores for each support type were 13, 14, 14, and 14 for emotional support, instruments support were 15, 15, 15 and 15, and information were 14, 15, 15 and 15, respectively, for Time 1, 2, 3 and 4 (Figure 4.6). Whereas the frequency for each support source for partner (support from a romantic partner), family (support from family members), friends (support from friends), and community (support from the community) were 6, 5, 6, and 6; 7, 7, 7, and 7; 3, 3, 3 and 3 and 3, 3, 3, and 3 respectively for Time 1, 2, 3 and 4 (Figure 4.7). The satisfaction scores for each support source for partner were 6, 8, 8 and 8; family were 12, 12, 12 and 12; friends were 12,

12, 12 and 12; and community were 12, 12, 12 and 12, respectively for Time 1, 2, 3 and 4 (Figure 4.8).

Figure 4.5

QFSSS, frequency for each support type for AB

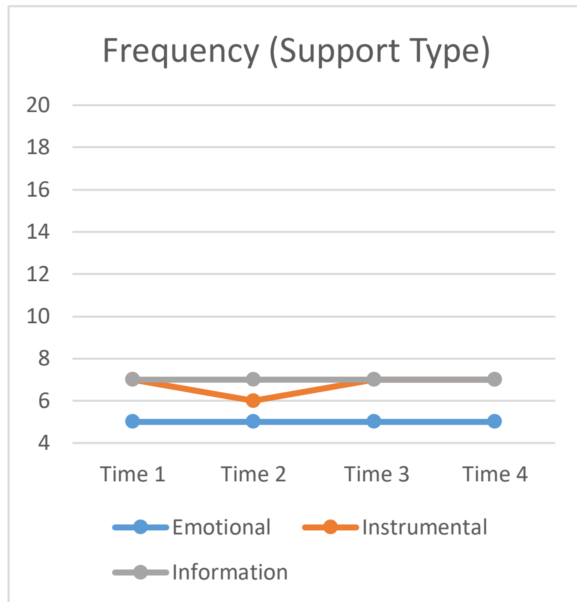


Figure 4.6

QFSSS, satisfaction for each support type for AB

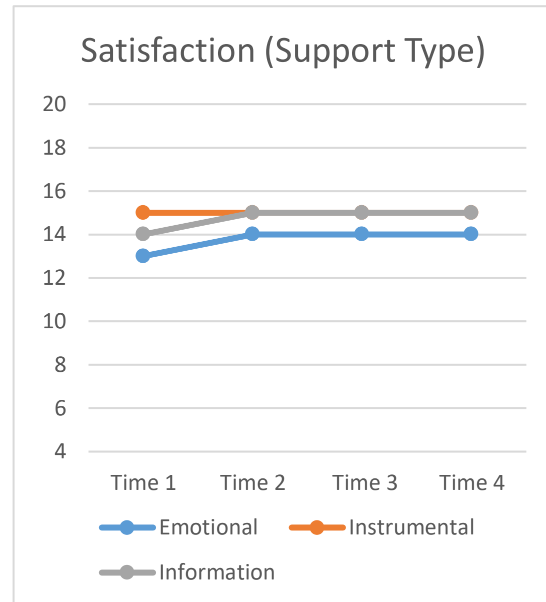


Figure 4.7

QFSSS, frequency for each support source for AB

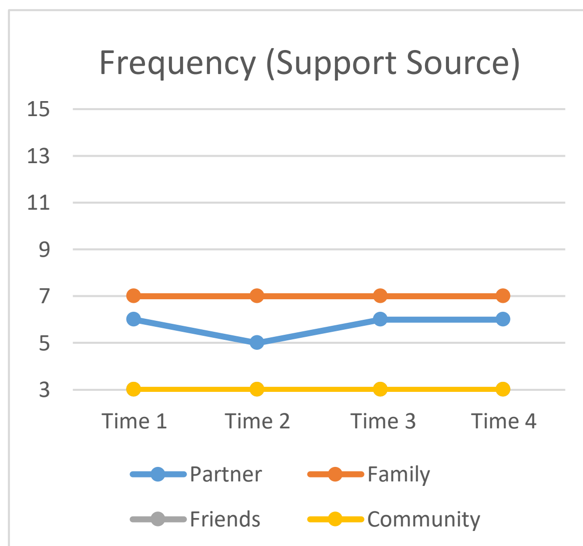
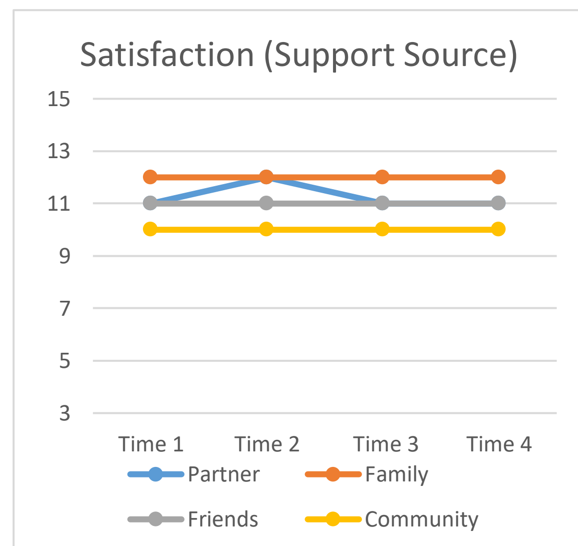


Figure 4.8

QFSSS, frequency for each support source for AB



AB’s score on the QFSSS reflected that, comparatively, she received less frequent support than the general population mean but was as satisfied as the general population mean. Comparatively, she received more, and was more satisfied with information and instrumental support than emotional support. On the other hand, she received more support from the family, followed by her husband and the least from the community and friends. However, she was most satisfied with the support received from her family, followed by friends, community, and least satisfied with the support she received from her husband. During the interview, AB shared that she still gets some support, even though she used to get more support from her sister when Deby was schooling. Currently, she would need to depend on her husband to care for Deby when AB needed to go out. Even though the adult activity centre provides a range of activities for Deby, AB only benefited a little from community service as the centre is far from her home. AB wished she had more practical support to care for Deby when running errands. When asked whether the support was sufficient, AB clarified that she was generally satisfied with the support she received, but she hoped for more support. When asked why she hoped for more support, AB shared that based on her caregiving experience, there are “*always uncertainties*” (lack of contingency planning). AB further shared that the plans for long-term placement change based on the support that she receives. She needed to find an alternative option if there were any changes to her current support system. Therefore, she concludes that "t*he more support, the better it is*".

Despite the lack of options, AB's resilience was evident as she worked towards forming a plan for Deby's long-term placement. The total score on the BRS was 19 (the average with six items was 3.17), indicating that AB falls within the normal resilience range. In the interview, AB's acceptance of Deby's diagnosis was a key point of emphasis; "*I felt that, you know, you have to accept it. What to do? Acceptance*." Her acceptance of the situation is an indication of her emotional strength and resilience.

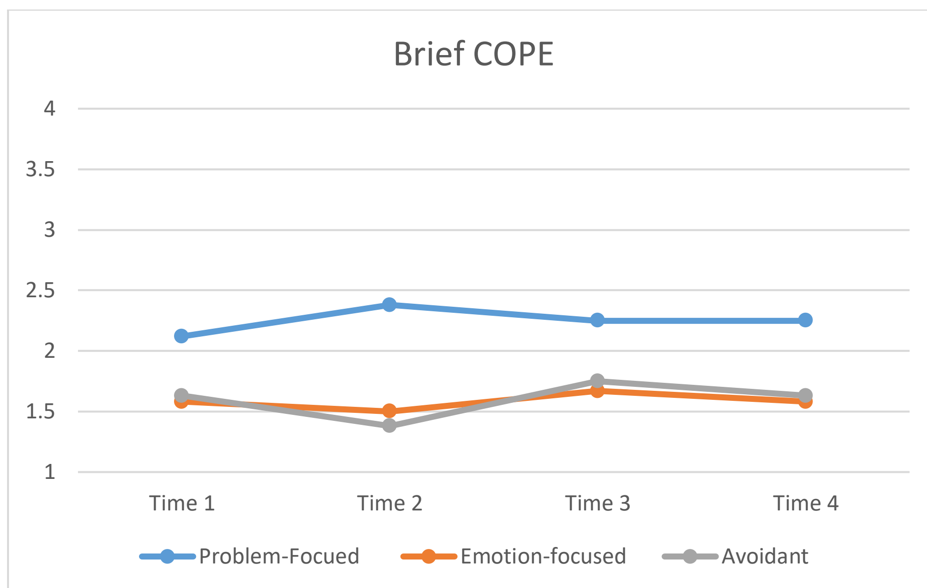
In addition, AB shared her concerns about possible abuses and use of restraints in the adult home. AB understands the difficulties in managing individuals with disability due to the lack of staffing in the adult home, based on her reading from the newspaper and hearing from others. AB was particularly distressed by the idea of Deby being restrained: "*they will just tie them up. I was like, oh my goodness*." AB also shared that Deby is vulnerable and unable to protect herself. Therefore, there might be a risk of Deby being exploited, "*Until now, I wouldn't let her go out on her own because she is too friendly. To outside people, she will just freeze, and then she won't do anything. She doesn't even shout*".

AB's averaged scores on her coping mechanism (Brief COPE) in each domain across Time 1, 2, 3 and 4; problem-focused coping was 2.12, 2.38. 2.25 and 2.25; emotion-focused coping was 1.58, 1.5, 1.67, and 1.58; and avoidant coping was 1.63, 1.38, 1.75 and 1.63 respectively (Figure 4.9). Consistently, AB scored highest on the problem-focused (approximately about 40%) and followed by the emotion-focused and avoidant coping (approximately 30% for each coping). During the interview, AB specifically shared her coping mechanism for managing Deby's challenging behaviour and plan. AB has received her sister's help in the past and is currently seeking community support, such as social clubs to fill Deby's time. To mitigate her future concerns about potential abuse and use of restraint in residential facilities, AB was planning to ask AB's nephew to visit and supervise Deby in the adult home occasionally as Deby's guardian. She hoped that the guardian would be able to ensure that Deby is "*fine*" and that her basic needs and safety are taken care of; "*just take care and make sure that she's not like abused in the home and her needs are more or less met*." AB was taking an extra step and has started visiting nursing homes to get a general idea and information on how the adult home care staff manage the residents. AB coped by gaining information and planning to mitigate the stress triggered by the challenging behaviour and future placement in the residential home. Overall, during the interview, AB's description of

her coping mechanisms aligned with the Brief COPE scores in that AB is generally more inclined to use problem-focused strategies such as positive reframing, planning and instrumental support rather than emotion-focused and avoidant strategies such as venting, denial and behavioural engagement.

Figure 4.9

Brief COPE across four Time points for AB

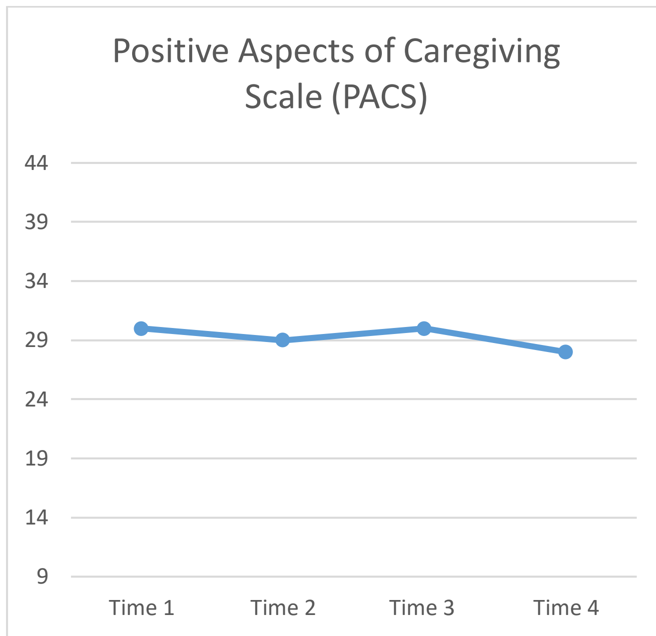


The total scores for the PACS were 30, 29, 30 and 28 out of a total score of 45 for Time 1, 2, 3 and 4, respectively (Figure 4.10). All the scores were lower than the female mean score of 33.5. The difference in PACS score between Time 1 and 2 is 2. The RCI is 0.47 (lower than 1.96). Hence there was no reliable change in the PACS. Despite some reported difficulty managing her day-to-day needs and concerns about the support, AB clarified during the interview that being a caregiver did generally add some value to her life, especially when she felt more useful and had the opportunity to appreciate and develop a more positive attitude toward life. On the other hand, when asked about the decision-making process for Deby's long-term placement plan, she expressed her desire to avoid burdening her extended family with continued caregiving duties, leading her to consider placing Deby in an

adult residential home. Her response, consistent with the score on item number 5 (Made me feel important) on the PACS across the four time points, suggested that she did not feel she was essential to the family.

Figure 4.10

Positive Aspects of Caregiving Scale (PACS) for AB

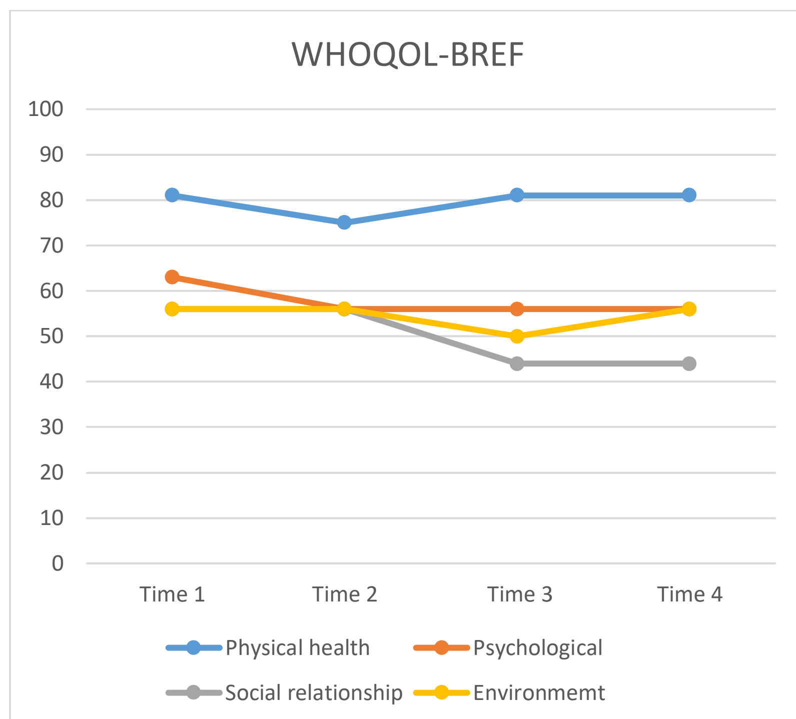


Although her current working plan for adult home is *"doable for now"*, AB is constantly concerned about the "*what if*" scenario. For example, what happens if there is no extended family members that she can approach to be AB's guardian in the future. The DFS score was 22 out of 30. The higher the scores on DFS, the higher AB's anxiety about the future. During the interview, AB described herself as a person who does not worry much about her future, but after Deby's diagnosis, she started to worry more about Deby's future. "*In fact, now I think a lot more, you know, than I used to. When I'm younger, I don't worry about tomorrow*." AB is also concerned about the "*what if*" scenario for her future as a caregiver and wonders how long she would live. Hence, AB is currently working to earn and save as much as she can if she lives longer than expected.

With the current work-from-home arrangement, AB reported that she usually felt "*tired after work and wants to rest in the evening*", which has generally become their routine, especially since the COVID-19 pandemic. Currently, AB spends less time in one-to-one interactions with Deby and other family members and going on trips, indicating poorer social interaction and relationships than when Deby was in school. During the interview, AB shared that she is generally satisfied with her physical health and finances. However, she wishes to get more help for her mental health, such as a "*safe place for to share my emotions and thoughts without being judged*". The information shared during the interview is consistent with AB's transformed scores on the WHOQOL-BREF. The overall quality of life and satisfaction with her health scores were 3 (neither poor nor good) and consistent over the four time points. AB consistently scored highest on the physical health domain across the time point 1, 2, 3 and 4; the scores were 81, 75, 81, 81 (higher than the general norm mean, 74.9). Then, followed by the scores on the psychological health domains (63, 56, 56 and 56; lower than the general norm mean, 72.5), environment domains scores (56, 56, 50 and 56; lower than the general norm mean, 72.0) and the lowest were social relationship domain scores (56, 56, 44 and 44; lower than the general norm mean, 74.0) across all the four time points (Figure 4.11). The scores were lower for the psychological and social relationship domains in Time 4 compared to Time 1 as it was possible that AB felt increasingly tired after work, and it became a routine that they did not have much out-of-home activity.

Figure 4.11

WHOQOL-BREF for AB



In summary, AB's long-term placement plan was based on caring for Deby in the family home as long as possible and only partially handing over the caregiving responsibility to the extended family members. Hence, she thinks of the adult home as necessary only when she and her husband can no longer supervise. At the same time, she has concerns related to potential abuses in an adult home based on information that AB read and heard and AB's values against the use of restraint. Hence, she hopes that the extended family members can provide the needed supervision to ensure Deby is safe in the adult home. Her decision making related to the out of home placement has been driven by her desires a mother to provide the best possible options for Deby, "*If I can give her a better place, better home, better place to go…"*. Even though there is an increasing trend in the frequency of the challenging behaviour and an increase in the difficulty in meeting her own day-to-day needs (actual demands related to caregiving) during the transition, AB's acceptance and problem-focused coping help her to

mitigate and cope with the current situation. Hence the reported perceived stress level is not congruent to the actual reported caregiving demands. AB consistently shared about "*what if*" scenarios but tries her best to handle the situation by taking action instead of coping emotionally or avoiding them. She concluded that she will do her best as a caregiver to ensure Deby's future is as safe as possible, "*If I can, I will do whatever I can for her future. Because she's my only child.*"

Case Study 5: Explanatory sequential design (Participant CD)

CD is a 57-year-old mother who takes care of her 19-year-old daughter, Cindy, who has been diagnosed with mild intellectual disability and anxiety. CD is a homemaker and currently sells home-based cookies. She lives with her husband, elder daughter, and Cindy. She has a helper who assists with household chores, supervises Cindy, and helps with home baking orders. CD does not have any additional caregiving responsibilities besides taking care of Cindy. The household income is reported to be above $7,501 per month. CD is a Christian and university graduate. She participated in a caregiver group but has not received any financial assistance or used respite care services. Cindy does not have a history of seizure episodes or any physical health concerns. She is the youngest of three children and stays at home, helping with baking and participated in the performance art centre for people with disabilities in Singapore.

Cindy enrolled in a vocational training program for six months after finishing school and the COVID-19-restricted movement period. However, Cindy found it challenging to cope with the training's demands and developed generalized anxiety. CD added, *"[Cindy] fought with the teacher a lot. One is the emotional part is not taken care. Another part is the job itself. It doesn't suit her. So that's how she struggles. Very, very challenging*". As a result, CD decided to withdraw Cindy from the program. After trying two other jobs in the community, it became clear that there was no suitable match between Cindy's skills and the available

jobs. CD also observed that other individuals with ID had a hard time finding suitable work. To overcome the difficulty of finding a suitable placement for Cindy, CD started a home baking business to help Cindy. She developed the home baking structure by considering Cindy's strengths and weaknesses. Initially, CD shared that she used clay and verbal prompts to teach Cindy the necessary baking skills and progressively developed the baking structure. The current baking team was comprised of Cindy, another adolescent with special needs, a neighbour who is an experienced baker, and the domestic helper. They bake to order and were paid based on the profits generated. When asked about why she started the home baking business, CD said, "*I want to help people with special needs like [Cindy]. Like [Cindy] hard to work outside, but they can work. And I believe they can work*".

CD had occasionally thought of placing Cindy for out-of-home placement. CD scored 2 (Occasionally I have given it a thought) in the modified PTI and there were no changes to the response across the four time point. CD was Cindy's primary decision-maker, and her husband usually supports her. During the interview, CD clarified that she initially expected her elder children to provide care for and supervise Cindy. However, due to the changes in the family circumstances, the siblings could no longer care for Cindy. Hence, CD wanting to train Cindy to be as independent as possible and hoped that Cindy can stay with her niece or nephew, "*so the plan is she stay in a family home with family members*". CD further explained that "*we don't know what is the future like, but ultimately is that she's happy with the person and the person accepts her*". CD has not confirmed which niece or nephew to ask for as she did not want to think "*too far*" and or worry too much about the future, "*one day at a time*", even though there was no concrete plan about the future living arrangement. CD scored 2 out of 30 on the DFS. CD's score on DFS is low, indicating that she does not have significant worries about the future. During the interview, CD shared that "*worries will eat up my energy*". When asked specifically about an adult home, CD did not want Cindy to

go to an adult home. CD shared that her perception of an adult home was like a "*nursing home*", and CD was concerned Cindy would be "*bullied*" in the adult home. She believed that Cindy could be independent as possible, so she should be working and not be a "*burden to others*".

When explicitly asked about the change after leaving school, CD shared, "*because school is long hour, now the hour dropped on my shoulder*". There were increased demands, especially when Cindy struggled transitioning to the adult centre. CD shared that she was responsible for teaching Cindy; "*part of the growing and learning all on my shoulder*". Then when Cindy was diagnosed with anxiety, CD had to attend counselling sessions with Cindy. Since CD has been co-regulating and supporting Cindy for past two years, CD shared that Cindy is becoming more manageable. It was reflected in the DBC-P24 that scores were 19, 18, 16 and 14 out of total scores of 48 for Time 1, 2, 3 and 4, respectively. There was likely decreasing trend in the reported challenging behaviour across the two years follow-up (Figure 4.12). The scores on items number 9 (jealous), 10 (kicks, hits other), 17 (stubborn, disobedient, or uncooperative), 18 (says he/she can do things that he/she is not capable of), and 21 (tense, anxious, worried) reduced from score 2 (very true or often true) to 1 (somewhat or sometimes true) across the two years. The frequency of challenging behaviour reduced over the two years possibly due to the intervention received from professionals and CD. CD's perceived burden score on managing Cindy's day-to-day needs was 5 (somewhat feeling stressed) at Time 1. The score reduced to 4 (neither feeling stress nor stress-free) at Time 2 and 3 and further reduced to 2 (mostly feeling stress-free) at Time 4 (Figure 4.13). During the interview, CD further clarified that she reported less perceived stress as she could see improvement in managing Cindy's *"meltdown*" episodes. Even though it can be "*challenging sometimes…"* CD knows the techniques for managing Cindy's "emotional meltdowns", CD feels "*more confident and less stress*".

Figure 4.12

Developmental Behavior Checklist (DBC-P24) for CD

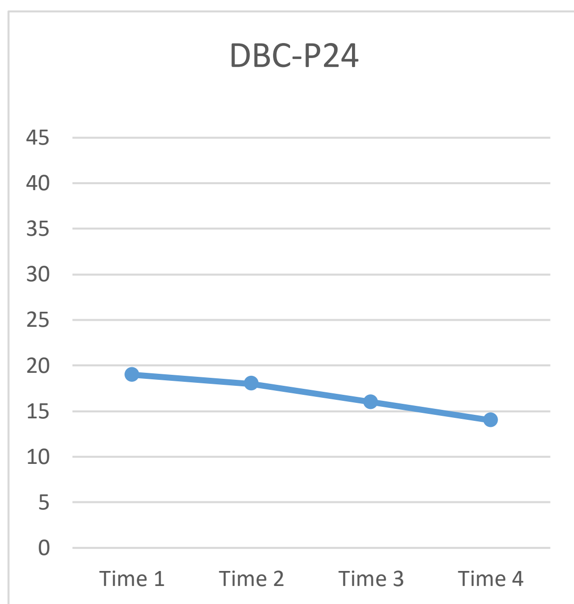
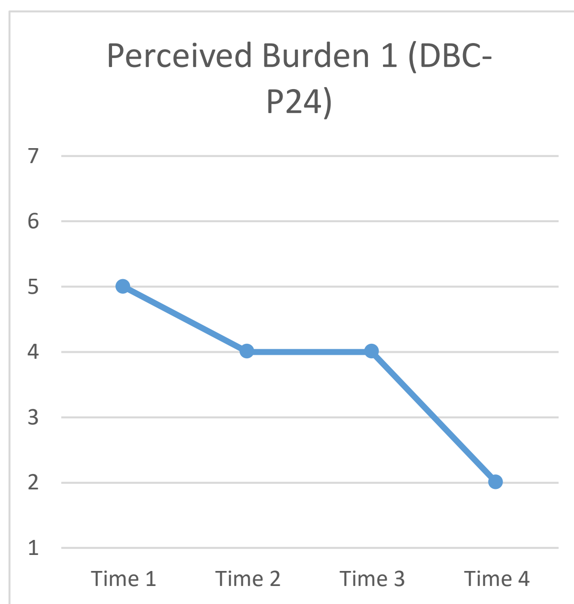


Figure 4.13

Perceived burden 1 (DBC-P24), managing Cindy's behaviour for CD



During the interview, CD shared that she could not spend much time on herself, as she initially prioritised Cindy's routines and needs, stating, "*I have to be there 24/7 too. I give her priority*". For example, she travelled with Cindy to the dance class on public transport (despite having a car), waited till the class ended, and then travelled back home via public transport to teach Cindy how to take public transport. She actively made an effort till Cindy could travel independently to the class. Since Cindy can now travel independently, CD can "*enjoy more me time*". The modified Objective Burden Scale (OBS) scores were 35, 35, 33 and 33 out of 50 for Time 1, 2, 3 and 4, respectively (Figure 4.14). The lower the score, the lower the demands of the caregiving have been affecting CD's day-to-day activities or needs. The trend of the scores was reducing and constant at Time 3 and 4. At Time 4, CD scored 4 (a little less worse) for items number 1 (amount of time you have to yourself), 2 (amount of privacy you have), 5 (amount of energy you have), 6 (amount of time you spend in recreational and/or social activities).

The perceived burden of managing CD's day-to-day needs was 4 (neither feeling stressed nor stress-free) at Time 1 and 2. The perceived burden score reduced to 3 (somewhat feeling stress-free) at Time 3 and 4 (Figure 4.15). Even though CD acknowledge the stress of managing Cindy's challenging behaviour after graduating from school, the perceived stress level in managing her needs remained neutral. The perceived burden score on managing her own needs reduced as Cindy become more independent, CD could ask the domestic helper to supervise Cindy when she needed to have "*me time*". CD emphasised that she needs to "*let go"* of Cindy, even though Cindy needs some supervision at this point. CD perceived Cindy as a "*fighter*", "*if [Cindy] has someone who she trusts, she can turn to, she can cry out, who can guide her, that's enough. You know, she's able to understand a lot of things now. Well, so without me, without me, she will still be good*".

Figure 4.14

Modified Objective Burden Scale (OBS) for CD

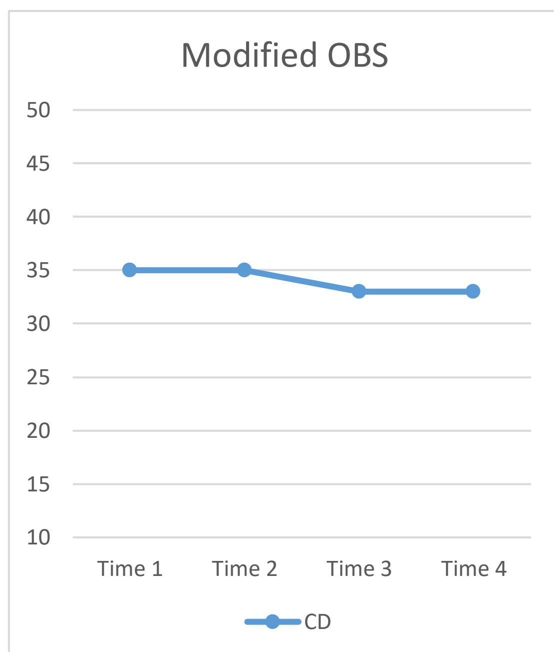
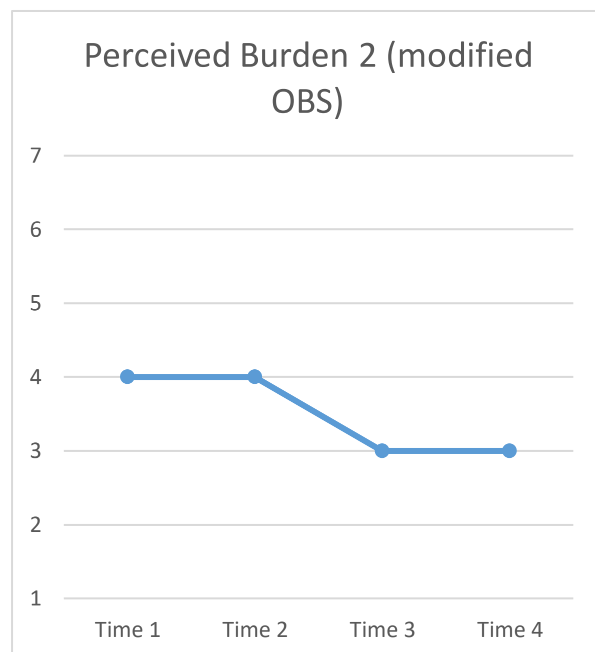


Figure 4.15

Perceived burden 2 (modified OBS), managing CD's day-to-day needs



The QFSSS measures the frequency and satisfaction of the received support. The total frequency of support received was 30, 33, 31 and 30 (lower than the mean frequency of 37.28), while the total satisfaction felt from the support received was 44 (higher than the mean satisfaction of 41.00) across the Time 1, 2, 3 and 4. Specifically, the frequency scores for each support type, such as emotional (support that addresses emotional needs), were 13, 13, 13, and 13; instruments (support that involves the use of tools or resources) were 10, 11, 10 and 10; and information (support that provides knowledge or advice) were 7, 9, 8 and 7, respectively, for Time 1, 2, 3 and 4 (Figure 4.16). Whereas the satisfaction scores for each support type were 14, 14, 14 and 14 for emotional support, instruments support were 17, 17, 17 and 17, and information support were 13, 14, 13 and 13, respectively, for Time 1, 2, 3 and 4 (Figure 4.17). The frequency for each support source for partner (support from a romantic partner), family (support from family members), friends (support from friends), and community (support from the community) were 11, 12, 11 and 11; 9, 10, 9, and 9; 6, 7, 6 and 7 and 4, 4, 4, and 3 respectively for Time 1, 2, 3 and 4 (Figure 4.18). The satisfaction scores for each support source for partner were 11, 12, 11 and 11; family were 12, 12, 12 and 12; friends were 11, 11, 11 and 11; and community were 10, 10, 10 and 10, respectively for Time 1, 2, 3 and 4 (Figure 4.19).

Figure 4.16

QFSSS, frequency for each support type for CD

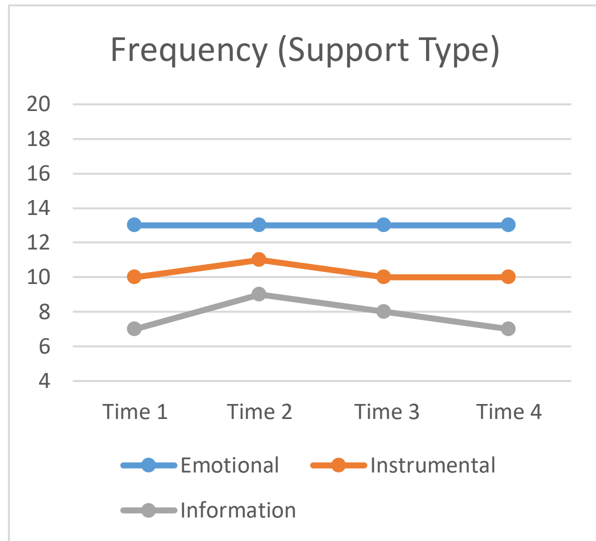


Figure 4.17

QFSSS, satisfaction for each support type for CD

Figure 4.18

QFSSS, frequency for each support source for CD

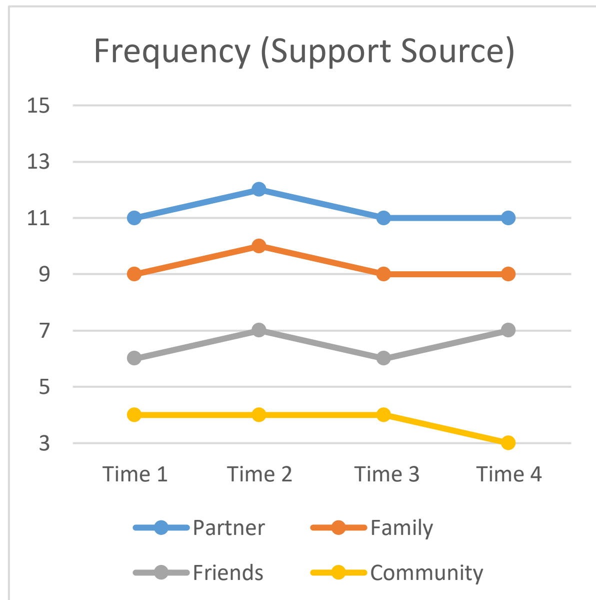
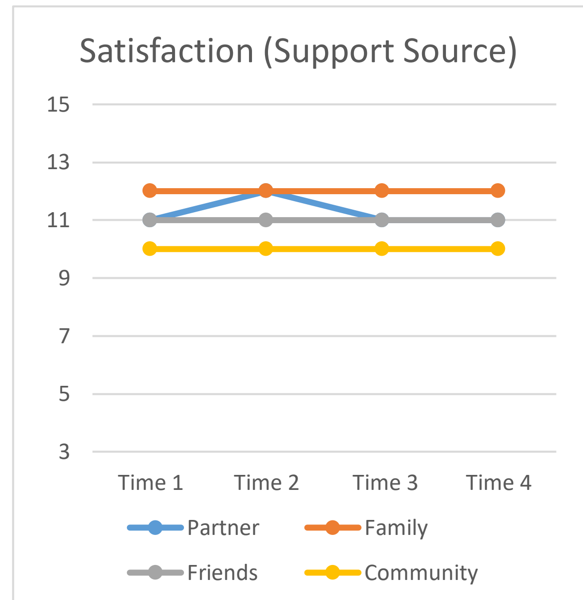


Figure 4.19

QFSSS, frequency for each support source for CD



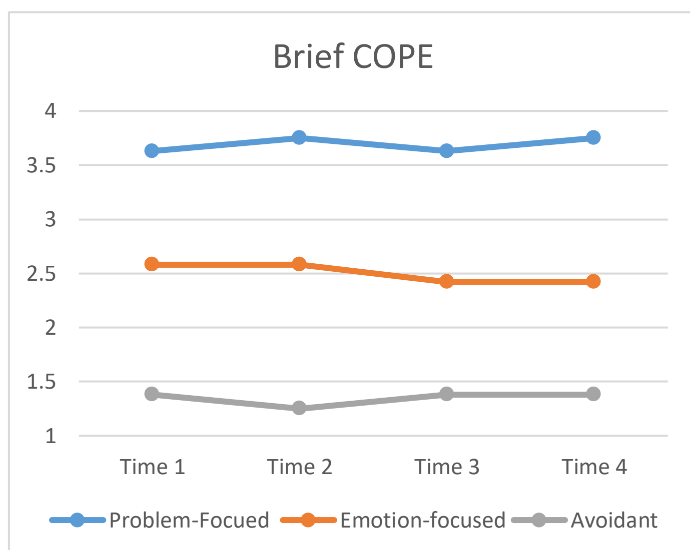
CD's score on the QFSSS reflected that, comparatively, she received a slightly less frequent support than the mean but reported to be more satisfied than the general population mean. Comparatively, she received more frequent emotional, followed by instrumental and information support. However, CD was reported to be most satisfied with instrumental, followed by emotional and information support. She received most support from her husband, followed by her family members, friends and community sources of support. She is most satisfied with the support received from the family, followed by her husband and friends, and was least satisfied with the community support. During the interview, CD consistently shared about the support that she received, especially from her husband and family members. She was adequately supported for her home baking, obtaining instrumental support such as money and baking tools, as well as emotional support from her husband, family and friends. When asked whether she proactively approaches others for support, CD clarified that the family members and the "*people around me join me happily*". CD shared that she is more interested in teaching Cindy and other individuals with ID work skills to sustain employment rather than profit-making. When asked about their financial strength, CD shared that she is "*gifted*" and hence, she had the intention to share her "*blessings*" with others. By teaching and occupying individuals with ID, she hoped to inspire other adolescents with ID to secure some financial contribution to their families and empower other caregivers. She acknowledged the lack of services in the community that were personalised for each individual and, hence, the difficulty of finding the correct fit.

CD's averaged scores for Brief COPE in each domain across Time 1, 2, 3, and 4 were 3.63, 3.75, 3.63, and 3.75; emotion-focused coping was 2.58, 2.58, 2.42, and 2.42; and avoidant coping was 1.38, 1.25, 1.38, and 1.38, respectively (Figure 4.20). The highest score was for problem-focused coping (approximately about 50%), followed by emotion-focused (approximately about 35%) and avoidant coping (approximately about 15%). During the

interview, CD consistently shared that she would generally recognize Cindy's challenging behaviour and try her best to understand and manage the behaviour. Her acceptance of the situation and problem-solving approach has enabled her to mitigate and cope with the challenges of managing the lack of fit for employment and the challenging behaviour due to the anxiety presentation (such as being tense, uncooperative, and self-hitting behaviour). Even though CD reported increased caregiving demands in finding the correct fit for Cindy regarding training and employment, she denied feeling "*very stressful*" or "*helpless*" in managing Cindy's and her needs as a caregiver. CD reported in the interview that she needed to look forward, "*Just do. As long as I'm creative enough, she can do a lot of things and she's still learning*". For instance, CD has been using innovative methods to help Cindy learn new skills, such as the use of clay in teaching kneading, using essential oils to calm Cindy and attending caregiver workshops to understand Cindy's abilities and needs. She did also actively cope with the "*hope*" and "*religion*" factor. She believed that she was being guided by her religious belief in her journey as a caregiver.

Figure 4.20

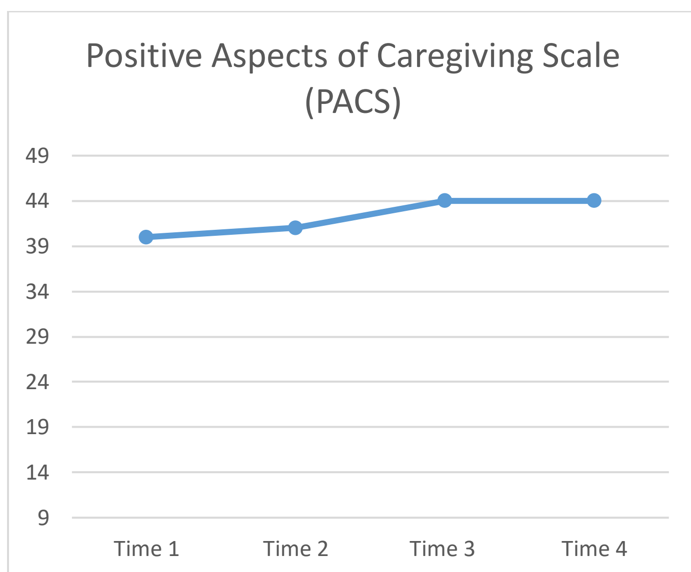
Brief COPE for CD



The total score on the BRS was 24 (the average with six items was 4). Based on the BRS score interpretation, CD falls within the category of normal resilience. Furthermore, there were consistently high scores on the PACS across the two years. The total scores for the PACS were 40, 41, 44, and 44 out of 45 for Time 1, 2, 3, and 4, respectively (Figure 4.21). All the scores across the time point were higher than the female mean score of 33.5. CD consistently scored high on PACS, indicating that caregiving had given her a positive experience, even when there were challenges during the initial stage of the transition. CD clarified that her role as a caregiver was rewarding and "*very meaningful when you see them [individual with ID] moving forward*". However, the difference in the PACS score at Time 1 and 4 were not reliable, RCI = -.95, lesser than 1.96.

Figure 4.21

Positive Aspects of Caregiving Scale (PACS) for CD

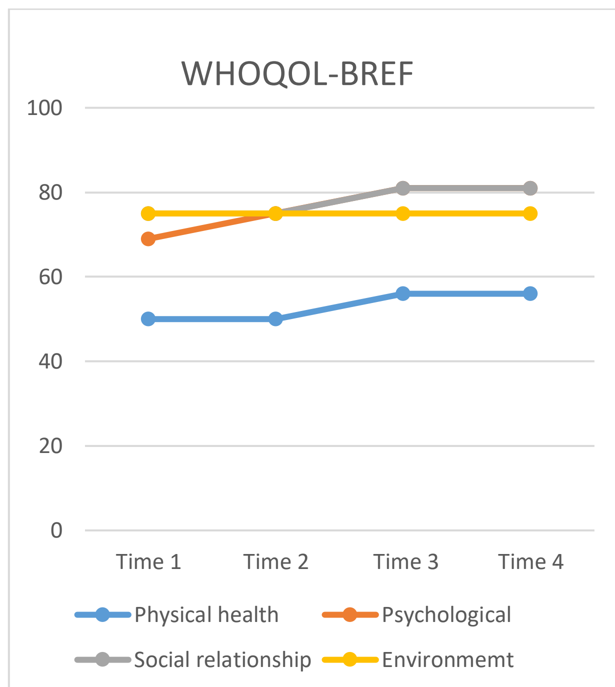


CD's quality of life was assessed using WHOQOL-BREF to understand the impact of being a caregiver for an adolescent transitioning to adult placement. The scores on the overall quality of life were 4 (good) at Time 1 and 2 and increased to 5 (very good) at Time 3 and 4. The overall satisfaction with her health scores was 3 (neither satisfied nor dissatisfied)

across all the time point. CD's transformed scores on the WHOQOL-BREF for physical health domain were 50, 50, 56, 56 (lower than the general norm mean, 74.9); psychological were 69, 75, 81 and 81 (generally similar and higher than the general norm mean, 72.5); social relationship was 75, 75, 81 and 81 (generally similar and higher than the general norm mean, 74.0) and environment were 75 across all time point respectively (generally higher than the general norm mean, 72.0), across the time point 1, 2, 3 and 4 (Figure 4.22). An increasing trend indicated a better quality of life across the two years, specifically in physical health, psychological and social relationships. When clarified during the interview, CD shared that she has existing concerns related to her thyroid and hypertension, but she is actively managing them, emphasising the importance of "*self-care*". She added, "*I'm happy. Now I have to keep myself fit, healthy*".

Figure 4.22

WHOQOL-BREF for CD



To summarize, CD plans to continue caring for Cindy in their family home, but she still needs to work out the details. CD has relied on religious coping to maintain hope, which has helped her to be proactive during this transition. CD believes in training Cindy as much as possible to maximize her independence and she does not want Cindy to become a burden to others. Although it was initially challenging, Cindy's participation in home baking and performance art has helped her feel grounded and to better manage her anxiety and "*meltdowns*”. CD described her journey as a caregiver as "*very rewarding*," and she looks forward to Cindy's improved independence. CD’s financial strength, drive to help other individuals with ID, and the support she received from the extended network were essential factors in her journey as a caregiver. Cindy further shared, “*This is my golden period. So now I'm 57 this year. So, I said, I give myself 20 years to train [Cindy].*” The overall impression from the information obtained during this case study was that more than Cindy’s difficulty during the change of service from school to work environment, CD views herself as a caregiver who is responsible for providing the guidance for Cindy. CD provided skills teaching appropriately to maximize Cindy’s independence, and proactively coped during the initial period of transition, which would possibly lead to a “successful” transition.

Summary and Possible Explanation of Findings

This chapter reported the results from a longitudinal investigation of five family caregivers of adolescents with ID. Follow ups occurred for at least the first year, and up to two years, following the adolescent leaving the schooling system. The PTI (adaptation outcome), perceived burden 1 and 2 and WHOQOL-BREF (stress response) of the primary family caregivers caring for adolescents with ID over the one or two years of follow-up mostly remained consistent. Although there was no significant change for the PTI, WHOQOL-BREF and perceived burden scores, this discussion focuses on identifying the

score trends between the stressors (DBC-P24 and OBS), factors affecting the protective factors (QFSSS, Brief COPE, PACS, BRS and DFS), stress response (perceived burden 1 and 2, WHOQOL-BREF) with the adaptation outcome (PTI).

There was an upward trend of DBC-P24 scores for all individuals with ID except for CD's daughter. The reliability change in the prevalence of the challenging behavior was not calculated due to a lack of information to calculate the SE. During the interview, AB and CD clarified that their child’s behaviour undoubtedly changed. They felt the need to shoulder the responsibility of managing their adolescent's needs at home without support from the school. The possible increase in challenging behaviours, could be related to the lack of social movement and engagement in adult services due to COVID-19 (Courtenay & Perera, 2020).

The changes in the trends of the DBC-P24 (prevalence of the challenging behaviour) scores may relate to similar changes in the perceived burden 1 score (managing the needs of individuals with ID) trends. This association, however, is not straightforward. For example, as the participant's Y, AB and CD scores on the DBC-P24 changed across the time points, the perceived burden 1 score did change accordingly, but not for participants X and Z (the perceived burden 1 score remained consistent). The lack of change in the perceived feeling in managing the adolescent with ID needs could be explained by the change in the prevalence and intensity of the challenging behaviours across the time point, which may need to be significant enough to initiate movement in the perceived burden. Alternatively, the buffering factor, such as the tolerance for challenging behaviour may differ for each caregiver, leading to different responses to the perceived feeling in managing the adolescent with ID needs despite the increase in the prevalence of challenging behaviours. Generally, the increase in the caregiving demands during the transition was associated with adolescents’ psychosexual needs (Biswas et al., 2017) and physically bigger and stronger than the caregivers, where the caregivers reported having difficulty managing the behaviour (Hubert, 2011). The tolerance

for the challenging behaviour could be that the caregivers are being overprotective of their child with ID (Hubert, 2011) and interpreting the challenging behaviours as an inability to communicate (Griffith & Hastings, 2014).

Similarly, there were changes in the OBS (higher or lower scores indicating more or less changes in caregivers' day-to-day routine tasks due to caregiving needs) score across the time points for participants Y, AB and CD. Interestingly, the OBS and the perceived burden 1 score for participants X and Z remained consistent despite the increase in the prevalence of the challenging behaviours. There were three combinations of the OBS score with the association of perceived burden 2 scores (managing own day-to-day needs), changes in OBS score (less or more impact on their day-to-day needs), changes in perceived burden 2 scores (feeling more or less stress); Increase in OBS score (more impact), but no change in perceived burden 2 scores (no changes to the perceived feeling) and OBS and perceived burden 2 scores remained the same across the time points (same demand and perceived feeling). These were no combination of scores with negative association (increased OBS but decreased perceived burden 2 scores). The possible explanation for the different patterns on the extent of change in the caregiver's day-to-day task and the perceived feeling in managing their day-to-day needs may be similar to DBC-P24 and perceived burden 1.

The potential impact on the well-being of caregivers may be due to the extent of change in caregiving demands and perceived feelings that affect their day-to-day routine, considering that the perceived feeling in managing the needs of adolescents with ID and the protective factors could influence the adaptation process. Similarly, even though there were more caregiving hours spent for individuals with ID during the transition (Gur et al., 2020) and financial burden (Ellman et al., 2020), there were mixed reports that not all caregivers needed to quit their jobs due to the caregiving duty during the transition (Roos et al., 2020; Gur et al., 2020). In addition, Griffith et al. (2014) emphasised the interlinked "love and

strain relationship", balancing the strain from caregiving to providing excellent and loving care for their child daily.

Although there was no significant change to the WHOQOL-BREF domain scores across the time points for all five participants, the possible association with the DBC-P24, OBS, and perceived burden scores 1 and 2 were visually compared. Participant Z and CD, for instance, scored 4 (good) and 5 (very good) on the overall quality of life score at Time 4. They associated with lower OBS (fewer changes in the day-to-day routine tasks due to caregiving) and PTI score 2 (Occasionally, I have given it a thought) compared to other participants. Therefore, the trend of scores may show that fewer changes in the day-to-day activities due to caregiving may be associated with a higher quality of life and a lower tendency for the caregivers to think about the out-of-home placement and vice versa, even though there were no significant overall changes of WHOQOL-BREF domain scores.

There were no differences in the scores across Time 1 and 2 or 4 for participants X, Y, Z, and AB (for the physical health domain) and X, Y, AB and CD (for the environment domain). Regarding the physical health domain, participant AB scored the highest and CD the lowest at Time 4. Based on the qualitative interview, AB shared that she was satisfied with her health and had not been diagnosed with any chronic disease. In contrast, CD reported the need for medical follow-up due to thyroid and hypertension. Hence, the changes in the prevalence of the challenging behaviour, the extent of changes in the caregiver's day-to-day needs and perceived feelings in managing the caregiving demands may not affect the caregiver's physical health and vice versa in this study. The lack of impact on physical health could be that the stressors have not been significantly present long enough to manifest into psychosomatic symptoms. AB and CD could delegate their caregiving duty to the helper or other family members. Hence, support may act as a buffering factor (Codd et al., 2021; Hubert, 2011; Gur et al., 2020).

In regards to the environmental domain, participants Z and CD scored the highest, while AB and X scored the lowest. The environmental domain may associate with the PTI score. Participants Z and CD scored 2 (Occasionally, I have given it a thought), while AB and X scored 3 (Yes, I have thought about it a lot, but have done nothing) and 4 (I have thought of it and enquired but have not done anything yet) respectively. Based on the qualitative interview, household finances would be a strength for the caregiver as they would have more time, resources, and mental space to engage with the adolescent with ID, and they would not be occupied with their work for survival (Ellman et al., 2020; Gur et al., 2020). Emerson et al. (2008) proposed that the minimization of poverty was the least researched but one of the essential themes in the social contexts model in terms of support, which could be part of the practical type of support.

Further, there were changes in the psychological domain scores for three participants (Y, AB and CD), while two participants' (X and Z) scores remained the same across the time points. The change in scores for participants Y, AB and CD on the psychological domain was negatively associated with DBC-P24, OBS, and perceived burden 1 and 2 scores. At the same time, participants X and Z had no change in the psychological domain scores, OBS and perceived burden 1 and 2 across the time points. Therefore, some caregivers may have felt that life is less satisfying and meaningful because of the increase in the prevalence of challenging behaviour, difficulty in managing their own needs due to caregiving needs and higher perceived stress in managing adolescents with ID and their needs and vice versa.

Participants Z and CD indicated increased scores across the timepoints regarding the social domain and generally similar to the general norm mean at Time 4. Participant Z and CD’s scores may indicate that these participants were generally satisfied with the social support in terms of personal relationships, social support and sexual activities. Caregivers who were satisfied with their social resources scored the same or lower on the perceived

burden 1 and 2 (feeling the same and lesser stress in managing the caregiving demands) and lower on the PTI (2; Occasionally, I have given a thought) across the time points, despite the changes in DBC-P24 scores (prevalence of challenging behaviour). Conversely, participants X, Y and AB, who scored lower than the general norm mean on the social domain (less satisfied), scored higher on the PTI (3 and 4). Hence, social satisfaction could be a possible indicator that influences the out-of-home placement decision, similar to the findings highlighted based on the qualitative data in this study.

The PTI score at Time 1 differed but remained consistent for each participant over one or two years. The PTI scores at Time 1 were crucial in this discussion as the scores may indicate the caregiver's initial perception or direction of the future placement of the individual with ID after graduating from the special school. Two participants reported a PTI score of 2 and 4 respectively, and one reported a score of 3. No pattern was associated with the DBC-P24, OBS and perceived burden scores when visually analysed with the PTI scores at Time 1, as participants who reported similar perceived burdens (participants X and Z) reported different PTI scores of 2 and 4. The different PTI scores at Time 1 could be due to multiple factors besides the influence of adaptation during the transition to adulthood. There is no published study yet that analyses the factors on why caregivers initiate placement except for crisis-driven placement. Grey et al. (2020) highlighted that the proactive coping style acts as a buffer to the caregiver adaptation and placement decision, and an individual with ID living independently was still an aspiration in the United Kingdom.

AB scored 3 (Yes, I have thought about it a lot but have done nothing) in relation to placing her daughter, Deby, out of the family home. Deby has been diagnosed with moderate ID comorbid with ASD, which predisposes Deby to the need for ongoing support, and AB reported that Deby is vulnerable. AB did not want to burden her extended family member but

hoped that one of them could supervise Deby in the residential home when AB and her husband could no longer care for their child in the family home.

In comparison, CD scored 2 (Occasionally, I have given it a thought) in relation to placing her daughter, Cindy, out of the family home. Cindy has been diagnosed with mild ID comorbid with anxiety. CD believes that Cindy can learn more skills to maximise her independence and was geared towards empowering Cindy. CD hoped that Cindy would continue to live in the family home under the supervision of CD's niece or nephew. Hence, the PTI score may not be a definitive indicator of the adolescent's placement tendencies but rather a reflection of the caregiver's current thoughts and feelings, possibly based on the functional ability of the adolescent with ID. So, the placement tendency index can be “fluid” based on the severity level of ID, the intensity and frequency of any prolonged challenging behaviours and vulnerability risk, as well as the participant’s perceived ability of the adolescent with ID to be independent, participant’s availability to provide the care, values related to caregiving, hope or fear and current resources for social support. Therefore, a significant increase in the stressors with the same or reduced social support would only cause a shift in the PTI score. AB and CD had no current plan to move their daughters out of home, but they were both already planning for the time when they could not take care of their child due to their own age, health or death. Besides that, two-year follow-ups of adolescents aged 19 to 21 may not capture the sensitive period of the PTI score movement in Singapore. Grey et al. (2020) conducted a one-year follow-up study with 30 families of individuals with ID ages ranging from 18 to 67 years, where changes in the PTI were reported. Therefore, the out-of-home placement tendency index can be a gradual process (occurs later) or “crisis” driven for some individuals with ID.

Protective Factors

Notably, there were associations between social support satisfaction and the caregiver’s perceived burden, quality of life, and decision-making regarding out-of-home placement. Interestingly, no association was found between the frequency and satisfaction of the social support received, assessed via the QFSSS. Participants Z, AB, and CD expressed general satisfaction (similar to the general mean score) with their social support and reported lower PTI (2 and 3) compared to participants X and Y. However, there were no observed trend scores in terms of support type and source between participants Z, AB, and CD. This could be due to the low number of participants and more variables in QFSSS (three supports types for all four support sources).

Related to coping mechanisms (Brief COPE), each participant's experience was unique. All reported the highest scores on the problem-focused coping domain, followed by emotion-focused and avoidant coping domains, but at varying degrees. This individuality was evident in the total mean scores, which differed for each participant. There was no discernible pattern associated with the coping domains. However, participants Y, Z, and CD shared approximately similar scores on all domains, except for participant Z. Participants Y and CD scored slightly lower on the avoidant domains, higher on the overall quality of life, and lower on PTI and DFS compared to participant Z. This suggests that participants who have less fear of the future likely engaged with less avoidant coping (physical and mental disengagement) and vice versa. Similarly, Biswas et al. (2017) highlighted that those caregivers who avoided considering their expectations of their adolescents with ID, did so to use the avoidance as a coping mechanism to manage their worries about the future. Griffith et al. (2014) highlighted a theme of “low expectation and high hope”, indicating that the caregiver of an individual with ID reported fear and uncertainty about the individual’s future, hence having high hope

(faith/belief) that the individual with ID would be taken care of, as per the caregiver's expectation, but not expecting for it to take place.

The PACS scores assessed the perceived satisfaction and reward of caregiving. Generally, all the participants scored higher than the mean score, indicating a positive perception of caregiving, except for participant AB, who scored slightly lower than the mean score. However, no association was observed with other measures, except for the scores related to problem-focused Brief COPE, which may indicate that a lower sense of satisfaction and reward gained from caregiving could be associated with lower problem-focused coping behaviours such as lack of initiative for planning, positive outlook, and informational support. Rapanaro et al. (2008) and Gillan et al. (2010) shared possible themes, such as the benefit for the caregivers in being more assertive and able to proactively seek the needed support during the transition. Higher sense of satisfaction and positive adjustment may relate to the items scored in PACS and problem-focused Brief COPE. However, no study found an association between both variables.

Overall, the findings of this study underscore the complex nature of caregiving. As Ellman et al. (2020) suggest, fluctuating caregiving demands can lead to mixed feelings. The participants in this study reported a range of scores for stressors and quality of life, indicating the expected nature of caregiving. The positive aspects of caregiving, such as the moments of fulfilment, pride, gratitude, and growth, could be a part of the caregiver's journey. However, the significance of the influence of these small perceived moments on the overall quality of life would be questionable. Participant CD's experience, for instance, was an extreme example as Cindy's improvement (in other words, prolonged and sustainable improvement) in the home baking program motivated CD to the extent of wanting to form a baking program for other adolescents with ID and the caregiver. It may not be able to be generalised to most

other caregivers as CD’s financial and extended social network strength as well as her individual personality may not be the norm presentation.

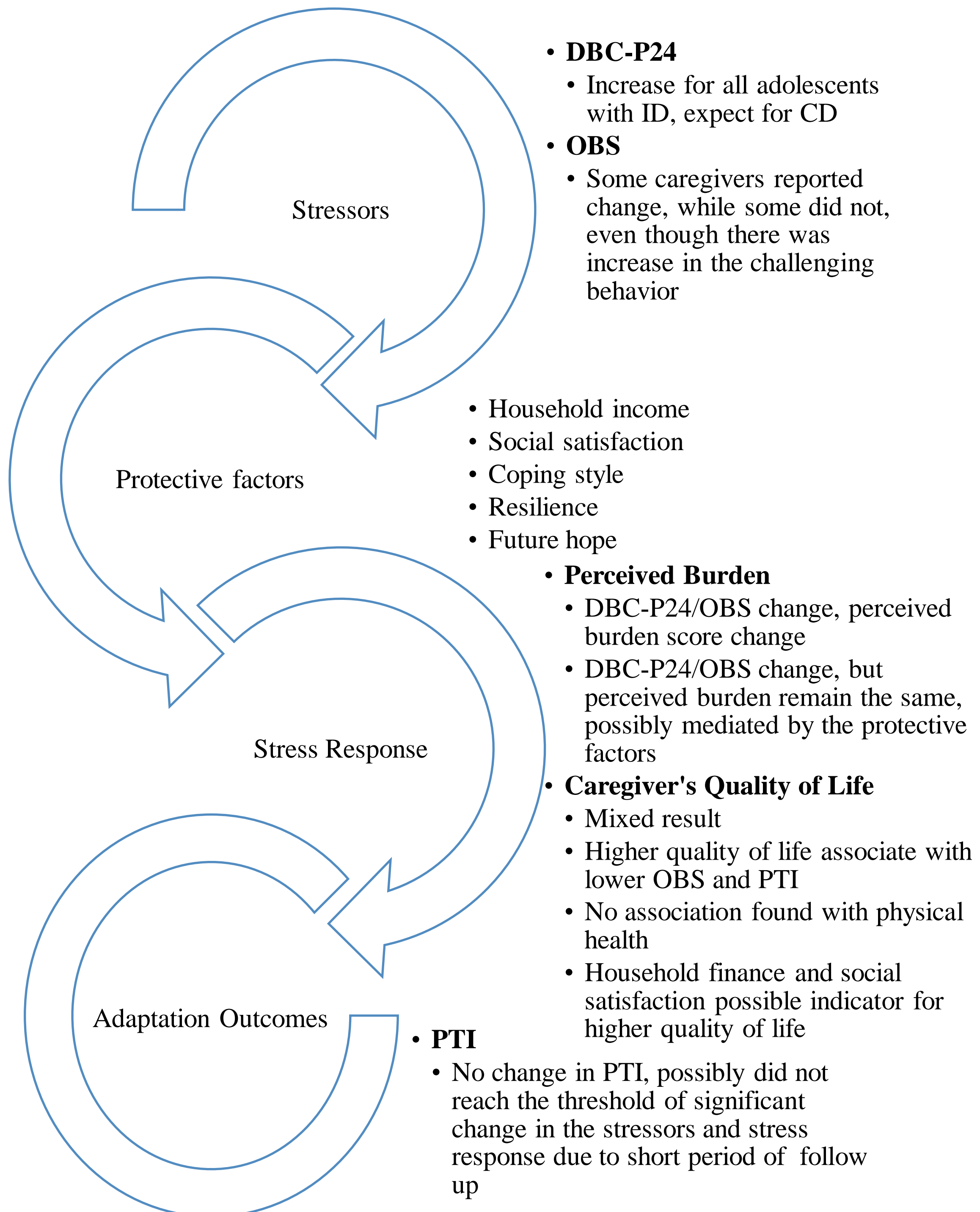
In conclusion, the influence of stressors and protective factors on decision-making and placement tendency is complex. The difference between the actual demand imposed due to the caregiving duty (stressors) with the perceived feeling in managing those demands (stress response) and subsequently the influence on the placement tendency decision-making (adaptation outcome) due to the protective factors was probably justified by Lazarus and Folkman's (1984) TMSC (Figure 4.23). The stressors, such as the increase in the intensity and frequency of the challenging behaviour (adolescent with ID), may associate with the higher extent of changes in the caregiver's day-to-day task, and subsequently lead to higher perceived burden in managing the adolescent with ID and caregiver's needs, lower quality of life (life is less satisfying and meaningful) and vice versa. However, the presence of protective factors, such as higher social satisfaction, higher household income, low mental or physical disengagement (avoidant) behaviour, and less future anxiety (more hope than fear), could mitigate the influence of the stressors on the stress response, offering the potential for positive outcomes. The lack of change in the adaptation outcomes in this study can be explained by the fact that the extent of the stressors or the stress response was not significantly high enough for the caregivers to move from the thoughts about the out-of-home placement to initiate the application for the adult disability home services.

Furthermore, based on the analysis of the qualitative data, it was shown that the decision-making for the out-of-home placement can be "fluid", a concept that acknowledges the dynamic and ever-changing nature of caregiving. This fluidity is probably based on the severity level of ID, the intensity and frequency of any prolonged challenging behaviours and vulnerability risk, as well as the caregiver's perceived understanding of the level of supervision needed, the caregiver's ability to care for their child, values related to caregiving,

"hope or fear" and their resources for social support at that point of time. Some of these variables were not assessed via the questionnaire (but gained from the interpretation of the qualitative interview), such as the vulnerability risk, caregiver's perceived understanding of the level of supervision needed, caregiver's ability to care for their child and values related to caregiving.

Figure 4.23

Adapted Lazarus & Folkman's 1984 Transactional Model of Stress and Coping (TMSC) for caregivers caring for adolescents with ID.



Since there is an overall increase in the reported challenging behaviour across the two years and the caregiver's perceived understanding and values probably affect the adaptation outcome, the same measures and procedures were repeated to understand caregivers' current perspectives in caring for an adult with ID in the clinical setting (Study 2; Chapter 5). This population of caregivers has been living in the community and receiving psychiatric treatment for their family members who are adults diagnosed with ID. Hence, for study 2 the majority of adult with ID have concerns related to their mental health, behaviours and activities of daily living activity (ability to care for the day-to-day task). This may heighten the probability of out-of-home placement (Murphy et al., 2005; McIntyre et al., 2002; Blacher et al., 1992; Bromley & Blacher,1991).

Chapter 5

Family Caregiver Perspectives on Caring for Adults with Intellectual Disability in Singapore

This study aimed to understand the factors related to the family caregivers' current stances or perspectives on the placement decision for managing adults with ID who are receiving treatment from a specialised mental health service, the Institute of Mental Health (IMH). A scoping review conducted by Tilley et al. (2022) aimed to understand the health, service frequency and resources to care for adults with ID (over 40 years old) and possible barriers to support a successful transition to other care settings in the United Kingdom. Based on the nine sources that were reviewed, the themes were the need to understand the adults with ID needs, promoting independence as much as possible (in terms of social skills), enhancing health and social care needs, the importance of training the care staff, resources to manage behaviours that can be challenging to others, and the absence of the resources that aid with the transition when needed. This review emphasised the importance of planning for managing an adult with ID care such as social resources to aid a successful transition compared to an unplanned or crisis-based transition.

Kandel and Merrick (2005) aimed to study the factors that affect the placement decision (family home versus out-of-home) with a sample population of 50 parents with a child with ID (severe range of ID) and 48 parents of adults with ID working in the sheltered workshop in Israel. Both groups of parents filled in a questionnaire with 21 items of possible factors that affect the decision-making in deciding to keep the child in the family home. The parents ranked each factor based on the Likert scale 1 (*very intense influence*) to 5 (*no influence*). The results of this pilot study reported that the factors that prevented the parents from sending their young or adult child for out-of-home placement are feelings of guilt,

family attitude, and support. Factors such as their child's support resources, functional level, and age were assessed to have lesser influence than the parents' guilt and attitude (values).

While there were mixed reports, specifically on the social resources and placement tendency for adults with ID, a significant research gap remains. To the best of the author's knowledge, only one study (Grey et al., 2020) has examined the placement decision for adults with ID, tracking a one-year period using PTI. Other studies with PTI have primarily focused on children and adolescents (Blacher & Hanneman, 1993; Perry & Black, 1997; Llewellyn et al., 2001; Llewellyn et al., 2005). This gap underscores the need for further research in this area to better understand and support caregivers caring for adults with ID.

To date, it is still unclear whether the results from the caregivers of children with ID can be generalised to the adult population. It can be argued that the caregivers have consciously decided to care for their child diagnosed with ID since birth rather than initiating out-of-home placement, compared to caregivers who decided to place the child out of the family home since they were young. In other words, it is possible to assume that the caregivers who decided to continue the care for their child with ID invested their effort and time to continue caring for the child with ID until adulthood.

Given the ongoing uncertainty about the factors influencing placement decisions for adults with ID, this study hypothesises that caregivers' stressors, protective factors such as coping strategies (Grey et al., 2020), and caregivers' perceived stress levels may influence the placement outcome ranking, assessed via the PTI. Based on Lazarus and Folkman's (1984) TMSC, this hypothesis suggests that the placement decision is the adaptation outcome. If proven, these implications could significantly impact the understanding and management of caregiver adaptation to care for an adult with ID in their family home.

Participants

A total of 98 primary caregivers were approached over a year, March 2023 to April 2024. However, only 41 (42%) caregivers agreed to participate and completed the measures. The reasons for declining the invitation to participate were as follows: Primary caregivers were not interested in joining due to the needed time commitment of an hour (n = 34), agreed to participate but did not attend the face-to-face or online interview despite two follow-ups (n = 15) and not interested as the primary caregivers had filled up such questionnaires in the school settings and there was no follow up from the survey conducted (n = 8).

The demographic information of the participants is presented in Table 5.1. The caregivers' average age was 58.9 years (SD = 5.42, range = 46 – 72 years). The average number of years of caregiving was 24.07 years (SD = 6.83, range = 2 – 41 years). Out of the 41 participants, five (12%) were males and 36 (88%) were females. There were 5 (12%) fathers, 35 (85%) mothers, and one (3%) sister. Thirty (73%) participants were Chinese, five (12%) were Indians, four (10%) were Malays, and two (5%) were other ethnicities. Thirteen (32%) participants identified themselves as Christian, 12 (30%) as Buddhist, five (12%) as Muslim, four (10%) as Taoist, three as Hindus and three as no religion (n = 3, 7%) and one as others (2%). Twenty-seven (66%) participants were married, nine (22%) were divorced, and five (12%) were widows. There were two (5%) participants with the highest education qualification below secondary school, followed by 16 (39%) participants with secondary school qualification, nine (22%) participants with post-secondary (non-tertiary), ten (24%) participants with a diploma and professional qualification, and four (10%) with a university qualification. Thirteen (32%) participants were homemakers, six participants (15%) were either retired or had full-time employment (office hours), five (12%) participants either had full-time employment (non-office hours/shift rotation) or were unemployed, three (7%) participants were self-employed, two (5%) participants were part-time employer, and one

(2%) participant was on no pay leave. Twelve (30%) participants reported household income per month below $2 500, three (8%) participants within the range of $2 500 to $3 500, four (10%) participants within the range of $3 501 to $4 500, nine (22%) participants with the range of $4 501 to $7 500, and twelve (30%) participants above $7 501. Nine (22%) participants lived only with the individuals with ID and no other family members, and the other 32 (78%) participants lived with family members (spouse, daughter, son, parents or parents-in-law). Nine (22%) participants had additional caregiving responsibility, while 32 (78%) did not have any additional caregiving responsibility. Thirteen (32%) participants had domestic helpers, while 28 (68%) did not have domestic helpers.

Table 5.1

Demographic information of participants

Participant		
Demographic	Mean	SD
Age	58.8	5.4
Years of caregiving	24	6.8
	n	%
Gender		
Male	5	12
Female	36	88
Caregiver relationship		
Father	5	12
Mother	35	85
Sister	1	3
Religion		
Chinese	30	73
Indian	5	12
Malay	4	10
Other	2	5
Ethnicity		
Christian	13	32
Buddhist	12	30
Muslim	5	12
Taoist	4	10
Hindu	3	7
No religion	3	7
Other	1	2
Marital Status		
Married	27	66
Divorced	9	22
Widow	5	12
Highest education		
Below secondary school	2	5
Secondary school	16	39

Post secondary (non-tertiary)	9	22
Diploma and professional	10	24
University	4	10
Employment		
Homemaker	13	32
Retired	6	15
Full time employment	6	15
Full-time employment (non-office hours/shift rotation)	5	12
Unemployed	5	12
Self-employment	3	7
Part-time employment	2	5
Other (no pay leave)	1	2
Household income per month		
Below $2 500	12	30
$2 500 to $ 3 500	3	8
$3 501 to $4 500	4	10
$4 501 to $ 7 500	9	22
Above $7 500	12	30
Living arrangement		
Only participant and individual with ID	9	22
Living with other family members	32	78
Additional caregiving responsibility		
Yes	9	22
No	32	78
Domestic helper		
Yes	13	32
No	28	68

Note. Forty participants reported the household income per month instead of 41, hence the valid percentage was presented in this table.

The demographic information of the adults with ID is presented in Table 5.2. The mean age of the adults with ID who were under the care of the participants was 26.2 years (*SD* = 5.2, range = 20 – 47 years). There were 28 (68%) males and 13 (32%) females. Of the 41 adults with ID, 25 (61%) had activity engagement in the adult services, ten (24%) were

not engaged with any adult service, three (7%) were on the waiting list for the placement, two (6%) were either in the supported and open employment, and one (2%) was studying in polytechnic. There were 15 (37%) adults diagnosed with ID, 13 (32%) adults diagnosed with ID and ASD, four (10%) adults diagnosed with ID and ADHD and nine (21%) adults with multiple or other mental illnesses. Five (12%) adults with ID had epilepsy, while 36 (88%) adults with ID did not have epilepsy. Three (7%) adults were reported to have visual impairment, mild spasticity in limbs, Carpal Tunnel Syndrome and Ezcema, while 38 (93%) adults with ID were reported not to have any physical health diagnosis.

Table 5.2

Demographic information of adults with ID

Adults with ID		
	Mean	SD
Age	26.2	5.2
	n	%
Gender		
Male	28	68
Female	13	32
Engagement		
Engaged in activity centre	25	61
Not engaged with any service provider	10	24
On waiting list to engage with adult services	3	7
Open or supported employment	2	6
Studying	1	2
Diagnosis		
ID	15	37
ID and ASD	13	32
ID and ADHD	4	10
Multiple and other mental illness	9	21
Epilepsy		
Yes	5	12
No	36	88
Physical Health diagnosis		
Yes	3	7
No	38	93

Note. ID = intellectual disability; ASD = autism spectrum disorder; ADHD = attention deficit hyperactive disorder.

Measures and Procedure

The self-report measures administered, and procedures followed were as described in Chapter 3.

Data Analysis

The data were analysed using IBM SPSS Statistic software (Version 29). This study's findings were reported in terms of the frequency of the scores for measures such as the DBC-P24, OBS, Brief COPE, PACS, Perceived Burden 1 and 2, WHOQOL-BREF scores for overall quality of life and health satisfaction, and PTI.

In addition, an independent *t*-test of this sample's means against the normative means was calculated using an online calculator (https://epitools.ausvet.com.au/twosamplettest). The measures with normative means that were compared in this study were BRS, DFS, DBC-P24, QFSSS, Brief COPE, PACS, and WHOQOL-BREF. The OBS was modified with the addition of an item in this study.

The statistical assumptions for the correlation (Pearson's r) were assessed. Regarding the assumption related to independence, this assumption was by the methodological procedure of having the participants participate once and their responses did not influence others. Edgell and Noon (1984) suggested that the correlation test is robust, given that the measures were independent. As this study was based on a clinical population, the violation of normality was considered and the outliers were not omitted. The outliers are required and it is valid information for comparison and interpretation with the general population. With respect to the central limit theorem, the distribution of the mean for a sample size larger than 30 satisfies the normality assumption (Kwak & Park, 2019; Kwak & Kim, 2017). The sample size of this study was 41 (> 30); hence, the normality of each measure was not assessed. The presence of a helper (yes or no) and household income (coded as below $4,500 and above $4,501) were categorised into two groups to run the correlation analysis. For statistically significant ($p < .05$) correlations, the strength of the correlation is reported following Cohen's (1988) guidelines of small ($r_s = 0.10$ to 0.29), medium ($r_s = 0.30$ to 0.49), and large ($r_s = 0.50$

to 1.0). Finally, a multiple regression analysis was reported for the five independent variables that met criteria for inclusion (i.e., $p < .05$ or $r > 0.30$) with the dependent variable (the PTI).

Results

Frequencies of Responses

Developmental Behaviour Checklist (DBC-P24). The DBC-P24 scores, assessing the frequency of challenging behaviours of adults with ID for the past six months are presented in Table 5.3. The responses scale for this measure was: 0 (*not true as far as I know*), 1 (*somewhat or sometimes true*), or 2 (*very true or often true*).

The frequency of the scores for item 1 (Becomes excited) was 0 n = 11 (27%), 1 n = 23 (56%), and 2 n = 7 (17%). The frequency of the score for item 2 (Chews or mouths objects or body parts), was 0 n = 23 (56%), 1 n = 9 (22%) and 2 n = 9 (22%). The frequency of the scores for item 3 (Confuses the use of pronouns) was 0 n = 23 (56%), 1 n = 5 (12%), and 2 n = 13 (32%). The frequency of the score for item number 6 (Has nightmares, night terrors, or walks in sleep), score 0 n = 31 (76%), 1 n = 8 (19%), and 2 n = 2 (5%). The frequency of the score for item number 8 (Inappropriate sexual activity with another), score 0 n = 29 (71%), 1 n = 9 (22%), and 2 n = 3 (7%). The frequency of the score for item number 13 (Refuses to go to school, activity centre, or workplace), score 0 n = 21 (51%); score 1 was n = 12 (29%) and score 2 were n = 8 (20%). The frequency of the score for item number 15 (Smells, tastes or licks objects), score 0 was n = 21 (51%), score 1 was n = 14 (34%), and score 2 was n = 6 (15%). The frequency of the score for item number 16 (Switches lights on and off, pours water over and over, or similar repetitive behaviour), score 0 was n = 26 (63%), score 1 was n = 7 (17%) and score 2 was n = 8 (20%). The frequency of the score for item number 17 (Stubborn, disobedient, or uncooperative), score 0 was n = 4 (10%), score 1 n = 25 (61%), and score 2 was n = 12 (29%). The frequency of the score for item number 19 (Sees, hears,

something that is not there, hallucination), score 0 was n = 27 (66%), and score 1 was n = 14 (34%). The frequency of the score for item number 21 (Tense, anxious, worried), score 0 was n = 10 (24%); score 1 n = 23 (56%), and score 2 was n = 8 (20%).

More than half of the participants scored 0 (*not true as far as I know*) for challenging behaviours such as chewing or mouthing objects or body parts; confused the use of pronouns (for example, used you instead of I); had nightmares; inappropriate sexual activity with another person; refused to go to school or activity centre; smelled, tasted or licked objects; repetitive behaviours; saw or heard somethings that were not there (hallucination). Whereas more of the half participants scored 1 (*somewhat or sometimes true*) for challenging behaviour related to emotion regulation (becomes overexcited and tense, anxious, or worried) and compliance (stubborn, disobedient, or uncooperative)

Table 5.3

The frequency and percentage of responses to the items of the Developmental Behaviour Checklist (DBC-P24)

Item Number	Item	Frequency and Percentage of scores		
		0	1	2
		n (%)	n (%)	n (%)
1	Becomes overexcited	11 (27)	23 (56)	7 (17)
2	Chews or mouths objects or body parts	23 (56)	9 (22)	9 (22)
3	Confuses the use of pronouns (e.g., uses you instead if I)	23 (56)	5 (12)	13 (32)
6	Has nightmares, night terrors, or walks in sleep	31 (76)	8 (19)	2 (5)
7	Impatient	5 (12)	20 (49)	16 (39)
8	Inappropriate sexual activity with another	29 (71)	9 (22)	3 (7)
13	Refuses to go to school, activity center, or workplace	21 (51)	12 (29)	8 (20)
15	Smells, tastes or licks objects	21 (51)	14 (34)	6 (15)
16	Switches lights on and off, pours water over and over, or similar repetitive behaviour	26 (63)	7 (17)	8 (20)
17	Stubborn, disobedient, or uncooperative	4 (10)	25 (61)	12 (29)
19	Sees, hears, something that isn’t there, hallucination	27 (66)	14 (34)	0
21	Tense, anxious, worried	10 (24)	23 (56)	8 (20)

Note. Score 0 = *Not true as far as I know*; 1 = *Somewhat or sometimes true*; 2 = *Very true or often true*

Objective Burden Scale (OBS). Table 5.4 summarised the frequency and percentage of the OBS scores, indicating the extent of day-to-day changes the primary caregivers undergo due to the need to care for an adult with ID. The response scale for this measure was 1 (*a lot more (better)*), 2 (*a little more (better)*), 3 (*the same*), 4 (*a little less (worse)*) and 5 (*a lot less (worse)*).

The frequency of the scores for item 1 (Amount of time you have for yourself) was 1 n = 1 (2%), 2 n = 2 (5%), 3 n = 12 (29%), 4 n = 18 (44%), and 5 n = 8 (20%). For item number 2 (Amount of privacy you have), the frequency for score 1 n = 1 (2%), 2 n = 1 (2%), 3 n = 13 (32%), 4 n = 20 (49%), and 5 n = 6 (15%). For item number 3 (Amount of money you have available to meet expenses), the frequency for score 1 n = 1 (2%), 2 n = 0, 3 n = 23 (56%), 4 n = 11 (27%), and 5 n = 6 (15%). The frequency of the scores for item number 4 (Amount of personal freedom you have) was 1 n = 1 (2%), 2 n = 1 (2%), 3 n = 11 (27%), 4 n = 19 (47%), and 5 n = 9 (22%). For frequency for the scores for item number 5 (Amount of energy you have) was 1 n = 1 (2%), 2 n = 0, 3 n = 13 (32%), 4 n = 23 (56%), and 5 n = 4 (10%). For frequency of the scores for item number 6 (Amount of time you spend in recreational and/or social activities) was 1 n = 1 (2%), 2 n = 1 (2%), 3 n = 7 (17%), 4 n = 17 (42%), and 5 n = 15 (37%). For item number 7 (Amount of vacation activities and trips you take), the frequency of the scores was 1 n = 0, 2 n = 3 (7%), 3 n = 13 (32%), 4 n = 9 (22%), and 5 n = 16 (39%). For item number 8 (Your relationship with other family members), the frequency of score was 1 n = 1 (2%), 2 n = 3 (7%), 3 n = 23 (56%), 4 n = 12 (29%), and 5 n = 2 (5%). The frequency of the sore for item number 9 (Your health) was 1 n = 0, 2 n = 1 (2%), 3 n = 23 (56%), 4 n = 13 (32%) and 5 n = 4 (10%). For item number 10 (Your work/job (for example, need to take time off), the frequency of the score was 1 n = 1 (2%), 2 n = 1 (2%), 3 n = 21 (54%), 4 n = 7 (18%), and 5 n = 9 (23%).

All the items were primarily scored above score 3, indicating that taking care of an adult with ID has not been better for each item. More than 50% of the participants scored 3, suggesting that their circumstances had remained unchanged for items related to the amount of money available to meet their expenses, their relationship with other family members, their health, and their work or jobs since they started taking care of the adults with ID. At least 40% of the participants reported having less time to manage their needs, privacy, freedom and energy due to the caregiving needs. The highest response for scale 5 (no time left) were reported for items on recreational, social activities and vacations.

Table 5.4

Frequency and percentage of responses to the items on the Objective Burden Scale (OBS)

Item Number	Item	Frequency and Percentage of scores				
		1	2	3	4	5
		n (%)	n (%)	n (%)	n (%)	n (%)
1	Amount of time you have to yourself	1 (2)	2 (5)	12 (29)	18 (44)	8 (20)
2	Amount of privacy you have	1 (2)	1 (2)	13 (32)	20 (49)	6 (15)
3	Amount of money you have available to meet expenses	1 (2)	0	23 (56)	11 (27)	6 (15)
4	Amount of personal freedom you have	1 (2)	1 (2)	11 (27)	19 (47)	9 (22)
5	Amount of energy you have	1 (2)	0	13 (32)	23 (56)	4 (10)
6	Amount of time you spend in recreational and/or social activities	1 (2)	1(2)	7 (17)	17 (42)	15 (37)
7	Amount of vacation activities and trips you take	0	3 (7)	13 (32)	9 (22)	16 (39)
8	Your relationship with other family members	1 (2)	3 (7)	23 (56)	12 (29)	2 (5)
9	Your health	0	1 (2)	23 (56)	13 (32)	4 (10)
10*	Your work/job (e.g. because of having to take time off)	1 (2)	1 (2)	21 (54)	7 (18)	9 (23)

Note. Score 1 = *A lot more (better)*; 2 = *A little more (better)*; 3 = *The same*; 4 = *A little less (worse)*; 5 = *A lot less (worse)*.

* There were 39 participants who answered item number 10, with 2 missing responses

Brief COPE. The frequency and percentage of responses to the items on the Brief COPE scale were summarised in Table 5.5. The frequency of the scores was grouped based on the categories of problem-focused, emotion-focused, and avoidance. The response scale for this measure was: 1 (*I haven't been doing this at all)*, 2 (*a little bit*), 3 (*a medium amount*), and 4 (*I've been doing this a lot*).

For the items assessing problem-focused coping, the frequency of the score for item 7 (active coping, I've been taking action to try to make the situation better) was 1 $n = 2$ (5%), 2 $n = 5$ (12%), 3 $n = 12$ (29%), and 4 $n = 22$ (54%).

For the items assessing emotion-focused coping, the frequency of the score for item 13 (self-blame, I've been criticising myself) was 1 $n = 29$ (71%), 2 $n = 9$ (22%), 3 $n = 2$ (5%), and 4 $n = 1$ (2%). The frequency of the scores for item 21 (venting, I've been expressing my negative feelings) was 1 $n = 22$ (54%), 2 $n = 16$ (39%), and 3 $n = 3$ (7%). For coping related to acceptance (items 20 and 24), the frequency of the scores for item 20 (I've been accepting the reality of the fact that it has happened) was 1 $n = 7$ (17%), 2 $n = 12$ (29%), and 3 $n = 22$ (54%). The frequency of the scores for item 24 (I've been learning to live with it) was 1 $n = 5$ (12%), 2 $n = 12$ (29%), and 3 $n = 24$ (59%). For coping related to humor (items 18 and 28), the frequency of the scores for item 18 (I've been making jokes about it) was 1 $n = 27$ (66%), 2 $n = 12$ (29%), and 3 $n = 2$ (5%). The frequency of the scores for item 28 (I've been making fun of the situation) was 1 $n = 34$ (83%), and 2 $n = 7$ (17%).

For the items assessing avoidant coping, the frequency of the score for the items related to denial, item 3 (I've been saying to myself "this isn't real") was 1 $n = 28$ (68%), 2 $n = 10$ (25%), and 3 $n = 3$ (7%); and item 8 (I've been refusing to believe that it has happened), was 1 $n = 28$ (68%), and 2 $n = 13$ (32%). For coping related to substance use (items 4 and 11), the frequency of the score for item 4 (I've been using alcohol or other drugs to make myself feel better), was 1 $n = 36$ (88%), 2 $n = 3$ (7%), and 3 $n = 2$ (5%). The frequency of the

score for item number 11 (I've been using alcohol or other drugs to help me get through it), score 1 n = 36 (88%), 2 n = 3 (8%), 3 n = 1 (2%), and 4 n = 1 (2%). The coping related to behavioural disengagement (items 6 and 16), the frequency of the score for the item number 6 (I've been giving up trying to deal with it) was 1 n = 28 (68%), 2 n = 9 (22%), 3 n = 3 (7%), and 4 n = 1 (2%). The frequency of the score for the number 16 (I've been giving up the attempt to cope) was 1 n = 30 (73%), 2 n = 9 (22%), and 3 n = 2 (5%).

In summary, these scores indicated that most participants tended to use active coping strategies, such as taking proactive steps to address the situation, with over half of them frequently employing these strategies. Acceptance was reported moderately, with the highest frequency of a score of 3. On the other hand, self-blame, venting, and humour were infrequently used, with over half of the participants scoring 1. Avoidant coping mechanisms like denial, substance use, and behavioural disengagement were rarely employed, with the most frequency for a score of 1.

Table 5.5

The frequency and percentage of responses to items on the Brief COPE scale

Item Number	Item	Frequency and Percentage of scores			
		1	2	3	4
		n (%)	n (%)	n (%)	n (%)
3	I’ve been saying to myself “this isn’t real”	28 (68)	10 (25)	3 (7)	0
4	I’ve been using alcohol or other drugs to make myself feel better	36 (88)	3 (7)	2 (5)	0
6	I’ve been giving up trying to deal with it	28 (68)	9 (22)	3 (7)	1 (2)
7	I’ve been taking action to try to make the situation better	2 (5)	5 (12)	12 (29)	22 (54)
8	I’ve been refusing to believe that it has happened	28 (68)	13 (32)	0	0
11	I’ve been using alcohol or other drugs to help me get through it	36 (88)	3 (8)	1 (2)	1 (2)
13	I’ve been criticizing myself	29 (71)	9 (22)	2 (5)	1 (2)
16	I’ve been giving up the attempt to cope	30 (73)	9 (22)	2 (5)	0
18	I’ve been making jokes about it	27 (66)	12 (29)	2 (5)	0
20	I’ve been accepting the reality of the fact that it has happened	7 (17)	12 (29)	22 (54)	0
21	I’ve been expressing my negative feelings	22 (54)	16 (39)	3 (7)	0
24	I’ve been learning to live with it	5 (12)	12 (29)	24 (59)	0
28	I’ve been making fun of the situation	34 (83)	7 (17)	0	0

Note. Score 1 = I *haven’t been doing this at* all; Score 2 = *A little bit*; Score 3 = *A medium amount*; Score 4 = *I’ve been doing this a lot*

Positive Aspects of Caregiving Scale (PACS). The frequency and percentage of the PACS scores are summarised in Table 5.6. The PACS assessed the perceived sense of satisfaction and reward that was gained from the caregiving experience. The response scale for this measure was 1 (*disagree a lot*), 2 (*disagree a little*), 3 (*neither agree or disagree*), 4 (*agree a little*), and 5 (*agree a lot*).

The frequency of the scores for item 1 (Made me feel more useful) was 3 n = 14 (34%), 4 n = 11 (27%), and 5 n = 16 (39%). The frequency of the scores for item 2 (Made me feel good about myself) was 3 n = 14 (34%), 4 n = 16 (39%), and 5 n = 11 (27%). The frequency of the scores for item number 3 (Made me feel needed) was 3 n = 13 (32%), score 4 n = 10 (24%), and 5 n = 18 (44%). The frequency of the scores for item number 4 (Made me feel appreciated) was 2 n = 2 (5%), 3 n = 16 (39%), 4 n = 8 (20%), and 5 n = 15 (36%). The frequency of the score for item number 5 (Made me feel important) was distributed across all the scores (unlike other items), the score was 1 n = 2 (5%), 2 n = 3 (7%), 3 n = 16 (39%), 4 n = 9 (22%), and 5 n = 11 (27%). The frequency of the scores for item number 6 (Made me feel strong and confident) was 3 n = 16 (39%), 4 n = 8 (20%), and 5 n = 15 (36%). The frequency of the scores for item number 7 (Enabled me to appreciate life more) was 2 n = 2 (5%), 3 n = 6 (14%), 4 n = 15 (37%), and 5 n = 18 (44%). The frequency of the scores of item number 8 (Enabled me to develop a more positive attitude toward life) was 2 n = 1 (2%), 3 n = 11 (27%), 4 n = 11 (27%), and 5 n = 18 (44%). The frequency of the scores for item number 9 (Strengthened my relationships with others) was 2 n = 3 (7%), 3 n = 15 (37%), 4 n = 12 (29%), and 5 n = 11 (27%).

Overall, participants expressed feeling a heightened sense of usefulness, self-worth, importance, strength, confidence, and an improved ability to nurture their relationships as primary caregivers. These positive aspects suggest that some participants felt neutral or more positive about their role as caregivers. Notably, close to half of the participants scored a 5,

indicating strong agreement, especially for items related to feeling needed, appreciating life more, and cultivating a more positive attitude.

Table 5.6

The frequency and percentage of responses to items on the Positive Aspects of Caregiving Scale (PACS)

Item Number	Item	Frequency and Percentage of scores				
		1	2	3	4	5
		n (%)	n (%)	n (%)	n (%)	n (%)
1	Made me feel more useful	0	0	14 (34)	11 (27)	16 (39)
2	Made me feel good about myself	0	0	14 (34)	16 (39)	11 (27)
3	Made me feel needed	0	0	13 (32)	10 (24)	18 (44)
4	Made me feel appreciated	0	2 (5)	16 (39)	8 (20)	15 (36)
5	Made me feel important	2 (5)	3 (7)	16 (39)	9 (22)	11 (27)
6	Made me feel strong and confident	0	0	14 (34)	13 (32)	14 (34)
7	Enabled me to appreciate life more	0	2 (5)	6 (14)	15 (37)	18 (44)
8	Enabled me to develop a more positive attitude toward life	0	1 (2)	11 (27)	11 (27)	18 (44)
9	Strengthened my relationships with others	0	3 (7)	15 (37)	12 (29)	11 (27)

Note. Score 1 = *Disagree a* lot; 2 = *Disagree a little*; 3 = *Neither agree or disagree*; 4 = *Agree a little*; 5 = *Agree a lot*

Perceived Burden 1 and 2. The data presented in Table 5.7 provides a summary of the perceived burden when managing the day-to-day needs of adults with ID. None of the participants reported feeling completely stress-free when dealing with adults with ID. Specifically, two (5%) participants mostly felt stress-free, one (2%) participant somewhat felt stress-free, and four (10%) participants neither felt stressed nor stress-free. The largest group, consisting of 19 (46%) participants, reported somewhat feeling stressed, followed by 10 (25%) participants who mostly felt stressed, and five (12%) participants who felt completely stressed. In total, 83% of the participants reported scores indicating that they felt somewhat stressed or above when managing the day-to-day needs of adults with intellectual disability.

Table 5.7

The frequency and percentage of responses to items on the Perceived Burden 1 scale on managing the adult with ID's day-to-day needs

Score	Item description	*n*	%
1	Completely stress free (no stress at all)	0	0
2	Mostly feeling stress free	2	5
3	Somewhat feeling stress free	1	2
4	Neither feeling stress nor stress free (neutral)	4	10
5	Somewhat feeling stress	19	46
6	Mostly feeling stress	10	25
7	Completely stressful (could not be more stressed)	5	12

The frequency and percentage of the Perceived Burden 2 scores, in relation to managing their own day-to-day needs are presented in Table 5.8. None of the participants reported feeling entirely stress-free. One (2%) participant reported feeling somewhat stress-

free, while 17 (42%) participants reported neither feeling stressed nor stress-free. Additionally, 13 (32%) participants felt somewhat stressed, eight (19%) participants felt mostly stressed, and two (5%) participants felt completely stressed. About 40% of the participants reported feeling neutral in managing their own day-to-day needs. This contrasts with the findings of the perceived burden 1 score, where almost half reported feeling somewhat stressed when managing the day-to-day needs of the adult with ID.

Table 5.8

The frequency and percentage of responses on the Perceived Burden 2 scale on the participants managing their own day-to-day needs

Score	Item description	*n*	%
1	Completely stress free (no stress at all)	0	0
2	Mostly feeling stress free	0	0
3	Somewhat feeling stress free	1	2
4	Neither feeling stress nor stress free (neutral)	17	42
5	Somewhat feeling stress	13	32
6	Mostly feeling stress	8	19
7	Completely stressful (could not be more stressed)	2	5

WHOQOL-BREF (Item 1 and 2). The frequency of the scores on items 1 and 2 of the WHOQOL-BREF, assessing overall quality of life and health satisfaction, respectively, are presented in Table 5.9. The frequency and percentages of the quality-of-life scores was 1 (*very poor*) $n = 5$ (12%), 2 (*poor*) $n = 3$ (7%), 3 (*neither poor nor good*) $n = 13$ (32%), 4 (*good*) $n = 18$ (44%), and 5 (*very good*) $n = 2$ (5%). In total, 76% of the participants reported *neither poor nor good* and *good* quality of life.

Whereas, the frequency and percentage of the satisfaction of health scores was 2 (*dissatisfied*) n = 2 (5%), 3 (*neither satisfied nor dissatisfied*) n = 21 (51%), 4 (*satisfied*) n = 13 (32%), and 5 (*very satisfied*) n = 5 (12%). It was notable that half of the participants reported feeling neither *satisfied nor dissatisfied* with their health.

Table 5.9

The frequency and percentage of responses to items 1 and 2 of the WHOQOL-BREF

Item Number	Item	Frequency and Percentage of scores				
		1	2	3	4	5
		n (%)	n (%)	n (%)	n (%)	n (%)
1	Quality of life	5 (12)	3 (7)	13 (32)	18 (44)	2 (5)
2	Satisfaction of health	0	2 (5)	21 (51)	13 (32)	5 (12)

Note. Item 1 score 1 = *Very poor*; 2 = *Poor*; 3 = *Neither poor nor good*; 4 = *Good*; 5 = *Very good*. Item 2 score 1 = *Very dissatisfied*; 2 = *Dissatisfied*; 3 = *Neither satisfied nor dissatisfied*; 4 = *Satisfied*; 5 = *Very satisfied*.

Placement Tendency Index (PTI). The initial PTI scores are presented in Table 5.10. PTI measures the step-by-step placement tendency process for moving an individual with a developmental disability from the family home into an adult home (out of family home). Nine (22%) participants scored 1 (*No, I have never thought about it*) and 2 (*Occasionally I have given it a thought*), ten (24%) participants scored 3 (*Yes, I have thought about it a lot, but have not done anything yet*), while 11 participants (27%) scored 4 (*I have thought about it and enquired but have not done anything yet*). In contrast, only one participant (2%) scored 5 (*I have taken steps to place; the paperwork is in the process*) and 6 (*The individual diagnosed with ID is on the waiting list for the adult home*). Notably, there was no response to item 7 (*The individual diagnosed with ID had moved out of home*) due to the exclusion criteria, which required participants to be caring for an adult with ID in their family home.

Table 5.10

The frequency and percentage of responses to the initial Placement Tendency Index (PTI)

Score	Item description	n	%
1	No, I have never thought about it	9	22
2	Occasionally I have given it a thought	9	22
3	Yes, I have thought about it and enquired but have not done anything yet	10	25
4	I have thought about it and enquired but have not done anything yet	11	27
5	I have taken steps to place; the paperwork is in process	1	2
6	The individual diagnosed with ID is on the waiting list for the adult home	1	2

Placement Tendency Index (PTI; after 6 to 9 months). The distribution of the PTI scores after the 6 to 9 months of the initial encounter are presented in Table 5.11. Thirty-three

participants were contacted (80.5%) after the 6 to 9 months. Out of the 33 participants, seven (17%) participants scored 1 (*No, I have never thought about it*), eight (19.5%) participants scored 2 (*Occasionally I have given it a thought*) and 3 (*Yes, I have thought about it a lot, but have not done anything yet*), seven (17%) participants scored 4 (*I have thought about it and enquired but have not done anything yet*), one participant (2%) scored 5 (*I have taken steps to place; the paperwork is in the process*) and two participants (5%) scored 6 (*The individual diagnosed with ID is on the waiting list for the adult home*).

Three participants reported one-point changes upward within the 6 to 9 months period and the other 30 (90%) participants did not report any change in the scores. For the three who reported a change, the changes in the response were from score 1(*No, I have never thought about it*) to 2 (*Occasionally I have given it a thought*); score 4 (*I have thought about it and enquired but have not done anything yet*) to 5 (*I have taken steps to place; the paperwork is in the process*); and score 5 to 6 (*The individual diagnosed with ID is on the waiting list for the adult home*).

Table 5.11

The frequency and percentage of responses to the Placement Tendency Index (PTI) after 6 to 9 months

Score	Item description	n	%
	Did not meet the 6 to 9 months period	8	19.5
1	No, I have never thought about it	7	17
2	Occasionally I have given it a thought	8	19.5
3	Yes, I have thought about it and enquired but have not done anything yet	8	19.5
4	I have thought about it and enquired but have not done anything yet	7	17
5	I have taken steps to place; the paperwork is in process	1	2
6	The individual diagnosed with ID is on the waiting list for the adult home	2	5

Comparisons with Normative Data

A series of independent *t*-tests were conducted to compare the results for the current sample with those reported for the normative data for each measure (Table 5.12). The comparison was made with the results from the normative data for the group that was most similar to the participants in the current study.

Brief Resilience Scale (BRS). The mean reported by the participants in this study ($n = 41$) was compared to the mean reported by female participants only who either had or did not had fibromyalgia in the Southwestern United States ($n = 50$; Smith et al., 2008). The *t*-test was statistically not significant, with this sample group's mean ($M = 3.40$, $SD = 0.70$) being 0.21 lower, 95% CI [-.12, -.54] than the normative mean ($M = 3.61$, $SD = .85$), $t(89) = 1.24$, $p = .22$, two-tailed.

Dark Future Scale (DFS). The mean reported by the participants in this study (n = 41) was compared to the mean reported by mothers who are caregivers of their children with ID in Iran (n = 196; Torfayeh et al., 2020). The t-test was statistically significant, with the participants of this study (M = 18.39, SD = 8.18) reporting a mean score 6.58 lower, 95% CI [-4.8, -8.36] than the normative mean (M = 24.97, SD = 4.45), $t(235) = 7.23$, $p < .01$, two-tailed. Therefore, the participants in this study, on average, reported lesser future anxiety than the mothers who are caregivers of their children with ID in Iran.

Developmental Behaviour Checklist-P24 (DBC-P24). The mean reported by the participants in this study (n = 41) was compared to the mean data from Australian Child to Adult Development study (Wave 3, mean age of the individual with ID was 19.5 years, n = 196; Taffe et al., 2007). The t-test was statistically significant, with this sample group (*M = 0.77, SD = 0.23*) reporting a mean score 0.36 higher, 95% CI [0.28, 0.44] than the normative mean (M = 0.41, SD = 0.26), $t(442) = 9.00$, $p < .01$, two-tailed. Therefore, the participants in this study, on average, reported more challenging behaviours than the data obtained from the Australia Child to Adult Development study.

Questionnaire on the Frequency of and Satisfaction with Social Support (QFSSS). The means for the frequency and satisfaction of each support (emotional, instrumental, and informational) and source (family, partner, friends, and community) were reported compared to the general residents' sample in Spain. The means for the participants in this study (n = 41) were compared to the means reported by the general residents' sample in Spain (n = 2042; Garcia-Martin et al., 2016).

Regarding the support type, the difference between the means for *emotional support* was statistically significant. The sample group (M = 22.24, SD = 5.78) reported a mean 5.85 lower, 95% CI [-3.99, -7.71] than the normative mean (*M = 28.09, SD = 6.03*), $t(2081) = 6.16$, $p < .01$, two-tailed. Therefore, the participants, on average, reported less frequency and

satisfaction of the emotional support than the general Spanish residents' sample. The difference between the means for *instrumental support* was statistically significant. The sample group (M = 22.26, SD = 5.19) reported a mean 4.51 lower, 95% CI [-2.65, -6.37] than the normative mean (M = 26.77, SD = 6.04), t(2081) = 4.75, p < .01, two-tailed. The significant correlation reflected those participants, on average, reported less frequency and satisfaction of the instrumental support. The difference between the means for *informational support* was statistically significant. The sample group (M = 21.73, SD = 5.36) reported a mean 5.39 lower, 95% CI [-3.43, -7.35] than the normative mean (M = 27.12, SD = 6.34), t(2081) = 5.39, p < .01, two-tailed. This indicates that the participants, on average, reported less frequency and satisfaction of the informational support.

In terms of the source type, the difference between the means for *family* source of support was statistically significant. The sample group (M = 19.39, SD = 5.46) reported a mean 4.90 lower, 95% CI [-3.21, -6.59] than the normative mean (M = 24.29, SD = 5.45), t(2081) = 5.70, p < .01, two-tailed. Therefore, the participants reported less frequency and satisfaction than the general Spanish residents' sample on average. The difference between the means for *partner* source of support was statistically significant. The sample group (M = 16.12, SD = 7.74) reported a mean 7.13 lower, 95% CI [-4.93, -9.33] than the normative mean (M = 23.25, SD = 7.11), t(2081) = 6.37, p < .01, two-tailed. This indicates that the participants reported less frequency and satisfaction from the partner source of support. The difference between the means for *friend* source of support was statistically significant. The sample group (M = 15.34, SD = 5.34) reported a mean 5.60 lower, 95% CI [-3.74, -7.46] than the normative mean (M = 20.94, SD = 6.01), t(2081) = 5.89, p < .01, two-tailed. The significant difference suggests that the participants reported less frequency and satisfaction of with support from the friend source. The difference between means for *community* source of support was not statistically significant, with this sample group (M = 15.39, SD = 4.11)

reported a mean 1.41 higher, 95% CI [.59, 3.41] than the normative mean (*M* = 13.98, *SD* = 6.51), *t*(2081) = 1.38, *p* = .17, two-tailed.

Brief COPE. The mean reported by the participants in this study (*n* = 41) was compared to the mean reported by caregivers who are caregivers caring for individual with autism in United States (US, *n* = 61; Lee et al., 2019). The *t*-test for the *adaptive coping mechanism* was not statistically significant, with this sample group's (*M* = 41.95, *SD* = 9.44) being 1.65 higher, 95% CI [2.13, 5.43] than the normative mean (*M* = 40.30, *SD* = 9.43), *t*(100) = .86, *p* = .39, two-tailed. The *t*-test for the *maladaptive coping mechanism* was also not statistically significant, with this sample group's (*M = 19.24, SD = 4.41*) mean being 0.26 higher, 95% CI [1.56, 2.08] than the normative mean (*M* = 18.98, *SD* = 4.63), *t*(100) = .28, *p* = .78, two-tailed.

Positive Aspects of Caregiving Scale (PACS). The mean reported by the participants in this study (*n* = 41) was compared to the family caregivers who lived and provided caregiving for their relatives (*n* = 1 219; Tarlow et al., 2004). The *t*-test was not statistically significant, with this sample group (*M* = 35.63, *SD* = 6.47) reported a mean 1.63 higher, 95% CI [1.15, 4.41] than the normative mean (*M* = 34.00, *SD* = 9.00), *t*(1 258) = 1.15, *p* = .25, two-tailed.

WHOQOL-BREF. The means reported by the participants in this study were compared to the combined data from a community and two clinic samples in Singapore (*n* = 454) for each physical health, psychological, social and environmental domains (Cheung et al., 2017). The *t*-test for the *physical health* domain was statistically significant, with the current sample (*n* = 40; *M* = 66.52, *SD* = 9.70) reported a mean 8.38 lower, 95% CI [-3.48, -13.28] than the normative mean (*M* = 74.90, *SD* = 15.50), *t*(492) = 3.37, *p* < .01, two-tailed. This indicates that the participants, on average, reported low physical health scores. The *t*-test for the *psychological* domain was statistically significant, with the current sample (*n* = 41; *M*

= 59.17, *SD* = 11.63) reported a mean 13.33 lower, 95% CI [-8.87, -17.79] than the normative mean (*M* = 72.50, *SD* = 14.10), *t*(493) = 5.87, *p* < .01, two-tailed. Therefore, on average, participants reported low psychological health scores (such as life enjoyment and being meaningful, ability to concentrate, self-satisfaction, and negative feelings). The *t*-test for the *social* domain was statistically significant, with the current sample (*n* = 39; *M* = 56.05, *SD* = 19.43) reported a mean 17.95 lower, 95% CI [-12.58, -23.32] than the normative mean (*M* = 74.0, *SD* = 16.10), *t*(491) = 6.58, *p* < .01, two-tailed. This suggests that the participants, on average, reported low social relationship scores (satisfaction related to personal relationships and support). The *t*-test for the *environmental* domain was statistically significant, with the current sample (*n* = 41; *M* = 64.61, *SD* = 14.47) reported a mean 7.39 lower, 95% CI [-2.86, -11.92] than the normative mean (*M* = 72.00, *SD* = 14.10), *t*(493) = 3.21, *p* < .01, two-tailed. Therefore, on average, the participants reported fewer scores related to environmental domains such as access to health services, living conditions, money to meet expenses, availability of information, and safety in daily life.

Table 5.12

The sample and normative means for all measures

Scale	Participant		Normative group		
	M	SD	M	SD	t
Brief Resilience Scale (BRS)[1]	3.40 (n = 41)	0.70	3.61 (n = 50)	0.85	1.08
Dark Future Scale (DFS)[2]	18.39 (n = 41)	8.18	24.97 (n = 196)	4.45	7.23*
Developmental Behaviour Checklist-P24 (DBC-P24)[3]	0.77 (n = 41)	0.23	0.41 (n = 403)	0.26	9.00*
Questionnaire on the Frequency of and Satisfaction with Social Support (QFSSS)[4]					
Support (frequency and satisfaction)					
Emotional	22.24 (n = 41)	5.78	28.09 (n = 2042)	6.03	6.16*
Instrumental	22.26	5.19	26.77	6.04	4.75*
Informational	21.73	5.36	27.12	6.34	5.39*
Source (frequency and satisfaction)					
Family	19.39	5.46	24.29	5.45	5.70*
Partner	16.12	7.74	23.25	7.11	6.37*
Friends	15.34	5.34	20.94	6.01	5.89*
Community	15.39	4.11	13.98	6.51	1.38
Brief COPE[5]					
Adaptive	41.95 (n = 41)	9.44	40.30 (n = 61)	9.43	.86
Maladaptive	19.24	4.41	18.98	4.63	.28

Positive Aspects of Caregiving Scale (PACS)[6]	35.63 (n = 41)	6.47	34.0 (n = 1219)	9.00	1.15
WHOQOL-BREF[7]					
Physical health	66.52 (n = 40)	9.70	74.9 (n = 454)	15.5	3.37*
Psychological	59.17 (n = 41)	11.63	72.5 (n = 454)	14.1	5.87*
Social	56.05 (n = 39)	19.43	74.0 (n = 454)	16.1	6.58*
Environmental	64.61 (n = 41)	14.47	72.0 (n = 454)	14.1	3.21*

Note. *p < .01

[1] Female participants in the Southwestern United States

[2] Mothers who are the caregivers of their children with ID in Iran

[3] Mean age of the individual with ID of 19.5 years in Australia

[4] General resident sample in Spain

[5] Caregivers caring for school-age children and young adults transitioning into adulthood who were diagnosed with ASD in United States

[6] Family caregiver who lived and provided caregiving for their relatives

[7] General population and participants from two clinic samples in Singapore

Correlational Analysis

Pearson's correlation coefficients (*r)* were calculated to assess the size and direction of the linear relationship within the independent variables such as caregiver household income, helper, BRS, DFS, DBC-P24, OBS, QFSSS (Frequency and Satisfaction), Brief COPE (Adaptive and Maladaptive), and PAC (Self-affirmation and Outlook). Then, the significant correlations of the independent variables with the dependent variables, such as the perceived burden 1 (OBS-related) and 2 (DBC-P24-related), WHOQOL-BREF (overall quality of life) and PTI at the point of assessment were reported (Table 5.13). Only statistically significant correlations, $p < .05$, are described here.

Caregiver household income. The significant bivariate correlation between caregiver household income and presence of helper was medium and negative $r(38) = -.34$, $p < .05$; BRS was medium and negative $r(38) = -.34$, $p < .05$; QFSSS (Frequency) was medium and positive $r(38) = .49$, $p < .01$; QFSSS (Satisfaction) was medium and positive $r(38) = .35$, $p < .05$; and Brief COPE (Adaptive) was medium and positive $r(38) = .32$, $p < .05$.

Helper. The significant bivariate correlation between the presence of helper and BRS was medium and negative $r(39) = -.37$, $p < .05$; QFSSSS (Frequency) was large and negative $r(39) = -.58$, $p < .01$; Brief COPE (Adaptive) was medium and negative $r(39) = -.45$, $p < .01$; and PAC (Outlook) was medium and negative $r(39) = -.34$, $p < .05$.

Brief Resilience Scale (BRS). The significant bivariate correlation between BRS and DFS was medium and negative $r(39) = -.35$, $p <.05$; QFSSS (Frequency) was large and positive $r(39) = .56$, $p < .01$; QFSSS (Satisfaction) was medium and positive $r(39) = .42$, $p < .01$; PAC (Self-affirmation) was medium and positive $r(39) = .40$, $p < .01$; and PAC (Outlook) was medium and positive $r(39) = .41$, $p < .01$.

Dark Future Scale (DFS). The significant bivariate correlation between DFS and DBC-P24 was medium and positive $r(39) = .36$, $p < .05$; OBS was medium and positive $r(37)$

= .38, $p < .05$; QFSSS (Satisfaction) was medium and negative $r(39) = -.39$, $p < .05$; and Brief COPE (Maladaptive) was medium and positive $r(39) = .42$, $p < .01$.

Developmental Behaviour Checklist (DBC-P24). The significant bivariate correlation between DBC-P24 and OBS was large and positive $r(37) = .63$, $p < .01$; Brief COPE (Maladaptive) was medium and positive $r(39) = .32$, $p < .05$; and PAC (Self-affirmation) was medium and negative $r(39) = -.34$, $p < .05$.

Objective Burden Scale (OBS). The significant bivariate correlation between OBS and PAC (Self-affirmation) was medium and negative $r(37) = -.32$, $p < .05$, and PAC (Outlook) was medium and negative $r(37) = -.41$, $p < .01$.

Questionnaire of Frequency and Satisfaction of Social Support (QFSSS; Frequency). The significant bivariate correlation between QFSSS (Frequency) and QFSSS (Satisfaction) was large and positive $r(39) = .56$, $p < .01$; Brief COPE (Adaptive) was medium and positive $r(39) = .49$, $p < .01$; and PAC (Outlook) was medium and positive $r(39) = .31$, $p < .05$.

Brief COPE (Adaptive). The significant bivariate correlation between Brief COPE (Adaptive) and PAC (Self-affirmation) was large and positive $r(39) = .61$, $p < .01$; and PAC (Outlook) was medium and positive $r(39) = .49$, $p < .01$.

Positive Aspects Caregiving (PAC; Self-affirmation and Outlook). The significant bivariate correlation between PAC (Self-affirmation) and PAC (Outlook) was large and positive $r\ (39) = .75$, $p < .01$.

Perceived burden 1 (DBC-P24) and 2 (OBS). The significant bivariate correlation between the perceived burden 1 (DBC-P24-related) and BRS was medium and negative $r(39) = -.33$, $p < .05$; DFS was large and positive $r(39) = .74$, $p < .01$; DBC-P24 was medium and positive $r(39) = .48$, $p < .01$; OBS was medium and positive $r(37) = .43$, $p < .01$; QFSSS

(Satisfaction) was medium and negative $r(39) = -.43$, $p < .01$; Brief COPE (Maladaptive) was medium and positive $r(39) = .35$, $p < .05$.

The significant bivariate correlation between the perceived burden 2 (OBS-related) and DFS was medium and positive $r(39) = .44$, $p < .01$; DBC-P24 was medium and positive $r(39) = .41$, $p < .01$; OBS was large and positive $r(37) = .58$, $p < .01$; QFSSS (Satisfaction) was large and negative $r(39) = -.56$, $p < .01$; Brief COPE (Maladaptive) was medium and positive $r(39) = .32$, $p < .05$ and perceived burden 1 (DBC-P24-related) was large and positive $r(39) = .60$, $p < .01$.

WHOQOL-BREF (overall quality of life). The significant bivariate correlation between the WHOQOL-BREF (overall quality of life) and caregiver household income was medium and positive $r(38) = .38$, $p < .05$; BRS was medium and positive $r(39) = .41$, $p < .01$; DFS was medium and negative $r(39) = -.49$, $p < .01$; OBS was large and negative $r(37) = -.58$, $p < .01$; QFSSS (Satisfaction) was large and positive $r(39) = .51$, $p < .01$; perceived burden 1 (DBC-P24-related) was large and negative $r(39) = -.55$, $p < .01$; and perceived burden 2 (OBS-related) was large and negative $r(39) = -.62$, $p < .01$.

Placement Tendency Index (PTI at the point of assessment). The significant bivariate correlation between the PTI and caregiver household income was medium and negative $r(38) = -.33$, $p < .05$; BRS was medium and negative $r(39) = -.45$, $p < .01$; QFSSS (satisfaction) was medium and negative $r(39) = -.46$, $p < .01$; perceived burden 2 (OBS-related) was medium and positive $r(39) = .31$, $p < .05$; and WHOQOL-BREF (quality of life) was medium and negative $r(39) = -.48$, $p < .01$.

Table 5.13

Correlations for Study Variables

Variables	n	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1. Caregiver household income [a]	40	-															
2. Helper [b]	41	-.34*	-														
3. BRS	41	-.34*	-37*	-													
4. DFS	41	-.27	-.23	-.35*	-												
5. DBC-P24	41	-.13	.03	-.30	.36*	-											
6. OBS	39	-.14	.23	-.27	.38*	.63**	-										
7. QFSSS Frequency	41	.49**	-.58**	.56**	-.20	-.09	-.09	-									
8. QFSSS Satisfaction	41	.35*	-.20	.42**	-.39*	-.14	-.21	.56**	-								
9. Brief COPE (Adaptive)	41	.32*	-.45**	.25	.13	-.04	-0.1	.49**	0	-							
10. Brief COPE (Maladaptive)	41	.18	-.3	-.07	.42**	.32*	.08	.23	-.04	.25	-						
11. PAC (Self- affirmation)	41	.30	-.28	.40**	0	-.34*	-.32*	.29	-.09	.61**	-.02	-					
12. PAC (Outlook)	41	.29	-.34*	.41**	-.08	-0.20	-.41**	.31*	.01	.49**	-.12	.75**	-				
13. Perceived Burden 1 (DBC-P24)	41	-.27	.25	-.33*	.74**	.48**	.43**	-.20	-.43**	.04	.35*	-.05	-.19	-			
14. Perceived Burden 2 (OBS)	41	-.15	.10	-.23	.44**	.41**	.58**	0	-.56**	.27	.32*	-.07	-.17	.60**	-		
15. WHOQOL-BREF (Quality of life)	41	.38*	-.30	.41**	-.49**	-.29	-.58**	.26	.51**	.19	-.14	.22	.23	-.55**	-.62**	-	
16. PTI	41	-.33*	-.10	-.45**	.28	-.13	.09	-.09	-.46**	-.06	.22	-.04	-.13	.19	.31*	-.48**	-

[a] 1 = below $4 500 and 2 = more than $4 501

[b] 1 = Yes and 2 = No.

*p < .05. ** p < .01.

Regression Analysis

To further investigate the relationship between the variables, the five variables that were significantly related to the initial PTI score were entered into a standard multiple regression with the PTI score as the dependent variable (DV).This allowed for an assessment of the extent to which the combination of the five variables of household income, resilience score, satisfaction with social support, subjective burden related to caregiver’s own needs, and overall quality of life predicted PTI scores. The total variance explained by the regression equation for initial PTI score was significant, $F(5,34) = 3.62$, $p = .01$. In total the five independent variables explained 35% (25% adjusted) of the variance in initial PTI scores. No individual variable reached significance, indicating that none of the independent variables made a significant unique contribution to the variability in initial PTI score.

Summary of Findings for Family Caregivers of Adults with ID

This chapter presents the key findings from a cross-sectional investigation of a group of family caregivers of adults with ID. The overall pattern of results for these family caregivers was mapped into the proposed model to understand the caregivers' current stances on the placement tendency (PTI score), which was assumed to be the outcome of their adaptation.

Stressors

Based on the distribution of the DBC-P24, the highest frequency score of the possible challenging behaviours for adults with ID receiving treatment in IMH are related to emotion regulation and concerns related to compliance. On the other hand, the score distribution of the OBS items indicated that more than half of the participants reported little to no time to spend on recreational and social activities, vacations, and trips and less energy left since being a caregiver. However, more than half of the participants had the same amount of time and effort for their relationships with other family members, health, and work. The results were

aligned with those from the other studies that state that work may not be crucial indicators in measuring the impact of caregiving on caregivers' day-to-day activities (Roos et al., 2020; Gur et al., 2020). The focus could be redirected to understanding the caregiver's capacity to be involved in social activities, vacations and the overall energy spent after fulfilling the caregiving roles to understand the impact of caregiving on the caregivers.

This sample reported significantly more challenging behaviours than individuals with ID (average 19.5 years) in Australia (Taffe et al., 2007). This study focused on a clinical sample that presented concerns about possible challenging behaviours, and the difference was expected (Buckley et al., 2020). Higher scores (more challenging behaviours) significantly correlated with higher perceived stress in managing adults with ID and their needs. Besides that, a greater extent of changes in the caregivers' day-to-day needs due to caregiving needs (OBS) significantly correlated with higher perceived stress in managing adults with ID and their own needs and the overall quality of life score. Overall, participants who reported higher scores on the challenging behaviours (individuals with ID needs) and had more changes to their day-to-day activities due to caregiving needs (caregivers needs) reported higher perceived stress in managing adults with ID and their own needs (Biswas et al., 2017; Gauthier-Boudreault et al., 2017; Hubert, 2011; Rapanaro et al., 2008). Nevertheless, neither of these stressors significantly correlated with the caregivers' tendency to move the individual with ID out of their family home, even though there was a significant impact on the perceived stress level.

Stress Response

Regarding perceived stress managing adults with ID needs scores, only 10% of the participants reported a *neither feeling stress or stress free (neutral)* score in managing individuals with ID needs. In comparison, 83% of the participants reported feeling somewhat stressed and more stressed. On the other hand, about 40% of the participants reported a

feeling stress or stress free (neutral) score in managing their day-to-day needs. A high proportion of participants reported feeling some level of perceived stress in managing the adults with ID compared to the proportion of the perceived stress managing their own needs. It may be interpreted that the perceived stress for managing adults with ID and the caregivers' needs can be assumed to be different, even though high perceived stress in managing adults with ID scores significantly correlated with high perceived stress in managing their needs. Higher perceived stress managing the adult with ID and their own needs scores were significantly correlated with higher caregivers' future fear (more fear than hope), higher challenging behaviours, more extent of changes to the participants' day-to-day activities due to caregiving needs, higher maladaptive coping strategies, and lower social satisfaction. Additionally, higher perceived stress in managing adults with ID scores were significantly correlated with lower resilience scores.

Regarding the WHOQOL-BREF measures, a higher proportion (49%) of the participants reported *good* and *very good* quality of life, 32% reported *neither poor nor good*, and about 19% reported *very poor* and *poor*. All the physical, psychological, social and environmental domains means were significantly lower than the normative (general resident of sample in Singapore) means (Cheung et al., 2017). The difference could be interpreted as the caregivers of adults with ID reporting significantly less satisfaction with their essential aspects of life than the general population in Singapore. The significant differences aligned with the previous studies that caregivers of individuals with ID score lower on quality of life compared with the non-caregiver population (Mitter et al., 2019; Werner et al., 2013). This sample's score was also consistent with a previous study in which caregivers scored highest in the physical health domain compared to other domains (Chou et al., 2007). Social domains, such as the satisfaction with personal relationships and social support, were reported to be the lowest among the physical health, psychological and environmental domains. The social

domains, in particular, need further emphasis and exploration to understand the impact of social satisfaction on the overall quality of life, compared to physical and mental health domains (Grey et al., 2018; Werner et al., 2013).

In terms of the correlations, participants who reported lower overall quality of life scores (item 1 of WHOQOL-BREF) were more likely to be from a lower household income, reported lower ability to bounce back from stress (resilience), lower social satisfaction, more fear than hope about their future, and more changes to their day-to-day activities due to caregiving needs. In terms of perceived stress, participants who reported lower quality of life scores reported higher perceived stress in managing adults with ID and their needs and vice versa.

Given that the age of the adults with ID in this sample ranged from 20 to 47 years old, 96% of the participants' responses were also relatively distributed across PTI score 1 (No, I have never thought about it) to score 4 (I have thoughts about it and enquired but have not done anything yet). Three participants indicated a one-point change towards the out-of-home placement within the 6 to 9 months, while the rest had no changes to the PTI score. No participant indicated a lower score than the initial PTI score and no crisis-driven placement within the 6 to 9 months. The findings indicate that while most participants had not taken any concrete action towards out-of-home placement, they might have given considerable thought to the matter. The possible factors that collectively and significantly influence higher PTI scores (moving towards out-of-family-home placement) were participants who reported lower household income, lower resilience score, lower satisfaction with social support, higher perceived burden in managing their day-to-day needs and lower quality of life scores.

Despite a negative trend, this study found no significant correlation between increased challenging behaviours and lower overall quality of life scores. Similarly, there were no significant correlations between out-of-the-family home placement with factors related to the

stressors (such as challenging behaviours and changes in the participants' day-to-day activity due to caregiving needs) and perceived stress in managing their needs scores. This lack of significant correlations between the stressors and the perceived stress and adaptation outcome aligns with the Lazarus and Folkman (1984) model. The model suggests that the increase in stressors, such as those related to the individual with ID and caregivers' needs, does not necessarily lead to the proportional increase in perceived stress levels and placement tendency. The relationship between the stressors and stress response further justifies that protective factors can mitigate the perceived stress response; not all caregivers with the same intensity of stressors would perceive a similar stress level (Shahrier et al., 2016; Momtgomery et al., 2009; Hastings et al., 2001; Dunn et al., 2001).

Interestingly, even though the scores between the perceived stress in managing adults with ID and their own needs are significantly correlated, the higher tendency to move towards placing the adult out of their family home only significantly correlated with higher perceived stress in managing caregivers' needs. The needs of individuals with ID can vary based on the support they need (ID severity level). Only when the demands for providing care for adults with ID start affecting the caregivers' day-to-day activities will there be a higher possibility that the caregivers may move towards placing the adults with ID out of their family homes. In other words, even if the demand for caregiving is high, as long as the caregivers are coping with their protective factors, there are lower chances of the caregivers placing the adults with ID out of their family homes. The significant role of caregiver's support in the decision-making process underscores the importance of their role. Factors such as the feelings of guilt, the family attitude (values) and support played a significant role related to the out-of-home placement compared to factors such as the child's support resources, functional level and age (Kandel et al., 2005).

Protective Factors

The protective factors will be discussed in terms of two categories: the factors that were and were not significantly correlated with the stress responses (perceived burden managing individual with ID and own needs, overall quality of life, and placement tendency).

The protective factors, including household income, social satisfaction, coping style (non-avoidant behaviours), resilience, and future hope (more hope than fear) indicators, were significantly correlated with the stress responses. These findings underscore the crucial role of these protective factors in understanding caregivers' adaptation. For instance, a caregiver who reported higher household income was more likely to report the presence of a helper, higher ability to bounce from stress, and satisfaction with social resources. These factors could be critical indicators for a better quality of life and a lower tendency for the participants to place their child out of their family home environment. It is consistent with the theme related to financial burden (Ellman et al., 2020; Grey et al., 2018). Emerson et al. (2005) stated the need to minimise poverty as one of the predictors of better quality of life, and it was one of the least researched factors.

The means of the frequency and satisfaction for each type of support (emotional, instrumental and informational) and sources (family, partner, friends, and community) were significantly different between the sample and normative (the general resident of the sample in Spain), except for community-based support. It could be interpreted that the participants in this study reported receiving significantly less support and satisfaction than the general residents in Spain, except for community-based support (Garcia-Martin et al., 2016). For the community-based support, the participants of adults with ID reported higher frequency and satisfaction than the general sample in Spain, but the differences were not statistically significant.

Participants who felt more satisfied with the support they received correlated also reported higher household income, received more frequent support, had more ability to bounce from stressors (resilience) and had more hope than fear. Higher social satisfaction scores were significantly correlated with all four stress responses (lower perceived stress managing adults with ID and own needs, higher overall quality of life and lower tendency to place the adult with ID out of their family home). Social satisfaction was the only factor significantly correlated with all the stress responses and could be interpreted as one of the critical factors that may indicate the caregiver's stress perception.

Overall, participants reported receiving less support and being less satisfied with the support received compared to the general population in Spain (Garcia-Martin et al., 2016). At the same time, social satisfaction could be one of the mediating indicators of stress response as it significantly correlates with all stress responses. This aligns with the findings from the previous studies that there was a consistent theme that social dissatisfaction was reported as one of the main concerns for caregivers caring for individuals with ID (Kanthasamy et al., 2024; Grey et al., 2018). Dada et al. (2020) highlighted that satisfaction with social support is a subjective account based on the outcome of the intensity of the stressors (caregiving demands) and perceived stress (stress outcome) and environmental factors such as the family members, facilities and disability services were taken into account as part of the social support.

With the Brief COPE measures, the mean scores of the coping strategy, for both adaptative and maladaptive, were similar to those of caregivers in the United States who have been caring for individuals with autism (Lee et al., 2019). Higher scores on the coping mechanism that was categorised as maladaptive were significantly correlated with scores where participants reported higher fear than hope about the future, more challenging behaviours, and stress responses such as perceived stress in managing adults with ID and own

needs. It could be that caregivers who tend to be more fearful about the future and caring for adults with a higher frequency of challenging behaviour would adopt more maladaptive coping mechanisms or vice versa, leading the caregivers to have higher perceived stress in managing adults with ID and their needs. However, there was no significant correlation between the maladaptive coping and placement tendency scores, even though positive trend scores were reported.

Regarding the resilience score, there was no significant difference between this sample and the normative (undergraduate students and primarily female participants in the United States) means (Smith et al., 2008). To the author's knowledge, no study has been conducted regarding the differences in resilience between caregiver and non-caregiver populations. A significant association between trait resilience, which moderated caregiver stress and personality traits in the caregiver population has been reported previously (Iacob et al., 2024). Therefore, resilience is an innate trait of an individual and may not differ between the caregiver and non-caregiver population. In this study, higher scores on resilience significantly correlated with lower scores on fear related to the future, higher frequency and satisfaction with the support received, and higher scores on the positive aspects of caregiving, and vice versa. The more resilient a caregiver is (ability to bounce back from stressful events), the more positive perspective of their caregiver role. Caregivers with higher resilience also reported significantly less perceived stress in managing adults with ID, higher quality of life, and a lower tendency to place the adult with ID out of their family home. This outcome aligns with the systematic review findings that resilience correlated with better quality of life and less emotional distress (Palacio et al., 2020; Iacob et al., 2020). Resilience is also associated with improved communication and seeking appropriate social support (Ike et al., 2024; Iacob et al., 2020).

With respect to the future anxiety score, there were significant differences between this sample and the normative (mothers who are caregivers of their children with ID in Iran) means (Torfayeh et al., 2020). The participants in Singapore were significantly less anxious than the mothers in Iran. This study had a mixture of male (12%) and female (88%) caregivers, whereas the study conducted in Iran had mothers only. Females scored higher in terms of future anxiety compared to male caregivers (Bujnowska et al., 2019). Based on the correlations, participants who are more fearful about the future may tend to have difficulty bouncing back from stressful events, have a higher tendency to report challenging behaviour, may have more remarkable changes to their day-to-day routines due to caregiving needs, have a tendency to report lower satisfaction with the support received, and to cope with maladaptive coping strategies. Participants who were more fearful about the future may report significantly higher perceived stress in managing the adults with ID and their needs as well as lower quality of life, but this did not significantly correlate with the placement tendency to place their adult child out of the family home. In other words, caregivers who are anxious may not necessarily place their adult child out of their family home but may report a higher frequency of perceived stress in managing the situation and a lower quality of life.

On the other hand, the factors that did not significantly correlate with any of the stress responses are the presence of a domestic helper, the increase in the frequency of the social resources received and adopting adaptive coping mechanisms (such as the practical approach to cope with stressful events, emotional support, emotional expression, humour, acceptance, and religion-focused), and positive aspects of caregiving (perceived sense of satisfaction and reward that was gained from the caregiving experience). There were positive correlations between these factors, which may measure similar "positive" constructs. Specifically, there was no significant differences between the positive caregiving constructs between this sample and family caregivers who lived and provided caregiving for their relatives (Tarlow et al.,

2004). Caregivers may report both positive and negative experiences related to the caregiving situation (Kanthasamy et al., 2024; Ellman et al., 2020), even though there were reports about fulfilment and pride moments (Rapanaro et al., 2008; Hubert, 2011; Gillan et al., 2010). Factors such as distress and grief, personal growth, challenges, rewards and coping strategies, and resources were part of the themes related to pleasant and unpleasant caregiving experiences (Young et al., 2020). The lack of significant correlations may also suggest that these factors may not have a significant direct effect on the stress responses. But given that they are significantly related to other independent variables that do predict the stress response, they could be considered to have an indirect effect on the stress responses. Both the direct and indirect effects underscore the complexity of caregiver stress in caring for an adult with ID in the community and the need for a more nuanced understanding of the factors that contribute to it.

In conclusion, although each adult with IDs' needs varies depending on their strengths and weaknesses, the difference between the actual caregiving demands (stressors) with the perceived stress in managing those demands (stress response) and, subsequently, the influence on the placement tendency decision-making (adaptation outcome) based on the protective factors was justified by Lazarus and Folkman's (1984) TMSC (Figure 5.14). The pattern of significant correlations between the stressors and protective factors with the stress response and adaption outcome was mapped. The stressors related to the demands of managing the adult with ID and caregiver needs and the impact of the perceived stress were evident. Specifically, the higher the extent of changes in the caregiver's day-to-day tasks due to the caregiving needs (caregiver demands), the lower the overall quality of life (life is less satisfying and meaningful). The implication of the protective factors such as higher household income, higher social satisfaction, low mental or physical disengagement (avoidant) coping mechanism, ability to bounce from stress and having more hope than fear

about the future may mitigate the impact of the stressors on the stress response. Reflecting on the possible protective factors that did not have any significant correlation with any of the stress responses, such as the presence of domestic helper, increase in the frequency of the social resources received, adopting adaptive coping mechanisms and positive caregiving experience, could be interpreted that these may have an indirect impact on the decision making related to the placement tendency. For example, receiving more social support does not equate to better coping, but it is more about the caregiver's perceived satisfaction based on the support received in managing their day-to-day needs.

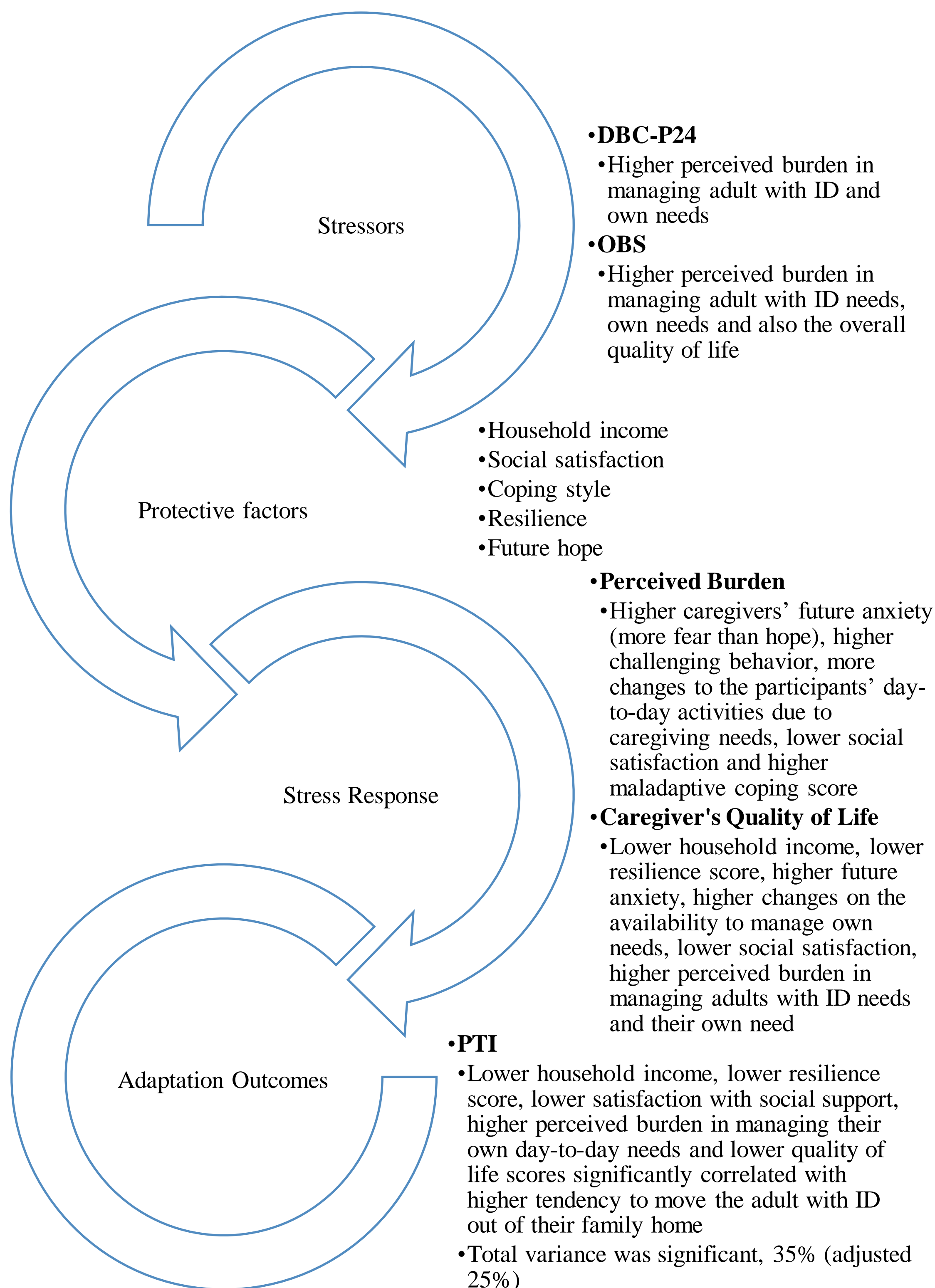
Another scenario could be that if one parent needs to stay home to care for an adult child with ID who requires substantial support and cannot be accommodated in an adult disability centre, the family would need to undergo an adaptation. Due to the high living expenses in Singapore, families with dual incomes typically enjoy a more favourable financial situation. However, if one of the parents leaves paid employment, the family will experience a decline in household income. Additionally, if the caregiver perceives a lack of support from his/her network or struggles to recover from stress, it can lead to dissatisfaction with his/her caregiving experience. Although beneficial factors such as receiving support from a helper, community, or extended family and engaging in problem-focused coping strategies may seem advantageous, they may not fully alleviate the caregiver's feelings of discontent. Adapting a mental or physical avoidance strategy in response to the situation might further escalate the caregiver's perceived stress, exacerbating their challenges. Hence, this primary caregiver has a higher tendency to report elevated levels of stress and a diminished quality of life, potentially considering the option of relocating their adult child out of the family home if caregiving responsibilities significantly disrupt their daily routines.

Depending on the care arrangement, the dynamic interaction between the stressors and perceived stress can be mitigated with the protective factors. The findings from this study

suggest that the decision to place the adult child with ID out of their family home occurs only when the caregivers are not coping with the demands. The following chapter, Chapter 6, integrates the outcome of the scoping review (Chapter 2), the findings from the case studies of caregivers caring for individuals with ID transitioning to adult services (Chapter 4) and the findings from this cross-sectional study of caregivers caring for adults with ID (Chapter 5), to provide a suggested typology of caregiver profiling for clinical use.

Figure 5.14

Adapted Lazarus & Folkman's 1984 Transactional Model of Stress and Coping (TMSC) for caregivers caring for adults with ID.



Chapter 6

General Discussion

This project consisted of three investigations: a scoping review, a series of longitudinal case studies, and a cross-sectional quantitative study. The scoping review examined existing literature on the sources of caregivers' objective burden, support systems, coping mechanisms, positive aspects of caregiving, and quality of life. It specifically focused on family caregiver adaptation during the transition to adulthood for individuals with ID. Study 1 sought to understand the caregiver adaptation process during the first two years of caring for adolescents with ID who had recently graduated from special education schools. It also explored caregivers' decisions regarding future care arrangements, considering options for care at home versus out-of-home placements. In contrast, Study 2 concentrated on family caregivers' current stances or perspectives on the placement decision for managing adults with ID who were receiving clinical services. The overall goal was to assess the variability and impact of prolonged caregiving on family caregivers providing care for adolescents and adults with ID in Singapore.

The selection of variables for this project was informed by Lazarus and Folkman's (1984) TMSC. This model was used to assess the decision-making process related to long-term placement and the factors related to caregiver adaptation. Study 1 provided the findings from a series of explanatory sequential case studies (quantitative data collected first, followed by qualitative data) conducted over two years. The outcomes of Study 2 were derived from a quantitative cross-sectional study of family caregivers whose family member with ID was receiving treatment from a specialised mental health service, the Institute of Mental Health (IMH).

In this chapter, based on the findings from the project, different types of transition (transition pyramid) and the future direction of caregiver typology and policymaking, which

hold significant implications for caregiver adaptation, are outlined. The material in this chapter not only enhances the understanding of each caregiver's unique and multi-faceted situation and moderators (protective factors) assessed in this project, but also provides practical strategies for mental health professionals.

Adaptation of Family Caregivers of Adolescents with ID and Types of Transition

The case study series focused on the family caregivers of adolescents over the two years after the family member with ID left secondary school. Previous literature has reported that the first two years of transition may not cause significant prolonged stress. Gur et al. (2020) reported that caregivers caring for individuals with ID who are above 31 years old reported more negative feelings and lower life satisfaction compared to caregivers caring for an individual with ID below 30 years old. The prolonged caregiver strain, which may affect the caregiver's physical and mental health with the lack of social and financial support, could be the combination of factors that influence the caregiver's overall quality of life (Kanthasamy et al., 2024). The impact of protective factors was discussed in Chapter 4, which mapped to Lazarus and Folkman's (1984) TMSC. However, a more detailed understanding of the processes involved in the adaptation process over the first two years for the caregivers of the adolescents may be suggested by the information obtained from the two caregivers who provided qualitative data on their experience.

Based on the qualitative interview, the information shared by participants AB and CD has been mapped with Ferguson et al. (1988), which shows three distinct types of transition to adulthood (i.e., bureaucratic, family life, and status transitions). Firstly, the bureaucratic transition was the change from special school to adult service. Based on the interview, it was understood that AB could tolerate the increased frequency and intensity of challenging behaviours most of the time. This tolerance level, a critical factor in managing challenging

behaviours, refers to the extent to which AB can endure or accept these behaviours without feeling overwhelmed and resorting to reactive management. AB's tolerance level was primarily consistent, as indicated by the perceived burden scores across the four timelines, with occasionally feeling overwhelmed when she could not manage the situation regarding Deby. In addition, AB reported feeling tired after work, which led to her and Deby spending time together only in the evenings, although they would be engaged in separate activities. Hence, AB's strategies for managing challenging behaviours could be described as primarily reactive or crisis-driven, as there was no report during the interview of proactive engagement in teaching Deby any particular skills. AB might use reactive management for various reasons; AB might generally be able to tolerate the challenging behaviour, lack of actual or perceived support to teach Deby the replacement behaviour, Deby's control over AB (Deby refusing to listen to AB), or a lack of a persistent and consistent approach which does not sustain the effectiveness of a proactive approach to management. AB chose to engage Deby in community activities once a week and mainly managed Deby with home routines and her work-from-home arrangement. AB shared that although she is aware of the range of activity engagement offered by the adult service centre, she had perceived less benefit for Deby participating in those activities. In other words, AB did not "complain" that she did not receive enough support, and at the same time, she demonstrated tolerance for Deby’s challenging behaviour and could still manage the current situation at the point of the interview. However, the risk would be if the challenging behaviours progressively increase in the future to the extent that AB is unable to continue tolerating the behaviours.

In contrast, CD had become a "support worker" as Cindy transitioned to adult services. CD consistently used proactive management techniques (Gillan et al., 2010; Ellman et al., 2020) to help manage Cindy's day-to-day needs, including initiating counselling sessions for Cindy, being the co-regulator during anxiety episodes and teaching her to use public transport

through progressive exposure tasks. CD removed Cindy from the adult training program after realising it was not the right fit. After multiple unsuccessful attempts to engage Cindy in the community setting, CD embraced the "support worker" role by creating a home baking training and business to help generate income for Cindy and actively advocated for Cindy. While Cindy's progress and CD's role as a "social worker" have been fulfilling, it requires ongoing effort with financial and emotional strength to initiate and sustain progress in the home-based program. CD mentioned that her strengths would be managing these demands through her household's financial stability and delegating responsibilities to her established social network.

Secondly, the family life transition, a pivotal phase in the journey to adulthood for the caregivers and other family members, was heavily influenced by the additional support or service received from adult services or other sources. The role of adult services in this transition cannot be overstated. Keeping the adolescent engaged with meaningful community activity or employment after graduating from school could be one of the critical factors in determining the level of caregiver involvement needed in managing adolescents with ID transitioning into adulthood. For example, adult services such as activity, training, or employment engagement are the six-hour replacement of school time. At the same time, the caregiver could take some time off from the caregiver's duties. However, the adolescent with ID may not fit into the services, or the caregivers might not engage the adult service full-time. In these cases, the caregivers need to solve the situation to provide meaningful engagement and supervision for the adolescent with ID at home, depending on the functional stability of the adolescent with ID. For instance, in AB's situation, after COVID-19, she had to request to maintain a work-from-home arrangement as one of her intentions was to supervise Deby at home. Regarding resources related to support, AB shared that she would hope for more practical support to supervise Deby at home when she needs to run errands. Deby mainly

does not allow AB to leave home without her, which is consistent with AB’s reported increase in day-to-day activities due to caregiving needs over the past two years. The dependency of Deby on AB could be interpreted as AB having little personal time to attend to her day-to-day needs due to the lack of resources available to delegate the caregiving responsibilities.

In contrast, CD emphasised that she had to focus and dedicate more of her time to occupy Cindy, such as in public transport and classes during the initial phase of the transition. The extent of changes in CD’s day-to-day activities due to caregiving needs reduced across the two years, indicating that Cindy's needs were progressively reduced, and consequently, CD's day-to-day needs related to caregiving duty were lessened. She had more "me time", and her daily activity did not revolve around Cindy, as she had a domestic helper to provide supervision when needed. Both the adolescents with ID, Deby and Cindy, were not engaged five days a week with any adult services (but they were known to adult services), and this had a spillover effect primarily on the primary caregivers' routine rather than the family as a whole. The difference was that AB hoped for more support than she currently has to delegate the caregiving duty, as she did not have a domestic helper. CD managed and trained Cindy to the extent that she could delegate the caregiving duty to the domestic helper when needed.

Thirdly, the status transition indicates the change from child to adult status. The status transition for the population with ID was outlined as sensitively and as practically as possible in this project in order to be able to generalise across all levels of support for adolescents with ID. Both participant AB and CD accepted their child's diagnosis of ID (Rapanaro et al., 2008) and the need for a supervised environment. AB and CD took into consideration based on their understanding or knowledge related to Deby’s and Cindy’s needs, such as the severity level of the ID diagnosis and comorbidities, their ability for independent living, the intensity of supervision needed, and the vulnerability risk in order to develop the tentative plan for long-

term care during the transition period to adult services. Since most individuals with ID may need some form of supervised environment, only a few would be able to manage independent living for the status change to adult to occur. Hence, instead of focusing on the clear-cut definition of "adult" for an individual with ID, the status transition can be viewed as a phase that enhances the training or learning skills to prepare adolescents, caregivers, family members and professionals in adult services for long-term placement planning (Kanthasamy et al., 2024; Nucifora et al., 2024; Murphy et al., 2011).

The outcome of the transition to adulthood process is one of the crucial drivers that affects the outcome of the long-term management plan. For example, if the adolescent with ID has been meaningfully engaged and their functional ability has been maximised, the chances of them living in the community could increase, given the support from the family member (similar to participant CD's profile). On the contrary, if the adolescents with ID were not meaningfully engaged, which could be one of the possible triggers for the increase in the challenging behaviours, and caregivers are unable to cope with the caregiving demands, the chances of them continuing to live in the community with their family members would be reduced. The alternative placement would be an adult disability home or the mental health institute in Singapore (McIntyre et al., 2002).

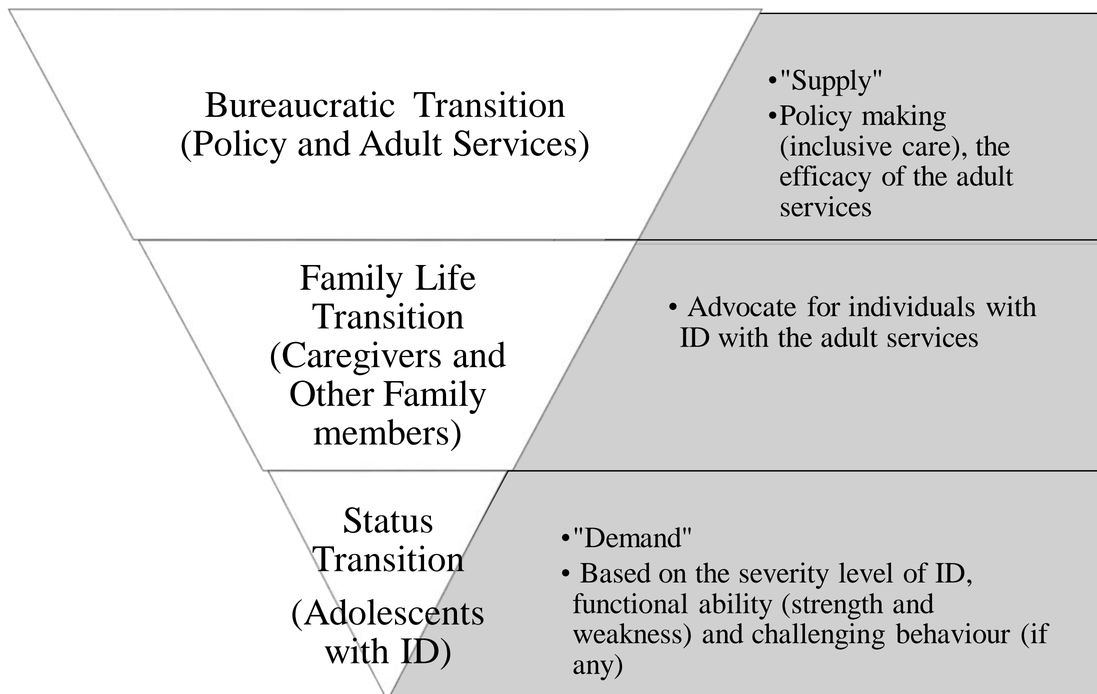
In summary, the qualitative data findings from Study 1 align with the three different transitions (bureaucratic, family life, and status), representing three different tiers of groups involved in the transition process. These groups are interlinked and can be seen in the Singapore context (Figure 6.1). At the top of the pyramid is the bureaucratic transition, representing the system, for example, the government policy, level of engagement of the adult service in the community and caregivers' concerns about the expertise of individuals working in the adult services. The bottom layer of the pyramid is the status transition referring to the adolescent with ID's support needs, for example, the severity level of ID,

functional ability (strengths and weaknesses), adolescents with ID's needs and wants, and challenging behaviour (if present due to the biological changes related to puberty or the transition gap after graduating from special school). The middle layer represents the transition in family life. The family life transition targets the primary caregiver and other family members directly or indirectly involved in the transition process.

Moreover, it has to be an inverted pyramid, and the governmental policy should be inclusive, as broad as possible, to capture all levels of support and integrated holistically to align with the needs of caregivers and individuals with ID. The outcome of the balancing between the adolescents with ID needs and the efficacy of the adult service system and professionals in engaging adolescents with ID would determine the extent of the adaptation needed for the family life transition. In other words, the primary caregiver acts as the bridge advocating between the "supply" (adult service system) and "demand" (the needs of adolescents with ID) and as a decision-maker across the lifespan (Kim et al., 2020). Hence, the role of a family caregiver is significant. Therefore, many resources have been allocated to support them (Ee et al., 2022; Riches et al., 2023; Parish et al., 2003), but does giving more resources to the caregivers significantly help them to cope with the prolonged caregiving demands? The increase in life expectancy, especially for those individuals diagnosed with a mild level of ID, does warrant the caregivers' additional long-term planning (a system to support the individual with ID when the caregivers are unfit or when they pass away).

Figure 6.1

Transition Pyramid (Adapted from Ferguson et al., 1988)



Family Caregivers of Adults with ID and Out-of-Home Placement

The second study was a cross-sectional study of family caregivers of adults with ID. These adults lived in the community with their family members and received clinical services from IMH. The significant correlations of the outcomes from Study 2 need to be mapped with the findings from the case studies, which will highlight the possible similarities and differences between caregiver adaptation managing adolescents and adults with ID. In addition, the question raised in Study 1 is: Does giving caregivers more resources significantly help them cope with the prolonged caregiving demands? This question was explored in Study 2 using a quantitative approach.

Based on the findings of the interviews conducted in Study 1, both caregivers shared that providing caregiving does cause some changes in their day-to-day activities, especially during the transition to adult services. AB had to adapt and sustain her work-from-home

arrangement. CD invested her time and effort in proactive involvement in teaching community skills during the transition period to support Cindy. The demands, such as the changes in the day-to-day tasks and increase in challenging behaviours due to the lack of adult services, may contribute to the amount of perceived stress that was reported by caregivers in Study 2 (Biswas et al., 2017; Gauthier-Boudreault et al., 2017; Hubert, 2011; Rapanaro et al., 2008). There is a lack of data to compare the extent of the perceived stress caused during (Study 1) and after (Study 2) the transition in this project. However, the successful transition may be associated with the adaptation of individuals with ID and their caregivers.

In terms of the stress response, Study 1 captured two different profiles of caregivers that have different transitions to adulthood, goals towards independent living and coping strategies, impacting their quality of life. Based on the outcome of Study 2, there were significant differences in the quality of life scores between the general population and the caregivers of adults receiving treatment in IMH. Caregivers who care for adults with ID who are also receiving treatment in IMH, Singapore, may score significantly lower in quality of life compared to the general population. However, because Study 2 used a clinical sample, these findings cannot be generalised to the general caregiver caring for adults with ID in Singapore. Based on the scoping review's outcome, it is consistent that caregivers from eight of the 12 studies reported perceived burden such as feeling physically and mentally tired, frustrated, and helpless. Poor quality of life may result from the caregiving situation when decision-making is complex, and caregivers may feel restricted in their day-to-day activities (Kanthasamy et al., 2024).

Regarding the placement tendency, AB and CD were transparent in their decision, stating that the handover would only occur when they could no longer care for their daughters due to their own physical limitations. AB was more worried about the future than CD, but

both were committed to their daughters' well-being. Deby was described as someone who needs more support in daily and community living skills than Cindy. AB directed her plans for her daughter more towards an adult disability home, whereas CD was planning for a family home under the supervision of extended family members. These findings can be mapped with the quantitative findings from Study 2. In study 2, only three participants reported a change in the placement tendency index within the 6 to 9 months period, and 96% of the caregivers' responses were distributed across scores between 1 (No, I have never thought about it) and 4 (I have thoughts about it and enquired but have not done anything yet). This suggests that it is a consistent theme that the out-of-home placement is initiated when the caregivers cannot cope with the caregiving needs and based on the individual with ID's independence level (Lee et al., 2019).

The protective factors such as household income and perceived satisfaction with the adult services in Study 1 were consistent themes between caregiver AB and CD. AB and CD were assessed to have financial stability and shared concerns about adult services, but they still wanted to engage in the services based on their daughters' needs. The importance of financial stability and service satisfaction cannot be overstated, as they are crucial for the well-being of caregivers and individuals with ID. Across the outcome of the scoping review and Study 2, satisfaction with social support was a consistent theme. On the other hand, the frequency of social support did not significantly correlate with any outcome measures, such as perceived stress, quality of life and placement tendency. The lack of a significant correlation between the frequency of social support reinforced the theme that it is not about caregivers getting more social support (even though it could help to a certain extent), rather it is their feelings of satisfaction with the support they received. Although the factor related to financial stability was not emphasised in the outcome of the scoping review, it was a consistent factor across the outcomes from Study 1 and 2.

In terms of future hope rather than fear, AB reported her concerns about the potential abuse in the adult disability home. Hence, she decided to care for Deby until she and her husband could no longer continue with the caregiving. The findings from Study 2 reflected AB's concern about future hope and how she mitigated her concerns by visiting a nursing home. The outcome of Study 2 highlighted that anxious caregivers may not necessarily place their adult child in an adult disability home due to potential concerns such as abuse. High future hopes were related to lower perceived stress and higher quality of life and vice versa. In other words, caregivers who display more fear than hope about the plan may not place their child out of their family home placement and may be experiencing stress, which may impact their quality of life.

Overall, the findings from this project suggested that the amount of caregiving demands (amount of changes in the caregivers' day-to-day activity) is not proportionally related to the stress response reported (perceived burden and caregivers' quality of life) and is mitigated by protective factors such as household income, satisfaction with social support, and future hope in caregivers caring for adolescent and adult population. The need for practical support, which has to be "sufficient" according to the caregivers' needs and situation, is highlighted across all three investigations.

A Typology of Family Caregivers of People with ID and Implications for Policy Making in Singapore

Building on Lazarus and Folkman's (1984) TMSC, the outcomes from this project, and the proposed transition pyramid (Ferguson et al., 1988), it is crucial to identify the caregivers' needs. The assessment, whether conducted by the transition or community support team or even in hospital settings, is instrumental in understanding and mapping the available services

in the community ("supply") and the level of support needed for the individual with ID ("demands").

Based on the data collected, this project found a consistent theme that caregiver dissatisfaction and maladaptive coping mechanisms could be possible causes of increased perceived stress, regardless of the caregiving demands. Therefore, it is important to understand the caregiver's approach as they balance their needs based on two roles: family member and caregiver. However, the typology also holds the potential for generalisation in future studies, offering hope for further impactful research.

Therefore, a caregiver typology is proposed as specific management plans (e.g., psychoeducation or mindfulness-based intervention) may not sustain the effectiveness of a one-size-fits-all solution (Gonzalez-Fraile et al., 2019; O Donnchadha, 2018). The management plans may not meet all the needs of the caregivers due to the demographic differences and multifaceted factors assessed in this project. Demographic factors such as the caregiver's age (risk factor related to ageing), household income (need for double income in most Singapore households (Quah, 2016), other caregiving responsibilities (more than one child with ID and/or caring for a spouse or parents), gender (may influence the caregiving approach due to gender differences; Grey et al., 2018) and the individual with ID's severity level (functional ability depending on the strength and weakness; Park et al., 2019; Barrio et al., 2016) are factors that may not be manipulated. The outcome of Studies 1 and 2 suggested that household income may significantly influence the caregiver's stress response.

The rationale for the caregiver typology template would be for it to be used for early identification of the possible risk in clinical and community settings and to redirect to the appropriate support as part of early redirection to maximise the available resources in the community. Based on the proposed caregiver typology, the caregiver's approach may be assessed based on two factors: (a) proactiveness in managing individuals with ID needs

(proactive versus passive), and (b) caregiver's perceived ability to care for an individual with ID needs, with or without the adult services.

Proactiveness is based on the caregiver's awareness of the individual with ID's needs and the ability to initiate actions to teach the needed skills to maximise their independence level and manage challenging behaviour. For instance, teaching to manage small grocery lists, travel independently to familiar places, and manage the triggers related to the challenging behaviour as much as possible. The term 'passive approach' describes caregivers who may not have a thorough or adequate understanding of the individual with ID's needs, have inappropriate (too little or much) expectations of the individual with ID (for instance, to keep the individual with ID "happy" with minimal activity demands or hope that their adult child will be independent to care themselves), have higher tolerance for challenging behaviour, be caregivers engaged with other day-to-day tasks (unable to optimise the engagement with individuals with ID due to their other day-to-day needs), or be unable to guide and teach the needed skills to manage the challenging behaviour (for various reasons).

The second proposed factor is the caregiver's perceived ability to care for the individual with ID's needs, with or without adult services. Caregivers who want to engage with adult services as caregivers believe it may benefit the individuals with ID to be socially stimulated and to delegate the caregiving hours. Another possible scenario would be that the caregiver wants to engage with an adult service, and attempts have been made to re-engage with any possible services, but the individual with ID refuses to attend. On the other hand, the caregiver's perceived ability to care for the individual with ID's needs without adult services is also considered. For instance, caregivers who did not initiate further action and coped by engaging the individual with ID at home when the individual with ID did not want to attend the adult centre, because there is no right fit and/or they have had unpleasant experiences

with the adult services. In other words, these caregivers did not initiate any further action to engage their child in adult services for various reasons.

It should be emphasised that maybe there is no right or wrong approach to managing adolescents or adults with ID living in the same household as their families. However, the proactive approach, as opposed to the passive approach, is more likely to reduce the risk of crisis due to challenging behaviours. The emphasis proposed here is that caregivers should be given enough information to support their decision-making. Informed decision-making and redirecting them to the resources they need or want as early as possible may aid the caregiver in being more in control of their situation. Being in control also may help the family caregivers feel empowered rather than helpless while uncertain about waiting for community services.

The support and risk for each profile group based on these two factors is outlined as follows (Figure 6.2):

1. Proactive, engaged with adult service (similar to CD's profile)

There are significant benefits to this preferred combination, where the adult service and caregiver's active involvement would sustain the individual with ID being meaningfully engaged in community-based activity. The caregiver's heightened awareness of the individual's needs and ability to provide timely intervention would be crucial. This combination may have the lowest risk, primarily related to situational triggers such as the individual's reluctance to attend an adult centre, changes in the family dynamic or adult centre, like the loss of a caregiver or family member, and changes in routine. Support would be provided to the caregiver or family members with the help of the professional in the adult service to assess the trigger and suggest a possible management plan promptly.

2. Proactive, but does not engage with adult services

The worst-case scenario for this type of caregiver may be that the caregiver, despite the caregivers' best efforts, feels overwhelmed in sustaining the effort to consistently engage the individual with ID, especially when there are high caregiving needs. These caregivers need more social support to delegate the caregiving duty, to be educated on the importance of self-care, and to be linked with a caregiver group where they may find solace and support. Additionally, these caregivers can be encouraged to consider adult services (if there is a right fit for the individual with ID to attend) to delegate the caregiving hours. The support system should be substantially adequate to cope with the caregiving demands.

3. Passive, engaged with adult service (similar to AB’s profile)

The worst-case scenario for this type of caregiver will be if the caregivers are engaged with other day-to-day tasks (fewer resources and mindset that did not prioritise engaging the individuals with ID proactively in the home environment for various reasons) and the individuals with ID are unable to sustain the placement (due to challenging behaviour) or do not want to attend the adult centre (lack of motivation). Another combination would be that the individual with ID can attend and regulate their behaviour at the adult centre but there is an increase in challenging behaviour (such as aggression) in the home setting. The third combination of this situation would be increased challenging behaviour in adult centres and home settings for various reasons. The possible risk would be that the caregiver would need practical support such as respite and an intensive behavioural management plan to manage the sustainability of the placement in the adult centre and reduce the challenging behaviour in the home setting. The effectiveness of the behavioural management plan would depend on the caregiver's availability or readiness to implement the plan in the home setting and the possibility of reducing the challenging behaviours. As this poses a risk to the caregiver or due to the significant caregiver stress, the caregiver could "give up" caring for the individual with ID, and the out-of-home placement would be requested. The caregiver would expect practical

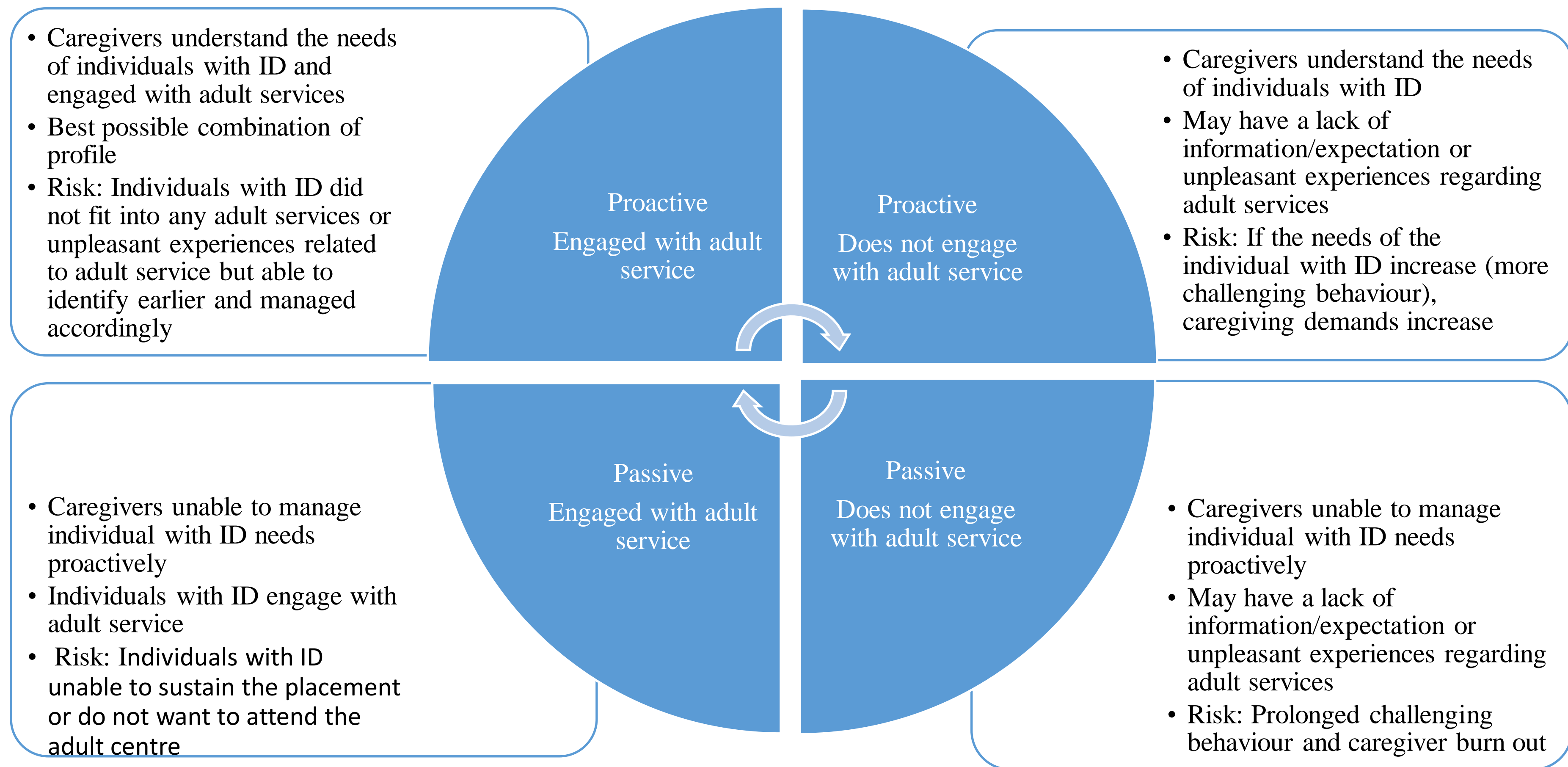
support, but the lack of practical support that can be provided globally (delay in respite care) would reinforce the helplessness and dissatisfaction with the support received from adult services and prolong the caregiver burden (Kanthasamy et al., 2024).

4. Passive, does not engage with adult services

A caregiver with this profile is unable or does not prioritise proactive management and, at the same time, does not want to engage with the adult services due to their perceived understanding of the adult services. These caregivers would be managing the individuals with ID in the home environment and possibly not be known to any adult services for active follow-up. The worst-case scenario here would be an increase in challenging behaviour if the individual with ID was not engaged meaningfully, an increase in refusal to adhere to the caregiver's instruction and the person with ID learning to use aggression to communicate their wants in the home setting (prolonged learned behaviour). These caregivers would probably tolerate the aggressive behaviours by passively managing the triggers with the perceived understanding that the adult services may not provide the needed practical support. The possible risk would be that the challenging behaviour will not be addressed over a long period (or relapse of the challenging behaviours or mental health related concerns). Only then, the individuals with ID or the caregivers will become known to the ID services, possibly due to a crisis situation. For example, the neighbours would have made a complaint, or the caregivers would have called the police due to the intensity of the challenging behaviour. It could be possible that the caregivers may feel stuck in their situation for some time due to their perception of no support from the adult services. The feeling of being "stuck" could be significant enough as a driver for the caregiver to "end the suffering" by initiating extreme measures such as homicide and suicide.

Figure 6.2

Caregiver typology



By profiling the caregivers, the possible intervention should focus upstream on recognising at-risk caregivers (who passively engage due to other day-to-day tasks, especially for lower-income groups) and individuals with ID (with high caregiving needs) in the special school to provide regular follow-up and home visits. Such cases should be highlighted to the adult service for high-priority case management. The caregivers could engage with possible practical support (financial support and respite care when necessary) due to the high risk and be instructed in achievable techniques for engaging the individual with ID at home, such as unstructured reward systems and weekend programs that would strengthen the relationship between the caregiver and the individual with ID, inspiring hope by focusing on day-to-day coping, assessing the social support network to delegate the caregiving duty and to employ a domestic helper (if possible), while the adult service manages the challenging behaviours (if any). The caregiver interventions, such as mindfulness-based and psychoeducation, can be provided as a supplement to the proactive engagement. Similar to the approach for individuals with ID, a proactive approach would be recommended as inclusive care rather than a reactive approach by "trying to fix" the caregiver stress and challenging behaviour of individuals with ID when the family member on the verge of giving up their role as caregiver.

An example of case management is that a widowed mother who is ageing and caring for an adult male with a moderate level of ID needs to be supported with routine follow-up by a case manager to ensure activity placement for the individual with ID (meaningful engagement) to reduce the hours of caregiving at home. The caregiver's health needs, financial assessment, social support and long-term placement should be assessed, discussed, and monitored. Therefore, the case manager in the region needs to be trained to provide the needed engagement and support for the caregiver caring for an individual with ID (inclusive care approach) rather than for the caregiver having to approach the specialised ID adult service when she is unable to provide the care for the individual with ID anymore. This

approach may also ensure that most individuals with ID and their caregivers are known to the community service for follow-up and are monitored for the necessary types of support, incorporating an inclusive care approach.

For individuals with ID, it is crucial to note that while it is impossible to 'cure' ID (Shree et al., 2016), a tailored approach can maximise individual functionality and employment skills through continual engagement and exposure to new skills. This approach should strive to identify their strengths and weaknesses and adjust the level of supervision accordingly. The optimal approach would be to create opportunities for individuals with ID, especially for higher functioning individuals, to maximise their ability and independence as much as possible. The case management follow-up fosters an inclusive society and a better quality of life.

On the other hand, for the lower functioning individual with ID, the support for activities of daily living and to lessen the vulnerability risk, the targeted services should emphasise supervision and engagement to maintain their current functioning. Firstly, the policy implementation may focus on the school and adult service agencies to identify the strengths and weaknesses of the individual with ID, categorising and outlining possible pathways of adult services before the individual graduates from the special school. The caregivers should be informed with a personalised communication booklet about the individuals with ID's needs and examples of proactive engagement tailored to each individual in detail (Gillan et al., 2010). Therefore, caregivers and family members can develop realistic expectations of the individual with ID and the possible pathways for engagement at home, adult service, and long-term placement plans. This approach empowers the caregiver with the information and projected plans (Kanthasamy et al., 2024), instilling confidence and capability, and may reduce possible avoidant strategies (physical and mental avoidance).

Globally, the caregiver is expected to advocate for individuals with ID and associate with adult services (Rapanaro et al., 2008). Therefore, the template for the caregiver assessment would include crucial indicators of stressors (such as the extent of changes in the caregiver's day-to-day tasks), protective factors (such as social satisfaction, coping mechanisms, and caregiver's resilience), and the perceived burden score in managing those stressors.

The assessment must be repeated (when necessary) due to the possibility of crisis-driven situational changes and the proposed caregiver typology does not suggest a permanent situation for the caregiver. Caregivers can change according to the stressors (caregiving demands), coping resources and stress response (perceived feeling in managing the caregiving demands). Challenges include the availability of caregivers for the caregiving duties, the caregivers' perceived concerns of adult services in engaging adults with ID, the lack of diverse adult services to accommodate the range of ID level of severity, the individuals with ID’s day-to-day needs and the biological changes triggered by puberty and the transitioning to adulthood affecting the behaviour of the individual with ID. One significant phase in the development of individuals with ID is when they start asserting their independence, (i.e., develop a "mind of their own"). This developmental milestone could impact caregiving needs. Besides that, the caregiver assessment should also be included in the personalised communication booklet, and the appropriate service should be referred for follow-up (if needed).

The current proposed intervention-needs typology is focused on the "prevention is better than cure" approach, with the acknowledgement that caregiving for an individual with ID would be stressful and the focus should be on the "salutogenic framework" (focusing on the factors that support wellbeing and not on identifying factors that cause disease; Young et al., 2020).

Strengths and Limitations of the Current Project

The strength of this project lies in its comprehensive research design. A scoping review was conducted to understand the available resources and information about the caregiver perspective in managing adolescents with ID who are transitioning to adulthood. This review, which set a base for this project, was instrumental in identifying the gaps in this field. The consistent themes regarding dissatisfaction with social support, the uncertainty and waiting period for services, and the lack of information in managing the needs of an individual with ID who has undergone puberty were all highlighted. These factors were then further explored in the subsequent studies, assuming the placement decisions as an outcome of the caregivers' adaptation.

Study 1, the longitudinal follow-up of caregivers managing adolescents who have just left the special school, with the explanatory sequential case studies, enabled the capture of information not assessed in the questionnaires. A caregiver's attitude and caregiving style may play an important part, as highlighted by the outcome of the interviews. Study 1 could be the first to measure challenging behaviour during the transition from special school to adult service in Singapore. Furthermore, Study 2 was expanded to the caregiver adaptation in the clinical settings for caregivers managing adults with ID to understand the caregiver's perspective and factors related to the placement decision. The reliability of the measures in Study 2 was mostly high, indicating that the participant's responses were consistent across the items in the measures.

The outcome of this project with the transitions pyramid, a model that effectively illustrates the stages of transition for individuals with ID, and the caregiver typology, a comprehensive tool for understanding caregiver characteristics and needs, enhances clinical assessment. Realistically, educating caregivers about the formulation of the presenting concern(s) and the proposed management plan(s) may not always lead to the caregivers'

"adequate" understanding. Understanding the caregivers' coping mechanism, such as the need for practical support for caregiving needs. Besides that, the impact of any prolonged learned behaviour(s) of individuals with ID in terms of communicating their needs and emotions can be challenging to modify or replace the behaviour(s). The caregivers may face burnout by then (subjective distress depending on the interpretation of the stressors). Hence, promoting community engagement and inclusive case management were important enough to be emphasised in this project. This project was designed, and the results were interpreted objectively to ensure their reliability and practical application to clinical work was as realistic as possible. Addressing caregivers' "realistic" expectations of themselves and the individual with ID by considering their resources, values and parenting approach could empower them to navigate their caregiver role more confidently and effectively.

Conversely, one of the project's limitations was the recruitment strategy followed for Study 1. But this was due to the impact of COVID-19 restrictions in Singapore. Although Study 1 was initially planned for face-to-face recruitment, the school community did not approve the face-to-face recruitment request. Recruitment conducted via email through school organizations may not adequately convey the investigator's intention and passion for this field. Comparatively, face-to-face recruitment in Study 2 had a more positive response. The importance of human interaction and approach does help to increase the response rate even though no token of appreciation was offered in Study 2.

A limitation for both studies in this project was the low number of participants. Hence, the proposed Lazarus and Folkman's (1984) TMSC could not be tested due to low statistical power associated with the sample size. As most special schools in Singapore conduct their own research, their support for external research can be limited. The sample size for the cross-sectional study (Study 2) of family caregivers of adults with ID was also small, further precluding extensive statistical analysis.

It is important to note that both studies have sampling bias. It is crucial to consider that the caregivers who agreed to participate in the studies may have had the "extra" time, while those with other priorities may not have come forward to participate. The generalisation of the findings from this study could be limited due to this potential sampling bias. This means that the results may not be fully representative of all caregivers managing individuals with ID. The 42% response rate for the cross-sectional study (Study 2) gave some overall understanding that the caregivers may prefer short questionnaires (less time needed to fill in the questionnaires) and may expect follow-up or change in the service from the outcome of the survey. It may be possible to minimise such sampling bias if all the caregivers were encouraged to give feedback as part of a service feedback survey and with the use of shorter questionnaires. Related to this, because the sample size for the regression was small, the results may not be reliable. However, it was considered informative to conduct the regression as a preliminary investigation of the role of the variables in predicting PTI scores. Despite this limitation, some potentially valuable insights were obtained from studying this group.

Even though the research was designed to be as holistic and comprehensive as possible, the uncertainties related to the COVID-19 pandemic and the subsequent modification of the recruitment methods for Study 1 affected the project's overall outcome to a certain extent. But, within the given timeframe, the project was completed with the maximum resources available and adapted to use other possible recruitment strategies.

Directions for Future Research

Given the potential significance of this project in understanding caregiver adaptation, a similar project should be conducted on a larger scale, with a national recruitment strategy. Future studies should target caregivers of individuals with ID from all agencies in the community, such as adult services, special schools, and hospitals that provide specialised

services for individuals with ID, with more extensive funding and resources. This would potentially lead to more comprehensive and impactful findings.

The two years of follow-up for the adolescents with ID (19 to 21 years old) may not capture the sensitive period needed to assess the change in the caregiver's adaptation outcome. Grey et al. (2020) were able to assess the change based on a one-year follow-up, but the age range of their individuals with ID was 18 to 67 years old. However, their study did not report the association of the changes in PTI score with the age of the individual with ID. Hence, it was unclear what was the sensitive period that caused the change in the placement. Therefore, future studies can focus on broadening the age of the individual of ID from 19 onwards. By broadening the age of the individual with ID, the sensitive period (when the caregivers are taking action for the out-of-home placement) and the associated factors (such as caregiver ageing and an increase in challenging behaviours) can be identified.

Conclusion

Transitioning to adulthood is a pivotal process for individuals with ID, and caregivers play a crucial role in advocating for individuals with ID and bridging the engagement with the adult service. This transition indicates the need for skill training or support via adult services while living in the family home for as long as possible. Although this study had a low response rate which precluded extensive statistical analysis, there were indications that not all caregivers who experience some form of stressors, such as managing challenging behaviours at home, reported a similar extent of changes in their quality of life and placement indexes. Consistent with Lazarus and Folkman's (1984) TMSC this project found that factors such as higher household income, higher social satisfaction, lower mental or physical avoidance behaviour, higher resilience, and more hope regarding the future can moderate the impact of stressors on caregiver responses in caregivers managing adolescents and adults

with ID. The outcome of this project may suggest that the lack of shift in the placement tendency could be attributed to stressors not being sufficiently high for caregivers to consider adult disability home services yet. Furthermore, it is essential to acknowledge that individuals with ID are living longer lives, possibly outliving their parents. Considering alternative caregiving options, like out-of-home placement, becomes essential when caregivers are unable to meet the evolving needs of individuals with ID due to the caregiver's ageing. A more personalized approach to caregiver typology was proposed, emphasizing the consideration of caregivers' individual needs and circumstances. This approach ensures that each caregiver feels that their possible unique situation is being taken into account, while recommending a policy framework that promotes early identification of high-risk profiles and case management as an inclusive approach. The early identification of high-risk profiles is an approach that would align with the Singapore government's fourth Enabling Masterplan 2030, which focuses on equipping caregivers to be available to empower individuals with ID. This project highlights that family caregivers balance the needs between two identities: a family member and a caregiver. They may or may not cope with the caregiving role while balancing it as a family member (mother, father, and sibling) based on their approach to the situation, their personal values, and the resources available.

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Appendix A

Family Caregiver Adaptation during the Transition to Adulthood of Individuals with Intellectual Disabilities: A Scoping Review

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Abstract: During the transition to adulthood, individuals diagnosed with intellectual disability (ID) and their family caregivers have unique experiences. This scoping review studies the sources of the family caregiver's objective burden, support, coping mechanisms, positive caregiving, and quality of life to understand the caregiver's adaptation process when the individual with ID transits to adulthood, according to Joanna Briggs Institute (JBI) Scoping Review methodology guidelines. The inclusion criteria included studies of family caregivers of any age who provide unpaid care and live with individuals diagnosed with ID who are transitioning to adulthood. Of 2875 articles identified, 12 published studies were included. The main themes included caregivers reporting dissatisfaction with the available adult services and exhaustion from being a caregiver. Overall, a vicious cycle of likely increased demands during the transition, with caregivers not being prepared to cope with these demands while concurrently being dissatisfied with the adult services system, leads the caregivers to develop a pervasive sense of helplessness. Future studies would benefit from recruiting caregivers from sources other than adult-only service centres and using qualitative (to identify the broad aspects of the key factors) and quantitative (to identify the significant differences between the key factors) methodologies.

Keywords: neurodevelopmental disorder; intellectual disability; transition to adulthood; family adaptation; family caregiver; positive aspects of caregiving; quality of life

1. Introduction

Caregiving for an individual with intellectual disability (ID) is a unique journey for each family caregiver. Due to the child's cognitive limitations, the limited availability of social resources, possible changes in government policy, and caregivers' ageing, the demands of caring for their son or daughter with ID who lives in a community setting may vary across the lifespan [1,2]. Family caregivers, the most prolonged and consistent care providers, continuously undergo adjustment and adaptation across their caregiving journey. This scoping review explicitly focuses on family caregiver adaptation in caring for individuals with ID transitioning from adolescence to young adulthood.

2. Individuals with ID Transitioning to Adulthood

An ID diagnosis implies an individual with significant impairment in cognitive and adaptive functioning. The diagnosis and severity level of the ID is determined by a clinician referring to criteria in manuals such as the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* [3] and the World Health Organization's *International Statistical Classification of Diseases and Related Health Problems* [4]. The assessment is based on the cognitive functioning scores and the clinician's clinical judgment in assessing the individual's ability to learn and adapt across conceptual, social, and practical skills in the early developmental (before 18 years old) period [5–7]. Based on a meta-analysis of 20 relevant articles, the estimated worldwide prevalence of ID ranges from 0.05 to 1.55% of the population [8]. Because of the aetiology of persistent neurodevelopment impairment, there is no "cure" for ID. In other words, ID is a permanent condition with life-long implications for management. The type and intensity of required support and training vary for each individual with the severity level of their ID (mild, moderate, severe, and profound). The severity level affects their ability for self-care, home living, health, safety, community living, and employment across the lifespan [9,10].

Individuals diagnosed with ID have significantly different challenges than neurotypical individuals during the transition to adulthood [11–14]. Generally, the transition from

adolescence to young adulthood in neurotypical individuals is defined as progressing from supported environments such as school and family towards a more self-directed and independent life as an adult [15]. It is unreasonable to generalise and conceptualise the expectation of self-directed and independent living for individuals with ID, as their abilities and needs for support vary depending on the severity of their ID and their risk of becoming a member of a vulnerable population [16,17]. However, Blacher [18] highlighted that the transition for an individual with ID is expected to occur from 18 to 26 years old, specifically when the special education school services end and community-based adult services begin.

Based on interviews with parents, Ferguson, Ferguson, and Jones [19] highlighted three different types of transition that coincide as the individual with ID turns 21: (a) bureaucratic transition, (b) family life transition, and (c) status transition.

2.1. Bureaucratic Transition

Bureaucratic transition is the change that occurs between the professional and agency services that support the individual with ID and their family. In this case, the transition is from special education schooling to community-based adult services. Regarding the caregivers' relationships with the professionals in adult services, four continuum types of patterns were categorised: abandonment, surrender, assimilation, and engagement. *Abandonment by professionals* is defined as when parents perceive that there is a lack of services provided by professionals, or they fail to find a suitable adult service placement. Ultimately, the parents feel that the responsibility of caring for their children lies entirely on them. *Surrender to professionals* is described as a process in which parents are conditioned to professionals' opinions and explanations. Parents are perceived to be more prompt-dependent and might be more passive. *Assimilation with professionals* is defined as parents progressively adapting to provide the needed services for their child. For example, they might proactively set up home-based services, be more resourceful, and take on a more active or advocate role for their child during the transition. Lastly, *engagement with professionals* is a collaboration between the parents and professionals with separate functions but equal

parental and professional responsibilities and engagement. These different types of relationships between the caregivers and professionals in adult services indicate the possible different styles of engagement and experiences during the bureaucratic transition and probably affect the outcomes for the individual with ID transitioning to adulthood.

2.2. Family Life Transition

Family life transition describes the changes within the family system, such as daily routine and responsibilities (family role), when the son or daughter completes their special education program. Individuals with ID and their family members transit from six hours of structured engagement to new, unforeseeable adult services. The uncertainty of placement and the sustainability of adult services warrant parents' effort and time. Hence, there is a need to accommodate the change in the caregivers' routines and roles within the family system.

2.3. Status Transition

Status transition is defined as the change of status from child to adult. Like neurotypical individuals, the change to adult status in individuals with ID can be described by events such as becoming 21 years old, leaving the special education system, possibly acquiring and maintaining a job, and ultimately moving away from the family home to lead an independent life. However, caregivers of individuals diagnosed with ID have identified that the change in status was more about the intensity and frequency of supervision needed, rather than gaining total independence. The caregivers shared that they were apprehensive about the vulnerability risk and were ambivalent about letting go of their sons and daughters whilst yearning for independent adult children [19].

These three transition processes involving adolescents with ID occur concurrently, involving family caregivers, professionals, and adult services. Due to the impairment in cognitive and adaptive functioning of an individual with ID, identifying a key person in the support system will help aid the transition process in the community setting [20–23]. In the United States, most care providers are the families of children with ID [24]. Similarly, in Singapore, most individuals with ID live with, and are supported by, their family members in

community settings. However, the family caregivers reported difficulty with their caregiver roles [25].

3. Family Caregiver Adaptation

Being a parent of a child born unexpectedly with a disability can be life-changing. Unlike other types of caregiving relationships (for example, spousal caregiving), family caregivers of adult children are considered distinct [26]. A scoping review was conducted to identify the factors influencing adult child caregivers' well-being [27]. The caregiver caring for the adult child's well-being was likely influenced by the caregiver's role and the parent-child relationship quality. In other words, caregivers who have additional distinct roles other than caring for their adult children (for example, being sole income providers and providing care for their spouses) and poor relationships with the adult children for whom they are providing care are more likely to experience poor well-being [27].

Early family caregiver well-being research was based on the pathogenic paradigm of illness-focused behaviour [28]. The pathogenic paradigm emphasizes adverse outcomes, such as caregiver stress [29] and stigma [30] and their impact on caregivers' mental health [31], physical health [32], and overall quality of life [33,34]. Similarly, in recent decades, various studies have focused on the family caregivers of individuals with ID based on the pathogenic paradigm [35–37]. The psychological interventions suggested based on the outcomes of these studies are equally geared towards reducing adverse consequences [38]. However, current researchers are taking steps to promote health by understanding the journey of caregiving based on a health paradigm rather than emphasizing the negative aspects of caregiver stress [39,40], while still acknowledging the family caregivers' struggles. The health paradigm focuses on actualizing the capacity of the caregivers and increasing the caregivers' health and well-being [28] by focusing on themes associated with personal growth and rewards for caregivers in raising children with developmental disorders [40].

Although much research is available about individuals with ID and their family caregivers' well-being, there are still gaps in understanding the "successful transition" [41].

Thus, understanding caregiver adaptation by mapping the factors that trigger and regulate the adaptation process will aid in understanding both the positive and negative factors of the caregiving journey, specifically during the transition to adulthood of an individual with ID.

4. Review Questions

A preliminary search in MEDLINE, the Cochrane Database of Systematic Reviews, and JBI Evidence Synthesis was conducted in February 2022 and found no systematic review, scoping review, or protocol related to this topic. The objective of this scoping review was to explore the breadth or extent of the available research literature and to map and summarise the evidence from the literature on family caregiver adaptation, specifically during the transition to adulthood, when caring for an individual with ID. Sources of the caregiver's objective burden, support, coping mechanisms, positive caregiving practices, and quality of life were reviewed to understand the caregiver's adaptation process when the individual with ID transits to adulthood. In addition, the review also examined the methodology of the research conducted on this topic.

Based on the available literature, the following questions were generated:

What are the reported sources of the family caregivers' objective burdens (stress related to the individuals with ID and caregiver factors) during the transition to adulthood of individuals with ID, for each severity level (mild, moderate, severe, and profound)?

What kinds of support and resources do the family caregivers report they need to manage individuals with ID, for each severity level (mild, moderate, severe, and profound), during the transition?

What coping mechanisms do family caregivers commonly use during the transition to adulthood of individuals with ID?

What positive aspects of caregiving help family caregivers during the transition to adulthood of individuals with ID?

What is the family caregivers' quality of life like (i.e., physical and mental health, perceived subjective burden) during the transition to adulthood of individuals with ID for each severity

level (mild, moderate, severe, and profound)?

Are other factors related to caregiving, such as the caregivers' anxiety levels or expectations about the future independent living of the individuals with ID, influencing the caregivers' quality of life during the transition?

5. Method

This scoping review was conducted according to the Joanna Briggs Institute (JBI) Scoping Review recommended methodology guidelines and was based on a three-step search strategy [42]. The JBI framework of Population, Concept, Context (PCC) was followed.

5.1. Inclusion Criteria

5.1.1. Population

Family caregivers are the caregivers who live with and provide unpaid care to an individual diagnosed with ID. Therefore, literature on collective families, siblings, teachers, and paid or professional caregivers was excluded. In terms of the diagnosis, the primary diagnosis was ID, which includes genetic disorders such as Down syndrome and Fragile X syndrome. Other specific neurodevelopment disorders such as autism spectrum disorder (ASD) or Asperger's syndrome, attention-deficit/hyperactive disorder (ADHD), specific learning disability (SLD), conduct disorders, vision and hearing impairments, dementia, as well as other mental illness, were excluded.

5.1.2. Concepts

The concepts of this scoping review were family caregiver adaptation and individuals with ID transitioning to adulthood. This scoping review included literature on factors related to the adaptation of family caregivers when managing individuals with ID [43]. The Transactional Theory of Stress and Coping [44] defines perceived stress as the outcome of a cognitive imbalance between the interpretation of the stressors and the available resources that an individual considers themself to have to cope with the stress. The concept of "adaptation" was broadly defined, as there was an objective to capture as much literature as possible. Thus, the factors on "adaptation" included, but were not limited to, family

caregivers' objective and perceived burden, support and resources, coping mechanisms, positive caregiving, and quality of life. Therefore, any factor related to the family caregivers' quality of life during the transition was included.

Another concept was that of the individual with ID transitioning to adulthood. The definition of adulthood from the General Social Survey highlighted being financially independent individuals, completing school, leaving home, and working full-time [45]. However, for individuals with ID, the expectation of achieving independent living is only sometimes realistic, depending on the range of severity from mild to profound. In this scoping review, the transition to adulthood was conceptualised as completing formal schooling (i.e., finishing high/secondary school). To broaden the search, "transition to adulthood" was included to capture literature on individuals with ID who did not attend or graduate from school. Literature on individuals with ID still attending school, transitioning from primary to secondary school, or transitioning from paediatric medical service was excluded.

5.1.3. Context

There was no restriction on context (cultural, geographic location, specific race or gender, specific settings) for this scoping review. All research literature meeting the inclusion and exclusion criteria for the participant and concept were included in this scoping review.

5.2. Types of Evidence Sources

This scoping review included academic literature sources from journal articles, conference papers, dissertations, and book chapters. The sources included but were not limited to study designs such as analytical observational studies, prospective and retrospective cohort studies, cross-sectional studies, and single or multiple case studies. Non-academic literature such as, but not limited to, newspaper articles, personal blogs or reviews, theoretical and opinion papers, and sources lacking original research were excluded from this scoping review.

5.3. Search Strategy

The search extended to published and unpublished (grey or tough-to-locate literature) sources. Only literature published in English was included since no resource was available to translate literature not written in English. There was no date range limitation in this scoping review.

5.3.1. Published Source Search

Initial Limited Search. An initial limited search in databases such as APA PsycInfo and Scopus was performed to identify literature on this topic. Guidance was received from a librarian. Google Search was used to find synonyms for "transition", and relevant terms were selected; transit, change, changing, move, or moving. The initial search terms that were used were ((school OR adult*) AND (transit* OR chang* OR move OR moving)) AND (parent* OR caregiver* OR father* OR mother*) AND ("intellectual disability" OR "intellectual disabilities" OR "intellectual disorder")). The key sources were screened for keywords and index terms.

Keywords and Index Terms. The keywords in the titles and abstracts of relevant literature (Appendix A) and the index terms were analysed to develop a full search strategy. After an iterative process, the identified keywords and index terms were adapted for all included databases (ProQuest (APA PsycInfo and ERIC), Scopus, and Web of Science; Appendix B). The search was completed in July 2023, and 2558 citations were identified for this review.

Reference List of Identified Sources. The reference list of all included literature (after the full-text screening) was assessed. There was no additional literature identified via the reference list.

5.3.2. Unpublished Source Search

Unpublished studies of grey literature were searched for using the following sources; ProQuest Theses and Dissertations (PQDT; https://www.proquest.com (accessed on 13 July 2023).) and Google Scholar. The search terms used were ((school OR adult*) AND (transit*

OR chang* OR move OR moving)) AND (parent* OR caregiv* OR father* OR mother* OR care giv*) AND (“intellectual disability” OR “intellectual disabilities” OR “intellectual disorder” OR “mental retardation”). A total of 317 sources were identified.

5.3.3. Source of Evidence Selection

All the citations identified from the above search strategy were imported into data management software, *EndNote 20* (Clarivate Analytics, PA, USA). A total of 999 citations were removed automatically using *EndNote 20* before screening. The process of citation selection was divided into two phases: title and abstract screening and full-text screening.

Title and Abstract Screening. During the screening process, 1876 citations were uploaded from *EndNote20* to *Abstrackr* (http://abstrackr.cebm.brown.du (accessed on 27 July 2023)). The titles and abstracts were screened based on guidelines outlined by Polanin et al. [46] to identify appropriate sources effectively while minimising bias. A screening tool (Appendix C) was drafted based on Polanin et al.’s [46] guidelines. Two screeners, the first and second authors, screened the titles and abstracts. The screeners learned and pilot-tested the screening tool by screening the abstracts using 30 abstracts. Once consensus was achieved with the screening tool, the screeners proceeded to screen the titles and abstracts independently. Each abstract received independent double screening. The screening was monitored continuously, and the pair agreement was calculated. Polanin et al. [46] suggested maintaining the agreement within 75%. High screener disagreement rates (less than 75% agreement) may indicate issues related to the screening tool or the training received. Screeners met and reconciled after completing 20% to 30% of the abstracts. Overall, the agreement achieved for this scoping review was 76%. The agreed-upon process for reconciling disagreements throughout the abstract screening process was followed. Any further disagreements were discussed with a third reviewer to obtain a consensus. A total of 252 citations were identified based on the screening tool inclusion and exclusion criteria for full-text screening.

Full-Text Screening. The two screeners conducted a full-text literature screening,

following the title and abstract screening process. After reading the full text, the screeners further assessed whether or not the papers met the inclusion criteria. Literature that did not fit the inclusion criteria was excluded. Authors of the screened citations were contacted when more information or clarification was needed. The details of both the included and excluded papers and brief explanations of reasons why papers were excluded are presented via a Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) [47] flow diagram (Figure 1). A total of 12 studies were identified based on the full-text screening tool's inclusion and exclusion criteria to be included in this scoping review (Appendix D).

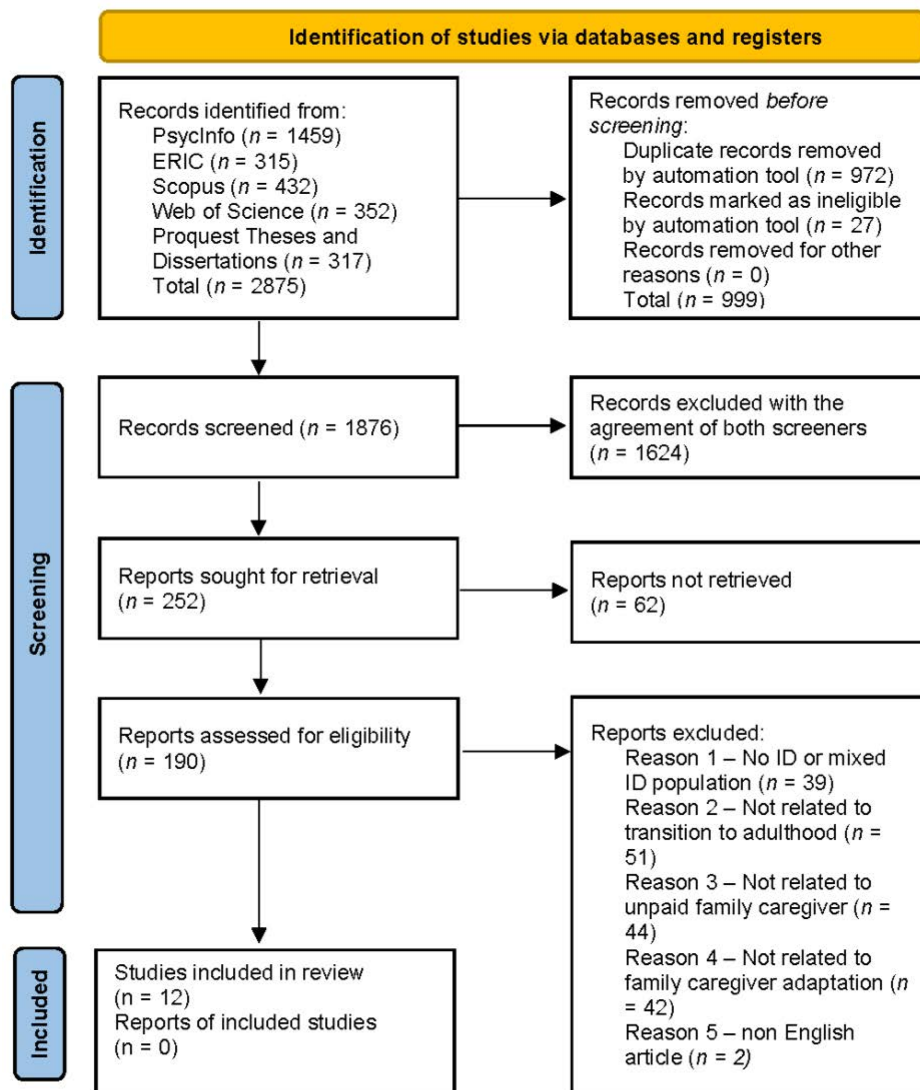

Figure 1. Outline of screening process according to PRISMA 2020 flow chart. Adapted from PRISMA 2020 flow chart.

6. Results

A total of 2875 citations were identified from published and unpublished source searches. After removing duplications and screening based on the inclusion and exclusion criteria, 12 full-text studies were included in this scoping review.

6.1. Characteristics of the Studies

The characteristics of these 12 studies are summarised in Table 1. The year of publication of these studies ranged from 2008 to 2022, with the highest number of studies published in 2020 (n = 3). The studies were conducted in the United Kingdom/England (n = 3), Australia (n = 3), Canada (n = 2), and one study each in Ireland, Israel, Norway, and South Africa. Eleven of the studies were qualitative, and one was quantitative. All qualitative studies used semi-structured one-to-one interviews, and one included a focus group. Ten studies were cross-sectional, and two were longitudinal in design.

In terms of participants, the number of family caregivers ranged from 2 to 301 caregivers, primarily females. None of the studies included individuals with ID as participants, but most reported the children's ID, age range, and severity level.

Table 1. Characteristics of the studies.

Author(s)/(Year of Publication)	Country	Aim(s)	Type of Study	Individual with ID (1) Diagnosis—Range (2) Age of the Individual with ID (3) Comorbid Diagnoses	(1) Caregivers Sampling (2) Number of Caregivers (3) Age Range of Caregivers (4) Ethnicity
Rapanaro, C. et al., (2008) [48]	Western Australia	To investigate the perceived benefits and negative impacts associated with stressful events and chronic caregiving demands encountered by parents caring for young adults with an intellectual disability in the period of transition to adulthood	Qualitative content analysis	(1) ID Mild, moderate, and severe or profound range (2) 16 to 21 years old (3) Not stated	(1) Purposive sampling (2) 119 parents (3) Mean age: 48.05 years old (4) Not stated
Gillan, D. et al., (2010) [49]	Ireland	To gain understanding of the impact on parents of the transition from high-support school environments to mainstream settings with potentially lower levels of formal supports	Qualitative Grounded theory (explorative in nature) Cross-sectional Semi-structured interview	(1) ID Mild range (2) 19 to 24 years old (3) Not stated	(1) Purposive sampling (2) 12 parents; 4 married couples and 4 single mothers (3) 42 to 65 years old (4) Not stated
Hubert, J. (2011)	England	To gain understanding of the experiences and	Qualitative	(1) ID	(1) Not stated

[50]		perspectives of families, especially mothers, of young people with these complex needs, including attitudes towards long-term residential care	Ethnographic study Informal interview and participant observation—over a period of 2 years (longitudinal)	Severe to profound range (2) 15–22 years old (3) Three-quarters had epileptic episode	(2) 20 parents (3) Not stated (4) Not stated
Isaacson, N. C. et al., (2014) [51]	Australia	To gain understanding of the future the young people and their families were seeking, important issues faced, difficulties and supportive factors, the impact on family relationships, and family perception of the purpose of the Community Living Plan (CLP) during this transition	Qualitative 2 case studies Interviews, observation and documentation review over a period of 7 months (longitudinal study)	(1) Down syndrome—moderate to high support needs (2) 21 and 25 years old (3) Not stated	(1) Purposive sampling (2) Both father and mother involved (3) Not stated (4) Not stated
Gauthier-Boudreault, C. et al., (2017) [52]	Canada	To document the needs of parents and young adults with profound ID during and after the transition to adulthood by exploring their transitioning experience and factors that influenced it	Qualitative Descriptive–interpretative approach	(1) ID Profound range (2) 18 to 26 years old (6 young adults still in school and 8 post-school) (3) Not stated	(1) Purposive and snowballing sampling (2) 14 caregivers; 12 mothers and 2 fathers (3) 49 years old and below: 5 caregivers 50 years old and above: 9 caregivers (4) Not stated
Biswas, S. et al.,	United	To explore parents' retrospective views of their	Qualitative	(1) ID	(1) Non-probabilistic

(2017) [53]	Kingdom	child's developmental transition into adulthood, and how parents adjust and adapt to this transition	Retrospective cross-sectional exploratory design	Severe range (2) 19 to 57 years old (3) Physical and sensory disability; some had physical care needs	purposive sampling (2) 12 parents of 11 children; 7 mothers, 3 fathers, 1 stepmother, 1 stepfather (3) 44 to 78 years old (4) White British
Wilcox, G. et al., (2019) [54]	Canada	To understand the particular experiences of two mothers and their perspectives on the process of transitioning from high school to adulthood for their children with intellectual disability (ID)	Qualitative Exploratory; 2 case studies	Case study 1: Male, mild ID, attending postsecondary education program, living independently in postsecondary residence Case study 2: Female, severe ID, supported group home	(1) Purposive sampling (2) 2 mothers (3) Not stated (4) Not stated
Gur, A. et al., (2020) [55]	Israel	To fill an important gap in the caregivers' well-being literature by focusing specifically on families of children with ID who are navigating the transition to adulthood	Quantitative; individual interview	(1) ID Mild to profound range (2) 3 age groups: Group 1: Under 21 years old Group 2: 21–30 years old Group 3: 31 years old and above	(1) Purposive sampling (2) 301 participants; 256 women and 41 men (3) Mean age: Group 1: 42.24 years old

				(3) Not stated	Group 2: 54.48 years old Group 3: 63.07 years old (4) Israeli
Roos, E. et al., (2020) [56]	Norway	To identify factors that improve the collaboration process between parents and employees, creating less burden for the parents of child with profound ID	Descriptive qualitative study Semi-structured interview; face-to-face individual interviews, or group interviews	(1) ID Profound range (2) 3 age groups: 18–20, 20–25, >25 years old (3) Not stated	(1) Purposive sampling (2) 9 parents; 7 mothers and 2 fathers (3) Not stated (4) Not stated
Ellman, E. et al., (2020) [57]	South Africa	To describe how parents experienced the transition from special school to post-school of their children with severe intellectual disability in a small town in the Western Cape	Qualitative; 5 case studies	(1) ID Severe range (2) 18–35 years old (3) Severe ID and some comorbid with Down syndrome or cerebral palsy	(1) Purposive sampling (2) 5 parents; 3 mothers and 2 fathers (3) Not stated (4) Not stated
Codd, J. et al., (2021) [58]	United Kingdom	To explore parental experiences of having a son/daughter with an intellectual disability transition to adulthood and what meaning parents make of this	Qualitative; semi-structured interview Cross-sectional Interpretive	(1) ID Mild to profound range (2) 18–23 years old (3) Down syndrome, ASD,	(1) Purposive sampling (2) 10 parents; 7 mothers and 3 fathers

			phenomenological analysis Learning Disability Screening Questionnaire (LDSQ) to validate diagnosis of ID	ADHD, Williams syndrome, FOXG1 syndrome	(3) 40 to 65 years old (4) British and Italian
Nucifora, A. et al., (2022) [59]	Australia	To examine parents' perceptions of adulthood for their children with an ID, as well as their experience of the child's transition to adulthood	Descriptive–interpretive qualitative; semi-structured interview Thematic analysis	(1) ID No severity indicated (2) 17–42 years old (3) Autism, Prader–Willi syndrome, Down syndrome, psychosis, genetic disorder	(1) Purpose and snowball sampling (2) 8 parents; 5 mothers, 2 fathers, and 1 kinship carer (3) 50–75 years old (4) Not stated

6.2. Review Findings

6.2.1. Question 1

What are the reported sources of the family caregivers' objective burden (stress related to individuals with ID and caregiver factors) during the transition to adulthood of an individual with ID, for each severity level (mild, moderate, severe, and profound)?

Individuals with ID. According to Rapanaro, Bartu, and Lee's study [48], 94 caregivers of 119 respondents reported having at least one stressful event in the past 12 months. The events were categorised into five categories: (a) young adult behaviour/conduct (38.3%), (b) issues with the service provider (22.3%; refer to *Objective 2*), (c) independence issues (16%), (d) health problem (13.8%), and (e) young adult vulnerability (9.6%).

Specifically, on *young adult behaviour/conduct* (38.3%), the behaviours were described as being aggressive, socially inappropriate (stealing and disruptive at work) and sexual conduct (having unprotected sex). Some caregivers identified the increase in challenging behaviours as being due to the difficulty of adjusting to adult programs [48]. Gauthier-Boudreault, Gallagher, and Couture [52] added that due to the lack of adult services, caregivers of individuals with ID in the profound severity range reported that it affected their children by reducing their children's capabilities and abilities, and increasing weight gain, boredom, and challenging behaviours.

"*Since leaving school, life has not been the same for my son. He loved school and was extremely happy. We found work for him [in a sheltered workshop] which he wanted to attend… He has changed positions many times to try and make him happy…Due to the unhappiness and frustrations he copes with at work, in a sheltered workshop, he has become very aggressive…*" (Rapanaro et al., p. 37 [48])

The transition to adulthood for an individual with ID also indicates the incongruence between their physical and cognitive–emotional development. Hubert [50] highlighted the challenges the mothers of children with ID in the severe to profound range undergo. As a child grows, their physical size and strength are bigger and stronger than their ageing mother's. It is more challenging to contain incontinence, maintain appropriate hygiene levels during menstruation, and manage violent and overt sexual behaviours during the transition. Similarly, caregivers of individuals with ID in the severe range in Biswas, Tickle, Golijani-Moghaddam, and Almack's study [53] expressed that their stress was triggered when they were unsure how to support the child's sexual development. Nucifora, Walker, and Eivers [59] reported that caregivers felt distressed when they were aware of the gaps between their

child's capacity and an individual of similar age with no ID (neurotypical).

"*When you see the gap gets bigger, every year she gets older, more things drop off that she is not able to do.*" (Nucifora et al., p. 5 [59])

Regarding *independence issues* (16%), the caregivers reported concerns about their child's lack of independence or seeking of independence. Lack of independence was reported when the child could not travel using public transport and had difficulty dealing with legal and financial issues independently. Seeking independence was described as the child's desire for freedom away from the family home but having difficulty coping with social demands. Caregivers can no longer guide the child due to the child's legal age and need legal authority such as power of attorney [48]. Caregivers shared that ongoing involvement was needed even when their contact with the child had reduced in cases when the child had moved out of the family home [51]. Caregivers reported extra responsibility in teaching their child skills needed to be independent such as travelling in public buses [59].

Health problems (13.8%) were reported to involve caregivers and their child's health. Some caregivers reported that their child had a comorbid physical disability. The associated demands, such as negotiating treatment and care plans as well as witnessing their child's pain and discomfort, were reported to be stressful by the caregivers. Due to caregivers' ageing, arranging respite care and funding was difficult, and their child reported being upset due to the changes [48].

Lastly, *young adult vulnerability* (9.6%) relates to abuse/harassment and being negatively influenced by others. Caregivers expressed concern that their children might be taken advantage of [48]. Biswas et al. [53] shared similar findings that caregivers' negative thoughts about adult services and institutions trigger their fear of their child's safety due to the risk of being vulnerable in the community. In addition, caregivers are more worried if the child has limited verbal ability and cannot report the possible abuse. These caregivers view barriers to adulthood as their inability to plan for adulthood-related activities, to count on professional support, and the child's limited cognitive and social skills as well as lack of personal responsibility.

Caregivers. Regarding caregivers' employment, Roos and Sondenaan [56] highlighted that some caregivers of individuals with ID in the profound range cannot sustain their employment because they need to take care of their children. Another study conducted by Gur, Amsalem, and Rimmerman [55] highlighted in detail that almost half of the caregivers of an individual with all ranges of ID were employed, and about 47.5% of the caregivers were

out of the workforce. Among those who were out of the workforce, 44.1% of the caregivers reported that they stopped due to the need to care for the child with ID, but the ID range was not specified in this study.

Gur et al.'s study [55] also outlined that apart from employment, a significant difference was found in caregivers of individuals under the age of 21 who can spend more time outside their home compared to the groups of caregivers of individuals with ID above 21 years of age. However, no significant differences were found among the caregivers of individuals with ID aged 21 to 30 and above 31 years old in the number of hours spent outside their home. Overall, almost half of the caregivers (41.2%), reported spending more than 15 h a day caring for their child with ID, and the time spent was higher when the caregivers cared for individuals with ID who were above 21 years old. Nucifora et al. [59] added that caregivers reported reducing their own "independence" due to the caregivers' strong sense of responsibility related to caregiving needs during the transition period.

"*The fact that it sort of restricts our independence in a way because we're having to supervise them.*"

"*I also don't have any free time um, it's a go from 5 am through to 10 pm at night*." (Nucifora et al., p. 8 [59])

The caregivers reported that the financial burden significantly affected some of the families. Beyond that, "*negotiating everyday occupation*" was a struggle as caregivers needed to make practical household arrangements with different routines during the transition period [57]. Nucifora et al. [59] highlighted that caregivers have an ongoing sense of responsibility and the need to supervise and support their child diagnosed with ID, so the caregivers develop a fear of ageing. The caregivers were concerned about how their child would be supported when the caregivers could not do so due to the caregivers' ageing factor.

6.2.2. Question 2

What kind of support and resources do the family caregivers report they need to manage individuals with ID for each severity level (mild, moderate, severe, and profound) during the transition?

Formal Support. Gillan and Coughlan [49] highlighted a list of barriers to the transition process shared by caregivers managing individuals with ID of mild severity. Examples included a lack of information provided, a lack of accommodation to individual needs for vocational service, a lack of coordination between child and adult services, a lack of parental involvement, and a lack of "real" alternatives for a vocational training provider.

Other barriers included being on a waiting list for the services, staff not adequately communicating, and staff "not listening" to caregivers. Beyond the adult service provider, caregivers reported negative experiences related to the environment and training in the employment service setting. The caregivers expressed the need for adequate formal support due to their children's needs.

Isaacson, Cocks, and Netto [51] reported that the caregivers had difficulties accessing formal support to manage their children with Down syndrome with moderate to high needs, such as a lack of information provided and long-term frustration with the system (filling out many forms). However, both families were ultimately satisfied with the trainers assigned to the children.

Biswas et al. [53] reported that caregivers of individuals with ID in the severe range reported perceived barriers to formal support and that little information was provided related to the transition. The professionals' understanding of the "normative" transition to adulthood contradicted caregivers' and their children's need for support. In other words, the professionals shared with the caregivers that since the child was above 18 years old, they were not the caregivers' "responsibility anymore". Thus, more negotiation between the parents and professionals regarding the management plan is needed. The current policy that promoted autonomy and independence evoked different views among the caregivers. Some caregivers in this study shared that it was helpful and advocated for "normal" adult development. On the other hand, some caregivers were concerned about the possible risk involved when their child is encouraged to pursue "normal" adult development due to the possible risk of being a member of a vulnerable population. Caregivers also reported that they required professional support for psychosexual development.

One of the themes that emerged for caregivers managing individuals with ID in the severe range was the need to manage the transition on their own; the "burden was theirs" [57]. Even though the caregivers expected some support, they did not initiate or seek opportunities to engage with the support system. They handled the situation as it arose on their own. Some caregivers reported that the presence of a non-governmental organisation (NGO) that offered to recruit their children was helpful with the transition.

Roos and Sondenaan [56] highlighted that the caregivers of individuals with ID of profound severity reported concern about the waiting list to move out of the family homes. The caregivers needed to know how long they had to wait and where the child would be moving. The caregivers reported dissatisfaction with the details given on the services in the

adult home and the absence of respite care during the waiting period. Once the child was placed, the caregivers reported concerns about the lack of fit for their children's needs with the co-residents, such as age, functioning level, and interest. Furthermore, the caregivers must visit their children frequently to help with their practical and leisure needs. Compared to the service received in the children's homes, caregivers also expressed concern about the reduced services in the adult homes. For example, caregivers did not receive updates from the adult home about the child's well-being. On the other hand, one out of nine caregivers expressed satisfaction with the placement. One caregiver reported that although it was concerning for the child to move out to the family home, it was perceived to be beneficial for the child to receive care from other staff and residents besides the "exhausted" parents.

Gauthier-Boudreault et al. [52] defined the themes of the caregivers' need to manage individuals with ID of profound severity. The caregivers expect material, informational, affective, and cognitive support. *Material support* was defined as the need for services and resources to solve the practical needs of everyday life. Caregivers reported possible barriers that they faced to receive material support. For example, late transition planning, lack of collaboration between organisations, professionals not being aware of their roles during the transition, and shifting of their responsibility to other areas caused service gaps in areas such as day activity centres and respite care, and difficulty accessing adult health services. *Informative support* was the need for support related to difficulty accessing information during the transition phase. *Affective support* was the lack of support for the caregivers to share and socialise. *Cognitive support* was related to the lack of intervention catered to their child with profound ID in the day activity centre and lack of expertise in the adult health care professionals.

There were reported stressful "service provider issues" events described by the caregivers of individuals with ID of all severity ranges, which accounted for 22.3% of those who had at least one stressful event in the past 12 months [48]. The perceived difficulties were related to issues accessing services and dissatisfaction with the organisations or the service staff. Examples of the concerns were related to the difficulty in gaining and maintaining adult services due to money and support factors, the application for accommodation service not being approved, the service providers mistreating the caregivers or the child with ID (lack of support and assistance), and the work situation not being satisfactory. Caregivers reported that they needed to advocate on behalf of their children.

"[her] work situation hasn't to date been satisfactory. The work is not challenging

enough and my child eventually wants to quit, which causes anxiety all round. This time it eventually caused her to have a re-bout of depression, which needed counselling…." (Rapanaro et al., p. 37 [48])

Wilcox, McQuay, and Jones [54] highlighted in their case studies that the mothers of individuals with ID in the mild to severe ranges reported that they needed support for a successful transition in the form of adult service providers. They expected better communication and follow-up about the transition process, expressed a need for more information on the available training and resources, and wanted a more planful transition. One mother highlighted the system strain as the service workers were overworked, and the staff turnover was high. The mothers also shared that a poor placement fit for the adult service, the paperwork, and the burden of advocating for the child had been stressful.

"*I think PDD workers are very over-worked."*

"The turnover is great. We went through so many caseworkers and they're so overloaded … they've got so many things on their plate" (Wilcox et al., p. 11 [54])

Gur et al. [55] reported no significant differences in caregivers' social participation as a function of ID severity. Similarly, no significant differences existed among the caregiver groups' per capita income and out-of-pocket expenses. However, there were substantial differences in the type of support received among the caregivers' groups. Caregivers of persons under the age of 21 received significantly more support from NGOs and used more services than caregivers of persons over 31. There were no significant differences in the type of support received among the caregivers of persons aged 21 to 30 and above 31 years old.

Codd and Hewitt [58] highlighted that caregiver reported negative experiences with adult service providers, irrespective of ID severity. Some positive experiences were reported, but they needed to be more consistent. Caregivers reported a lack of support and trust and perceived professionals to be incompetent in the adult compared to the child services.

Nucifora et al. [59] reported that the increase in funding and flexibility in service selection via the personalised support service in Australia, known as the National Disability Insurance Scheme (NDIS; established in 2016), does help to increase some of the caregivers' levels of trust towards the support staff. Although the NDIS was perceived to be more flexible than the previous services, caregivers raised concerns that the other government-based services were not flexible enough. The shift from school to new adult services was perceived as lacking structure and not helping the caregiver transition. In addition, caregivers reported that the legal definition of "adulthood" complicates access to certain services.

Informal Support. Isaacson et al. [51] reported that the caregivers of moderate to high-need people with Down syndrome were supported by their extended family members and friends when needed. Biswas et al. [53] highlighted that those caregivers of individuals with ID in the severe range reported perceived support from informal sources such as a supportive network. Caregivers of persons under 21 years of age received significantly more support from family and friends and used more services than caregivers of people over 31 [55]. Nucifora et al. [59] highlighted that some caregivers shared that having a supportive family does help with the caregiving demands during the transition to adulthood, as the caregiving demands are being shared. Having supportive friends was seen as necessary support for both caregivers and their children with ID.

"*When I see Daniel with his mates ... I just feel confident that they'll be there for life… that's when I feel most relaxed*" (Nucifora et al., p. 8 [59])

However, some caregivers, especially the father in this study, reported feeling reluctant to share their concerns to avoid being burdensome to others [53]. The mothers caring for individuals with ID in the severe to profound range shared negative experiences of being socially isolated as their extended family members became harsher and fearful of their adult child [50].

6.2.3. Question 3

What coping mechanisms do family caregivers commonly use during the transition to adulthood of individuals with ID?

Information Gaining. There were different types of coping mechanisms reported in each study. One common theme was the need to gain information by communicating with others and taking a proactive role. The caregivers of individuals with ID in the mild range reported that regular communication with the adult service providers helped them cope with the service system [49]. Biswas et al. [53] reported that caregivers of individuals with ID in the severe range coped by researching to gain more information about the transition process generally. Caregivers of individuals with ID in the profound range reported that they preferred to be connected with other families to plan the housing option independently without depending much on the service providers [56].

Accessing the Support System and Proactive Roles. Caregivers reported that "accessing resources and a support system" such as "faith in a higher power, families, personal skills and abilities, organisations and influential people in the community" helped them deal with the transition when managing individuals with ID in the severe range [57]. Six

of eight families said they are always in "fighting" or "battling" mode to receive the appropriate support, resources, and employment for their adult child. In addition, caregivers reported taking a proactive role in their children's management [49]. Similarly, caregivers shared that they had to access support systems such as social connections and government-based services to cope with the transition. Additionally, caregivers had to constantly advocate with the appropriate government-based services for their children [59].

"*You've got to advocate the whole time within the healthcare system to get people to look at her as an individual…. A continual battle*" (Nucifora et al., p. 6 [59])

Setting up Routines for Caregivers. Ellman, Sonday, and Buchanan [57] reported that caregivers of individuals with ID in the severe range developed coping mechanisms as they struggled with the changes during the transition. One of the coping mechanisms was "*setting up a routine*". Some caregivers volunteered at the NGO while their children attended the activities. It helped them to keep an eye on their child. Some caregivers reported that the NGOs were short of staff, so they decided to help. At the same time, others reported that they volunteered to secure their children's placement at the organisation.

Managing Expectations. Caregivers' managing and accepting reasonable expectations of their children was reported to be one of the coping mechanisms. Caregivers of individuals with ID in the severe range who do not perceive the transition to adulthood to be based on chronological age may have lower expectations and be more accepting of the change in the "learning disabilities sub-culture". Lower expectations lead these caregivers to have a more positive outlook on the children's adult life and to be able to manage their worries [53].

6.2.4. Question 4

What positive aspects of caregiving help family caregivers during the transition to adulthood of individuals with ID?

Mixed Feelings. Rapanaro et al. [48] reported that almost half of the caregivers of individuals with all severity ranges of ID (43 out of 94 caregivers, 45.7%) reported positive outcomes of stressful episodes and almost three-quarters of the caregivers reported overall perceived benefits from the chronic demands of being a caregiver (77 out of 119 caregivers, 64.7%), for only positive or both positive and negative aspects. Similar to Rapanaro et al. [48], Ellman et al. [57] reported that caregivers of an individual with ID in the severe range reported "*mixed feelings*". The situation factor, such as the physical and social environment, influenced the fluctuation of positive and negative experiences. It was reported that there were more negative than positive experiences.

Sense of Fulfilment and Pride. Rapanaro et al. [48] drew attention to the theme of fulfilment and pride (a sense of purpose and fulfilment), personal growth (tolerance, patience, appreciation of life, and greater acceptance), enhanced social networks, and absence of specific care demands (no need to dress, bathe, or entertain as the child gains independence in their daily living activities). Hubert [50] also reported a related theme of fulfilment and pride. Although the mothers caring for individuals with ID in the severe to profound range in the study were socially isolated, they reported that having positive relationships with their children was rewarding. They felt proud of their children and themselves through their caregiving journey.

Gratitude. Gillan and Coughlan [49] reported that all 12 caregivers of individuals with mild ID reported positive experiences at the beginning of the transition. One positive experience was that at least one service provider provided the needed support in one way or another. Thus, although there was a concern about inadequate services, as reported above, the caregivers expressed gratitude for having at least one service provider to guide them.

Benefits for Caregivers. There were two categories of themes: (a) enhanced caregivers' resources and growth, and (b) seeking more formal and informal support [48]. For example, caregivers reported that these stressful events had helped them to be more assertive and determined to have an increased understanding of their needs for the transition. The caregivers also shared that they managed to get new and improved support from the community and possibly became more close-knit with family.

Benefits for Individuals with ID. Similarly, for their children with ID, caregivers reported that their children could learn new coping skills, improve challenging behaviour, and increase confidence and maturity [48]. Gillan and Coughlan [49] also reported that the children's capability for positive adjustment was rewarding for the caregivers during the transition. Seven out of twelve caregivers reported that their child was observed to have increased in confidence. Ten out of twelve caregivers claimed that their child enjoyed their work or training setting.

6.2.5. Question 5

What is the family caregivers' quality of life like (i.e., physical and mental health, perceived subjective burden) during the transition to adulthood of individuals with ID for each severity level (mild, moderate, severe, and profound)?

Negative Emotions Due to Lack of Support. Overall, the caregivers of individuals with mild ID reported a consistent theme of perceived stress and anxiety due to the nature of

the service system. Nine out of twelve caregivers reported frustration "dealing with the inflexible and unresponsive service," and four reported helplessness due to the lack of substitute services [49].

Caregivers of individuals with Down syndrome who had moderate to high support needs expressed that they were physically and mentally tired. One of the caregivers reported having "mild depression during the initial period of moving out". However, after the children left the family home, the caregivers could spend more time with their spouses [51].

Similar to this, Hubert [50] reported that caregivers caring for individuals with severe to profound ID were "emotionally and physically exhausted" as the daily needs to care for their children were time-consuming and exhausting.

Caregivers of individuals with severe ID reported "feeling uncertain and confused" due to unfamiliarity with the transition period. Decision-making was difficult and their daily life activities felt restricted during the transition period due to the lack of information received during the pre-transition period. There was much uncertainty and not knowing what to expect. A sense of loneliness was reported as the caregivers would not approach their family and friends for help and vice versa during the transition [57].

In Norway, an application for an apartment is made once the child reaches 16 years of age. However, the child's placement usually will be based on a crisis [56]. Specifically, caregivers of individuals with profound ID expressed an "unsustainable burden of care" while waiting for housing, mainly after their children were 18 years old.

"*I don't think they (staff in the municipality) understand and see signs of an exhausted body—they understand it's tough, but no one realises how tough it really is—I have parents who have helped for many years—but they are also starting to get old—I had to call them one night when I couldn't do it anymore—there was a crisis—then they came. It hits a whole family*." (Roos et al., p. 5 [56])

Irrespective of the severity range, caregivers of individuals with ID reported feeling sad and tired of being the "fighters and advocates" for their children. The parenting chores may change, but the intensity and effort needed during the transition are still the same [58]. Gur et al. [55] reported that the average score on the well-being measures of caregivers of people with ID aged 31 years and above was significantly lower than that of persons caring for people with ID aged 21 to 30. Caregivers of persons aged 31 years and above were reported to be more frustrated than caregivers of persons under 21. The average score on the life satisfaction measure of the caregivers caring for children with ID was the lowest when

the child was above 31 years old, followed by the caregivers of children below 21. Caregivers caring for children with ID aged 21 to 30 and above 31 years old reported being sadder than caregivers caring for a child under 21.

Rapanaro et al. [48] highlighted those caregivers of individuals of all ranges of ID had common themes revolving around negative feelings such as guilt, resentment, anger, fear of repeat events and the future, depression, hopelessness, low self-worth, mistrust, and wishing that they did not have a child with a disability. Caregivers reported extra resource demands, financial strain, and failure to access adult services. The caregivers further highlighted the negative impact on family relationships, where the other siblings were affected (due to fear or embarrassment), marriages were strained, and the relationships with their children with ID diagnoses were affected due to the need for caregiving duties to be performed. Caregivers also reported a loss of freedom and independence in their personal aspirations and social activities.

"*it has been bloody stressful—so much so, I nearly died of an asthma attack. I was unconscious, [my] husband resuscitated me…lifting has caused lower back pain…and occasional feelings of impending heart attack due to[the] physical exertion of lifting and carrying*" (Rapanaro et al., p. 42 [48])

6.2.6. Question 6

Are other factors related to caregiving, such as the caregivers' anxiety levels or expectations about the future independent living of the individuals with ID, influencing the caregivers' quality of life during the transition?

Independence and Vulnerability Risk. Gillan and Coughlan [49] emphasised that caregivers of individuals with mild ID shared their hesitation to provide more independence to their adult children. The caregivers' hesitation was due to their apprehension of their adult child being vulnerable because of cognitive limitations. Six and nine caregivers reported concerns about others taking advantage of their adult children and the children lacking assertive skills in work settings, respectively. Consistently, caregivers of individuals with moderate to profound ID shared their concern about their children's independence, considering the vulnerability risk [51]. Similarly, Codd and Hewitt [58] highlighted that irrespective of severity level, caregivers of individuals with ID reported their dilemma of "*letting go and separation*" and apprehensiveness to support independence due to their children's vulnerability and their lack of trust in adult services. Nucifora et al. [59] added that the caregivers struggled cognitively and emotionally with the degree of independence and

caregiver monitoring needed during the transition to adulthood. The caregivers were aware of their children's vulnerability and, due to fear of abuse, the caregivers reported difficulty trusting the support providers.

"*With James, it is still like having a kid in some ways because he still needs the same amount of care*" (Isaacson et al., p. 275 [51])

"*It's hard to let go of doing it for so long. It's just purely your instincts and your protection*" (Nucifora et al., p. 7 [59])

Caregivers' Anxiety. Codd and Hewitt [58] highlighted that irrespective of severity level, caregivers of individuals with ID reported uncertainty and worries regarding the sudden change to unknown adult services. Hubert [50] emphasised that the caregivers of individuals with severe to profound ID reported being overprotective and anxious due to the need to manage high-needs children with a perceived lack of "adequate" support. For all severity levels, caregivers of individuals with ID aged above 31 years were more concerned about their children's diagnosis than caregivers of individuals with ID aged 21 to 30 years [55].

7. Discussion

This scoping review aimed to study the sources of the caregiver's objective burden, support, coping mechanisms, positive caregiving, and quality of life to understand the caregiver's adaptation process when the individual with ID transits to adulthood. The caregiver's objective burden was divided based on the needs of the individual with ID and the needs of the caregiver. Regarding the caregiving demands related to individuals with ID, stressful events were divided into young adult behaviour/conduct [48,52] and incongruency between the physical and cognitive–emotional development of individuals with ID [59]. In other words, caring for an individual with ID who is physically growing stronger and bigger with challenging behaviours [50] and psychosexual development needs [53] was reported to be stressful. The prevalence of challenging behaviour in a study conducted with 265 adults with ID was 18.1% (about one-fifth of the adult population with ID, [60]). The challenging behaviours in adults with ID are more persistent and stable over time, whereas there is a tendency for the challenging behaviours in typically developing children to decrease over time [61]. No studies have been conducted yet that make comparisons between the prevalence of challenging behaviour in individuals with ID pre-, during, and post-transition to adulthood. Three studies discussed the caregiver's objective burden related to independence issues (individuals with ID either had a lack of independence skills or were seeking independence) and the need for ongoing involvement even when the child has moved out of

the family home [48,51,59]. Two studies reported caregiving demands related to young adult vulnerability and safety concerns [48,53]. Lastly, one study discussed the stress related to health problems, especially when the child had a physical disability [48].

Regarding the caregivers' objective burden factor, there was a mixed report on the effect on the caregivers' employment; not all caregivers reported needing to be out of the workforce due to their caregiving needs [55,56]. When a comparison was made among caregiver needs of three different age groups (under 21, 21 to 30, and above 31 years old) of individuals with ID, there were significantly higher needs for caregivers caring for individuals with ID above 21 years old. Caregivers reported spending 15 out of 24 h on caregiving needs [55]. One study highlighted the financial burden and the need to manage practical household arrangements during the transition [57]. In summary, only one study indicated a significant difference between the caregiving hours before, during, and after the transition period, and few studies reported the specific factors contributing to the caregiving demands.

Regarding support and resources, two categories were reported, formal and informal. Regarding formal support, a consistent theme emerged in all 12 studies regarding the caregiver's overall perceived dissatisfaction with adult, compared to child, services, even though some caregivers in each study reported being satisfied with individual service providers. The subthemes related to the dissatisfaction were a lack of information and lateness of the planning provided related to the transition (six studies), a lack of fit or accommodation to individual needs for adult services (five studies), caregivers' needing to manage the transition on their own (three studies), a lack of adult support services compared to child services (three studies), a lack of parental involvement (two studies), a long waiting list for adult services (two studies), staff not adequately communicating (two studies), paperwork stress for the caregivers (two studies), possible incongruency between the professionals and caregivers' understanding and expectations related to the transition (two studies), and one study each identified concerns such as a lack of "real" alternatives for vocational training providers, the application for accommodation service not being approved, a lack of coordination between child and adult services, professionals "not listening" to caregivers, negative experiences related to the environment and training in the employment service setting, requiring professional support for psychosexual development, the absence of respite care during the waiting period, service providers mistreating the caregivers or the child with ID, and the service workers being overworked with high turnover of staff.

Regarding informal support, there were mixed results on its effectiveness. Four studies reported that the caregivers benefited from informal support such as extended family members and friends, supportive networks, parent–child relationships, and parent groups. On the other hand, two studies reported that caregivers were reluctant to reach out and isolated themselves to avoid being burdensome to others and due to perceiving others to be fearful of their adult children, respectively.

Gauthier-Boudreault et al. [52] labelled the caregivers' needs for formal and informal support in four categories: material, informational, affective, and cognitive support. Material support is the need for resources to cater to practical needs during the transition, related to transition planning. Specific to the caregivers' needs, caregivers expressed the need for informational support. It is necessary for information related to the transition, such as legal services, long-term planning, and service availability, for the caregivers to be more available and for aid with the decision-making process to be provided. Affective support would allow the caregivers to share experiences and socialise with other caregivers to cope emotionally. Lastly, caregivers reported the need for a proper fit of adult services to keep their children occupied and maximise their children's ability through cognitive support. Due to the prolonged responsibility related to caregiving demands, all these support works may be needed concurrently for a "successful transition", even after the transition period.

The coping mechanisms reported may be explicitly related to the transition period or overlap with formal and informal supports such as material, informational, affective, and cognitive support [52]. Only five of the twelve studies reported specifically on the coping mechanisms. Caregivers from three studies reported that they coped by gaining information related to the transition (informational support; [49,53,56]). Three studies highlighted the coping mechanism of, when needing to get access, taking a proactive role to reach for the support system, even though some caregivers reported hesitance (material support; [49,57,59]). One study reported that setting up a routine for the caregivers to volunteer in NGOs while the children attend the centres helped the caregivers to watch over their children and, at the same time, secure the children's placement [57]. Lastly, another study reported that when caregivers had lower expectations, they could manage their worries better [53].

Based on the health approach, there has recently been more emphasis on the positive aspects of caregiving [28]. But only four of the twelve studies reported the positive aspects of caregiving factors. Two studies reported mixed feelings related to caregiving needs during the transition [48,57]. Not all caregivers reported only positive or negative experiences

related to caregiving needs. The positive and negative experiences are possibly due to the fluctuation in the physical and social environmental factors and the intensity of the caregiving demands that the caregivers have to cope with [57]. The possible themes that had been highlighted were the sense of fulfilment and pride in their children and themselves [48,50]; gratitude towards at least one of the multiple service providers [49]; benefits for the caregivers (being more assertive and determined in meeting the transition needs enhanced caregivers' resources and growth and ability to seek more formal and informal support [48]); and benefits for the individuals with ID (increased confidence and maturity, learning new coping skills, improvements in challenging behaviours, possible positive adjustment [48,49]).

Although possible positive aspects of caregiving were reported during the transition period, a perceived subjective burden was reported in eight of the eleven studies. Most of the studies reported negative emotions such as feeling physically and mentally tired of being the "fighter and advocate for their child" [48,50,51,58] and feeling helplessness or hopelessness, expressed in ways such as "feeling uncertain and confused" [48,49,57], being frustrated when "dealing with the inflexible and unresponsive service" [49], and having an "unsustainable burden of care" [56]. The caregivers reported that decision making was complex, and their daily activities felt restricted during the transition period. There was much uncertainty and a need to know what to expect [57]. Caregivers caring for children above 31 years old reported more negative feelings, evidenced in ways such as lower scores of well-being, more frustration, lower life satisfaction, and more sadness, compared to other caregiver groups caring for children who were below 30 years old [55]. Other reported feelings were guilt, resentment, anger, fear of repeat events and the future, depression, low self-worth, mistrust, and wishing that they do not have a child with a disability [48]. The caregiver could spend more time with their spouse only when the child left the family home [51]. The consistent themes linked to these negative feelings were the lack of support and dissatisfaction with the service system. There may have been a vicious cycle that made the caregivers feel physically and mentally tired, hopeless/helpless, and confused about what they could do during the transition period.

Some studies reported other factors that influence the caregivers' quality of life during the transition. Four studies highlighted the caregivers' concerns related to independence and vulnerability risk, such as the dilemma of letting go and separation [49,51,58,59]. Three studies also highlighted caregivers' anxiety. Anxious caregivers tend to be overprotective in managing their high-need children, as the caregivers perceive that there is a lack of adequate

support for the children [50,55,58].

In summary, the situation for caregivers of individuals with ID who are transitioning to adulthood is multi-faceted. One facet is that they have children who neuropathologically have potential ceiling effects on their cognitive abilities since birth and may also have multiple physical disabilities and health problems. Transitioning to adulthood adds more demands when there is a combination of biopsychosocial factors, possibly due to their physical development, psychological needs, and social and environmental settings. From the caregiver's perspective, the caregivers are probably in the stage of life wherein they are more vulnerable to health and mental issues and more fragile than they used to be due to progressive ageing, interrupted career progression, possible retirement planning, financial needs, family dynamics, and other parenting needs. Possibly due to the incongruency between the services expected by caregivers (since there might generally be an increase in the care demands during the transition and/or based on caregivers' expectation or understanding of "adulthood") and the actual services that the system and professionals have offered, caregivers have consistently reported their overall dissatisfaction with adult services. Especially when the comparison with the child service system is made, the caregivers may feel that they are left alone, and that the responsibility for the child ultimately rests with them. Therefore, practical coping mechanisms such as information gaining, setting up a routine, taking a proactive role, accessing the support system, and managing their expectations are reported to help deal with the transition phase. There are also reported mixed feelings depending on the situation and the demands of care that the situation requires, even though most of the research studies emphasise the caregiver's negative emotions and exhaustion in terms of being a caregiver compared to the positive aspects of caregiving. The vicious cycle of the increased demand during the transition, caregivers probably not being ready and hence unable to cope with the demands, concurrent with their perceived dissatisfaction with the services offered by the adult service system, leads the caregivers to develop helplessness. This cycle may be reinforced by the long waiting period to access the expected adult services, and caregivers continue to be overprotective and anxious due to the risk of vulnerability for their child.

Transition Types

As Ferguson et al. [19] described, the transition to adulthood is a complex process with several key factors and groups of individuals involved. Based on this review's findings, the expectations and contributions of the caregivers, the functional abilities and needs of the

individuals with ID, and the formal and informal support systems, including professionals who work in the adult service centres, are expected to affect each other in this system. Thus, the bureaucratic transition, changes in professional and agency services, and the relationships formed (e.g., abandonment, surrender, assimilation, and engagement with professionals) with the caregiver during the transition may differ for each caregiver based on their circumstances. Those caregivers who gain sufficient information and can take a proactive role during the transition [57,62,63] may benefit more when they collaborate with the professionals (engagement with professionals) or provide needed services for their child (assimilation with professionals). On the other hand, those caregivers who experience a high burden of care due to other stressors may not be able to meet the commitment needed for the transition and, hence, may not benefit from the relationship with the professionals [15,64].

The outcome of the bureaucratic transition and the perceived relationship with professionals may spill over into the family life transition. Based on the adult service placement outcome, the caregivers and the family must accommodate their routines and roles within the family. The caregivers and other family members are expected to cope with the changes and make any alternative arrangements needed in their family home setting, if the adult service placement is inaccessible or unsuitable. It is a possible theme, as reported by the caregivers, that they were not prepared for the transition and felt hopeless when the cycle was reinforced by the prolonged waiting period [65].

Finally, the status transition is the status change from child to adult. This review's findings on the caregiver's apprehensiveness related to independence and risk of vulnerability align with Ferguson et al.'s [19] study that the status transition could be more related to how much more or less supervision their child with ID needs, rather than them expecting that the child will be able to gain total independence as they reach the age of 21. Some caregivers viewed the individual with ID as a "little child," not a teenager. Hence, it may be more helpful for the caregivers to view the transition from a more constructive perspective, which includes all stakeholders and focuses on deciding the "right thing to do", rather than categorising what is "right" and "wrong" concerning what an adult would do [59,66].

8. Limitations and Future Directions

The studies included in this scoping review focused on the caregiver's adaptation to adult services when their child is known by the service providers. Even though the literature on "transition to adulthood" was considered with the intention to broaden the search and capture literature on individuals with ID who did not attend school or adult services, the

findings from this scoping review may only generalise to caregivers caring for individuals with ID who attended special education, completed their schooling, and transitioned into adult services. The data from the caregivers of individuals who dropped out of the school system and are unknown to the adult service system have not been captured. These cases may include an extreme spectrum of caregivers coping with the transition and not approaching the adult services for extra support or who have not been coping and did not want to approach the adult services. Further, caregivers caring for their children with challenging behaviours since childhood may have a different profile of needs. These caregivers would have sought support earlier in their children's lives, such as children's group homes and respite care. Therefore, future studies may consider recruiting caregivers from various sources, such as child guidance and development assessment centres, hospitals, and respite care and community-based service settings such as group homes, as this review did not find any studies representing this population of children and their caregivers.

There was only one quantitative study and eleven qualitative exploration studies. Most of the studies were designed based on the explorative qualitative method to gain a broad and deeper understanding of the caregivers' needs during the transition via open-ended questions. The qualitative research method is valuable in this under-investigated area of caregivers' well-being, specifically during the transition to adulthood, as it will help identify key factors that can be used as a base for more critical analysis via quantitative research methods [67]. Quantitative studies allow for comparing the caregiver groups' needs to understand the significant differences between the critical factors in this area [67]. Therefore, future study research design should involve quantitative methods to assess for significant differences between caregivers providing care for individuals with ID across the three stages of pre-transition, during transition, and post-transition to adulthood. Additional research could compare these three stages with caregivers caring for young adults with typical development.

Regarding this scoping review methodology, only literature published in English was included. Future review methodology may include non-English literature for more comprehensive review findings.

9. Conclusions

Although most of the studies reviewed were based on qualitative findings, the explorative nature of the study design did capture as broadly as possible the factors that affect caregivers' adaptation process in caring for individuals with ID during the transition to

adulthood. Although there were no studies on the significance of the increase in caregiving demands, specifically during the transition to adulthood, one study highlighted the significant need to spend more hours on caregiving during the transition period. However, the theme regarding caregivers' dissatisfaction with formal adult services was consistent and, in a vicious cycle, affected caregivers' negative emotions related to caregiving needs, increasing their dissatisfaction. Some studies highlighted the "mixed feelings", including the positive factors related to the caregiving experience, depending on the setting factors. This review's findings highlighted caregivers' apprehensiveness relating to the vulnerability risk and definition of independence for their children. The coping mechanisms discussed in this review need to be studied in more detail but provide direction for a practical approach to meeting the demands of this particular caregiving role. The findings in this review may suggest the importance of preparing and educating caregivers before their children graduate from child services about the possible changes in caregiving demands, increased vulnerability risk, and ways of dealing with adult services during the transition period. This may aid the caregivers in forming their definitions of independence, with possible shifts in expectations and comparison with the typical definition of adulthood. Future research may focus on quantitative studies comparing caregivers providing care for individuals with ID across the three stages of pre-transition, during transition, and post-transition to adulthood. Additional research could compare these three stages with caregivers caring for young adults with typical development. There is a need for more information to understand the relationship between caregiving demands and caregivers' perceptions or sense of helplessness that significantly affect their quality of life.

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Appendix A (Scoping review)

Table A1. Finalised keywords.

intellectual disabilit*	caregiv*	((school or adult*) AND (transit* OR chang* OR move OR moving))
intellectual development disorder*	care giv*	
intellectual dysfunction	parent*	
mental deficien*	mother*	
mental deficit	father*	
retard*	grandparent*	
mental disability	family	
intellectual impairment		
mental handicap		
mental incapacity		
mentally handicapped		

Appendix B (Scoping review)

Table A2. Keyword and index terms for each database.

Name of database:	APA PsycInfo
Date coverage:	1927–2023
Library:	James Cook University
Limits:	No limits applied
Search string:	(MAINSUBJECT.EXACT("Adolescent Mothers") OR MAINSUBJECT.EXACT("Single Mothers") OR MAINSUBJECT.EXACT("Grandparents") OR MAINSUBJECT.EXACT("Stepparents") OR MAINSUBJECT.EXACT("Parents") OR MAINSUBJECT.EXACT("Mothers") OR MAINSUBJECT.EXACT("Foster Parents") OR MAINSUBJECT.EXACT("Single Fathers") OR MAINSUBJECT.EXACT("Fathers") OR MAINSUBJECT.EXACT("Caregivers") OR MAINSUBJECT.EXACT("Caregiving") OR MAINSUBJECT.EXACT("Adoptive Parents") OR MAINSUBJECT.EXACT("Single Parents") OR MAINSUBJECT.EXACT("Homosexual Parents") OR MAINSUBJECT.EXACT("Caregiver Burden") OR caregiv* OR ("care given" OR "care giver" OR "care givers" OR "care giving") OR parent* OR mother* OR father* OR grandparent* OR famil*) AND (MAINSUBJECT.EXACT.EXPLODE("Neurodevelopmental Disorders") OR

	MAINSUBJECT.EXACT(“Cognitive Impairment”) OR MAINSUBJECT.EXACT(“Developmental Disabilities”) OR (“intellectual disabilities” OR “intellectual disability”) OR “intellectual development disorder*” OR “intellectual dysfunction” OR (“mental deficiencies” OR “mental deficiency”) OR “mental deficit” OR retard* OR “mental disability” OR “intellectual impairment” OR “mental handicap” OR “mental incapacity” OR “mentally handicapped”) AND (MAINSUBJECT.EXACT(“Transition Planning”) OR MAINSUBJECT.EXACT(“School to Work Transition”) OR ((school OR adult*) NEAR/6 (transit* OR chang* OR move OR moving)))
Number of hits:	1459

Name of database:	ERIC
Date coverage:	1960–2023
Library:	James Cook University
Limits:	No limits applied
Search string:	(MAINSUBJECT.EXACT(“Education Work Relationship”) OR MAINSUBJECT.EXACT(“Individualized Transition Plans”) OR ((school OR adult*) NEAR/6 (transit* OR chang* OR move OR moving))) AND (MAINSUBJECT.EXACT.EXPLODE(“Intellectual Disability”) OR (“intellectual disabilities” OR “intellectual disability”) OR “intellectual development disorder*” OR “intellectual dysfunction” OR (“mental deficiencies” OR “mental deficiency”) OR “mental deficit” OR retard* OR “mental disability” OR “intellectual impairment” OR “mental handicap” OR “mental incapacity” OR “mentally handicapped”) AND (MAINSUBJECT.EXACT(“Family Role”) OR MAINSUBJECT.EXACT.EXPLODE(“Parents”) OR MAINSUBJECT.EXACT(“Parent Role”) OR MAINSUBJECT.EXACT(“Caregivers”) OR MAINSUBJECT.EXACT(“Caregiver Child Relationship”) OR MAINSUBJECT.EXACT(“Caregiver Role”) OR caregiv* OR (“care given” OR “care giver” OR “care givers” OR “care giving”) OR parent* OR mother* OR father* OR grandparent* OR famil*)
Number of hits:	315

Name of database:	SCOPUS
Date coverage:	1971–2023
Library:	James Cook University
Limits:	No limits applied
Search string:	(TITLE-ABS-KEY (“intellectual disabilit*” OR “intellectual development disorder*” OR “intellectual dysfunction” OR “mental deficien*” OR “mental deficit” OR retard* OR “mental disability” OR “intellectual impairment” OR “mental handicap” OR “mental incapacity” OR “mentally handicapped”) AND TITLE-ABS-KEY (((school OR adult*) W/6 (transit* OR chang* OR move OR moving)))AND TITLE-ABS-KEY (caregiv* OR “care giv*” OR parent* OR mother* OR father* ORgrandparent* OR famil*))

Number of hits:	432

Name of database:	Web of Science
Date coverage:	1985–2023
Library:	James Cook University
Limits:	No limits applied
Search string:	“intellectual disabilit*” OR “intellectual development disorder*” OR “intellectual dysfunction” OR “mental deficien*” OR “mental deficit” OR retard* OR “mental disability” OR “intellectual impairment” OR “mental handicap” OR “mental incapacity” OR “mentally handicapped” (Topic) and (school OR adult*) NEAR/6 (transit* OR chang* OR move OR moving) (Topic) and caregiv* OR “care giv*” OR parent* OR mother* OR father* OR grandparent* OR famil* (Topic)
Number of hits:	352

Name of database:	ProQuest Theses and Dissertations
Date coverage:	Up to 2023
Library:	James Cook University
Limits:	No limits applied
Search string:	“intellectual disabilit*” OR “intellectual development disorder*” OR “intellectual dysfunction” OR “mental deficien*” OR “mental deficit” OR retard* OR “mental disability” OR “intellectual impairment” OR “mental handicap” OR “mental incapacity” OR “mentally handicapped” (Topic) and (school OR adult*) NEAR/6 (transit* OR chang* OR move OR moving) (Topic) and caregiv* OR “care giv*” OR parent* OR mother* OR father* OR grandparent* OR famil* (Topic)
Number of hits:	317

Appendix C (Scoping review)

Screening Tool

Citation, Title, and Abstract Screening

1. Does the title or abstract use English?

a. Yes: continue screening

b. No: stop screening

Abstract Screening

2. Does the abstract indicate intellectual disability (ID) causing significant impairment of cognitive and adaptive functioning in the sample that was studied?

a. Yes or Unsure/Unclear: continue screening

Comorbid ID with other diagnoses is acceptable

b. No: stop screening

For example, study sample with only other neurodevelopmental disorders such as autism

spectrum disorder (ASD), attention deficit and hyperactive disorder (ADHD), specific learning disability (SLD), conduct disorders, impairment in vision and hearing as well as other mental illnesses, and dementia.

3. Does the abstract indicate that an individual with ID "transitioning to adulthood" sample was studied?

The search allows capturing literature on individuals with ID who did not attend or graduate from school. To broaden the search, literature on the "transition to adulthood" will be included. The "transition to adulthood" will be conceptualised as completing formal schooling (i.e., finishing high/secondary school).

a. Yes or Unsure/Unclear: continue screening

b. No: stop screening

For example, individuals with ID are still attending school or transitioning from primary to secondary school.

4. Does the abstract indicate that an individual family caregiver of any age who lives with and provides unpaid care to an individual diagnosed with ID sample was studied?

a. Yes or Unsure/Unclear: continue screening

b. No: stop screening

For example, the study only samples collective family and sibling adaptation, teachers, as well as paid and professional caregivers.

5. Did the abstract indicate that factors related to the "adaptation" of family caregivers when managing adolescents with ID were studied?

The factors that possibly affect the "adaptation" process will include, but not be limited to, family caregivers' objective and perceived burden, support (emotional, instrumental, and informational) and resources, expectations, coping mechanisms, positive caregiving, and quality of life.

Apart from that, positive and negative factors related to the adaptation outcome, such as quality of life and mental and physical health during the transition, will be included.

a. Yes or Unsure/Unclear: continue screening

b. No: stop screening

Decision: Should this article be included?

a. Yes, all five screening questions answered Yes or Unclear

b. No, at least one answer was definitely "No"

Appendix D (Scoping review)

Data extraction form

Article title
Source (journal, volume, issue, pages)
Author(s)
Year of publication
Aim(s)
Context
Country (where the study was conducted)
Participants (details, e.g., age/sex and number)
Type of study
Methodology/methods
Questionnaire used
Outcomes Key findings that relate to the scoping review question/s: What are the reported sources of the family caregivers' objective burden (stress related to the caregiving factors and related to the individual with ID) during the transition to adulthood of individuals with ID, for each severity level (mild, moderate, severe, and profound)? How is the caregiver's objective burden assessed? What kind of support and resources do the family caregivers report they need to manage the individuals with ID, for each severity level (mild, moderate, severe, and profound), during the transition? What coping mechanisms do family caregivers commonly use during the transition to adulthood of individuals with ID? What positive aspects of caregiving help family caregivers during the transition to adulthood of individuals with ID? What is the family caregivers' quality of life like (i.e., physical and mental health, perceived subjective burden) during the transition to adulthood of individuals with ID for each severity level (mild, moderate, severe, and profound)? Are other factors related to caregiving, such as the caregivers' anxiety levels or expectations about the future independent living of individuals with ID, influencing the caregivers' quality of life during the transition?

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Appendix B

Demographic Information:

Caregiver:

1. Caregiver age:

2. Caregiver gender: Male/ Female

3. Ethnicity: Chinese/ Malay/ Indian/ Others

4. Religion: Buddhist/ Christian/ Muslim/ Taoist/ Hindu/ No religion/ Others

5. Marital status: Single/ Married/ Widowed/ Divorced/ Separated

6. Highest education: Below secondary/ Secondary/ Post-secondary (non-tertiary)/ Diploma & Professional Qualification/ University

7. Employment status: Full time employment (office hours)/ Full time employment (non-office hours/shift rotation)/ Self-employment/ Part time employment/ Homemaker/ Retired/ unemployed/ others

8. Household income (per month): $2500 and below/ $2,500 to $3,500/ $3,501 to $4,500/ $4,501 to $7,500/ Above $7,500

9. People living in same household: Relationship – Age

10. Do you have any helper? Yes/ No

11. Caregiving relationship: Mother/ Father/ Grandmother/ Grandfather/ Aunt/ Uncle/ Sister/ Brother/ Others (Specify)

12. Years of caregiving:

13. Other caregiving responsibility:
    Yes – child under 18 years without disability
    Yes – child under 18 years with disability
    Yes – adult
    Yes – older adult
    Yes – others
    No

Individual with Intellectual Disability:

1. Age:

2. Gender: Male/. Female

3. Current engagement:

School/ ITE/ Polytechnic / University
Day activity centre (DAC)
Social clubs
Sheltered workshop
Home or case management-based services
Healthcare (IMH)
Open employment
Supported employment
On waiting list for any service placement
Not engaged with any service provider
Others (specify)

4. Diagnosis: Intellectual Disability / Autism Spectrum Disorder (ASD) / Attention Deficit Hyperactive Disorder (ADHD) / Tic Disorder / Anxiety Disorder / Obsessive – Compulsive Disorder (OCD) / Depressive Disorder / Bipolar Disorder / Schizophrenia / Others (Specify)

5. Epilepsy (seizure fit) : Yes/ No
   Yes – when was the last episode?

6. Physical health related diagnosis? (Open respond)

DBC-P24

The following behaviours may or may not apply to the adult in your care **now or within the past six month.**

Item		0 Not true as far as I know	1 Somewhat or sometimes true	2 Very true or often true
1	Becomes overexcited	0	1	2
2	Chews or mouths objects or body parts	0	1	2
3	Confuses the use of pronouns (e.g., uses *you* instead of *I*)	0	1	2
4	Doesn't show affection	0	1	2
5	Grinds teeth	0	1	2
6	Has nightmares, night terrors, or walks in sleep	0	1	2
7	Impatient	0	1	2
8	Inappropriate sexual activity with another	0	1	2
9	Jealous	0	1	2
10	Kicks, hits others	0	1	2
11	Laughs or giggles for no obvious reason	0	1	2
12	Preoccupied with only one or two particular interests	0	1	2
13	Refuses to go to school, activity center, or workplace	0	1	2
14	Repeats the same word or phrase over and over	0	1	2
15	Smells, tastes or licks objects	0	1	2
16	Switches lights on and off, pours water over and over, or similar repetitive behaviour	0	1	2
17	Stubborn, disobedient, or uncooperative	0	1	2
18	Says he/she can do things that he/she is not capable of	0	1	2
19	Sees, hears, something that isn't there, hallucinations	0	1	2
20	Tells lies	0	1	2
21	Tense, anxious, worried	0	1	2
22	Underreacts to pain	0	1	2
23	Upset or distressed over small changes in routine or environment	0	1	2
24	Wanders aimlessly	0	1	2

SB 1

Overall, how do you feel managing the individual for their day-to-day needs?

Rating scale:

Completely stress free (no stress at all)	Mostly feeling stress free	Somewhat feeling stress free	Neither feeling stress or stress free (neutral)	Somewhat feeling stress	Mostly feeling stress	Completely stressful (could not be more stressed)
1	2	3	4	5	6	7

OBS

Since you began caregiving, how has assisting or having contact with him/her affected the following aspects of your life?

Item		A lot more (better)	A little more (better)	The same	A little less (worse)	A lot less (worse)
1	Amount of time you have to yourself	1	2	3	4	5
2	Amount of privacy you have	1	2	3	4	5
3	Amount of money you have available to meet expenses	1	2	3	4	5
4	Amount of personal freedom you have	1	2	3	4	5
5	Amount of energy you have	1	2	3	4	5
6	Amount of time you spend in recreational and/or social activities	1	2	3	4	5
7	Amount of vacation activities and trips you take	1	2	3	4	5
8	Your relationship with other family members	1	2	3	4	5
9	Your health	1	2	3	4	5
10	Your work/job (eg: because of having to take time off)	1	2	3	4	5

SB 2

Overall how do you feel in managing your own day to day needs?

Rating scale:

Completely stress free (no stress at all)	Mostly feeling stress free	Somewhat feeling stress free	Neither feeling stress or stress free (neutral)	Somewhat feeling stress	Mostly feeling stress	Completely stressful (could not be more stressed
1	2	3	4	5	6	7

QFSSS

Indicates the frequency of and satisfaction with support received from your partner, family, friends and the community

Indicates the frequency of and satisfaction with support received from your partner, family, friends, and the community	HOW OFTEN DO YOU RECEIVE SUPPORT?					HOW SATISFIED ARE YOU WITH THE SUPPORT RECEIVED?				
	1. Rarely 2. Sometimes 3. Quite often 4. Almost always 5. Always					1. Dissatisfied 2. Barely satisfied 3. Fairly satisfied 4. Quite satisfied 5. Very satisfied				
PARTNER	**FREQUENCY**					**SATISFACTION**				
EMOTIONAL SUPPORT: your partner is loving, affectionate and listens to you when you want to talk and express your feelings.	1	2	3	4	5	1	2	3	4	5
INSTRUMENTAL SUPPORT: Would do you a favour if needed or is willing to do specific things for you, such as providing money, taking you to the doctor or helping you in any other activity	1	2	3	4	5	1	2	3	4	5
INFORMATIONAL SUPPORT: Gives you useful advice and information regarding questions, problems or daily tasks	1	2	3	4	5	1	2	3	4	5
FAMILY	**FREQUENCY**					**SATISFACTION**				
EMOTIONAL SUPPORT: They are loving and affectionate and listen to you when you want to talk and express your feelings.	1	2	3	4	5	1	2	3	4	5
INSTRUMENTAL SUPPORT: Would do you a favour if needed or are willing to do specific things for you, such as providing money, taking you to the doctor or helping you in any other activity	1	2	3	4	5	1	2	3	4	5
INFORMATIONAL SUPPORT: Give you useful advice and information regarding questions, problems or daily tasks	1	2	3	4	5	1	2	3	4	5
FRIENDS	**FREQUENCY**					**SATISFACTION**				
EMOTIONAL SUPPORT: they are loving and affectionate and listen to you when you want to talk and express your feelings.	1	2	3	4	5	1	2	3	4	5
INSTRUMENTAL SUPPORT: Would do you a favour if needed or are willing to do specific things for you, such as providing money, taking you to the doctor or helping you in any other activity	1	2	3	4	5	1	2	3	4	5
INFORMATIONAL SUPPORT: Give you useful advice and information regarding questions, problems or daily task	1	2	3	4	5	1	2	3	4	5
COMMUNITY (support from neighbours, the parish, associations and clubs, and the community in general)	**FREQUENCY**					**SATISFACTION**				
EMOTIONAL SUPPORT: they are loving and affectionate and listen to you when you want to talk and express your feelings.	1	2	3	4	5	1	2	3	4	5
INSTRUMENTAL SUPPORT: Would do you a favour if needed or are willing to do specific things for you such as providing money, taking you to the doctor or helping you in any other activity	1	2	3	4	5	1	2	3	4	5
INFORMATIONAL SUPPORT: Give you useful advice and information regarding questions, problems or daily tasks	1	2	3	4	5	1	2	3	4	5

Brief COPE

The following questions ask how you have sought to cope with a hardship in your life. Read the statements and indicate how much you have been using each coping style.

		I haven't been doing this at all	A little bit	A medium amount	I've been doing this a lot
1	I've been turning to work or other activities to take my mind off things.	1	2	3	4
2	I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
3	I've been saying to myself "this isn't real".	1	2	3	4
4	I've been using alcohol or other drugs to make myself feel better	1	2	3	4
5	I've been getting emotional support from others.	1	2	3	4
6	I've been giving up trying to deal with it.	1	2	3	4
7	I've been taking action to try to make the situation better.	1	2	3	4
8	I've been refusing to believe that it has happened.	1	2	3	4
9	I've been saying things to let my unpleasant feelings escape.	1	2	3	4
10	I've been getting help and advice from other people.	1	2	3	4
11	I've been using alcohol or other drugs to help me get through it.	1	2	3	4
12	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
13	I've been criticizing myself.	1	2	3	4
14	I've been trying to come up with a strategy about what to do.	1	2	3	4
15	I've been getting comfort and understanding from someone.	1	2	3	4
16	I've been giving up the attempt to cope.	1	2	3	4

		I haven't been doing this at all	A little bit	A medium amount	I've been doing this a lot
17	I've been looking for something good in what is happening.	1	2	3	4
18	I've been making jokes about it.	1	2	3	4
19	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
20	I've been accepting the reality of the fact that it has happened.	1	2	3	4
21	I've been expressing my negative feelings.	1	2	3	4
22	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
23	I've been trying to get advice or help from other people about what	1	2	3	4
24	I've been learning to live with it.	1	2	3	4
25	I've been thinking hard about what steps to take.	1	2	3	4
26	I've been blaming myself for things that happened	1	2	3	4
27	I've been praying or meditating	1	2	3	4
28	I've been making fun of the situation.	1	2	3	4

PACS

Some caregivers say that, despite all the difficulties involved in giving care to a family member with intellectual disability, good things have come out of their caregiving experiences too. How much do you agree or disagree with these statements?

Item		Disagree a lot	Disagree a little	Neither agree or disagree	Agree a little	Agree a lot
1	Made me feel more useful	1	2	3	4	5
2	Made me feel good about myself	1	2	3	4	5
3	Made me feel needed	1	2	3	4	5
4	Made me feel appreciated	1	2	3	4	5
5	Made me feel important	1	2	3	4	5
6	Made me feel strong and confident	1	2	3	4	5
7	Enabled me to appreciate life more	1	2	3	4	5
8	Enabled me to develop a more positive attitude toward life	1	2	3	4	5
9	Strengthened my relationships with others	1	2	3	4	5

Resource checklist:

What form of service(s) do you receive for the individual diagnosed with ID currently?

What form of service(s) do you receive for yourself as a caregiver?

Do you receive any form of financial assistance? Yes/No
If yes, please describe what type/source of financial assistance below:

Have you use the respite care service? If yes, how many times?

Modified PTI

Some caregivers might consider out of home placement for various reasons. Read the options carefully. Indicate one option that most accurately defines your intention.

1	No, I have never thought about it
2	Occasionally I have given it a thought
3	Yes, I have thought about it a lot, but have done nothing
4	I have thought about it and enquired but have not done anything yet
5	I have taken steps to place; the paperwork is in process
6	The individual diagnosed with ID is on the waiting list for the adult home
7	The individual diagnosed with ID had moved out of the home

There will be additional questions on understanding the decision-making process related to the placement tendency as below:

i) Did your decision making regarding the out of home placement changed from the past 6 months?

Response: Yes / No

If yes, what cause the change?

ii) My family members and I are in agreement related to the future management plan.

Strongly disagree

1

2

3

4

5

6

7

Strongly agree

WHOQOL-BREF

Please read the question, assess your feelings, for the last two weeks, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the **last two weeks**.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5
6	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	An extreme amount
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	Have you enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information you need in your daily life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15	How well are you able to get around physically?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the **last two weeks**.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26	How often do you have negative feelings such as blue mood, despair, anxiety or depression?	1	2	3	4	5

DFS

The statement below concerns your attitude towards the future. Read them carefully. If a given statement accurately describes your attitude, indicate number "6" on the attached scale. If the statement is not a true description of your attitude, indicate "0". Each statement may reflect your attitude to a different degree. Indicate the number that most accurately defines your point of view. There are no 'right" or "wrong" answers. All answers are valuable, provided they are sincere.

The scale:

0—Decidedly false; 1—False; 2—Somewhat false; 3—Hard to say; 4—Somewhat true; 5—True; 6—Decidedly true

1. I am afraid that the problems which trouble me now will continue for a long time	0	1	2	3	4	5	6
2. I am terrified by the thought that I might sometimes face life's crises or difficulties	0	1	2	3	4	5	6
3. I am afraid that in the future my life will change for the worse	0	1	2	3	4	5	6
4. I am afraid that changes in the economic and political situation will threaten my future	0	1	2	3	4	5	6
5. I am disturbed by the thought that in the future I won't be able to realize my goals	0	1	2	3	4	5	6

BRS

How strongly do you agree or disagree with the following statements?

Respond to each statement below by circling **one answer per row.**		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
BRS 1	I tend to bounce back quickly after hard times.	1	2	3	4	5
BRS 2	I have a hard time making it through stressful events.	5	4	3	2	1
BRS 3	It does not take me long to recover from a stressful event.	1	2	3	4	5
BRS 4	It is hard for me to snap back when something bad happens.	5	4	3	2	1
BRS 5	I usually come through difficult times with little trouble.	1	2	3	4	5
BRS 6	I tend to take a long time to get over setbacks in my life.	5	4	3	2	1

Appendix C

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PARTICIPANT INFORMATION SHEET

PROJECT TITLE: **A family view on what happens when adolescents with intellectual disability leave school**

You are invited to take part in a research project that aims to understand how adolescents with an Intellectual Disability (ID) and their families adapt when the adolescent finishes their schooling. This project follows up with adolescents and their families in the first two years after the adolescent has graduated from the special education school system. This study is being conducted by Shivasangarey Kanthasamy (Ms Shiva) and will contribute to her thesis for the Doctor of Philosophy (PhD) degree at James Cook University in Singapore.

You are being asked to participate as the 'primary family caregiver' of the adolescent with ID. If you agree to consider being involved in this study, you will be interviewed (approximately 1 hour). This interview can take place at your home or in an office at James Cook University, as you wish. If you then agree to take part in this project you will be asked to fill in some questionnaires and give permission for your adolescent family member with ID to be assessed (about 30 minutes).

You will also be invited to take part in 4 follow-up interviews over the next 2 years (2022 and 2023). At each follow-up interview you will be asked to complete questionnaires about the recent behaviour of the adolescent, how you responded to any difficult situations with the adolescent, positive things that have occurred, support or services that you have used, and your thoughts about the future for the adolescent and your family. You can choose either an online or face-to-face interview to complete the questionnaires. Each follow-up interview will take about 30 minutes to complete.

Your responses and contact details will be kept strictly confidential. Once data collection is completed all identifying information will be removed from the data set. Only anonymous and non-identifiable data will be stored, the data from this study will be used in research publications and reports (journal articles and theses). You will not be identified in any way in these publications.

Taking part in this study is completely voluntary. Even if you agree to take part in this study you can change your mind at any time and withdraw from the study. If you withdraw, you can also ask for the information that you have already given to be withdrawn. You will not need to give an explanation for why you want to withdraw and there will not be any effect on the support or services you and your family receive.

Your participation in this study may potentially benefit caregivers of adolescents with ID here in Singapore through a greater understanding of the situations faced by the families of the adolescents with ID. We are hopeful that the results will lead to meaningful recommendations about appropriate and necessary services or support for these families in the future.

You may experience distress when you are recalling difficult life experiences, for example you may feel sad, worried or angry. If you experience any distress while participating in this project and you feel you would benefit from further support, you may contact:

- Samaritans of Singapore (24-hour Helpline):1800 221 4444
- The Institute of Mental Health (24-hour Helpline): 6389 2222
- Silver Ribbon Singapore: 6385 3714
- TOUCHline (Counselling): 1800 377 2252

If you have any questions about the study, please contact:

Principal Investigator:
Shivasangarey Kanthasamy (Ms Shiva)
School of Social and Health Sciences
James Cook University
Singapore
Email: shiva.kanthasamy@my.jcu.edu.au

Primary Supervisor:
Professor Nigel V. Marsh
School of Social and Health Sciences
James Cook University
Singapore
Phone:
Email: nigel.marsh@jcu.edu.au

If you have any concerns regarding the ethical conduct of the study, please contact:
Human Ethics, Research Office
James Cook University, Townsville, Qld, 4811
Phone: (07) 4781 5011 (ethics@jcu.edu.au)

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Semi-Structured Interview Schedule Form

Main Research Question (not to asked directly of participants):

- What influences placement decisions for caregivers during the transition from the education system?

I am Shiva, and I am the principal investigator of this study. I want to ask you some questions about your concerns and adaptation to the caregiving journey of caring for an individual with intellectual disability (ID). This interview should take about 30 minutes to 1 hour.

A. General questions on the transition to adulthood

1. How have things been at home since your child left the school?

   Prompts:

   a. Have there been any changes in the caregiving demands?
      - What are the changes?
      - Are you spending more, less, or about the same time on caregiving?

   b. Tell me about any significant changes to your routine since your child has left the school.

   c. Since your child left school, has caregiving become more manageable, challenging, or stayed the same? And why?

B. Placement Decisions

1. I can see from your responses on the questionnaires that you are still [*INSERT Placement Tendency Index response*]. Tell me more about this decision and your thoughts behind it.
2. I can see from your responses on the questionnaires that you [*agree/disagree*] as a household/family about the placement decision. Please tell me how you came to a decision about placement as a family/household.
3. Has anything happened since your child left school that made you query/question this decision? If yes, please tell me about it.

C. Future caregiving arrangement

1. What is your future caregiving plan as your child gets older?

   Prompt:

   i. What is the specific plan that you have in your mind? (e.g. family members, residential placement, independent living)

2. How did you come up with this plan?

3. What beliefs or values drive you for your chosen future caregiving plan?

Prompt:

i. Any parenting, cultural, religious beliefs or values etc

4. What are your hopes for your child's future?

D. Concerns about future

1. As a caregiver, what are your concerns about your child's future and caregiving needs?

Prompts:

i. How do you feel about their safety in the future?

ii. What do you think the potential risks are for them in the future?

2. Have you got any concerns about your ability to keep providing care?

Prompt:

i. Financial, ageing, health, retirement etc

3. How might that affect your future caregiving plan?

Prompt:

i. Do you have a backup plan?

E. Support

1. Overall, how do you feel about the support you received during this transition?

Prompts:

i. What is your most significant support (formal or non-formal support)?

ii. What additional support have you needed during this transition that you are not getting?

F. Closing Question

1. Is there anything else you want to tell me about caring for your child during this transition period?

I appreciate the time you spend on this interview. Thanks a lot.

Appendix D

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How Families Adapt While Caring for Individual Diagnosed with Intellectual Disability

Do you have to take care of an adult family members who has been diagnosed with Intellectual Disability?

We are seeking volunteers to be recruited in this research study. The purpose of this research study is to understand the process of caregiver adaptation, caring for individual with intellectual disability (ID) and how this effects decisions on the future possibility of care arrangements (home vs out-of-home).

You May Qualify If You:

- Unpaid primary caregiver of individual with diagnosis of Intellectual Disability
- Able to read and write in English
- Singapore citizen or permanent resident

Potential Benefits:

Participating in this study may help us to understand the situation that you face as a caregiver. We are hopeful that the results will lead to meaningful recommendations about appropriate and necessary services or support for these families in the future.

Participation Involves:

- You will be interviewed, to fill in some questionnaires (approximately 1 hour).
- Then there will be a short phone follow up after 6 to 9 months of the initial contact (approximately 3 minutes).

Location:

Face to face session in Institute of Mental Health, IMH (10, Buangkok View, Buangkok Green, Medical Park, 539747)
(Specific location will be advised once you expressed your interest)

Contact details:

Email: shivasangarey_kanthasamy@imh.com.sg

Or

IMH Contact Center: 63892000 (please kindly pass the message to the operator that you would like to speak to Ms. Shiva regarding research participation)

Recruitment Poster (Version 3) 8 September 2022

To understand how families adapt while caring for individual diagnosed with ID

Dear caregivers,

We are seeking volunteers to be recruited in this research study. The purpose of this research study is to understand the process of caregiver adaptation, caring for individual with intellectual disability (ID) and how this effects decisions on the future possibility of care arrangements (home vs out-of-home). We would appreciate and value receiving information from your own perspective. Your participation in this study may potentially benefit caregivers of adolescents with ID here in Singapore through a greater understanding of the situations faced by the families of the individual with ID. We are hopeful that the results will lead to meaningful recommendations about appropriate and necessary services or support for these families in the future.

You will be eligible for this study if you are unpaid primary caregiver of individual with diagnosis of Intellectual Disability, able to read and write in English and Singapore citizen or permanent resident.

I am Shivasangarey Kanthasamy (Ms Shiva). I am a Clinical Psychologist and the Principal Investigator for this research project. My clinical experiences for the past six years have been primarily working with individuals diagnosed with ID and ASD, as well as their family caregivers.

What will be expected from you?

If you agree to consider being involved in this study, you will be interviewed, to fill in some questionnaires (approximately 1 hour). This interview will be conducted either face to face in IMH (10, Buangkok View, Buangkok Green, Medical Park, 539747) or via Zoom.

Then there will be a short phone follow up after 6 to 9 months of the initial contact (approximately 3 minutes).

If you are willing to participate, please kindly contact me via my email address or contact centre to know more about this study. I will contact you to know your preferred date and time to schedule for a consent taking session either face to face or via Zoom.

Contact details:
Email: shivasangarey_kanthasamy@imh.com.sg
or
IMH Contact Center: 63892000 (please kindly pass the message to the operator that you would like to speak to Ms. Shiva regarding research participation)

Thanks and stay safe!

Regards,
Ms Shiva
Senior Clinical Psychologist, IMH

Letter of Invitation (Version 4) 1st December 2022

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