

# **Born To Challenge**

## **Adjustment and Personal Growth of Adults Raised by a Parent with a Mental or an Intellectual Disability**

Ph.D. Thesis

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## **A few personal words**

*"A hero is an ordinary individual who finds the strength to persevere and endure in spite of overwhelming obstacles." (Christopher Reeve)*

This work, in my eyes, deals with real-life heroes. The children of people with disabilities are born into challenging lives and are faced with the need to overcome and persevere from day one and through-out. The fact that they do still amazes me after over a decade of research in this field. I am proud to have had the opportunity to shed much needed light on them and their unique lives.

I would like to thank all the participants of this study for enabling me an honest and open view of their lives. I believe that in doing so they challenged me and us as professionals and as a society, to look within ourselves at what we know about people with disabilities and how we address them and their families.

I would also like to thank them for reminding me of all the things I have to be thankful for in my life- my exceptional parents, Adina and Yacov Weshler who make sure I always have whatever I need to accomplish my goals and fulfill my dreams, my personal family cheer team and above all Asaf and Yonatan who supported me and allowed me the needed time to invest in perusing this task, and last but not least my family of choice- my amazing friends, too many to name, who encouraged me every step of the way.

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Reminding us all that real-life heroes live among us!

*Dorit Weshler*

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## **Summary**

Progress in the discourse and legislation concerning the human rights of people with disabilities has led to the realization of their rights across many life domains, including the right to marry and to bear children. With regard to the potential impact of disability on parenting, most research until now has focused on parenting as experienced by the parents themselves. However when exploring the implications of parenting, the perspective of the child – a crucial component of the context – remain under-researched. The objective of this study was to explore the unique and combined contribution of intrapersonal factors (attachment orientation and self-esteem), social-ecological factors (social support), and coping strategies – the three representing protective factors – in the adjustment (mental health) and personal growth of adults raised by a parent with a mental or intellectual disability (a risk factor operationalized by perceived stress and parental bonding). A comparative analysis assessed these factors alongside a sample population of adults raised by parents without a disability

Search words: Parents with a disability, Intellectual Developmental Disability, Mental Disability, adjustment, growth, Equal Rights of Persons with Disabilities.

## **Abstract**

Progress in the discourse and legislation concerning the human rights of people with disabilities has led to the realization of their rights across many life domains, including the right to marry and to bear children. With regard to the potential impact of disability on parenting, most research until now has focused on parenting as experienced by the parents themselves. However when exploring the implications of parenting, the perspective of the child – a crucial component of the context – remain under-researched.

Drawing from the theoretical framework presented by Wallander et al. (1989), the objective of this study was to explore the unique and combined contribution of intrapersonal factors (attachment orientation and self-esteem), social-ecological factors (social support), and coping strategies – the three representing protective factors – in the adjustment (mental health) and personal growth of adults raised by a parent with a mental or intellectual disability (a risk factor operationalized by perceived stress and parental bonding). A comparative analysis assessed these factors alongside a sample population of adults raised by parents without a disability.

A number of 215 adults aged between 25 and 55 participated in the study. 100 had been raised by a parent or parents with a disability (PWD); 115 had been raised by a parent or parents without a disability. The participants were recruited through Israel's National Insurance Institute, and through professional contacts and social networks.

This study used a mixed method approach utilizing a concurrent triangulation strategy (Terrell, 2012). The first and main part of the study was quantitative in nature, using a number of tools including: Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983); Parental Bonding Instrument (Parker, Tupling & Brown, 1979); Experience in Close Relationships scale (Brennan, Clark & Shaver, 1988); Rosenberg Self-Esteem Scale (Rosenberg, 1965); The Multidimensional Scale for

Perceived Social Support (Zimmet et al., 1988); The Coping Orientation to Problems Experienced (Carver et al., 1989); The Mental Health Inventory (Veit & Ware, 1983), and Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996).

Given the relatively scarce body of knowledge regarding this population, it was decided to incorporate a qualitative approach to the study, to facilitate a contextual and in-depth engagement with the phenomenon of children raised by PWD. Nine participants from the quantitative study, all raised by PWD, took part in in-depth interviews.

The quantitative aspect of this study partially confirmed the research hypotheses. As predicted, differences in levels of perceived stress were found between the participants raised by a PWD and those who had not, with the former presenting higher levels of perceived stress. Perceived stress was found to significantly mediate the impact of being raised by a PWD on both the mental health and personal growth of the research participants. The children of PWD perceived themselves as having received lower levels of paternal and maternal care than the participants raised by a parent without a disability. The research results further found a difference in parenting patterns between the two groups; the children of PWD presented patterns of affectionless control parenting, while the second group displayed optimal parenting patterns. The participants who had been raised by a PWD also reported a lower perception of social support. In the realm of mental health, participants raised by a PWD reported lower levels of mental health, in comparison with participants raised by a parent without a disability. The commonalities between these very different groups of people was interesting in itself, exceeding the expectations of the research study. The study's hypothesis had presumed that differences would be found across all aspects between the participants raised by a PWD and those who were not. Despite

this assumption, no significant differences were found in levels of self-esteem, coping strategies, attachment orientation and personal growth.

The six main themes identified in the qualitative part of this study, with regard to the experience of growing up with a PWD, were: Knowledge – or lack thereof – of a parent's disability, its meaning, and the need to contextualize the vague explanations they had been given; the role played by members of the extended family in their lives, as caregivers and as surrogate parents; the lifelong search for meaningful adult figures to serve as role models and mentors; mixed feelings towards their parent/s, when viewing them as a burden; role reversal at a young age, and the strain that this responsibility placed upon them; and an inner drive towards success despite the odds, to prove their worth to the world. A connection was established between these themes and the results of the quantitative study, allowing for a better understanding of the quantitative data regarding the experience of being raised by a PWD.

When looking at parental bonding, paternal care was found to moderate the link between being raised by a PWD and perceived stress. This underlines the important role of the father and the father-child relationships, and the emphasis that this construct deserves – an emphasis usually directed by research and practice toward the role of the mother. The shame that the children of PWD participants in the study reported as forming a part of their childhood experiences, and the mixed feelings that they had with regard to their parents, may have also had an impact on the bond that developed between them and their parents. Avoidant attachment orientation was found to mediate the impact of perceived stress on mental health; the stronger the effect of avoidant attachment orientation, the higher the reported levels of mental health. The constant need to conceal the family “secret”, the PWD, together with ingrained societal stigma regarding disability issues, may have contributed to the further development of these avoidant patterns. Perceived social support was not

found to be a moderator of the impact of perceived stress on growth and mental health, although the study did find that this perception manifested at high levels for both the research participants raised by a PWD and those who were not. For the PWD group, the perception of the presence of a social support system in their current lives may have been informed by the lifelong lesson shaped by the childhood experience of the role of the extended family and other significant (but not parental) adult figures. Similarly, self-esteem was not found to act as a moderator of the impact of perceived stress on growth and mental health. That said, the research participants raised by a PWD too reported high levels of self-esteem. The foundations for this may be rooted in the expectations placed on them at a young age to fulfil adult roles and responsibilities, coupled with the ability to face these challenges successfully. Problem-focused coping was found to mediate the impact of perceived stress on mental health, with a correlation between the capacity to apply problem-focused strategies and higher reported levels of mental health. The expanded household roles that the PWD participants were obliged to fulfil from a young age may have created the foundation for this enhanced capacity for problem-focused strategizing and coping. The extended family, and the example they set in engaging with the children of PWD – as a mission to be negotiated – may also have contributed to their capacity for problem-focused coping. Emotional-focused coping showed the reverse effect as the perceived stress as a result of being raised with a PWD has a greater negative effect on personal growth at individuals having higher emotion-focused coping capacities. This may coincide with their tendency to gravitate towards problem-focused coping. It would seem that the experience of being raised by a PWD is a source of greater perceived stress, impacting on the optimal bonding experience between parent and child, on the child's sense of social support, and on levels of mental health. However, in all other areas of life, the experience of being raised by a

PWD did not have as significant an impact as initially anticipated. This may be an indicator of the effect of various life experiences, at different stages of growing up and achieving maturity, on one's adjustment and growth and in shaping them into the people they have grown up to be.

The findings of this study will add nuance and depth to policy makers' engagement with the human rights of people with disabilities, specifically with regards to their capacity for parenting. The study identifies the specific needs of the children of PWD and supportive family members, and can feed into the development of appropriate programs to address the unique challenges that these families face.

A number of recommendations arise from this study. They include the importance of identifying such families at the earliest possible opportunity; the development and implementation of parenting programs that address their specific needs; the need for frank and honest explanations as to the nature and meaning of the parent's disability; the development of guidance and support protocols for the children of PWD and the extended family; and crucially, the need to acknowledge, gauge and assess the scope and unique needs of this group.

## **1. Introduction**

Recent surveys suggest that approximately 1.5 million people in Israel, approximately 18% of the country's population, are classed as having a disability (Central Bureau of Statistics, 2017). In its international classification of functioning, the World Health Organization (2013) defines disability as an umbrella term for impairments, activity limitations and participation restrictions. Disability is the interaction between individuals with a health condition and personal and environmental factors.

The realm of disability is broad and diverse. The global conversation about human rights has informed the expansion and regulation of the concept of human rights for persons with a disability (Commission of Equal Rights of Persons with Disabilities, 1998). For many years, the rights and wishes of people with a disability – even though recognized in law as equal to those of the non-disabled population – remained unfulfilled across a number of domains, including sexuality and reproductive concerns (Asch & Fine, 1985; Schaaf, 2011). Today, increasing numbers of people with disabilities are articulating and claiming their rights across all life domains – including the right to bear and raise children (Addlakha, Price & Heidari, 2017; Conway, 2018). In light of these changes, it has become evident that there is a need for a broader understanding of this reality, and deeper engagement with the factors that effect the outcomes for children raised by parents with a disability (PWD). Until now, most research on PWD has focused on the adult half of the parent-child dyad (Ackerson, 2003; Feldman, 2002; Feldman & Aunos, 2010; Llewellyn, McConnell & Ferronato, 2003; Royster, 1981). However, the perspective of the child, crucial to a full understanding of the implication of parenting of PWD, remains under-researched.

These children, as adults, are the focus of this study. The principal objective of this study is to evaluate the adjustment and growth resulting from the experience of being raised by a PWD. The theoretical framework designed by Wallander, Varni, Babani, Basis, & Wilcox (1989) in their conceptual model of disability-stress coping was employed to this

end. According to this model, stress (operationalized in this study through an appraisal of the stress, and the risk to parental bonding as a result of the unique life circumstances of growing up with a PWD) is mediated by intrapersonal factors (operationalized in this study as attachment orientation and self-esteem), social-ecological factors (perceived social support), and coping strategies (ways of coping). These risk resistance factors can be related, directly and indirectly, to adjustment, which for the purposes of this study is operationalized as mental health and personal growth.

Because these factors encompass a life-long perspective, and because childhood experiences inevitably play a crucial role in adulthood, this study explores the adult's present adjustment in relation to past and present attributes and resources. In line with this model, this study evaluates the experiences of the children of parents with two life-long disabilities, different in several respects but nevertheless with fundamental common attributes: intellectual and developmental disability (IDD), and mental disability (MD), specifically schizophrenia and bipolar disorder. The study takes on a comparative aspect by placing the experiences of the research participants raised by PWD with those of a second group, raised by parents without a disability. These two specific disabilities were chosen for the differences in their origins and how society views and enables their rights as well as enabling a view of two unique experiences of being raised by a PWD.

The contributing resources leading to adult adjustment/maladjustment were examined in each of the research groups and compared between them. In order to better understand the factors predicting the adjustment of these children in adulthood, there is a need to first understand the concept of disability.

## **2. Overview**

The review will first address the concept of PWD: it will explore the definition and meaning of their disability, focusing on mental and intellectual disabilities and the

implications of these disabilities for family life and parenting. It will then focus on the children of PWD: it will conceptualize their unique life circumstances, and then will address the resources that contribute to their adjustment and personal growth across childhood and into adult life.

This population, the children of PWD, has received insufficient research attention up till now for a number of reasons. These include the paucity of data regarding their actual numbers, and the general lack of awareness regarding their unique circumstances. In essence, this group has been "flying under the radar" of social welfare, support and intervention services for many years, unnoticed. In order to fully grasp the underlying purpose and necessity of this study, it is important to first acknowledge their existence, and the extent of the phenomenon.

The scope of the population of children with PWD in Israel, determined by data obtained from the National Insurance Institute of Israel - a body that acts under law to implement the welfare policy of the Israeli government and which, amongst other functions, administers the payment of state-funded disability allowances - will be presented here as both confirmation of the phenomenon and reference point. The expectation is that this study will accord this phenomenon the prominence it warrants; it will broaden our understanding of the phenomenon with regard to children currently growing up with PWD, and create an opportunity to plan for these children and those that inevitably become a part of this construct in the future.

## **2.1 Scope of the population**

The children of PWD have tended, to the present time, to exist largely beneath the radar of research and professional support agencies. It is my opinion that an appreciation of the scope of this unique group is essential for conceptualizing the importance of new updated knowledge in this field, and the development of much-needed services.

Around 700,000 Israeli adults (18-64) are classed as having a disability significant enough to restrict daily life and activity (Myers-JDC- Brookdale, 2018). Of this number 7.5% (approximately 52,500) are diagnosed with a mental disability (MD), and 4.2% (approximately 29,400) with an intellectual developmental disability (IDD). Data regarding their offspring is limited and incomplete, for a number of reasons. First is the fact that to date, there has been no systematic analysis of the issue of the children of PWD. Several factors feed into this lack: this population of parents were not identified or targeted at a preliminary stage (during pregnancy or childbirth); social services only direct attention to specific children, such those reported as being at risk of neglect and/or in need of out-of-home placement; and the suspected concealment of parental disability by family members, to avoid institutionalization. (These factors were all cited as possible explanations by professionals and family members).

An overview of this population, supplied by the National Insurance Institute specifically for this study, took four main disabilities into account, in order to grasp the scope of children of PWD in Israel as a whole. The current study, however, will focus solely on those raised by parents with IDD or MD. Data presented encompasses working-age adults (18-64/67, depending on gender) listed as receiving disability allowance from Israel's National Insurance Institute, and their known children. As there is no facility in place at the present for monitoring these families and their children, and given the paucity of existing data as discussed above, the working assumption is that the actual number of PWD is much higher than that cited above. As of 2017, records indicate 5,394 parents with IDD, and 36,431 parents with MD, with 15,353 and 115,021 known children respectively (Table 1). All the data supplied by the NII was granted specifically for this study and was preceded by a written request to the NII research committee

**Table 1- Number of parents with a disability and their children**

Parental disability	Number of allowance recipients*	Number of recipients who are parents**	Number of children of recipients
Intellectual	33,207	5,394	15,353
Mental	77,357	36,431	115,021
Sensory	14,966	9,877	35,993
Physical	109,898	84,334	301,326
	235,428	136,036	467,693

\*As of Jan 2017. Data provided by the National Insurance Institute (NII)

\*\* Data applies to working age adults receiving disability allowance from the NII, and their known children

One interesting detail relates to the ages of these known children (Table 2). Taking into consideration the social and political history of parents with disabilities raising children – specifically parents with IDD (i.e. the eugenics movement, involuntary sterilization) – the increasing amount of children of PWD indicates a change in social mores regarding people with disabilities. The number of children born to parents with IDD over the last 18 years is approximately equal to the number that were born in the preceding half century. This data, as provided by the NII reflects significant changes in the lived reality of people with disabilities, anchored by acknowledgement of their human rights and the drive to ensure that these rights are honored and respected by society at large.

**Table 2 – Number of children of parents with disability**

Parent disability	Number of children under 18	Number of children over 18
Intellectual	7612	7741
Mental	49,348	65,673
Sensorial	11,838	24,155
Physical	76,150	225,176
	144,948	322745

\*As of Jan 2017. Data provided by the National Insurance Institute (NII)

\*\* Data applies to working age adults receiving disability allowance from the NII and their known children

Historically, the presumption has been that if allowed to have children, people with disabilities will ultimately become parents to children with disabilities themselves. This point was underlined by United States Supreme Court Justice Oliver Wendell Holmes in the 1927 case of *Buck v Bell*, when he opined that “three generations of imbeciles are enough” in asserting the validity of a historical state statute permitting the compulsory sterilization of the unfit, “for the protection and health of the state.” However, the premise that PWD will inevitably produce children with a disability is undermined by the available data (Table 3). In fact, only 30-38% of children of PWD receive state allowances as a result of a disability of their own (the data does not include information regarding the type and severity of the disability). It should also be noted that these disabilities may not be directly linked to the parent's disability (e.g. acquired disability, insufficient prenatal services and postnatal care etc.)

**Table 3 – Number of children with a disability**

Parent disability	Number of children	Children with disability
Intellectual	15,353	5,835
Mental	115,021	35,421
Sensorial	35,993	10,053
Physical	301,326	83,143
	467,693	134,452

\*As of Jan 2017. Data provided by the National Insurance Institute (NII)

\*\* Data applies to working-age adults receiving disability allowance from the NII, and their known children

The data presented here is rudimentary and with significant unknowns; nevertheless, it does present a clear picture regarding the scope of the issue of children of PWD, specifically those this study focuses on- IDD and MD.

## **2.2 Intellectual and mental disability**

Intellectual and developmental disability (IDD) is characterized by significant limitations to both intellectual functioning and adaptive behavior as evidenced across a range of everyday social and practical skills, and originating before the age of 18. Intellectual functioning refers to overall mental capacity, and includes the capacity for learning, reasoning, and problem-solving (also known as the I.Q. level); adaptive behavior refers to a grouping of learned conceptual, social, and practical skills, performed in everyday life. As such, people diagnosed with IDD usually require assistance and guardian supervision throughout their lives (Shalock et al., 2010). The diagnosis of an IDD often brings with it social implications, affecting not just the diagnosed but also their nuclear and extended family, and society as a whole (Katz & Lazcano-Ponce, 2008).

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (APA, 2013) defines a mental disorder (MD) as “a syndrome characterized by clinically significant disturbance in an individual’s cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning.” It further proposes that significant distress or limitations in social and occupational activities may often be a consequence of these disorders. Two well-known major lifelong disorders within the spectrum of mental disorders are Bipolar disorder and Schizophrenia. People with bipolar disorder experience unusually intense emotional states, during distinct periods called mood episodes. Mood episodes, whether manic or depressive in orientation, present as a drastic change from a person’s usual mood and behavior. Extreme changes with regards to energy, activity, sleep, and behavior manifest as aspects of these changes in mood (NIH, 2014). Schizophrenia is characterized by a wide range of symptoms related to cognitive, behavioral, and emotional dysfunctions. These symptoms are defined by the manifestation of one or more of five specific behavioral domains: delusions, hallucinations, disorganized thinking (speech), grossly

disorganized or abnormal motor behavior (including catatonia), and negative symptoms (disruptions to normal emotions and behaviors). Schizophrenia is often associated with impaired marital, occupational or social functioning (APA, 2013). Bipolar disorder, Schizophrenia and IDD are all ongoing disorders, with a profound impact on the everyday personal, familial, and societal lives of both those with the disorder and the people around them.

The Eugenics movement of the early 20<sup>th</sup> century influenced the passing of laws permitting the involuntary sterilization of people with developmental, mental, sensory, and physical disabilities (Silver 2004). Dramatic social developments over recent years have resulted in a more tolerant approach to people with disabilities, which in turn has informed improvements in their legal status. Nevertheless, such pejorative attitudes still exist to some extent, exercising a marked influence over their lives (Meadow-Orlans, 2002). Recent legislative advances have succeeded in further securing the rights of individuals defined as having a disability, such as their right to bear and raise children (UN, 2006). This progress underlines the imperative to establish a cohesive body of knowledge regarding the characteristics and implications of parenting with a disability, in order to bridge the gap between the articulation of these rights and their realization in practice.

### **2.3 Parents with a disability**

Parenting encompasses a diverse range of behaviors, strategies, and techniques. However, there is general consensus that effective parenting is characterized by warmth and acceptance of the child, the provision of structure, and the encouragement of age-appropriate autonomy (Maccoby & Martin, 1983; Skinner, Johnson, & Snyder, 2005). Specifically, the mother's ability to read her infant, attune herself to its needs and to behave in predictable ways is commonly cited as the most important aspect of the early

parent-child dyad; these factors inform the child's subsequent attachment security and developmental progress (Smith 2010).

The quality of parenting is considered the most important variable in a child's life. Variations in quality of parenting can be identified and tracked in children's health, behavior and wellbeing, as well as in intelligence and scholastic performance (Smith 2010). These effects are assumed to have a lifelong impact: influencing wellbeing in adulthood, as well as key life trajectories such as mental health, social relations, familial relations, and career choices.

The role and responsibilities of parenting may present enhanced functional challenges for adults with mental or intellectual disabilities. PWD have often been characterized, in the absence of a nuanced or qualitative evaluation, as incompetent and posing a risk to the development and adjustment of their children. Women with disabilities are viewed even more critically than men, due to the importance ascribed to the mother-child dyad, and the apprehension that an impaired relationship may cause lasting harm or neglect to their children (Asch & Fine, 1988).

As of today, opinions regarding to the parental competency of people with disabilities are varied. Unfortunately, there is scant literature regarding parents with disabilities, and the impact of their disability on their children. Literature in this field is mainly concerned with child welfare, and the thresholds for determining the need to remove a child from the home and terminate parental rights (Benjet, Azar & Kuersten-Hogan, 2003; Proctor & Azar, 2013; Feldman, McConnell & Aunos, 2012). A number of studies have identified the need for further research on the topic, and the development of a broader perspective that would allow for an informed approach to evaluating the parental competence or otherwise of PWD (McConnell & Llewellyn, 2000; Feldman, 1994; Whitman and Accardo, 1993). However, given the broad acceptance of the equal right of these individuals to become parents, the discussion should extend beyond the issue of rights.

There is a need to define what qualifies as adequate parenting, and to identify the factors that contribute to both positive and negative childrearing outcomes. The discussion needs to shift to addressing not just the specific conditions that may engender inadequate parenting. The discussion should engage not only with disabilities, but also with abilities.

#### **2.4 Being raised by a parent with a disability - a potential source of stress**

Being raised by a PWD can have implications across the emotional, familial and social developmental contexts.

In the emotional realm, research suggests a link between disruptions to *parental bonding* and the development of mental disorders later in life (Canetti et al., 1997). Children raised by PWD have been shown to be prone to developing maladaptive behaviors when their parent displays symptoms of their illness. These include withdrawing, avoiding, and distancing behavior (Maybery, Ling & Szakacs, 2002). Long-term over-reliance of such emotion-focused activities can contribute to stress on the individual level (Folkman et al., 1991). There is also evidence to suggest that a parent's pathology of mental illness can have a detrimental effect on the children of such parents (Ackerson, 2003). The home environment of children with a mentally ill parent might be chaotic and/or threatening at times – particularly so if the unwell parent incorporates the child in their delusional behavior (Jacobsen & Miller, 1998). Children whose parents have an IDD may be at risk of neglect (although, usually, not abuse), and developmental, academic, behavior and psychiatric problems (Feldman & Aunos, 2010).

Concerns regarding the children of parents with IDD relate to the parent's limited ability to fully grasp social intentions and behaviors. This diminishes their capacity to protect their children from harm, set boundaries, and provide suitable structure.

Furthermore, the limited communication skills of parents with IDD may possibly have a knock-on effect on their children's language and cognitive development (Myers-JDC-

Brookdale Institute, 2009). Within MD cognitive deterioration is a common feature of schizophrenia; this may include a decline in declarative memory, language function, and other executive functions (APA, 2013).

Within the familial realm, a parent's illness and disability may affect the family's functioning, placing a heavy burden of caregiving on their children (Pakenham & Cox, 2011). The home environment may be affected by a parent's illness or disability, such that some children experience neglect, family conflict, stress, and abuse – particularly in the case of children caring for a parent with a mental illness (Leverton, 2003). Studies over the years have identified possible obstacles impacting on family processes through the overburdening of children with household and family tasks; and the possibility of role-reversal and the (non-elective) parentification of children, as they are compelled to take on responsible adult roles in the family setting (Meadow-Orlans, 2002). While assuming domestic and emotional responsibilities on behalf of an ill or disabled parent during childhood is normal to some extent, the excessive degree that may be expected or is necessary in a home where a parent has a disability is not always appropriate to the child's age, developmental milestones and attainments, or capabilities (Aldridge & Becker, 1999; 2003). Children who become young caregivers may be obliged to take on – without the element of choice – a wide variety of responsibilities, including domestic tasks, physical and emotional support for their parents, and caring for younger siblings (Dearden & Becker, 1995; Lackey & Gates, 2001).

Furthermore, PWDs and their children may place a strain on the extended family network and existing family structures – a process with significant implications for these children. The extended family – when one exists – often has to take on responsibility for supporting family member with a disability, a responsibility that extends to the children of the family member. Grandparents provide child care, financial aid, mentoring, and even custodial care for many children, support particularly relevant in cases when children

become vulnerable to harm due to parental absence or neglect (Burnette, Sun, & Sun, 2013; Uhlenberg & Cheuk, 2010). In this context, there is a differentiation between multigenerational households, where children, parents, grandparents and sometime other family members co-habit; and custodial or skipped generation households, where a child lives with a family member without a parental presence, in the form of an informal, kinship-based, fostering relationship (Cherlin & Furstenburg, 2008; Smith et al., 2008; Leinaweaver, 2014; Uhlenberg & Cheuk, 2010). The involvement of grandparents in families, to the extent of becoming a child's surrogate parents, is imbedded in cultural beliefs of mutual support among family members, and the feeling of responsibility –mostly by grandmothers – to ensure that appropriate care is available for their families (Aldgate and McIntosh, 2006; Connolly, 2003; Gladstone, Brown & Fitzgerald, 2009; Beegle et al., 2010; Worrall, 2001). As Campbell & Handy (2011) define this situation, they – the family members, and specifically grandmothers – are "bound to care". It has been suggested that as a substitute for a missing parent, grandparents (with the emphasis on grandmothers) are the best placed substitute. Children generally respond to them as positive attachment figures, the benefits accompanying them into adulthood (Hayslip, 2013; Hayslip & Smith, 2013; MD-Yunus, 2017). However, research suggests that children raised by family members other than their parents are at risk of emotional and behavioral problems, and find it much more difficult to attain emotional and social well-being (Billing, Ehrle, & Kortenkamp, 2012). That said, the assumption is that these risks may be linked to the underlying circumstances that led to the children being raised by a family member in the absence of their parent or parents (Kelch- Oliver, 2011).

On the social level, such caregiving arrangements have been associated with limiting young people's recreational and friendship opportunities (Atkin, 1992). Children as caregivers report they often experience difficulty in openly revealing or displaying the feelings engendered by the role (Banks et al., 2002). There is a strong likelihood that such

children will harbor feelings of shame and embarrassment with regards to their parent's disability (Meadow-Orlans, 2002). They are often unwilling to share their feelings of burden, due to the possible stigma that they may encounter as a result, or the fear of the authorities intervening and separating them from their parents (Pakenham et al., 2006). This stigma can be a source of significant emotional stress for children, along with their caregiver role (Pakenham & Cox, 2011).

The children of parents with IDD are at risk of experiencing developmental, academic, behavioral, and social adjustment problems (Feldman, 2002); the children of parents with MD are often subject to severe stress and personal limitations, and themselves are at a greater-than-normal risk of developing a mental illness (Beardslee, 2002).

These childhood stressors can have significant implications for their adulthood experiences in these domains, as expressions of perceived stress as described in the research model. *Perceived stress*, in Wallander et al.'s (1989) model, refers to the effects of chronic strain. More generally, chronic strain is defined as the persistent objective conditions that require continual readjustment, repeatedly interfering with the adequate performance of ordinary role-related activities (Pearlin, Lieberman, Menaghan, & Mullan, 1981). In the present study, it is operationalized as resulting from being raised by a PWD

Lazarus (1966) defined stress as occurring when one perceives the demands of external situations as being beyond one's perceived ability to cope with them. In the psychological context, stress is commonly conceptualized as the occurrence of significant life events that an individual interprets as undesirable (Lazarus & Folkman, 1984). Stress is not definable by a specific environmental event such as a stimulus, but rather by how an individual perceives and defines this event. For this reason, stress is thus best regarded as a complex rubric encompassing many variables, deriving from the interaction between the individual's personal resources, the demands of the events, and the environment around him (Lazarus et al., 1985). Being raised by a parent with a MD or IDD may place

significant social and emotional strain on the child; this can consequently be the basis for perceived stress, with a potentially lifelong and detrimental effects on the individual's wellbeing.

Folkman et al.'s (1986) perceived stress theory identifies two separate yet essential processes occurring within a stressful event, acting as mediators for wellbeing. The process of cognitive appraisal allows the individual to evaluate whether a stressful encounter with his/her environment is relevant to his/her wellbeing; the process of coping allows for the individual to seek out options to overcome and prevent future harm.

When appraising childhood events as stressful some may attribute their inability to cope with the situation to their own shortcomings, rather than to the external stressful situations (Garber & Seligman, 1980). Thus, some people will succeed in adapting to stressful life situations, and may even grow from them, whilst others will not.

## **2.5 Adjustment and growth in the face of stress**

*Adjustment* refers to a multidimensional function, with both positive and negative manifestations (Pakenham et al., 2006). The adjustment component of Wallander et al.'s (1989) theoretical model is operationalized in the present study as the existence of high levels of personal mental health. In this context, personal mental health is conceptualized by a decrease in psychological distress, an increased sense of wellbeing, and high levels of personal growth. Stress may contribute to emotional distress, which may manifest through a wide range of physical and mental disorders, such as anxiety and depression within maladaptive adjustment; adaptive adjustment to stress should lead to positive outcomes, such as decreased anxiety and overall life satisfaction (Zeidner, 1998). Successful adjustment in adulthood is presumed to reflect high levels of mental health, conforming with societal expectations of developmental milestones such as productivity, and the establishment and maintenance of social relationships (Luhmann et al., 2012).

Alongside the many life stressors with a negative impact on adjustment, there is evidence suggesting that parental disability does not have a wholly negative affect on the child's adult adjustment. Whilst there are obvious strains associated with the demands of adopting an adult role early, some studies argue that this experience may also have positive aspects in the long term. These unexpected early responsibilities may serve as a training ground for the development of useful personal skills, and contribute to future feelings of competency (Mazur, 2006). These reported positive changes do not, it should be noted, appear to remove the adverse impact and suffering that typically accompanies following negative events; rather, they seem to present another aspect of the overall experience of coping with and adjusting to stressful events (Park & Fenster, 2004).

Overcoming life's various stressful circumstances can also contribute to personal growth. *Personal growth* encompasses the view that the struggle to negotiate major life crises can contribute to the experience of significant positive development (Tedeschi & Calhoun, 1995). Studies on post-traumatic growth indicate that increased growth often accompanies increased stress (Tedeschi & Calhoun, 2004): While stressful circumstances often take their toll on personal resources, it has also been suggested that successfully addressing challenging circumstances can result in the growth of personal resources (Baltes, 1997; Hobfoll, 1988, 1998). Tedeschi & Calhoun (2004) identified five major areas of personal growth in the face of stress: the enhancement of interpersonal relationships and appreciation of others; a positive change in self-perception; the reevaluation of one's life philosophy; a new appreciation for life and the setting of new priorities. Therefore, people who are open to fully engaging with the spectrum of emotions associated with challenging life events may be able to examine their experiences as less threatening and potentially beneficial; such individuals, it seems, are able to derive meaning from these experiences, and are able to face uncertain futures with more confidence (Tedeschi & Calhoun, 1996). While crisis can contribute to a reduction in

wellbeing, the experience may nevertheless contribute to personal growth and development (Taubman-Ben Ari, Findler & Kuint, 2010). This potential growth may be a positive consequence of the need to overcome stressful life events.

Whilst most research on personal growth focuses on the capacity to overcome acquired trauma following stressful life events (Tedeschi & Calhoun, 1995, 1996, 2004), this study hopes to expand this view by approaching growth as a result of pre-existing life circumstances. Although this does not exist in Walander et al.'s original model, post-trauma personal growth will be examined in this study as a possible outcome of the lifelong stress resulting from being raised by a PWD.

In this context, intrapersonal and social-ecological resources are assumed to create risk-resistant factors, and to moderate the impact of stressful situation.

## **2.6 Risk-resistant intrapersonal factors**

The intrapersonal factors described by Wallander et al. (1989) as risk-resistant will be operationalized in this current study by the internal resources of *attachment orientation* and *self-esteem*. Attachment refers to a global and stable orientation toward close relationships, a capacity developed during early childhood through a child's relationship with their caregivers; it is assumed to remain relatively stable throughout adulthood (Hazan & Shaver, 1994). The quality of attachment interactions with the primary caregiver during infancy produces mental working schemas which organize one's cognition, affect and behavior, and shape one's self-image; these eventually influence one's capacity to enter intimate and social relationships in adult life (Mikulincer, Florian, & Tolmacz, 1990). The effects of attachment appears to extend further than the mother-child relationship; affective events during childhood, particularly within child-caregiver relationships, tend to exercise a strong influence on the nature and quality of an individual's adulthood relationships

(Bowlby 1979; Maccoby 1980). Furthermore, Bowlby (1988) claimed that the successful accomplishment of affect-regulation results in attachment security – the sense that the world is a safe place and that one can rely on others. Adults with secure attachment are likely to have experienced consistently responsive early caregiving (Ainsworth et al., 1978). Therefore, positive attachment interactions play an important role in the development of a sense of security and emotion regulation.

Most studies that draw from attachment theory assess two basic dimensions of insecure attachment: avoidance and anxiety (Brennan, Clark, & Shaver, 1998). Individuals who are low in both dimensions display a secure style of attachment; on the whole, they conceptualize the world as a safe place where they can securely and effectively engage with others. Thus, they are able to cope constructively with stress (Mikulincer, Shaver, & Pereg, 2003). Adults with avoidant attachment are believed to have experienced caregiving that was emotionally unresponsive; this led to them becoming self-reliant, due to their discomfort with close or trusting relationships. It has been suggested that individuals with the anxious style of attachment experienced an unstable caregiving, and consequently exhibit an ongoing pattern of fleeing from close relationships, as a response to an ingrained fear of abandonment (Bowlby, 1979; Bartholomew, 1993).

Early parent-child interactions may be influenced by the strain of parental disability, affecting their ability as a caregiver to respond sensitively to a child's needs (Cunningham, Harris, Vostanis, Oyebode, & Bissett, 2004). A mother's (or primary caregiver's) ability to be attuned to a child's needs, and to consequently behave in a predictable fashion, are key to a child's developmental progress and future attachment, security, and adaptation (Smith, 2010). A mother with a disability may respond to the child's needs in an atypical manner, such as indifference or non-responsiveness or emotional unpredictability. This may prove problematic in the long run (Whitman & Accardo 1990). Parents with a mental illness may have unusual or inappropriate means of

responding to their children's needs; parents with IDD might find it difficult to put their child's needs before their own, thus constituting a risk factor for insecure attachment. Hence, an adult's attachment orientation may be effected by the disability of their parents.

Self-esteem is a general evaluation and appraisal of an individual's sense of worth (Orth, Robins & Widaman, 2012). High self-esteem has been found to be a factor in stress resistance, and is related to adjustment (Cohen & Edwards, 1989; DuBois & Flay, 2004). Individuals with high levels of self-esteem are assumed to be less likely to interpret life's difficulties as a mark of their own diminished worth; they tend to experience less negative affect from negative events (Rosenberg, 1965). Self-esteem and secure attachment are closely linked. High self-esteem based on secure attachment is key to the ability to adapt to changing circumstances, and to have faith in oneself and in ones' future. An individual's ability to feel good about himself rests on believing oneself to be a part of a supportive network, and of being valued within that network (Holmes, 2001). A child's self-esteem may be affected by the underlying mother-child relationship, and by stigma. In the present study, the feeling of stigma may include a fear that the parent's disability or its manifestations will be associated with them as well (Perkins et al., 2002).

## **2.7 Social-ecological risk resistance factors**

The social-ecological factor, also conceptualized by Wallander et al. (1989) as risk-resistant, is operationalized in the present study in terms of *social support*. Social support refers to the provision, by a social network, of psychological and material instrumental resources intended to benefit an individual's ability to cope with stress in testing times as well as everyday life. Social support is often expressed in terms of three types of resources: instrumental support, such as material aid serving as a facilitator in reducing stress; informational support, such as advice and guidance, which helps in appraising a stressor and reacting with appropriate coping responses; and emotional support, such as

empathy, reassurance and trust, serving as a buffer against the loss of self-esteem (Cohen, 2004; Cohen & Wills, 1985; House & Kahn, 1985).

Antonovsky (1974) theorized that relationships with supportive others act as a resistance resource to the effects of social stressors. Such support may be transmitted, either directly or as a buffer, at two junctures when dealing with stressful life events: as a mediator between the stressful event itself and the subsequent adjustment; and between the experience of stress and the onset of possible pathological outcomes (Cohen, 1988; Cohen & Wills, 1985). Adequate social support may serve to attenuate an individual's appraisal of and response to stress, thus influencing the outcome (Williams & Galliher, 2006). Social support has also been proved to be significant in predicting growth (Taubman-Ben Ari, Findler & Kuint, 2010). The lack of such support may be a source of increasing psychological distress (Park et al., 2006).

Being raised by a parent with MD or IDD may provoke feelings of shame and embarrassment; these can contribute to social seclusion and inordinate self-reliance on the part of the child. Household relationships play a pivotal role in the emotional development of a young child, as children need a parent or caregiver's guidance and support in order to develop effective social skills (Bowlby 1969). Beyond the immediate family, children also require the opportunity to develop and enhance meaningful social and emotional connections in wider social circles within and outside of the family (Reupert & Maybery, 2007). The enhancement provided by members of the extended family, usually present in the home setting when there is a PWD, can give a child a number of adult role models to depend on; it can strengthen the family's emotional closeness; and it may provide useful lessons for the children about how to be more responsible and more accepting of people with disabilities, lessons with concomitant positive benefits for adulthood (Armistead, Klein, & Forehand, 1995; Olkin, 1999; Prilleltensky, 2004). Such childhood experiences of social support may serve as a sounding board for experiences of support in adulthood,

and for allowing others to support and assist. Whether or not supportive relations did exist during childhood, substituting for lacking parental support, or if they exist in adulthood and serve the same purpose, there is no denying their utility as a resource in the present for coping and adjustment. Supportive relationships – or even the perception of available support resources – are believed to enhance coping capabilities, supporting the less stressful appraisal of threatening situations (Lakey & Cohen, 2000). It is suggested that the critical factor in the role of social support operating as a stress buffer is the perception that others will provide appropriate support when needed (Cohen, 1988; Uchino et al., 1996) – thus its conduciveness to one’s ability to establish and maintain social relationships.

## **2.8 Coping strategies as risk-resistant**

Stress processing, as conceptualized by Wallander et al. (1989) as risk-resistant, is operationalized in the present study in terms of present *coping strategies*. Coping is defined as one's cognitive and behavioral efforts to manage specific external demands appraised as challenging or exceeding one's personal resources (Lazarus & Folkman, 1984). Coping mostly manifests in two main strategies: emotion-focused coping, which regulates stressful emotions; and problem-focused coping, which modifies the person-environment troubled relationship that has caused distress (Folkman et al. 1986; Park & Folkman, 1997; Aldwin, 2007).

Positive coping strategies – the use of emotional or instrumental support, venting, positive reframing, humor, and acceptance, to give a few examples – help in managing and attenuating the perceived threat posed by a stressful situation (Carver et al., 1989). A study about the young caregivers of parents with disabilities found less reliance on problem-focused coping. It suggested that this may be because parental illness or disability may limit the exposure of young caregivers to parental modeling of problem-solving coping strategies (Pakenham et al., 2006). In a study about adults raised by a parent with IDD,

positive and meaningful-focused coping strategies allowed for conceptualizing this lifelong stress as a challenge, resulting in high levels of resilience (Weshler, 2009). Coping strategies utilized by an individual dealing with stress derive from social and intrapersonal factors affecting that individual's adjustment and personal growth.

## **2.9 The current study**

The group of adults targeted in the current study is one that has been largely overlooked in research and policy. To further and thoroughly understand the variables contributing or impeding the positive adjustment and growth of the children of PWD a deep understanding of their unique life circumstances must be reached. This study will explore the implications of stress, which is operationalized in this study through patterns of parental bonding and perceived stress, on adjustment, operationalized through mental health and personal growth. We will further explore the attributes of personal factors, such as attachment orientation and self-esteem, and those of social ecological factors such as perceived social support and stress processing, operationalized through coping strategies on adjustment and personal growth. The history of parents with disability, the scope of this phenomenon, the implications of this disability on family members and offspring, and the diverse challenges they encounter are all directly relevant to this research study's objectives.

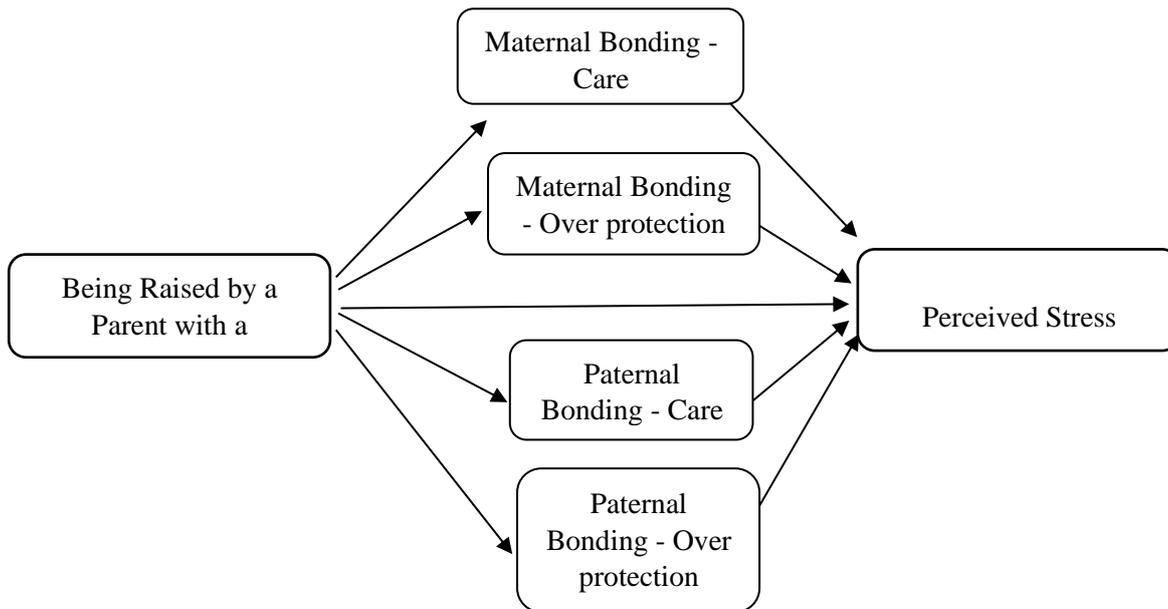
Due to the importance of understanding the unique personal experiences of this newly-explored population, it is anticipated that the added value of life story interviews will shed more light on the phenomena, bringing forth another possible layer of knowledge. This multi-faceted approach is directed towards building a suitably nuanced and informed perspective on the phenomena – one largely absent from academic research on the topic at the present time.

In the quantitative phase of this study children of PWD include both those with parents with IDD and MD. This group was eventually combined and is referred to as one, as no significant differences were found between the groups at this phase. Though the quantitative phase addressed their present functioning the more in-depth qualitative data was collected with a perspective of their past recollections allowing for differences between the parental disabilities to arise.

### **3. Research Hypotheses**

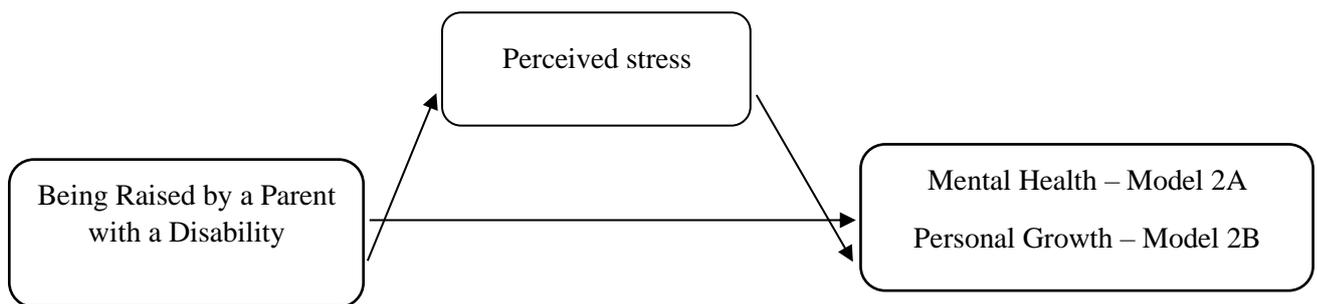
**Hypothesis 1** - Adults raised by a PWD will report lower levels of parental bonding, self-esteem, social support, problem-focused coping strategies, and mental health. In addition, adults raised by a PWD will report higher levels of perceived stress, attachment avoidance and anxiety, emotion-focused coping strategies, and personal growth.

**Hypothesis 2 - Parental bonding mediation model – Model 1.** The pathway between being raised by a PWD and perceived stress will be mediated by the four parental bonding variables. That is, being raised by a PWD will be associated with lower levels of maternal and paternal care, and higher levels of maternal and paternal overprotection; these in turn will be associated with greater levels of perceived stress. The conceptual model for this hypothesis is presented in Figure 1.



**Figure 1.** Parental Bonding Mediation - Model 1 (Hypothesis 2)

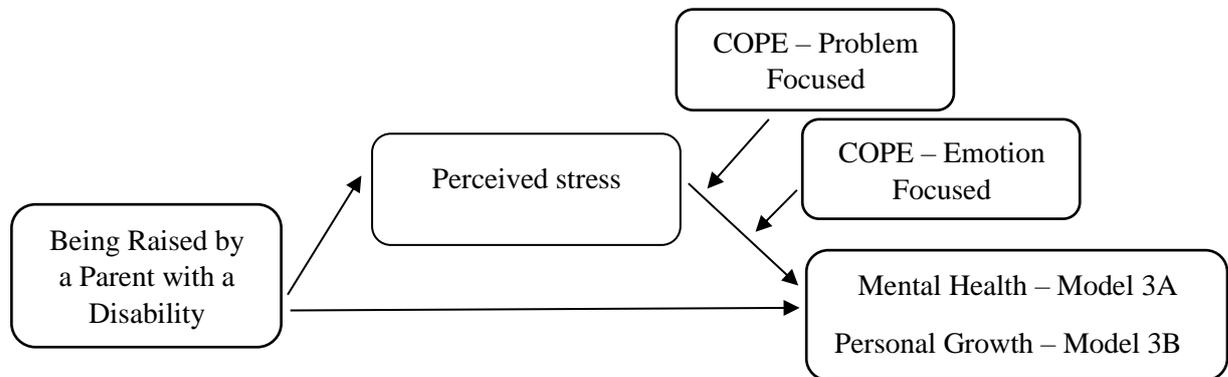
**Hypothesis 3 - Perceived stress as a mediator of the relationship between being raised by a PWD and mental health / personal growth – Models 2A, 2B.** The pathway between being raised by a PWD and mental health/personal growth will be mediated, at least partially, by perceived stress: individuals with PWD will experience higher levels of perceived stress, which in turn will be associated with lower levels of mental health or personal growth. Figure 2 presents the conceptual model for this hypothesis.



**Figure 2.** Perceived stress mediation - Models 2A, 2B (Hypothesis 3)

**Hypothesis 4 - Moderated-mediation models, coping strategies as moderators - Models 3A-3B.** The role of perceived stress as a mediator of the pathway between being raised by a PWD and mental health/personal growth will be moderated by coping

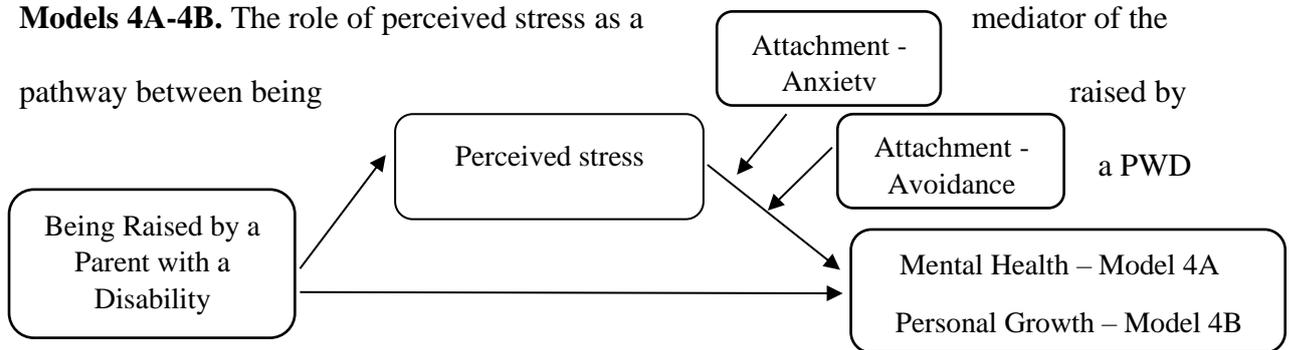
strategies, such that the negative effect of perceived stress on mental health/personal growth will be smaller for individuals with higher levels of problem-focused coping strategies and lower levels of emotional-focused coping. Figure 3 presents the conceptual model for this hypothesis.



**Figure 3.** Perceived stress moderated-mediation with COPE as moderators - Models 3A, 3B (Hypothesis 4)

**Hypothesis 5 - Moderated-mediation models, attachment measures as moderators -**

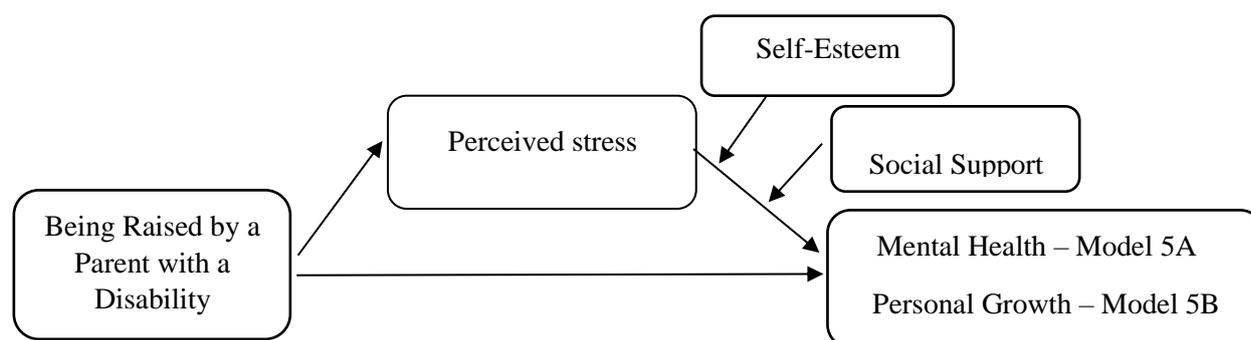
**Models 4A-4B.** The role of perceived stress as a mediator of the pathway between being raised by a PWD and mental health/personal growth will be moderated by attachment measures: the



**Figure 4.** Perceived stress moderated-mediation with attachment measures as moderators - Models 4A, 4B (Hypothesis 5)

negative effect of perceived stress on mental health/personal growth will be greater for individuals with higher levels of anxious or avoidant tendencies. Figure 4 presents the conceptual model of this hypothesis.

**Hypothesis 6 - Moderated-mediation models, self-esteem and social support as moderators - Models 5A-5B.** The role of perceived stress as a mediator of the pathway between being raised by a PWD and mental health/personal growth will be moderated by coping strategies: the negative effect of perceived stress on mental health/personal growth will be greater for individuals with lower levels of self-esteem or social support. Figure 5 presents the conceptual model for this hypothesis.



*Figure 5.* Perceived stress moderated-mediation with self-esteem and social support as moderators - Models 5A, 5B (Hypothesis 6)

## 4. Research Methodology

### 4.1 Mixed method research

This study's objective was to identify the factors that relate to adjustment and growth among adults who were raised by a PWD. This was done in two phases, a combination of quantitative and qualitative research methodologies.

Data regarding the parenting capabilities of PWD, and of their children, is limited and incomplete at this point in time. Neither professionals in the field nor policy makers have succeeded in addressing this issue, as is evidenced by the paucity of existing data sufficient to even estimate the scope of this phenomena. An earlier study on this issue (Weshler, 2009) underlined the paucity of knowledge regarding the phenomenon of the children of PWD, and the challenges they face as a result of their unique life circumstances. Analyzing data obtained from Israel's National Insurance Institute (NII)

proved that this population actually exists, and on a larger scale than previously acknowledged. This group of individuals, at the present time, is transparent and largely unknown to most professional support and welfare workers. Due to this reality and the limited access to viable participants with PWD, it was important that the present research allowed for a breadth of knowledge with regards to their unique life circumstance – the key factor that informed the decision to use a mixed method approach. To accurately trace the unique attributes that distinguish children raised by a PWD from those who were not, data obtained by qualitative methods will not suffice in itself. The aspiration of this study was to extend beyond the raw data, and to develop a richer understanding of the characteristics of this group through a quantitative prism, together with an appreciation of the different circumstances – as identified by a preceding quantitative examination – that made a difference in their lives.

Thus, there is a valid case for adopting a multi-strategy research approach in this study – an approach with especially strong support in the research world (Tashakkori and Teddlie, 2003). Multi-strategy research provides the wealth and contextual richness of data that allows researchers to discover uses for data that they had not anticipated (Bryman, 2006). Mixed-method research combines qualitative and quantitative approaches, enabling a greater breadth and depth of understanding (Johnson, Onwuegbuzie & Turner, 2007), because it allows for the integration of different forms and sources of data (O’Cathain, Murphy & Nicholl, 2010). The concurrent triangulation strategy was applied, allowing for two concurrent data collection phases and the integration of data during the interpretation and analysis phase (Terrell, 2012)."

Qualitative and quantitative research methods are each based on a particular paradigm – a patterned set of assumptions relating to reality (ontology), knowledge of that reality (epistemology), and the particular ways of understanding that reality (methodology) (Guba, 1990). A combination of the two approaches has the potential to multiply

unanticipated outcomes (Bryman, 2006). Merged integration is a mixed method in which both qualitative and quantitative data is collected and analyzed; the findings can be used to complement each other by assisting in the identification of differences and similarities within the research findings, and facilitating a better understanding of the subject at hand (Creswell & Plano Clark, 2011).

Quantitative research is deductive in nature; it focuses on quantifying a phenomenon, establishing prevalence and paths in order to generalize the findings across large populations (Curry & Nunez-Smith, 2015; Hulley et al., 2013). While quantitative research allows new understandings through data analyses techniques, qualitative research for its part places emphasis on a relatively open-ended approach to the research process, and is often presented as a strategy with the capacity to yield new and surprising insights (Bryman, 2006). As at this point there is no sufficient understanding of the phenomenon of PWD, this current study hopes that the use of both research methods will enable a broader view of this phenomenon.

It is broadly acknowledged that people can make sense of their worlds, and the worlds of the people around them, through the telling and constructing of stories. Story-telling allows the journey of life to be arranged within stories and narratives, a form of communication essential for the development of bodies of knowledge within society at large (Czarniawska, 2004; Polkinghorne, 1988). For a qualitative research to be effective, it should deal with a relevant topic and entail both a personal meaning and a broad contribution to the existing body of knowledge (Tracy, 2010). The telling of stories is at its core a way to ascribe meaning to life events and allows participants to arrange their perceptions of their lives (Shkedi, 2004; Atkinson, 1998). These interviews were conducted as a way to add depth and perspective to the quantitative phase of this research.

A combined quantitative and qualitative approach, in the present case, has the potential to allow the researcher to delve into the complex lives of people raised by a

PWD, and through this to grasp both the consequences of this upbringing and the individual experiences that fed into it. Sale, Lohfeld and Brazil (2002) have proposed that qualitative and quantitative work can be carried out simultaneously or sequentially in a single study, and can complement each other.

There are clear unknowns concerning the phenomenon of the children of PWD. However, the implications of the experience remain largely unacknowledged in academic research; adults who were raised by PWD, and their unique formative experiences, tend to come to the attention of professional services only in crisis circumstances. A quantitative approach to the topic, under the circumstances, does not seem sufficient to fully grasp the context that informs their adult lives.

The qualitative aspect of this research study was underpinned by the wish to build a richer understanding of the implications of being raised by a PWD, as informed by the conclusions of the broad quantitative data. The variations of the PWD (whether mother or father), the family structures, the different adult figures in their lives, the different life experiences gained, the socio-economic environment raised in – all have potential implications that warrant explication.

A merging of quantitative and qualitative approaches in the present case will hopefully allow for the emergence of the wealth of knowledge and perspectives vital for developing a representative and informed picture of this phenomenon. This combination of perspectives aims to allow for both greater understanding and generalization as to this research group.

## **4.2 The quantitative research phase**

### **4.2.1 Participants**

215 young Israeli adults (162 women, 53 men) were recruited to participate in the study.

100 participants had at least one parent with IDD or MD; the comparison group of 115 was made up of participants whose parents did not have either of these disabilities.

The ages of the participants ranged from 22 to 52 years ( $M = 36.38$ ,  $SD = 7.70$ ). Most participants were married (61%), were in employment (89%), and had an academic level education (67%). Participants' characteristics by study group are presented in Table 4.

Data indicate that, as compared to the “parents without a disability” group, the group with PWD was younger, and with a higher percentage of male participants themselves with disabilities. Therefore, participants' sex and age were statistically controlled throughout the analyses.

Participants were recruited principally with the help of the National Insurance Institute's research department, through established and virtual (i.e. online) support organizations and via a designated Facebook page.

**Table 4 - Participants Characteristics by Study Group (N = 215)**

	Raised by a Parent with a Disability			Raised by Parents without Disabilities				$\chi^2$	p-value
	N	M	SD	N	M	SD	t		
Age	100	33.84	7.25	115	38.59	7.43	4.73		< .001
Sex - n (%)								8.8	.003
Male	34 (35%)			19 (17%)					
Female	66 (66%)			96 (83%)					
Having a Disability	15 (15%)			7 (6%)				4.6	.03
Raised									
At home-parent/s	78 (78%)			111 (96%)					
By extended family	8 (8%)			2 (2%)					
Out of home placement	14 (14%)			2 (2%)					
Family Status									
Single	37 (37%)			33 (29%)					
Married	57 (57%)			74 (64%)					
Divorced/Widowed	6 (6%)			8 (7%)					
Being a Parent	50 (50%)			65 (94%)				0.9	.33
Education									
High school graduate	25 (25%)			10 (9%)					
Secondary studies	17 (17%)			14 (12%)					
Academic studies	53 (53%)			91 (79%)					
Currently Working	88 (88%)			104 (91%)					

### **4.2.2 Procedure**

Both adults who were raised by PWD and with parents without a disability within the desired age group were approached through a variety of sources and means.

Recruiting the comparison group was done through social network contacts. The core research group, on the other hand, posed significant recruitment difficulties, as many were not in touch with welfare professionals or relevant interest groups. Participant recruitment for this group was carried out using a snowball approach via on-line networking, media advertising, intermediaries in the professional world, and direct letters distributed through the National Insurance Institute.

The questionnaires were all completed on-line and anonymously, with responses confidentiality recorded. Active consent was sought and received from all the participants before they were included in the research study (as part of the study introduction page). Participants were able to contact the researcher prior to participation as well as after completing the questionnaires with any questions or comments via contact information supplied in the questionnaires.

The study was approved by the Research Ethics committee at Bar-Ilan University.

#### **4.2.2.1 Research questionnaires**

All the research questionnaires used are attached in the Appendix (Items 1 and 3). Following the theoretical framework of Wallander et al. (1989), the questionnaires sought to determine and measure the risk factors associated with being raised by a PWD, together with the protective factors (intrapersonal and socio-ecological) and stress processing strategies presumed to mediate or moderate the effects of these risks on adjustment (mental health) and personal growth.

**Risk factors were measured using the following scales:**

**The Perceived Stress Scale** (PSS: Cohen, Kamarck, & Mermelstein, 1983) assesses an individual's subjective perception of his or her level of stress. In the current study, this self-report instrument was comprised of 10 questions (revised from the original 14-item scale for the purpose of this study) (Cohen & Williamson, 1988).

Respondents were asked to indicate how frequently they experienced each of a range of feelings in the preceding month (e.g., "How often have you been upset because of something that happened unexpectedly?") on a 5-point Likert scale ranging from 1 (never) to 5 (very often). Positive items (4, 5, 7, and 8) were reverse coded prior to the analyses. The reliability and construct validity of the scale has been demonstrated in previous studies, with a Cronbach's alpha ranging from .78 to .91 (Cohen, Kamarck, & Mermelstein, 1983; Cohen & Janicki-Deverts, 2012; Fidler, 2014). In the present study, the PSS was found to have a high internal consistency (Cronbach's  $\alpha = .88$ ). The scale's score was computed by averaging all the items, a higher score indicating a greater perception of stress.

**Parental Bonding Instrument** (PBI: Parker, Tupling & Brown, 1979) assesses participants' perceptions of their parents' bonding behavior in childhood. Subjects were asked to fill out this 25-item self-report scale twice – with regard to their mother and father, separately. Each item in the questionnaire describes a type of parental behavior; subjects were asked to indicate the degree to which it described the parent in question on a 4-point Likert scale, ranging from 1 (very much unlike my mother/father) to 4 (very like my mother/father). The PBI consists of two subscales: Care, containing 12 items which measure "care/involvement versus indifference/rejection"; and Overprotection, containing 13 items which measure

“control/over-protection versus encouragement of independence”. Items 3, 4, 7, 8, 15, 16, 21, 22, and 25 were reverse coded prior to the analyses. A Cronbach’s alpha of .91-.93 was found for the parental care subscale and .86-.88 for the parental overprotection subscale (Cohen & Finzi-Dottan, 2005). In the present study, the two subscales were found to have high internal consistencies. Cronbach's alpha's for the Care subscale were found to be .94 and .93, for the mother and father questionnaires respectively; and .87 and .83 for the Overprotection subscale, for the mother and father questionnaires, respectively. Consequently, four measures – mother's care, mother's overprotection, father's care, and father's overprotection – were computed, by averaging the relevant subscales items. Higher scores on the subscales indicated higher levels of parental care and overprotection.

In addition, four types of parental rearing emerged for each parent bond. Parents were effectively assigned to one of four quadrants, according to the sum score of their care and overprotection scale scores: optimal parenting (high care/low protection), affectionate constraint (high care/high protection), affectionless control (low care/ high protection), and neglectful parenting (low care/low protection). Higher scores of optimal parenting indicated the preferred rearing type, and neglectful parenting the least optimal.

**Protective factors** were measured using the following scales:

**Assessment of Intrapersonal Factors:**

**Experience in Close Relationships scale** (ECR: Brennan, Clark & Shaver, 1988) was used to evaluate the construct of adult attachment. Participants rated 36 statements: 18 items relating to attachment anxiety (e.g., “I worry about being abandoned”), and 18 to attachment avoidance (e.g., “I prefer not to show a partner how I feel deep down”).

Participants were asked to rate the extent to which each item described their feelings

on a 7-point Likert scale, ranging from 1 (not at all) to 7 (very much). The following items were reverse coded prior to the analyses: 3, 15, 19, 22, 25, 27, 29, 31, 33, and 35. The reliability and construct validity of the two subscales have been demonstrated across a broad variety of samples (Mikulincer & Florian, 2000; Taubman & Spielman, 2014). Cronbach's alpha ratings were found to be .81-.88 for the anxiety scale, and .83-.86 for the avoidance scale. In the present study, the two subscales were found to have high levels of internal consistency: Cronbach's  $\alpha$ 's= .90 and .88 for the anxiety and avoidance subscales, respectively. Subscales score were computed by averaging the relevant items for the anxiety and avoidance subscales. Higher scores indicated higher levels of anxiety and avoidance.

**Rosenberg Self-Esteem Scale (RSES:** Rosenberg, 1965). This self-report questionnaire, consisting of 10 items rated on a 4-point Likert scale from 1 (strongly disagree) to 4 (strongly agree), is used to assess an individual's appraised self-esteem. Five of the items have positively worded statements (e.g., "I feel that I have a number of good qualities") and five have negatively worded ones (e.g., "I feel I do not have much to be proud of"). In the present study, the negative items (2, 5, 6, 8, and 9) were reverse coded prior to the analyses. Reliability and validity have been demonstrated in previous studies, and the scale was found to have a Cronbach's alpha ranging between 0.78 and 0.90 (Hobfoll & Walfisch, 1984; Rosenberg, 1965). In the present study, Cronbach's alpha was also found to be high,  $\alpha$ = .89, indicating the scale's high level of internal consistency of the scale. Following this, a self-esteem score was computed by averaging the scale's items, with higher score representing higher levels of self-esteem.

#### **Assessment of Social-Ecological Factors:**

**The Multidimensional Scale for Perceived Social Support** (MSPSS: Zimet et al., 1988) was used to assess the respondent's subjective perception of the social support received from family, friends and significant others (e.g., "I can talk with my friends about my problems"). Responses to the 12 items were marked on a 7-point Likert scale ranging from 1 (not true) to 7 (very much the case). Cronbach's alpha was found to be .91 for the scale as a whole (Zimet et al., 1988) and .88-.93 for the subscales (Findler, 2014). In the present study, Cronbach's alpha for the scale as a whole was also found to be high,  $\alpha = .93$ , indicating a high level of internal consistency. Consequently, a social support score for each participant was calculated by averaging the responses on the items of each subscale, higher scores indicating greater levels of social support.

**Stress Processing** was measured using the following scale:

**The Coping Orientation to Problems Experienced** (COPE: Carver et al., 1989) assesses the various ways in which individuals respond to stress. The scale covers 15 sub-scales within 2 general dimensions: problem-focused coping (e.g., "I tried to get advice or help from other people about what to do"), and emotion-focused coping (e.g., "I feel great distress and express this feeling"). The revised model of this instrument (Carver, 1997) used in the present study consisted of 30 items rated on a 4 point Likert scale and was later adapted to Hebrew (Ben-Zur & Zeidner, 1995). Response choices for each item ranged from 0 (I usually don't do this at all) to 3 (I normally do this a lot). The reliability and construct validity of the scale have been demonstrated (Litman, 2006). In the present study, Cronbach's alpha's for the two subscales were found to be high,  $\alpha = .78$  for the problem-focused coping and  $\alpha = .70$  for the emotion-focused coping, indicating a high level of internal consistency of the

scales. Two scores were computed by averaging the two subscales' items, the higher score representing greater use of the relevant coping strategy.

**Adjustment** was measured using the following scale:

**The Mental Health Inventory** (MHI: Veit & Ware, 1983) taps adjustment on the personal level. The scale reflects the participant's affective states of mental health from emotional distress (e.g., “difficulty trying to calm down”) to wellbeing (e.g., “relaxed and free of tension”). The revised short version was made up of 18 items (out of the 36 items of the original version). Respondents were asked to rate how often in the past month they had experienced each of the designated states, ranging from 1 (all of the time) to 6 (never). Items 1, 3, 6, 8, 9, 11, 15, and 17 were reverse coded prior to the analyses. The full-length version of the MHI has been found to have a Cronbach's alpha of .96 (Taubman-Ben Ari, Findler & Kuint, 2010), while the short version has an alpha of .82 (NMSS, 1997). In the present study, Cronbach's alpha's was found to be high,  $\alpha = .95$ . A total score of mental health was computed by averaging the items' ratings. Higher scores reflect higher levels of mental health.

**Personal Growth** was measured using the following scale:

**Post Traumatic Growth Inventory** (PTGI: Tedeschi & Calhoun, 1996). This 23-item self-report scale includes five dimensions of personal growth arising from difficult life events. In this study, the participants were asked to think of their childhood experiences, in the family that they were raised in and in comparison to others. The participants were asked to rate how these childhood experiences had effected their lives (e.g.: “I changed my priorities about what is important in life”) on a 6-point Likert scale ranging from 0 (not at all) to 5 (to a great degree). The reliability

and construct validity of the scale have previously been demonstrated with a Cronbach's alpha of .93 (Zimmerman, 2011). In the present study, Cronbach's alpha's was found to be high,  $\alpha = .91$ . Scoring was computed by averaging the ratings on all items, with higher scores representing greater sense of personal growth.

**Background information** was collected through a series of questions constructed for the present study pertaining to age, sex, personal status, personal history, and specific parental disability.

### **4.3 The qualitative research phase**

#### **4.3.1 Participants**

As part of the research study's quantitative data collection phase, participants were given an opportunity to participate in the subsequent qualitative phase, a semi-structured interview. Participants who expressed an interest in being interviewed were asked to provide their contact information (phone/e-mail). They were contacted via phone, and the interview process was explained to them in detail. Nine adults (3 men and 6 women) aged 28-45 were interviewed; they represented equally their reported parental disability (an equal number of participants from each study group – parents with IDD versus MD), and the variety of ages represented allowed for a broad spectrum of life perspective. Another consideration was their place of residence (as many variations as possible were chosen), and their ability to devote the time needed for a long in-depth interview (2-3 hours).

All the participants granted informed consent to participate in the qualitative phase of the research study – specifically a recorded personal interview at a location of their choice, and after signing a consent form.



**Table 5 - Demographic characteristics of participants (N=9)**

<b>Interview #</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>
Name	Jo	Lea	Martha	Naomi	Alex	Ori	Tom	Shay	Shlomit
Gender	F	F	F	F	F	M	M	M	F
Age	31	35	28	44	25	37	45	36	42
# of parents with disability	2	1	1	1	2	2	2	1	2
Parent disability**	M-IDD F- MD	M-MD	M-MD	M-MD	M-IDD F-PD/MD	M-MD F-MD	M-IDD F-Other	M-IDD	F-PD/MD M-PD
#of siblings	2	7	2	0	2	3	0	0	4
Academic degree	+	+	+	+	+	+	+	-	+
Work yes/no	+	+	+	+	+	+	+	+	+
Relationship	S	M	M	M	M	M	D	M	M
Children yes/no	-	-	+	+	+	+	+	+	+
Has a disability	-	+	-	-	-	-	-	-	-

*\*All names presented here have been changed. \*\* IDD- intellectual developmental disability; MD- mental disability; PD- physical disability ; F- Father M- Mother*

#### **4.3.1.1. Demographic characteristics of participants**

Nine participants took part in the qualitative part of this research, a semi-structured interview (Table 5).

The ages of the interviewees ranged from 28 to 45; three were men, and six were women.

With regards to parent disability, four reported having a parent with an IDD; four reported having a parent with a MD; and one interviewee reported that one parent had a MD, and the other an IDD. One participant reported that they had a MD.

Six of the interviewees were raised at home by parents or family members, and three were raised in out-of-home settings from an early age.

Six of the interviewees had siblings.

All of the interviewees were at the time of the interview employed, six in therapeutic roles. Eight of the interviewees had an academic degree.

With regards to family status, seven were married at the time of the research; one was divorced, and one was single. Seven of the interviewees were parents themselves.

#### **4.3.3 Procedure**

A series of nine semi-structured in-depth interviews were conducted, as a means of further understanding the unique life experiences that growing up with a PWD entailed. Participants from the quantitative study who had indicated an interest in participating in the qualitative stage were contacted. Of those, nine participants were eventually approached and interviewed. Interviews were held at a location chosen by the participant.

The in-depth interviews were informed by a phenomenological approach. The interviews sought to cover the participants' reflections on their lives; their relationships with their parents, siblings and other meaningful figures in their life;

their understanding of their parent's disability and how this effected them (such as on a personal, familial, social, scholastic level etc.); their adjustment to life's demands; and their relationships with their parents at the present time. The interviews were held in accordance with the interview manual prepared for this study (Appendix, items 2 and 4).

Each interview consisted of three sections. First, participants were asked to share their personal narrative, as broadly and freely as possible (i.e., "Please tell me your life story"). When they completed the narration of their personal story, they were then asked directed questions, intended to draw out further salient details from their account or to expand on specific incidents (i.e. "Can you recall the first time you realized your parents were different?" "What were you told, if you were told, about your parent's disability?" "What other adult figures participated in your upbringing?" "What is your relationship with your parents today?"). Finally, participants were asked to suggest a title for their life story (i.e. "If a book or a movie was based on your life's story, what would be its title?"). As this was essentially a conversation, the participants digressed on occasion, and discussed other life experiences. I took this stroll down memory lane with them; indeed, most of these memories and stories were in their essence linked to their unique life experience as the child of a PWD. All of the participants clearly manifested curiosity and interest about the purpose of this study, my motivations as a researcher, and my findings from the earlier stage of the study. As promised, on completion of the interview, I engaged fully with their questions, which led to several interesting ancillary discussions. These materials were transcribed too, and form part of the data for this aspect of the research study.

## **5. Research Findings**

### **5.1. Quantitative phase findings**

#### **5.1.1 Data analyses**

Data analyses was conducted in four stages. First, a one-way Multivariate Analysis of Covariance (MANCOVA) was performed, to analyze the differences between the two study groups across all of the study variables. Second, Pearson correlations were conducted with all the study variables. Third, two multiple mediation models were tested, to analyze the mediating role of parental bonding (maternal and paternal care, and overprotection) on the path linking being raised by a PWD and subsequent levels of mental health and personal growth. Lastly, a series of mediation and moderated-mediation models were tested, in which perceived stress served as mediator for the path linking being raised by a PWD and mental health and personal growth as outcomes; different personality variables served as moderators for separate models.

#### **5.1.2 Descriptive statistics and group differences**

Descriptive statistics and results of differences between groups on all study variables are presented in Table 6. In order to test whether the number of parents with a disability had an effect on study variables, a one-way MANCOVA was conducted on all the study variables, number of PWD (only one/both) serving as the independent variable, and sex and age as covariates. The multivariate effect was not found to be significant,  $F < 1$ . Therefore, the number of parents with a disability was not considered further in the analyses.

**Table 6 – Descriptive Statistics<sup>1</sup> and ANOCVA Results for the Differences between the Groups on all the Study Variables (N=215)**

Variable	Raised by a Parent with a Disability			Raised by Parents with No Disabilities			F	P- value	$\eta^2$
	M	SD	Range	M	SD	Range			
PSS	2.72	0.76	1-5	2.49	0.60	1-5	5.31	.02	.03
PBI – Mother Care	2.70	0.98	1-4	2.99	0.80	1-4	5.30	.02	.03
PBI – Mother Overprotection	2.06	0.85	1-4	1.89	0.68	1-4	2.15	.14	.01
PBI – Father Care	2.61	0.92	1-4	2.98	0.84	1-4	8.24	.01	.04
PBI – Father Overprotection	1.90	0.85	1-4	1.69	0.77	1-4	3.23	.07	.02
ECR – Anxiety	4.43	1.32	1-7	4.67	1.12	1-7	1.75	.19	.01
ECR – Avoidance	4.47	1.18	1-7	4.76	1.08	1-7	3.08	.08	.02
RSES	3.02	0.65	1-4	3.15	0.53	1-4	2.55	.11	.01
MSPSS	5.25	1.39	1-7	5.72	1.19	1-7	6.23	.01	.03
COPE – Problem- Focused	2.93	0.48	0-3	3.00	0.38	1-4	1.33	.25	.01
COPE – Emotion- Focused	2.09	0.43	0-3	2.07	0.37	1-4	0.06	.80	.00
MHI	4.16	0.99	1-6	4.43	0.81	1-6	4.24	.04	.02
PTGI	3.22	0.85	0-5	3.39	0.80	0-5	1.90	.17	.01

Notes: <sup>1</sup>Adjusted for sex and age; PSS = Perceived Stress Scale; PBI= Parental Bonding Instrument; ECR = Experience in Close Relationships Scale; RSES = Rosenberg Self-Esteem Scale; MSPSS = Multidimensional Scale for Perceived Social Support; COPE = Coping Orientation to Problems Experienced; MHI = Mental Health Inventory; PTGI = Posttraumatic Growth Inventory.

As can be seen in Table 6, distinct differences emerged between the study groups on many of the study variables. The analysis shows that the research participants raised by a PWD reported higher levels of perceived stress, but lower levels of maternal and paternal care, perceived social support, and mental health. With all the other research variables, no distinct differences were identified between the participants raised by PWD and those who were not.

Descriptive statistics and bivariate correlations among all study variables are shown in Table 7. In order to test whether the type of parental disability has an effect on study variables, a one-way MANCOVA was conducted on all the study variables, with type of parental disability (cognitive vs. mental) serving as the independent variable, and sex and age as covariates. The multivariate effect was not found significant,  $F < 1$ . Therefore, parental disability type was not considered further in the analyses.

**Table 7- Descriptive Statistics and Pearson Correlations Among all Study Variables**

<i>Variable</i>	<i>M</i>	<i>SD</i>	95% CI	1	2	3	4	5	6	7	8	9	10	11	12
1. PSS	2.60	0.69	2.51 – 2.69	—											
2. PBI – Mother Care	2.86	0.87	2.75 – 2.98	-.18**											
3. PBI–Mother Overprotection	1.97	0.77	1.87 – 2.07	.19**	-.11										
4. PBI – Father Care	2.81	0.90	2.68 – 2.93	-.23**	.43**	-.10									
5. PBI – Father Overprotection	1.79	0.81	1.68 – 1.90	.18**	-.06	.31**	.02								
6. ECR – Anxiety	4.56	1.23	4.40 – 4.73	.39**	-.15*	.23**	-.16*	.13							
7. ECR – Avoidance	4.63	1.15	4.47– 4.77	.36**	-.27**	.19**	-.23**	.12	-.39**						
8. RSES	3.09	0.60	3.02 – 3.17	-.67**	.35**	-.17*	.24**	-.20**	-.50**	-.50**					
9. MSPSS	5.50	1.32	5.33 – 5.67	-.44**	.45**	-.27**	.41**	-.21**	-.34**	-.58**	.53**				
10. COPE – Problem-Focused	1.96	0.43	1.91 – 2.02	-.19**	.21**	-.12	.23**	-.10	-.03	-.40**	.28**	.43**			
11. COPE – Emotion-Focused	1.08	0.40	1.02 – 1.13	.36**	-.01	0.13	-.14*	.15*	.39**	.25**	-.36**	-.15*	.14*		
12. MHI	4.30	0.91	4.18 – 4.42	-.80**	.25**	-.23**	.25**	-.21**	-.45**	-.47**	.71**	.58**	.33**	-.38**	.
13. PTGI	3.31	0.82	3.20 – 3.41	-.43**	.32**	-.12	.22**	-.15*	-.27**	-.52**	.59**	.52**	.47**	-.10	.51**

*Notes:* PSS = Perceived Stress Scale; PBI= Parental Bonding Instrument; ECR = Experience in Close Relationships Scale; RSES = Rosenberg Self-Esteem Scale; MSPSS = Multidimensional Scale for Perceived Social Support; COPE = Coping Orientation to Problems Experienced; MHI = Mental Health Inventory; PTGI = Posttraumatic Growth Inventory. \*  $p < .05$ ; \*\*  $p < .01$

As shown in Table 7, perceived stress, mental health and personal growth correlate with all the other variables. Perceived stress was positively correlated to maternal and paternal over-protection, attachment insecurity, and emotional focused coping; it was negatively correlated to paternal and maternal care, self-esteem, perceived social support problem-focused coping, mental health and personal growth. Both mental health and perceived social support were positively correlated to maternal and paternal care, self-esteem, problem-focused coping and growth, as well as to each other. They were negatively associated with perceived stress, maternal and paternal over-protection, insecure attachment orientations and emotional focused coping. Personal growth emerged as positively correlated with parental care, social support, problem-focused coping and mental health; and as negatively associated to perceived stress, parental over-protection, attachment insecurity, self-esteem, and emotion-focused coping.

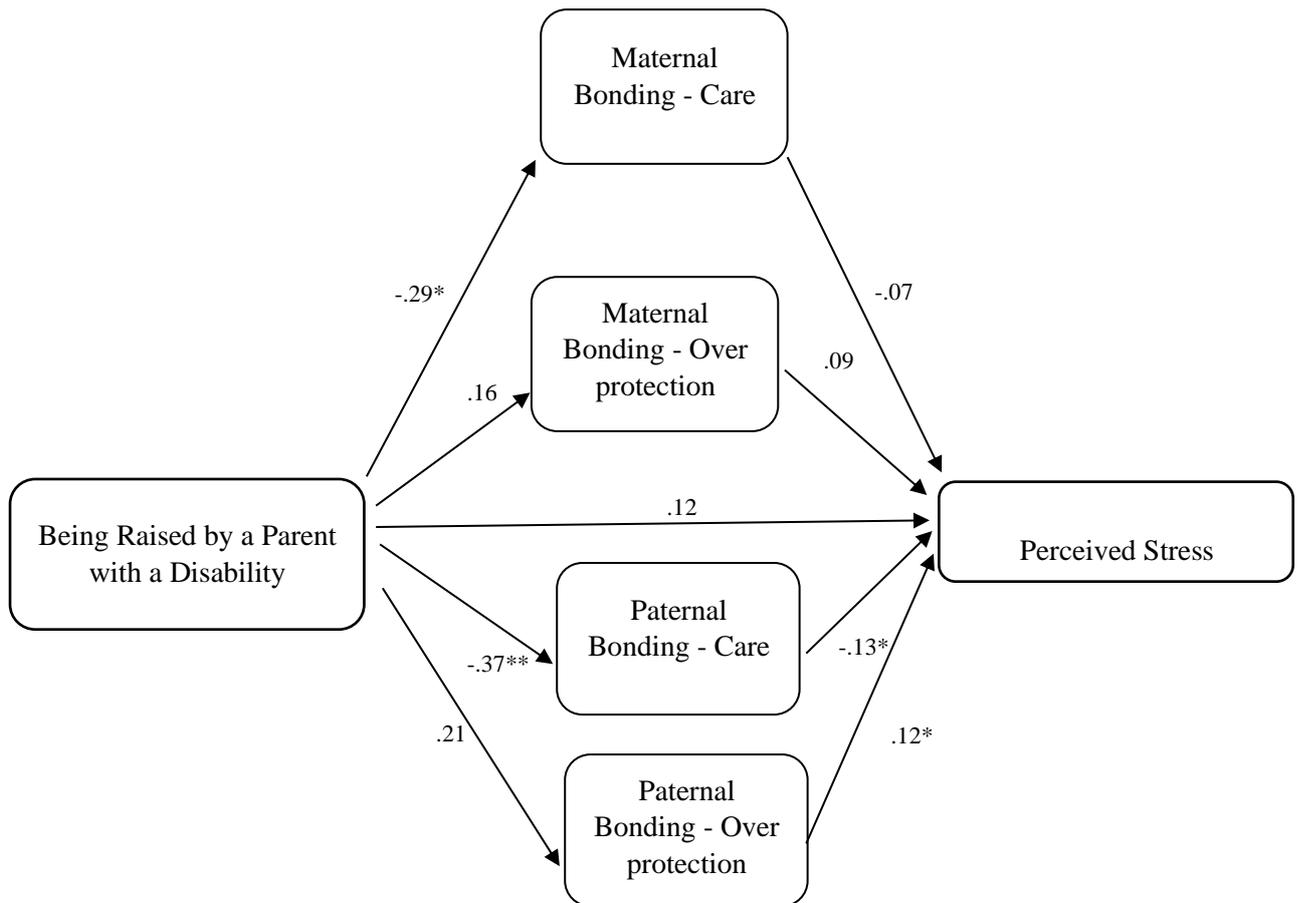
### **5.1.3 Mediation model predicting Perceived Stress (Model 1)**

In order to test the multiple mediation model depicting parental bonding as mediating the association between being raised by a PWD and perceived stress (Hypothesis 2), we used Hayes's (2013) PROCESS SPSS Macro (Model 4), with sex and age as covariates.

Confidence intervals (95% CI) for the indirect effects were determined by 10,000 bias-corrected bootstrapping resamples. Simulations have demonstrated that the bootstrapping method for determining the SEb is less biased, as compared to the Sobel test (Hayes, 2013). If the CI does not contain zero, this indicates that the mediator is significant. All mediators were entered simultaneously in one model.

The results of our mediation model, presented in Table 8 and Figure 6, partially support Hypothesis 2. Only paternal care mediated the raised by a PWD – perceived stress link. The coefficients presented in Figure 6 indicate that being raised by a PWD is associated

with less paternal care, which in turn is associated with greater perceived stress. The preliminary conditions for analyzing the indirect paths, i.e., significant a and b coefficients, were met for the indirect path. Moreover, the direct path was not significant, indicating that most of the effect of being raised by a PWD on personal stress is mediated by paternal care.



**Figure 6.** Mediation model of direct and indirect associations predicting perceived stress - Model 1 (Hypothesis 2). Values represent standardized coefficients. \*  $p < .05$ , \*\*  $p < .01$

**Table 8 - Results of the Multiple Mediation Model Predicting Perceived stress (Model 1)**

	<i>b</i>	<i>SEb</i>	<i>p</i>
Direct Path (c')	.12	.10	.23
Indirect Path- Maternal Care	.02	95% CI:- .01, .08	
Indirect Path- Maternal Overprotection	.02	95% CI:- .01, .06	
<b>Indirect Path- Paternal Care</b>	<b>.05</b>	<b>95% CI: .01, .12</b>	
Indirect Path- Paternal Overprotection	.03	95% CI: -.01, .09	

Follow-up moderated-mediated analyses, including sex of the participant as a moderator in the pathways between being raised by a PWD and each of the parental bonding variables (Model 7, Hayes, 2013), or between each of the parental bonding variables and perceived stress (Model 14, Hayes, 2013), revealed no significant moderated-mediation paths. That is, the sex of the participants does not serve as a moderator in this mediation model.

**Table 9 - Parental rearing patterns—frequency of combined scale scores (N=f-213/m-215)**

Parenting pattern	PWD		PWOD	
	Father	Mother	Father	Mother
Affectionate constraint	9	16	10	10
Optimal parenting	28	<b>54</b>	30	<b>46</b>
Affectionless control	<b>42</b>	23	<b>36</b>	28
Neglectful parenting	20	21	24	31
Total	99	114	100	115
	<b>213</b>		<b>215</b>	

Results further revealed a difference in parental patterns between children of PWD and those without a disability, the former reporting more patterns of affectionless control parenting and the latter displaying more optimal parenting patterns (Table 9).

#### 5.1.4 Mediation model predicting Mental Health and Personal Growth (Models 2A, 2B)

In order to test the multiple mediation model depicting perceived stress as a mediator of the association between being raised by a PWD and mental health/personal growth (Hypothesis 3, Figure 2), we used Hayes's (2013) PROCESS SPSS Macro (Model 4), with sex and age as covariates. Confidence intervals (95% CI) for the indirect effects were determined by 10,000 bias-corrected bootstrapping resamples. The results of our mediation models, presented in Table 10, fully support Hypothesis 3.

**Table 10 - Results of the Mediation Models Predicting Mental Health and Personal Growth (Models 2A, 2B)**

	<i>b</i>	<i>SEb</i>	<i>P</i>
Mental Health			
Direct Path (c')	-.02	.08	.80
<b>Being Raised by a PWD → Perceived Stress</b>	<b>.22</b>	<b>.10</b>	<b>.02</b>
<b>Perceived Stress → Mental Health</b>	<b>-1.05</b>	<b>.06</b>	<b>&lt; .001</b>
<b>Indirect Path</b>	<b>-.23</b>	<b>95% CI: -.43, -.02</b>	
Personal Growth			
Direct Path (c')	-.05	.11	.68
Being Raised by a PWD → Perceived Stress	.22	.10	.02
Perceived Stress → Personal Growth	-.51	.08	< .001
Indirect Path	-.11	95% CI: -.23, -.01	

The findings presented in Table 10 support Hypothesis 3, for both mental health and growth as outcomes: Perceived stress was found to significantly mediate the effect of being raised by a PWD on both mental health and personal growth, as the 95% CI's of both indirect paths did not include 0. An inspection of the relevant coefficients revealed that, as expected, being raised by a PWD is positively associated with perceived stress, which in turn is related to lower levels of both mental health and personal growth. The preliminary conditions for analyzing the indirect paths, i.e., significant a and b coefficients, were met for both the indirect paths. Moreover, for both models, the direct paths were not significant – indicating that most of the effect of being raised by a PWD on mental health and personal growth is mediated by perceived stress.

#### **5.1.5 Moderated-mediation analyses predicting Mental Health and Personal Growth – Coping Strategies as moderators (Models 3A, 3B)**

To test the multiple moderated-mediation models with COPE as moderators (Models 3A, 3B, Figure 3), we used Hayes's (2013) PROCESS SPSS Macro (Model 16), with sex and age as covariates. Confidence intervals (95% CI) for the indirect effects were determined by 10,000 bias-corrected bootstrapping resamples. The two COPE variables – problem-focused and emotion-focused coping strategies – were entered in the model simultaneously.

The results of the moderated-mediation model, shown in Table 11, partially support Hypothesis 4. With regard to mental health as the outcome, perceived stress marginally interacted with problem-focused coping, and did not interact with emotion-focused coping. More importantly, the role of perceived stress, as a mediator of the path between being raised by a PWD and mental health, was itself moderated by problem-focused coping, such that the mediation of perceived stress was more evident at lower levels of problem-focused

coping. In other words, the perceived stress that results from being raised with PWD has a greater negative effect on the mental health of individuals with low problem-focused coping capacities.

**Table 11 - Results of the Mediation-Moderation Models Predicting Mental Health and Personal Growth with Problem- and Emotion-Focused COPE as Moderators (Models 3A, 3B)**

	<i>b</i>	<i>SEb</i>	<i>p</i>
Mental Health			
Direct Path (c')	-.01	.07	.87
Perceived Stress × Problem-Focused	.24	.12	.06
Perceived Stress × Emotion-Focused	-.12	.12	.34
<b>Indirect Moderated Path - Problem-Focused as Moderator</b>	<b>.05</b>	<b>95% CI: .01, .15</b>	
Indirect Moderated Path - Emotion-Focused as Moderator	-.03	95% CI:- .10, .01	
Personal Growth			
Direct Path (c')	-.01	.10	.98
Perceived Stress × Problem-Focused	.01	.16	.92
<b>Perceived Stress × Emotion-Focused</b>	<b>-.37</b>	<b>.16</b>	<b>.02</b>
Indirect Moderated Path - Problem-Focused as Moderator	.01	95% CI: -.08, .10	
<b>Indirect Moderated Path - Emotion-Focused as Moderator</b>	<b>-.08</b>	<b>95% CI:-.22, -.01</b>	

With regard to personal growth as an outcome, the picture that emerged was reversed: perceived stress significantly interacted only with emotion-focused coping, and not with

problem-focused coping. More importantly, the role of perceived stress as a mediator of the path between being raised by a PWD and personal growth was moderated by emotion-focused coping, such that the mediation of perceived stress was more evident at higher levels of emotion-focused. In other words, the perceived stress resulting from being raised with a PWD had a greater negative effect on personal growth for individuals with higher emotion-focused coping capacities.

#### **5.1.6 Moderated-mediation analyses predicting Mental Health and Personal Growth – Attachment Scales as moderators (Models 4A, 4B)**

To test the multiple moderated-mediation models with anxiety and avoidance scales as moderators (Models 4A, 4B, Figure 4), we used Hayes's (2013) PROCESS SPSS Macro (Model 16), with sex and age as covariates. Confidence intervals (95% CI) for the indirect effects were determined by 10,000 bias-corrected bootstrapping resamples. The two attachment scales, anxiety and avoidance, were entered into the model simultaneously.

The results of the moderated-mediation model, presented in Table 12, partially support Hypothesis 5. With regard to mental health as the outcome, perceived stress did not significantly interact with either anxiety or avoidance. However, the role of perceived stress as a mediator of the path between being raised by a PWD and mental health was moderated by avoidance, such that the mediation of perceived stress was more evident at lower levels of avoidance tendency – suggesting that perceived stress, as a result of being raised with a PWD, had a smaller negative effect on mental health for individuals with elevated avoidance tendencies.

**Table 12 - Results of the Mediation-Moderation Models Predicting Mental Health and Personal Growth with Anxiety and Avoidance Attachment Scales as Moderators (Models 4A, 4B)**

	<i>b</i>	<i>SEb</i>	<i>p</i>
Mental Health			
Direct Path (c')	.01	.08	.85
Perceived Stress × Anxiety	-.02	.04	.60
Perceived Stress × Avoidance	.09	.05	.08
Indirect Moderated Path - Anxiety as Moderator	-.01	95% CI: -.04, .02	
<b>Indirect Moderated Path - Avoidance as Moderator</b>	<b>.02</b>	<b>95% CI: .01, .06</b>	
Personal Growth			
Direct Path (c')	.01	.10	.88
Perceived Stress × Anxiety	.07	.06	.20
Perceived Stress × Avoidance	.00	.06	.98
Indirect Moderated Path - Anxiety as Moderator	.02	95% CI: -.01, .06	
Indirect Moderated Path - Avoidance as Moderator	.00	95% CI: -.03, .03	

With regard to personal growth as the outcome, no significant interactions between perceived stress and anxiety or avoidance were identified. Moreover, the role of perceived stress as a mediator of the path between being raised by a PWD and personal growth was neither moderated by avoidance nor by anxiety.

### 5.1.7 Moderated-mediation analyses predicting Mental Health and Personal Growth – Self-Esteem and Social Support as moderators (Models 5A, 5B)

To test the multiple moderated-mediation models with self-esteem and social support as moderators (Models 5A, 5B, Figure 5), we used Hayes's (2013) PROCESS SPSS Macro (Model 16), with sex and age as covariates. Confidence intervals (95% CI) for the indirect effects were determined by 10,000 bias-corrected bootstrapping resamples. Self-esteem and social support were entered into the model simultaneously.

**Table 13- Results of the Mediation-Moderation Models Predicting Mental Health and Personal Growth with Self-Esteem and Social Support as Moderators (Models 5A, 5B)**

	<i>b</i>	<i>SEb</i>	<i>p</i>
Mental Health			
Direct Path (c')	.02	.07	.76
Perceived Stress × Self-Esteem	-.01	.04	.81
Perceived Stress × Social Support	-.01	.09	.96
Indirect Moderated Path - Self-Esteem as Moderator	.00	95% CI: -.05, .05	
Indirect Moderated Path - Social Support as Moderator	.00	95% CI: -.03, .02	
Personal Growth			
Direct Path (c')	.02	.10	.87
Perceived Stress × Self-Esteem	-.02	.06	.77
Perceived Stress × Social Support	.04	.12	.71
Indirect Moderated Path - Self-Esteem as Moderator	.01	95% CI: -.04, .08	
Indirect Moderated Path - Social Support as Moderator	-.01	95% CI: -.04, .02	

The results of the moderated-mediation model, shown in Table 13, did not support Hypothesis 6. With regard to both mental health and personal growth as the outcomes, perceived stress did not interact significantly with either self-esteem or social support; neither self-esteem nor social support moderated the perceived stress mediation effect. That is, being raised by a PWD affects perceived stress, which in turn affects mental health and personal growth; this mediation path is not dependent on the individual's self-esteem or social support.

## **5.2 Qualitative phase findings**

### **5.2.1 Data analyses**

The nine in depth interviews were conducted in accordance with the phenomenological tradition. Each interview contained three sections: (a) participants were asked to share their personal narrative; (b) participants were asked directed questions designed to draw out further details of their account; and (c) participants were asked to suggest a title for their life story.

All interviews were recorded and transcribed. Every interview underwent a holistic analysis (Lieblich et al., 1998); subsequently, a focused thematic analysis was conducted to crosscheck the data between interviews and identify main themes (Shkedi, 2004; Tutty, Rothery & Grinnell, 1996). Thematic analysis was used to unearth the salient themes in the texts at different levels (Attride-Sterling, 2001). This uncovering process is especially useful and important for topics such as this, given that they are largely unacknowledged and have remained invisible to critical scrutiny.

The data analyses included a dissection of the information that emerged from the interviews, and then re-constructing so as to identify and understand the subjective meanings that emerged (Rosenthal, 1993). These themes were later analyzed, to assess the main

categories and meanings that the data provided. Finally, a theoretical analysis allowed for the identification of the relationships between categories and their theoretical framework (Shkedi, 2011). Combining these methods is considered optimal, as analyzing the text structure should relate to its context and vice versa (Sabar Ben Yehoshua & Dargish, 2001). This integration facilitates the identification of each individual story's principal axis.

The strategy which individual participants choose to tell their life stories enables the researcher to grasp the meaning that they give to their experiences. The identification of these strategies was important in the present research, due to its primacy in engaging with the implications of being raised by a PWD. As there is scant literature on this topic, the possible attributes it added to the available knowledge was a leading factor in unearthing as much data as possible.

### **5.2.1 Holistic summary of participants' life stories**

#### Interview 1: Jo

At the time of the interview, Jo was 31 years old, and lived in one of Israel's biggest cities. She carried out her compulsory army service as a Welfare non-commissioned officer, helping soldiers to overcome financial and personal problems. After completing her service, she began to work as a social worker with at-risk young girls. The middle child of a secular family, both of her brothers became observant Orthodox Jews. Both her parents had disabilities. Her mother has both physical and cognitive disabilities; while alive, her father contended with both mental and physical disabilities. Her maternal grandparents played a crucial role in her upbringing. She felt like they were the ones who really saw to her needs – personal and financial – continuing to do so to date. Jo described her childhood as "enchanted with fairy dust", because she always felt protected, primarily by her grandparents, as though her parents' disabilities did not play a crucial role in her life. In the interview, she expressed

the opinion that the system had let her down, neither she nor her siblings received any help or support, and they were obliged to fight in order to assert her parents' disability rights.

The title she gave to her life story is: *Life – Just Like That*.

### Interview 2: Lea

35 years old, at the time of the interview Lea lived in a city in central Israel, and was in a long-term relationship. She worked as a school facilitator with children on the Autism spectrum. The second of seven siblings, she was raised in a small religious settlement. Now secular, she remains in touch with her siblings, most of who are Orthodox Jews. Her parents, both from well-off secular families in the U.S.A, immigrated to Israel as an observant Orthodox young couple. Her parents had no support system in Israel, other than a trust fund that her maternal grandparents had set up for her mother. Her mother was diagnosed with a mental disorder (schizophrenia) when Lea was a young girl after several episodes that ended up in hospitalization. Lea related many memories of her mother's eccentric behavior. Her parents divorced when she was a teenager. At that time, she left home for an all-girls boarding school, where she spent her high school years. She recalled spending weekends away at her friends' homes, but never daring to invite anyone for reciprocal visits to her own home. Her paternal grandfather is a psychiatrist, and she expressed regret that he wasn't there for them earlier in life, either to explain her mother's condition or later, when her brother was diagnosed with a MD. Lea herself had dealt with episodes of mental illness. At the time of the interview, she had been her mother's legal guardian for a number of years.

The title she gave her life story is: *This is Life*.

### Interview 3: Martha

Martha, 28, immigrated to Israel eight years before the interview from the former Soviet Union, after a summer visit during which she met her husband. At the time of the interview,

they had have been married for five years, with two children. As a student, Martha also had an administrative job at her university.

She was the youngest of three siblings. Her older brothers, 18 and 14 years older than her, both immigrated to Israel when she was a child. She stated that her parents had desired a girl for many years, and that after she was born her mother stopped working, in order to raise her. Martha had recollections of a very warm and loving childhood, where she was the center of attention. As a teenager she became interested in religion, and has been an observant Orthodox Jew since the age of 15.

She believes her mother's MD – later diagnosed as bi-polar disorder – was one of the reasons that led to her emigrating to Israel. While reflecting on her childhood, she was able to pinpoint instances of unusual behavior on her mother's part from a young age: her mother following her around and being overly involved in her personal life, or distancing herself from friends and neighbors. Nevertheless, Martha believed that her emigration to Israel was the proximate trigger for her mother's breakdown.

Her husband's grandfather, a psychiatrist, helped with the diagnoses; because her parents reside in a country with inadequate facilities for treating mental treatment, he also helps by sending medication to her mother. She had tried many times to encourage her parents to emigrate to Israel, so that the family can be reunited.

The title she gave her life story is: *In-between Worlds*.

#### Interview 4: Naomi

Naomi, 44 years old at the time of the interview, was born in Eastern Europe. An only child, she claimed that she had never been told the full story of her childhood and of her mother's disability. Whilst it was and remained a well-kept secret, she did know that her mother was hospitalized a short time after giving birth to her. Naomi spent her first months in an

orphanage, until her mother was discharged. Her mother had 9 elected abortions, which all led to hospitalizations. Naomi moved in and out of her aunts' homes with each successive hospitalization until the age of 6. At that time, her family immigrated to Israel. Naomi reported remembering her mother disappearing for varying periods of time, which she subsequently understood were spells in mental health hospitals. At the age of eight, she returned home one day and discovered her mother after attempting to commit suicide. This was the time, she reported, that she understood that her mother had a disability. She grew progressively closer to her father, until his sudden death when she was 15. At her family's decision, she moved to a boarding school. Her mother passed away, while hospitalized, when Naomi was 25. It was only around that time that she learned that her mother suffered from schizophrenia and depression. In her recollection, it was her relationship with her future husband that saved her then. At the time of the interview, they had two daughters, and lived in a central city. Naomi worked as a social worker; our interview was the first time that she had told anyone her full life story.

The title she gave her life story is: *Nothing is Taken for Granted.*

#### Interview 5: Alex

Alex, 25, lived at the time of the interview in a rural community with her husband and two children. The middle of three sisters, she was raised in her parent's home in a big city. Her mother had an IDD; her father had a physical disability, and also, possibly, an undiagnosed MD. Her parents had a very difficult relationship. Her maternal grandparents, who lived a few minutes away, provided a warm and safe base away from home. Together with her aunts and uncles, they provided many of her meaningful models as a child. Visiting them every day, she recalled during the interview, was like suddenly walking into a normal environment for her. She described her mother as a warm and loving person; however, in Alex's

recollection, she didn't know how to put her children's before her own, and couldn't protect them. Alex reported difficult childhood memories, such as taking herself to the doctor at age of five when she was sick, and looking after her younger sister.

She described herself as an introverted child with a rich inner world; she explained that she only started to speak at age of three, because there was little communication with the outside world. She left home at age 16, and rented an apartment with a friend – a period during which, as she recalled, the world opened up for her. At the time of the interview, she was employed as a therapist.

Alex reported feeling that the authorities had let her down: if they had supervised her parents and counseled them and the wider family, her life would have been easier. It was easier, in her opinion, for the authorities to ignore her and her sisters. It is her role today, as it has always been, to take care of her parents – a role that nobody prepared her for.

The title she gave her life story is: *Roller Coaster*.

#### Interview 6: Ori

Ori, 37 years old, lived on a kibbutz with his wife and three children at the time of the interview. He met his wife at a friend's wedding; he said that she is the best thing that had ever happened to him. They had been together for more than a decade at the time of our interview.

The oldest of three brothers, he indicated feeling a sense of responsibility for his younger siblings for his entire life. His father was an alcoholic, and his mother suffered from MD. Both parents had gambling problems. They lived in a poor neighborhood in a development town. Violence and neglect were ever-present aspects of his home life, as indeed they were for most of the children in his neighborhood. Several members of his extended family

members had also been diagnosed with mental disabilities; aside from his maternal great-grandmother, he did not have any positive adult role models while growing up at home.

Ori and his brothers were moved to foster families when he was six. After living in 23 foster homes, he was placed in a boarding school at the age of age 12. He expressed significant resentment towards the authorities who, in his opinion, didn't do their jobs in caring for the welfare of his family.

At the age of 18, he changed his last name, in order to detach himself from his original family. In his opinion, his real life began then. He retains a relationship with his mother and tries to look out for her. At the time of the interview, he worked in a technical capacity in one of the country's ports. He reported a sense of contentment with his life.

The title he gave her life story is: *Everything Passes*.

#### Interview 7: Tom

Tom, 45, divorced with two children, lived in a rural community at the time of the interview. He is an only child. His mother has an IDD, and his father had an undiagnosed developmental disability. He spent his early childhood living with his maternal grandparents, across the street from his parent's house. At age 10, after his father passed away, his mother moved in with his grandparents, and he decided to move to a boarding school. He became his mother's legal guardian at the age of 18.

After completing his education, he worked his way up in the world of industry. But at age of 36, after some personal reflection, he left everything. He sold all his possessions, and took a trip around Israel on his motorbike. As he had no home of his own at that time, he regarded his mother's apartment at the residential treatment community she lived in as his home. His mother, who he been ashamed of and had run away from for much of his life, at this point

suddenly became the mother that he never felt he had. They grew close, and from that point on defined her as his spiritual teacher.

At the time of the interview, Tom and his mother ran joint workshops, narrating their life story and special connection in the hope of opening people's hearts and drawing their attention to the phenomena of parents with special needs and their children. He reported feeling that he is in a good place today, despite – and because of – his personal circumstances.

The title he gave her life story is: *The Diamond Inspiration*.

#### Interview 8: Shay

Shay was 36 years old at the time of the interview. Although he always knew his mother was different, he had only learnt of his mother's diagnosis of (mild) IDD six months prior to the interview, when he attended a committee convened to review her case. He had started regular visits to a foster family after school at age of eight, only returning home in the evenings. He struggled with ADHD and had trouble at school; and at age nine, he moved in with his aunt and her family, remaining with them until the age of 12, when he was sent back home. He missed having a mother whom he could talk to about his day and his feelings. Now, he reported, he feels that this experience would have had a positive effect on his life, especially during his difficult school years. His maternal grandmother, who had four children with IDs – including his mother – was a great support to him while alive. His cousin and good friend had similar family circumstances, and they have supported and comforted each other since their childhood.

Many of his romantic relationships ended due to his mother's disability. At the time of the interview, he was married with one child, in a technical job that he enjoyed. As his mother's guardian, he visits his parents, with his wife and daughter, every fortnight.

The title he gave his life story is: *No Sympathetic Ear, But Lots of Love*.

#### Interview 9: Shlomit

Shlomit, 42 years old, was married with three children at the time of the interview. The oldest of five siblings, she lived close to her mother – who was in her care – in her hometown. Her parents divorced when she was 13, after many years of strife. Both of her parents contended with both mental and physical disabilities. In her narrative, she recalled instances of being scared of her mother's erratic behavior, behavior which eventually led to hospitalizations. At such times, they all moved in with her grandparents. Her maternal grandparents lived nearby, and had been important positive figures in her life. In her mind, she had no idea where she and her siblings would have ended up without them. As the oldest child, she took charge of the house and her siblings as a teenager. She stated feeling that she had missed out on her childhood, and had only learnt to fully enjoy life as an adult. Today, she allows herself have fun.

Her parents didn't value education, and couldn't support her with her school work. Her maternal aunts and uncles, all well-educated, were a crucial driving force in her childhood, remaining so to the present day. Shlomit, at the time of the interview, worked as a special education school teacher; very accomplished, she reported being satisfied with her choice of profession. Her sensitivity towards others, she said, came from her mother.

The title she gave her life story is: *Cinderella Story*.

#### **5.2.2 Thematic categories**

The main themes that were found and that will be discussed were:

1. The knowledge (or lack thereof) of their parent's disability and its meaning

2. The role of extended family members on their lives
3. The search for positive adult figures
4. Mixed feelings about the parent/s
5. Role reversal
6. An inner drive towards success

### **5.2.2.1 An unspoken story: what do they really know about their parents?**

A main theme that emerged from the interviews was that of “living with a cover story”. All of the participants described understanding that their parents and their home lives were different from an early age, but never receiving an explanation other than, perhaps, a very vague definition of the disability or its import.

“It was never spoken about. Nobody said ‘Mom has this, Dad has that...it was just reality’.”(Alex). Neither extended family members nor authority figures thought it necessary to bring the children in on the family secret – to sit them down with them and help them grasp the reasons why their parents were different from the other parents they saw around them. Ori, like many others, understood at an early age that his parents were not like other parents. “I understood but not in hearing the words or a conversation, you understand – it’s in the situations.” Similarly, Tom, who grew up with his grandparents, with his parents as neighbors, related that “It was very clear...I don't remember anything specific – I just grew into it... I understood from a very early age.” He was not given any official communication of the illness until much later, when he became his mother's guardian at the age 18.

Naomi related a story, in which her mother was never part of the day-to-day family life: “It was something different.” She claims that “it wasn't even in my consciousness, there was never any discussion about it – that I have a mother who suffers from something.”

In the rare cases when explanations were offered, more often than not they were vague and unsatisfactory. “I never knew what was different,” Lea noted; when she was 12, her mother was hospitalized following a post-partum related nervous breakdown. Her mother went to the hospital to give birth and didn't return home for 6 months. Whenever she or her siblings asked about their mother, they were merely told that she was still in hospital. She remembered this as the first time that she had a term for her mother's condition, even though no-one had ever explained to her what had happened and what it meant. “It's the first time I had a label to attach to her, why my mother was different because until then we just thought she was weird. When I was 12 I was finally able to label her as ‘Crazy’.”

In many instances, the discovery that the parent was dealing with a disability came about by accident – a passing remark, an overheard conversation between adults, the arrival of a formal letter from the authorities. Jo, who discovered such a letter relating to her mother, explained it thus: “In it were all kinds of diagnosis, but they didn't mean anything to me.” While her father was dealing with a physical disability that was acknowledged and discussed openly, her mothers' IDD was never explained. “I think with my mother, it was something that took me a lot longer to understand.” This example, a physical disability in the open while a MD or IDD was covered up, was mentioned many times in the interviews. Martha, a social work student, recalled a revelation during a class on psychopathologies: “I remember it so clearly, how I suddenly understood my mother has depression, that she has manic-depression.” In high school, Shlomit wrote a paper with a friend about mental illness. Researching the topic together with her friend exposed her for the first to terms that, she felt, explained many aspects of her mother's behavior: “And that's when I understood that my mother has schizophrenia”

Neither a family member nor a professional sought to sit down with them and explain what about their parents was different. Nothing of age-appropriate clarity was presented to

them; the information they did have usually consisted of snippets picked up here and there. As of the time of the interviews, the participants who were not their parents' legal guardians could not describe with certainty and clarity the disability in question, or its full meaning. They were, and sometimes still are, missing a diagnoses or definition – a label that could ascribe meaning to their unique situation.

A comment by Shay underlines this issue: “I understood why I needed to go into foster care as a child, I understood my mother wasn't 100% and that she doesn't know how to help me and so I am given help. But I would have been glad to have tools to deal with it such as information- your mom is like this, she has this and that”.

#### **5.2.2.2 It's a family affair: the role of the extended family**

Another main recurring theme in the life stories related by the interview participants is the role played by extended family members. The presence of functioning adult figures in the extended family was the main factor determining whether they lived at home or not.

“My grandmother and grandfather, who are totally my additional parents...they are the ones who took care of us, and still do” (Jo). Members of the extended family, whether grandparents or aunts and uncles, played a crucial role in the participants' lives and subsequent life outcomes, in their opinion. “My grandmother raised us for the bigger part of our lives,” Shlomit reported, with respect to life for her and her four siblings after her mother's breakdown and hospitalization. “If it wasn't for her, I don't know where we would be today.” On the whole, the interview participants were very thankful for this involvement, viewing it as a refuge from the life that they might have experienced if this help and support had not been in place.

Alex spent many childhood hours in her grandparents' home. “It was really an amazing place for us, warm and healthy, my uncles and aunts were always there...I had

important meaningful childhood figures there.” Naomi's mother suffered a breakdown after her birth: “My grandmother moved in with us when I was born and raised me until she passed away when I was 11 months old...then I was moved to my aunts until my mother got better.” Similarly, Lea's parents immigrated to Israel, their families remaining abroad. Her grandparents created a trust fund for her mother, to ensure her future and that of their grandchildren.

“My aunt and uncle took over the responsibility to care for her when my grandmother died. When I wanted a sympathetic ear, I would talk to my grandmother, my aunts or my cousins” (Shay). Shay was supposed to be moved to out-of-home care, due to his parents’ inability to take care of him. But his aunt intervened: “My aunt, who lives up north, heard about this, and she said: you don't need to send him anywhere, he'll move in with me...they were a well-off family, and my older cousin helped me with my studies...it was a really normal home.” “My mother was less interested in our education” Shlomit reported. “It's due to her own deprivation, but she had educated siblings...they pushed us. My uncle was like a father to me in that sense.”

In many cases, the fact that they were “taken care of” stopped social workers from intervening. Of the nine participants interviewed, six were raised exclusively within their family; the other three spent at least some of their childhood in out-of-home care facilities or foster care.

The decision regarding raising the children at home or not was largely influenced by the presence (or not) of supportive, capable and willing family members, aside from the parents themselves.

Ori was raised in foster care from a young age. “My family is three generations of screwed up people – every one of them has some kind of illness. My great grandmother was the only one with whom I had normal contact, and she cared for us as much as she could.” He

explained this central role in terms of the absolutely basic needs of himself and his siblings. “In the morning my mother wouldn't feed us. We would leave the house around noon when she managed to get herself in order, go to our grandmother's house, a 15-minute walk, and there we would eat.”

Tom, who chose out-of-home care at a young age, explained: “I was raised at grandmother's house. When my father passed away I was 10, and left for a boarding school of my own choice, and my mother moved in with my grandparents.”

### **5.2.2.3 Significant others: the role of positive adult role models throughout their lives**

The need for significant adult role models and the ongoing search for them throughout their lives is another main theme of the life stories. Family members who were usually present and were very significant to their everyday lives played a crucial role.

Shay spoke about his aunt's family. They took him in and, for a few years gave him a model of a normal home environment. He remained very close with one of his older cousins – also with PWD – and felt the fact that they could share their experiences helped them both cope through their challenging childhood years. “He's the one I could talk to, he was in my situation and pulled through so he understood me best. He was my support system.”

Likewise, Shlomit experienced the presence of her aunts and uncles as surrogate parents, and as her sounding board. “My uncle, he's like a father to me. I spent a lot of time with him and he was the one who supported me throughout life.”

This aside, the interviewees also discussed the importance of figures outside the family who could guide and educate them. “I feel my close friends and especially their parents were very significant. I visited their homes a lot and something about just being there and seeing how decisions were made and the atmosphere...it was very normal” (Jo).

Similarly, Lea recalled friends playing a significant role in her life. “At some point, it was very important to me to have people that I chose for myself. Friends became really important in my teenage years and I really relied on them.” This role, she observed, was now filled by her partner, especially with regards to helping her cope with caring for her mother.

Similarly, Martha described being able to draw great comfort from her husband and his family. “I shared my mother's depression with my mother in-law, and since then she is a big help to me and helps me provide for my mother.” Ori described his wife and her family as a great light in his life. “I married the perfect woman and she has a warm loving family living in a very loving community. My children have a good experience of being part of a family.” In general, he described his children as his source of strength today, keeping him balanced.

Naomi spoke of a family friend whom she had been in touch with all through her life. “She was really amazing for me. She was always there for me and I could call her, share my thoughts and consult her...I felt it was very authentic and she would advise me but not in a ‘know it all’ adult way... At a latter age when I was an adult, she felt she could also share her thoughts and feelings and consult me, and I felt I had someone who sees me eye to eye.” As a teenager, Martha found in God the help and support she needed. She described her religion as a central part of her support to the present day. “My religion is a great help, my faith... I believe He (God) helps me and keeps challenging me.”

Between the ages of six and 13, Jo was a keen ice skater. She spoke about this period and hobby as a very formative experience: “My instructors were very meaningful. It was something very committing and it shaped me in many ways.” Naomi spoke about her relationship with her literature teacher in similar terms, as very meaningful for her. “She told me she saw something special in me and wanted to get to know me better. I could share what happened in my life with her.” She went on to describe how this teacher later invited Gila Almagor, a famous Israeli author, to the class, to discuss with them a book she had written

about her own life – with a mother with a MD. “[The teacher] said she wanted to show me that it's possible to grow and prosper even from a very difficult place. They both, my teacher and the author, added a dedication for me in the book. She was someone who really saw me and it made a great difference.”

#### **5.2.2.4 Mixed feelings: on loving and hating their parents**

The burden of having mixed feelings about one's parents came up repeatedly in the participants' accounts of their life stories. On the one hand, they had internalized many complicated childhood experiences and memories; but on the other – in part due to the passage of time and a more rounded relationship with their parents – they had also become more understanding about their parents' difficulties. Some even stated that they had no right to resent them or to feel anger and disappointment – one simply has to accept things as they are. Alongside these feelings, they also possessed a clear sense of responsibility, drilled into them from a young age: they also had the responsibility of caring for their parents.

“In my account she wasn't a parent...she was just there” Lea commented about her relationship with her mother. Years later, as an adult, she described growing closer to her mother – she now possessed a better understanding of her, and the issues that she had contended with. But these mixed feelings also took a toll. As Alex phrased it: “It's like always carrying an extra heavy load on myself.”

“My dream was to be a ‘latchkey kid’ and my parents wouldn't be home when I arrived from school,” Jo commented in similar vein.

Ultimately, their parents are their parents; like any other child, they want to love them and look up to them. But it is not always easy to understand their parents' incapacity and adapt to these circumstances. Naomi, for example, recalled a difficult period with her mother when she was 14. “She said she was sorry she ever had me and I took it very badly. I know

she didn't mean it...it was out of her distress, and we were having a hard time.” Jo described her own greatest fear as that of turning into her mother: “There was a great fear of becoming like her, to be crazy, to not know what I'm doing...and in all that there is still a distinction between her fate and mine.”

Some of the interviewees described reaching the understanding that their parents simply were not as capable as the parents of their peers, and the mixed feelings that this realization brought to the surface. Ori, for example, observed: “In the beginning I was all for my mother, tried to help her and everything... but then you realize how crazy she is.”

Shay shared a similar experience. “As the level at school progressed homework became harder, and there was no help at home – my dad would work and my mother didn't know how to help.” This absence was crucial. “My school years were the time I felt that if I had a mother who understood it could have helped...if she was more involved in my life.” Ori stated, in clear and decisive fashion: “My mother was not a mother –unequivocally! Everything she ever told me it was all a mistake.” Today, he takes care of his mother from afar, mostly by helping her out financially. Shlomit described her mother's breakdowns: “It's not easy to witness... It's scary that your mother is suddenly not the mother you are used to seeing.”

When their parents were unable to function as expected (or desired), the children experienced conflicting emotions. On the one hand, there was the helplessness and the feelings of anger. But nevertheless, the underlying realization remained: these are my parents. Martha described her mother visiting her after she had given birth to her own child. “We came back from the airport and she just sat there, and I can't recognize my mother-who is this?! Strange, quiet, no appetite for life, and why did you come? What will we do now? I need help and now I need to take care of someone else.” Lea recalled once making dinner for her seven siblings. When her mother joined them at the table, “I thought to myself: I didn't

make dinner for you...do you really think you're sitting down with us? I didn't count her in, she was just somewhere in the background for us.” Now, Lea and her mother have grown closer. “Today as an adult I can think, and this was dramatic for me, that she was just a 30-year-old woman, alone in a foreign country with many hardships, with a partner she doesn't understand and pregnancies she might not have wanted...”

Many times, these mixed feelings were prompted by interactions with people outside the family. Tom, for example, said that “I always felt that my mother wanted to be my mother, she always had something maternal about her...but the messages I got from people around me...it was...I was ashamed.” Time lends perspective and clarity, however. Tom now runs workshops together with his mother: “Today I see her as my spiritual teacher. We went through a long and interesting process together.” With the passage of time, the children have found the capacity to be more forgiving and understanding of their parents. Naomi described a revelation she had during a trip abroad after her army service, and telephoning home. “The most amazing thing for me is finding out I really love her....I love her and she is important to me.” During this trip – one of many ways she attempted to run away as far as possible from her mother – she reached an understanding. “I slowly started understanding that this is what she is, this is what she is capable of.” In her interview, Jo summed up this epiphany clearly: “I carried the fantasy of having an all mighty dad, my father has a ladder [paraphrasing a well-known Israeli children’s song] ...so he didn't have a ladder...but he had other things.”

#### **5.2.2.5 Who's in charge? Dealing with role reversal**

Role reversal, in the case of a child growing up with a parent who is not fully functional, is not an uncommon expectation. Where the gaps manifest, even young children tend to recognize the need to step up and do what needs to be done. In many cases, it is the parents themselves who enlist the child's help for the everyday tasks. These children often find

themselves many times exposed to information and situations not suited for their age and knowledge. In the case of a PWD, many children find themselves running the household, becoming decision-makers early on in life.

“I remember my mom telling me about some kids in the neighborhood bullying her...and me, the young boy going after them to protect her.” Tom's recollection, from when he was eight, is representative of the many examples of role-reversal in the case of a PWD. “I knew I had to be a really good girl and not upset her and ...well – take care of her,” Naomi explained. Shlomit, for her part, observed that as the oldest of five siblings, she started taking charge of the house at a young age. “I actually didn't have a childhood. When my friends went to the beach, I had to clean and help around.” Looking back on the period, she described only getting "to be a child" as an adult, after leaving her parents' home.

Most of the interviewees had vivid recollections of missing out on childhood, of doing things that children aren't usually expected to do at home, and from a very young age. Jo: “Only children of parents with a disability know these things. They escort their parents to the doctor, run errands, have to explain things, and make phone calls to bureaucratic offices.” Alex's recollections add to this thread: “I needed to yell at people all day on the phone about why they take advantage of my parents.” As an only child, Shay played a crucial role in his family's survival. “I started helping around the house, helping with food and financially. That's how living at home was...It wasn't simple.”

Martha recalled facilitating her parent's relationship as a young girl. “As a teenager my parents fought, there were many complications in their relationship and I felt like the bridge between them...then I also started studying psychology and really became the house therapist”. Lea, the oldest of eight 8 children, described playing a crucial role in the home, taking care of her siblings when her mother was unable to function. Later in life, she became

her mother's guardian: "I had to start taking responsibility for her. Our discourse, and this was not for the best, became something else, less close and more managerial."

After spending most of his life in foster families and boarding school, Ori became this mother's caregiver. In the interview, he said that he understood it to be his role to look out for his siblings. "I have two little brothers, and it was my job to take care of them. When asked about her mother's role in her life, Jo replied: "I don't know, it's a tough question what role she has, because mostly I have a role – to be her daughter."

Given their early understanding of the need for them to assist or due to the expectations that the people surrounding them created, most of the interview participants accepted the role of caregiver at an early stage. In a simple and very rational way, Jo described her situation, taking care of her parents and household matters from a young age: "I think with all people, with the years the roles shift...but for me it happened a little earlier." Alex expressed her current relationship with her parents in similar terms. "There is a need to go there and keep them company and be a child to them for a minute...to give them a place to be parents even though it's a kind of game. But it needs to be done." As she summed it up: "Alongside the fact that I am evolving and moving forward, and I really do a lot in my life, but still this goes with me and I need to cope with it daily, in anything I do. Even on the physical practical level of life, the fact that I need to take care of them, always with all the burdens I have to carry, I have them as well."

#### **5.2.2.6 The glass half full: positive outlook as a growth accelerator**

Perhaps unsurprisingly, all of the interviewees are happy and accomplished; they feel that they successfully overcame life's challenges. They expressed the constant need to prove their worth and ability. Generally, the sense was that they had overcome many challenges, coming out the better for this experience. Their stories were threaded with expressions of undoubted

pride for proving to everyone, especially those who did not have faith in them, that they succeeded and against the odds. It may be that those who felt they overcame and are satisfied with how their lives turned out are those who chose to be interviewed. And still, they paint a very complex yet positive picture.

“Listen – there is the bottom and you can only go up. Some things hurt us but it became a trigger for us.” A sense of pride emerged from Ori’s description of the distance he has succeeded in establishing between his current life and his childhood one. Like most of the participants, he described working hard to succeed against the odds, and to prove that they can be more than “those poor kids” as he remembers being called. “If you’re smart enough to grasp things...you can exploit everything in your favor... All that happened made me stronger.” As Shlomit phrased it “That’s the thing that haunts me to this day, I can’t forget it in anyplace I am today, I’m proud of where I was and where I am today – it’s very moving.

The interviewees described the concept of an inner strength, a force that saved them and kept driving them forward. “It takes a lot of strength not to fall...to build a normal life, to raise kids normally...it takes a lot of strength to carry this thing – that’s obvious” Naomi observed, after hearing herself speak about her childhood. Jo underlined this point. “As a child, I don’t think I felt that I’m missing something. I had good and healthy mechanisms to protect me, even in places when I was missing something.”

All of the participants tried to give examples of the “upsides” to having a PWD. “I always had a hot meal waiting for me at home when I came back from school” Shlomit recalled. “It’s something the kids who had career driven parents didn’t have.” Martha described being very proud of her sense of capability and independence in life. “I remember that my mother from a very young age encouraged my independence. She would give me assignments, from age five or six I think, to go buy something in the grocery store...she would walk behind me and watch and I would go in by myself and buy something and she

was very proud of me.” Martha also reflected on the notion that she was the defining purpose of her mother's life. “I was always in the center: come stand on a chair and sing, tell stories and read to us...it was a lot of fun.”

In his interview, Shay described the advantages of his upbringing. “My mother, with everything that's wrong with her...she understands other things – she knows how to love a child and give...in that she's better than a regular mother...I feel I got my warmth and compassion from home. Because my mother is good-hearted I am a better person...I learned to be good and not exclude anybody, I learned to accept and love, the way she did.”

Reflecting on her life, Alex stated: “This situation has taught me. It brought me to a place of compassion, of flexible thinking, of creativity, of a rich inner world. It made me develop things that otherwise probably wouldn't have developed if I wasn't raised this way.” Tom described similar sentiments. “I remember myself at a very young age observing other people's behaviors. Maybe because my circumstances were so different and I wanted to understand why me and not others, so I looked how other people acted and responded and I drew patterns.” Tom, with a career in the therapeutic services – like five of the other interview participants – credited his career to his upbringing.

Mostly they described feeling strong and accomplished; that they had succeeded, even though the odds were against them. In Alex's words: “My life is really good and...I feel I deserve it – that I worked hard for it.”

## **6. Discussion**

Being raised by a PWD creates unique challenges with short- and long-term implications on the personal, familial and social levels. Naturally families, just like people, vary, as does the manner in which they handle adversity. This study will hopefully provide

new insights into the childhoods that they experienced, the lives they now lead, and the factors that contributed to their positive adjustment and personal growth.

## **6.1 Growing up with a parent with or without a disability: differences and commonalities**

*"It's not a regular mother...it's something completely different" (Naomi)*

Surprisingly, and despite the variations in their childhood circumstances, the common denominators in the outcomes of children raised by a parent with a disability and those that were not one are abundant.

The first and main difference is in the levels of *perceived stress*, participants raised by a PWD expressing higher levels of perceived stress. Regardless of the type of parental disability, being raised by a PWD is considered a source of stress. Chronic strain is defined as persistent objective conditions that require continual readjustment, repeatedly interfering with the adequate performance of ordinary role-related activities (Pearlin et al., 1981). Wallander et al.'s (1989) model conceptualizes perceived stress as a result of the effects of such chronic strains.

Stress is perceived to be the product of the imbalance that a person may experience between the demands of the environment and the available personal resources (Lazarus et al., 1985): the greater the demands on limited resources, the greater the perceived stress. It is evident that this perception, of life as a stressful situation, would be greater for people raised by PWD. Their childhood stories speak of life filled with uncertainty and unpredictability; of shame, discrimination, and the stigma associated with mental disabilities; and of overwhelming responsibilities, not always age appropriate. These experiences, together with the added burden of their present lives – the lack of parental support systems and the need to

take care of their parents – may be the source of this stress. In Alex's words, “it's like always carrying an extra heavy load on myself.” This perceived stress has, it is presumed, further negative implications on growth and adjustment.

As the stressful life situation of being raised by a PWD has implications on the emotional, familial and social levels, differences between these groups were found in other aspects of life as proposed by Hypothesis 1 – that adults raised by a PWD will differ from adults raised by a parent without a disability, with respect to both intrapersonal and social ecological factors.

In terms of differences in perceptions of *parental bonding*, people raised by PWD perceived lower levels of paternal and maternal care than those raised by a parent without a disability, as predicted by Hypothesis 1.

PWD may at times be less available to meet their children's essential needs, leaving them lacking in terms of parental care and involvement. “She functioned at home on some level...but I didn't consider her a parent,” Lea observed. Similar feelings emerged from most of the interviews, supporting the perception of lower levels of parental bonding. In Ori's words: “My mother was not a mother – unequivocally! Everything she ever told me, it was all a mistake.”

A parent's early interactions with their child may be influenced by the strain of living with a disability, which may affect their ability as caregivers to sensitively respond to a child's needs (Cunningham et al., 2004).

With regards to parental patterns, it was interesting to see the variations in perception between the two groups. The research participants raised by PWD did not perceive their parenting as optimal – far from it, actually. While a pattern of optimal parenting (characterized by high care and low overprotection scores) recurred more frequently for the

participants who did not have a parent with a disability, in the PWD group, the most frequent recurring pattern was affectionless control (characterized by low care and high overprotection scores). In essence, they reported that while their parents functioned to the best of their ability, they personally did not feel that their parents indeed cared for them as they perceived parents should. They did not feel that their parents fully understood them and their troubles. “I always missed that part of talking to my mother – what's up? How was school?...My mother didn't take interest in those things” (Shay). As Alex attempted to explain this feeling, saying: “There was something warm and cheery about her, but it was very impersonal.”

Affectionless control parenting style is frequently reported by patients with depression (Parker, Tupling & Brown; Parker, 1983, 1984; Grant et al., 2012), anxiety disorders (Parker, 1984; Silove et al., 1991; Wiborg & Dahl, 1997; Grant et al., 2012) and suicidal tendencies (Martin & Waite, 1994), and has also been linked with impairments in the formation of positive working models of the self and other (Otani et al., 2016). In essence, the distinction between being raised by a PWD and not is captured in the feeling of less care and greater overprotection from their parents.

Those who were raised by a PWD reported a lower perception of *social support*. This included, among other factors, the feeling of lacking someone close when needed, and not always receiving needed support from family and friends.

Their past struggles may explain the perceptions of lower support that they experience today. As children, they dealt with overcoming prejudice directed towards their parents – and, by implication, towards them as their offspring. They were "those parents' children", as Lea put it –describing how many of them felt being perceived. They were often reluctant to share their feelings of burden due to the possible stigma that they may encounter in response, or the fear that the authorities may intervene and separate them from their parents (Pakenham et al., 2006). These reasons contributed to their families, very often, deciding to distance

themselves voluntarily from the community around them – and thus, ironically, distancing themselves from the very support that they might have received otherwise.

In her interview, Lea said that her siblings don't talk much about her mothers' disability: "We only talk about certain episodes but don't dig deep." She also stated that of the people she has met in her adult life, only one friend knew about her mother. This friend was dealing with similar issues, encouraging her to finally confide in her, albeit with reservations: "I don't think we ever sat down and properly talked about it." For the research participants in the PWD group, their parent's disability remained a well-kept secret, not easily shared with new people in their lives. There seems a clear risk that they still harbor feelings of shame and embarrassment with regard to their parents' disability (Meadow-Orlans, 2002); consequently, they distance themselves from those around them, a strategy that may be the cause of the lower levels of social support that they perceive to be an aspect of their present life experience.

In the realm of *mental health*, the research participants raised by a PWD reported higher levels of emotional distress – and thus, decreased levels of mental health – in comparison with those raised by a parent without a disability.

It has been argued that the experience of being raised by a PWD places immense strains on the individual. This distress has its roots in their childhoods, as is evident from the interviews conducted in the qualitative stage of this research study. "I remember myself (at the age of four or five) truly, emotionally hurting," Alex recalled. Many people raised by PWD exhibited the tendency to develop maladaptive behaviors when their parent was displaying the symptoms of their illness – withdrawing, avoiding, and distancing behaviors, for instance (Maybery, Ling & Szakacs, 2002). There is a common presumption that a parent's pathology can be detrimental in its effects on their children (Ackerson, 2003).

According to Jo, there “was a great fear of becoming like her, to be crazy, to not know what I’m doing.” This fear still accompanies her today. Children who have PWD may be at risk of neglect (although, usually, not abuse) as well as developmental, academic, behavior and psychiatric problems (Feldman & Aunos, 2010). All these experiences may contribute to the diminished sense of mental health that often characterizes the adult life of people raised by a PWD. Alex: “I’m still in a very painful story. Even as I evolve and my life changes and I do things it all leads back to my childhood story...it follows me...and I still need to address it and deal with it.”

The commonalities – or rather, the sparse differences – between these very different groups of people was interesting in itself and exceeded the expectations of the study’s hypotheses. Hypothesis 1 assumed that differences would be found in all aspects between participants raised by a PWD and those who were not. Despite this presumption, no significant differences were found in levels of self-esteem, coping strategies, attachment orientation and personal growth.

When looking at *attachment orientation* this lack of differences takes on a greater significance. Attachment to a primary stable caregiver, usually the mother, from early childhood is considered to have a crucial effect on one's development. The lack of distinctive differences in attachment orientation suggests that growing up with PWD incorporated both productive and unproductive interactions with the caregiving adults in the immediate environment (though these were not necessarily their parents). No marked differences in this respect could be identified between them and those who grew up with parents without a disability. Events during childhood, particularly within child–caregiver relationships, tend to strongly influence the nature and the quality of an individual’s adulthood relationships (Bowlby 1979; Maccoby 1980). “I tend to assume it has to do with the fact we were seen

from so many angles by parents and grandparents,” Jo said, describing childhood for her and her siblings as a shielded one. “We grew up feeling secure.”

Following the same line, no significant differences were found in the levels of *self-esteem*. Both groups displayed high levels of self-esteem. This suggests that those who grew up with a PWD may have felt valued by those around them, quite possibly due to the extensive responsibilities that they took upon themselves, giving them a higher sense of self-worth. It can be assumed that because they were able to overcome their adversities, they are less likely to interpret life’s difficulties as a mark of their own lowered worth, and thus experience less negative affect in negative events (Rosenberg, 1965). It may be that in hindsight the ability to grasp what they had overcome and accomplished has also contributed to a heightened and positive self-image. Shay, for example, proudly recounted his conversation with his in-laws when he asked for their daughter's hand. “Your daughter could have chosen a pilot, an officer, a millionaire...whatever she wanted she could have but she chose me – with no degree and a family with a disability...she chose me because I make her happy and that's what's important.”

No differences were found in the use of *coping strategies*, with both groups scoring higher on problem-focused coping as opposed to emotion-focused coping. “All the extra duties...You get used to it,” Jo remarked. “You learn to handle it day-to-day.” Coping is the process that allows an individual to pursue various options in the process of overcoming challenges and preventing future harm (Folkman et al., 1986). The creative ways they had been obliged to learn, and from a young age, in order to accomplish life's many tasks may have served as an incubator for effective coping. The various adult figures in their lives may have served as a good opportunity for observing and learning many different models of coping.

No differences were found in *personal growth* either, with both groups displaying high levels of growth. Personal growth is seen as the end point of a successful struggle with adversity in life (Tedeschi & Calhoun, 1995). According to Ori: “Everything passes...and at some point it (this childhood) becomes a trigger for you.” Being raised by a PWD can be a potential catalyst for personal growth, as too other significant life events encountered that people raised by parents without a disability, leading to similarities between these groups.

As with self-esteem, the perspective from a later age in life may enable a broader, more positive view of personal journeys and accomplishments. Speaking about what she gained from her unique life, Alex remarked that “this situation has taught me...it made me compassionate, advanced my flexible thinking, my creativity, my inner world. I mean this situation brought me to gateway of many things that probably wouldn't have evolved if I had grown up differently.”

It seems that although being raised by a PWD can be a source of greater perceived stress, and does take its toll on the parent-child bonding experience, the child’s sense of social support and levels of mental health, in other areas of life this toll was not as significant as anticipated. The parenting that they experienced may have had more significant consequences in these, areas rather than in others.

Attachment orientation, coping strategies and self-esteem were similar, as was the eventual personal growth. It indicates that various life experiences, at different stages in life, had an effect on one's adjustment and growth and shaped the people they grew up to be.

## **6.2 Parents with IDD or MD – does the disability make a difference?**

Disability as a broad term does not reflect the various implications of different disabilities. In this study, two distinct parental disabilities were explored – MD and IDD. While the quantitative data did not reveal any distinctions in the experience of being raised by a PWD

with regard to the specific parent disability, the qualitative data raised a few interesting and noteworthy findings.

When addressing the issue of the well-kept family secret concerning the parent's disability (Theme 1), differences emerged with regards to how the participants described their dealings with this issue. In the case of PWD with a MD, the notion of a well-kept family secret was more distinct and present. Hospitalization of a parent could not be completely hidden from the child, self-evidently; often, this was masked by explanations for the parent's lengthy absence from home. Due to the apprehension of stigma and judgmental attitudes, the child was directed to keep the family circumstances secret. Either due to a greater fear of stigma or the ability to better conceal the disability, it would seem that the atmosphere surrounding a diagnosis of a parent with a MD is a family bore deeper implications.

An analysis of key terms used in the interview texts highlighted that the phrases “ill” or “illness” were used 10 times more in the interviews with participants raised by a parent with a MD (40 times) as opposed to those raised by a parent with an IDD (4 times). The phrases “disability” or “disabled” were used 3 times more in the latter category (52) than the former (17). The different choice of words when describing the parent's difficulties indicates clearly the way the understanding was constructed for the child. In an effort to make sense of these differences our choice was to seek explanation in the common "everyday" definitions as presented in the Oxford Dictionary. The Oxford Dictionary's (2019) definition of the two phrases sheds light on this distinction:

*Illness:* A disease or period of sickness affecting the body or mind.

*Disability:* A physical or mental condition that limits a person's movements, senses, or activities.

An illness is considered more of a temporary state, while disability is a more limiting and permanent one. At times, manifestations of the parents' MD appeared sporadically or at a

later stage in life, unlike IDD, which is generally a congenital condition. Within mental illness, there are phases of remission and functioning; these give hope and add to a sense of normalcy. IDD, on the other hand, is a permanent and given state without many elusions. This key element could explain the difference in participants' attitudes, brought on by what they learned at home, with regards to their parents' state of being.

The words "difficult" or "difficulty" appeared more often in interviews with participants raised by a parent with a MD than those raised by a parent with IDD (113 to 71). This is not to say that one parental disability raises more difficulties for the children than the other; rather, it raises the possibility of differences in their states of mind.

Because this study is concerned with adults who, as children, were raised by PWDs, it is largely retrospective in nature. The differences in the way the participants viewed their parents' disabilities may be reflected in how they grasp its implications for their lives, and how it shaped their futures. This can be seen in two separate descriptions of how interviewees saw their parents. Regarding her mother, who had a MD, Lea said: "To me she wasn't a parent...I never viewed her as one and explains her fear of being crazy like her and not know what I'm doing." Tom, whose mother has an IDD, observed: "I always felt she wanted to be my mother – there was always something maternal about her." He then described the need he felt, at the time, to protect her from the neighborhood kids.

An earlier study about being raised by parents with IDD raised an interesting perspective – anger towards the parent was, on the whole, not part of the feelings that arose in their life stories (Weshler 2009). Mostly, they did not blame their parents for the cards they had been dealt, because they as they viewed their parents as children – mostly innocent, and not responsible either for their choices or for the outcomes of those choices. The atmosphere that emerged from this state of mind was one of acceptance; this seems to have freed them

from being bogged down in difficult emotions to no end, and allowed for meaningful participation and eventually greater resilience.

The quantitative phase of this study did not identify significant differences between children raised by a parent with MD as opposed to those raised by a parent with IDD. For this reason an in order to shed a greater light on this phenomenon discussion on these two groups was done in unison. Combining both dimensions- the quantitative data with the sentiments expressed in the qualitative interviews- may open a window on to a deeper understanding of these children and their lives.

### **6.3 Effects of perceived parental bonding patterns on perceived stress**

“My dream was to be a ‘latch key kid’ – to come home and my parents wouldn't always be there” (Jo)

Parental bonding was a key element in this research, specifically the attempt to distinguish its effect on the levels of stress experienced by those growing up with a PWD, when experiencing lower levels of maternal and paternal care and overprotection (hypothesis 2).

In this study, a positive association was identified between perceived stress and both paternal and maternal overprotection. In addition, care and overprotection were positively associated to *both* mothers and fathers – leading to an understanding of a synchronized parental effect, of either care or overprotection from both parents.

An interesting finding was that even though being raised by a PWD was linked with lower levels of perceived maternal and paternal bonding, it is the paternal care factor that served to mediate the connection to perceived stress (Figure 6). The father – or rather, the paternal caring bond – seems to play a crucial role in the child's perceptions and outcome, whether the father is the PWD or not.

When considering the impact of parental bonding, the study adhered to the constructs of perceived care: the child's perception of nurture and warmth, as opposed to neglect and rejection and perceived protection, and an appropriate level of concern for the child's safety and security, as opposed to overprotection and intrusive control (Parker, Tupling, & Brown, 1979).

It has been observed that parental bonding – or rather the lack thereof – is linked with childhood adversity and influences future psychological distress, with an emphasis on the combination of low levels of parental care and high levels of parental overprotection as being notably detrimental (Cubis, Lewin & Dawes, 1989; Gao et al., 2010; Parker, Tupling & Brown, 1979; Parker, 1983).

The perception of paternal rejection, was found to be a strong predictor of psychological distress and subsequent low self-esteem. Likewise, the perception of parental rejection (low care) was a greater predictor of psychological distress than the perception of a parent as over-controlling (high overprotection) (Curcio, Mak & George, 2018).

Stafford et al. (2016), in their study of young adult women found that paternal care was more strongly associated than maternal care to a child's future wellbeing. A study assessing the impact of parental bonding on their children's future quality of life (Rikhye et al., 2008) found that the quality of paternal bonding was linked to the effect of childhood maltreatment on the adult quality of life. Furthermore, the study found that paternal care, as opposed to maternal care, is a unique predictor on adult quality of life, indeed more so than the childhood maltreatment itself.

Whether maternal or paternal, these complicated bonding patterns are also evident in the qualitative data, as expressed by the mixed feelings that the children of PWD had towards their parents (Theme 4). “I always felt my mother wanted to be a mother, there was

something maternal about her,” Tom reflected, going on to explain: “but the messages I received from those around me...it made me feel ashamed of her.”

Most people look up to their parents: they admire them, and see in them the adults they aspire to become. For the participants in this study, these particular feelings are mostly unfamiliar. It's not always easy being *those parents' children*, as Lea put it. They love their parents; but yet, they also resent them for the hardship that is part and parcel of their relationship. They experience feelings of shame and anger, for the burden they must bear. But they still wish to find in them the parents that they desire.

These mixed feelings play an ongoing central role in their lives. In her very candid manner, Ronai (1997, p. 40) articulates this sentiment: “I feel ambivalent, one moment protective of my mother, the next furious, and the next profoundly sad. I want to avoid her and control her life for her, all at the same time.” As adults, the interviewees still struggle with balancing their feelings towards their parents, a balance that can easily be tilted. Lea, for instance, described her greatest fear as that of becoming her mother. “I didn't consider her a parent. When she was a zombie I wasn't sorry for her...I was sorry for us...I had awful fears to become like her – crazy.”

Children growing up with a parent with a MD or IDD may lead unstable lives. The situation is not always clear-cut for young children, and less so if not mediated properly. As Naomi recalled, “She started falling apart and talking nonsense...I found it very funny [as a child].” It was only years later that she understood the import of this “funny behavior” and felt conflicted at her behavior.

The children may also be incorporated into the parent's delusional behavior, or be subject to emotionally unavailable parents (Jacobsen & Miller, 1998; Reupert & Maybery, 2007). Jo put it in context when she observed: “There is something very unnatural to talk to a child about madness and expect her to understand.” The children of parents with intellectual

disabilities are at risk of neglect on multiple levels; their parent's limited ability to protect them, due to their inability to fully grasp intentions and behaviors of those around them, becomes a defining feature of childhood (Feldman & Aunos, 2010). All these descriptions of life experiences coincide with the affectionless control and neglectful parenting patterns as described by Parker, Tupling & Brown (1979).

“It's like constantly carrying an extra weight on my shoulders” (Alex). This weight must be negotiated early on. Understandably, the children feel burdened, but at the same time yet are conflicted, due to this same feeling. Harboring these feelings of shame and embarrassment that emerges from awareness of their parents’ condition, as well as the higher levels of stress associated with these bonding patterns, may impact not only on the relationship they have with the parent but also on relationships with others around them as well, a pattern that may well follow them throughout their lives.

#### **6.4 Avoidant Attachment Orientation as an asset**

*“You can grow up without food, without water, without clothes...everything passes”*  
(Ori)

With regard to personal growth as the outcome, no significant interactions between perceived stress and anxiety or avoidance were identified. Moreover, the role of perceived stress as a mediator of the path between being raised by a PWD and personal growth was neither moderated by avoidance nor by anxiety. (Hypothesis 5).

While perceived stress was found to be associated with both insecure attachment orientations, it was only avoidant attachment that interacted as a mediator. Avoidant attachment thus seems to be adaptive, as it mediated the effects of stress on mental health. Avoidant attachment is viewed as allowing to adjust children's behavior to the requirements

of an inconsistently available attachment figure, by encouraging the suppression of negative emotions (Mikulincer & Shaver, 2007). People with avoidant orientation are assumed to be more inclined to rely on cognitive and emotional distancing in order to cope with stressful events (Holmberg et al., 2011; Shallcross, Frazier & Andres, 2014).

Given as the life experiences of those raised by PWD may very likely have been defined by the instability of caregiver relationships, the role of avoidance as the mechanism that preserved their vitality and allowed for necessary everyday functionality seems clear. Furthermore, it may also have enabled them to adapt to a higher level of adjustment and resilience. Avoidance, as an attempt to block out attachment needs that are not met, is often accompanied by the regulation of emotions such as fear, anxiety, shame, distress, guilt and anger – all of which have the potential to exacerbate feelings of vulnerability (Mikulincer & Shaver, 2007). While adaptive in uncertain childhood situations, avoidant tendencies can be harmful to the wellbeing of adults with low interdependence capabilities, and are not able to seek support and help from those around them (Shaver & Mikulincer, 2002).

These sentiments of distress, shame and anxiety coincide with the imperative to withhold the secret of their parents' disability (as presented in Theme 1) that characterizes children of PWD. Their parents were different from other parents – there was never any doubt about that, and they understood this distinction from an early age. But why? What made them different? What were their parents dealing with? These questions, and many more, remained unanswered for many years; on some level, these questions still remain unresolved. “I didn't know what was different,” Lea recalled. She, as well as the other participants, raised the issue of vague explanations, concealment and ambiguity with regard to the full nature and extent of the parent's disability. The participants noted that they were not given an explanation, whether from a family member or a professional, as to the nature of their parent's disability. They grew up hearing limited and unconvincing explanations;

listening in on conversations and picking up threads of information; trying to unravel ambiguous comments and unambiguous insults directed towards them and their meaning. All this time, they had the responsibility of keeping the family secret, but not knowing why. This practice of “what happens in the family stays in the family” may have taught them to rely solely on themselves, and to limit their trust in those around them.

This secrecy may have many sources. Reid and Walker (2003), defining it as “a selective denial of uncomfortable truths” (p.85) suggest that in the context of undisclosed illness, secrecy may lead to an unequal power imbalance in the family relationship. These uncomfortable truths were mostly well-hidden or denied in the lives of the participants in this study, as they describe them. Most remain unclear regarding the precise diagnosis, or the full meaning of their parents’ disability.

The fear of stigma is one reason for keeping family secrets. Stigma as a term refers to a discrediting characteristic, rendering someone as flawed or inferior in others perspectives, and can lead to social disapproval and a devaluation of social status (Crocker, Major & Steele, 1998; Bos et al., 2009; Bos, et al., 2013). As Tom explained: “I always felt that my mother wanted to be my mother, she always had something maternal about her...but the messages I got from people around me...it was...I was ashamed, especially as a teenager.” Stigma affects the person with an illness or disability as well as the members of their immediate family – a phenomena described as stigma by association (Van Der Sanden et al, 2014). Lea, who grew up in a small settlement, recalled receiving help from the community; but yet, “they looked at us weird...sometimes ignored us.... We were ‘the kids with the crazy mother’; I think every small community has one.” As with children of incarcerated parents, the associated shame and stigma leads many families to conceal the parent's status from the outside world as well as the inner one – that of the children (Lockwood & Raikes, 2015). Jo, for example, spoke about constructing a cover story for her father's absence whenever he was

hospitalized. “I learned many concealment behaviors,” she said. These partial truths and elaborate constructed stories to account for a parent's absence may themselves create significant stressors. Though failing to openly share secrets is viewed as detrimental to an individual's well-being, (Bradshaw, 1995; Hunt & Paine-Gernee, 1994; Webster, 1991), uncovering family secrets may also have unfavorable and sometimes harmful effects on individuals and their interpersonal relationships; consequently, this generally occurs only under certain circumstances (Vangelisti, Caughlin & Timmerman, 2001). Naomi recalled that “I was told I should never say anything about it to anyone, it was a very defining statement – you can't talk about it!” The avoidant practices learned in childhood may accompany then into their adult relationships – keeping people at arm's length, but losing out on the possibility to seek assistance as a consequence.

Carol Ronai (1997, p. 1) writing of her experiences with her intellectually disabled mother gives a very clear picture of this stress. “I am never sure how to speak of this to others. When I am asked, ‘Is your mother still alive?’ or ‘What does your mother do for a living?’ or ‘Where does your mother live?’ I am filled with dread.” She explains how even today, as a successful adult, she is faced with conflict whenever she has to decide whether to use a cover story and evade the need to answer, or to “fess up” and tell the truth about her mother. The conflict exists due to the irrevocable change – or the anticipation of this – in the relationship with the person asking these questions, once the answer is given. Tell the truth and endure pity or awe as to your normal outcome; or evade the question and seem distant and alienating.

In the course of the interviews that constituted the qualitative stage of this study, several examples detailing the variety of forms of communication within the families were mentioned. For some, it was concealed completely. This was the case with Martha and Lea, up until the point where it was impossible to conceal it any longer. In other cases, like Naomi,

Shlomit, Alex and Jo, it was swept aside, labelled as inappropriate knowledge for children and ignored. With Shay, Ori and Tom, it just hovered in the background of their reality, never receiving further explication.

All of the interview participants described the feeling of missing important knowledge and understanding of their parents' disability, information that they now believe would have been crucial for them at the time. The burden of keeping the secrets, and lacking the proper tools needed to deal with the stigma that they faced was a great stressor in their lives. This distress was intensified by the awareness of the wider public's typically negative attitude to the parent's disability – and to the family, by association, as well (Van Der Sanden et al, 2014). There is evidence suggesting that the inability to reveal and process personal information can have negative physical and psychological outcomes for the individual (Petrie, Booth & Pennebaker, 1998; Greenberg & Stone, 1990).

Throughout their childhoods they learned to conceal their family secret from those around them, to keep their distance and rely on themselves and these learnt efforts have followed them, partially or fully, into adulthood. In light of all this it appears avoidance has a potential of serving them well in mediating the possible negative effects of stress on their mental health.

## **6.5 The contribution of Social Support to Adjustment and Growth**

*“I think miraculously I was blessed with having many good and positive people around me that bettered my life” (Jo).*

A network of significant others –family, friends, teachers and other empathetic figures able to accompany and support – are considered an important asset in one's life, especially in times of stress. For this reason, this study sought to examine social support as a possible moderator

of perceived stress on the growth and mental health of those raised by PWD. Surprisingly, it did not produce this desired effect in the current study (Hypothesis 6); this is not to say it was not in itself significant, however.

Though social support was not found to serve as a significant moderator of perceived stress, it nevertheless was found to manifest – and in equally high levels – for both the participants raised by PWD and those who were not. In addition, social support was found to have a negative association to perceived stress, such that the more social support one perceives oneself as possessing, the less perceived stress experienced. A perception of social support was also found to be associated with life satisfaction, with high levels of mental health, and with personal growth.

Social support refers to the experience of being valued, respected, cared about, and loved by others who are present in one's life (Gurung & Belmont, 2006). These experiences can present themselves in various forms: either tangible assistance or the perception of having support readily available when needed (MdYasin & Dzulkifli, 2010; Hengl, 1997).

This perception that others around us will support us when we need help is an important asset, carrying the potential to shield us from the detrimental effects of stress (Cohen, 1988; Uchino, Cacioppo & Kielcolt-Glaser, 1996). It also facilitates social skills, responsibility and competence and overall positive self-conceptions (Oswald & Suss, 1994), and contributes to growth and adjustment (Taubman-Ben Ari, Findler & Kuint, 2010).

These feelings – reflecting their perception of adequate social support today, and manifested accordingly in the results of the quantitative study – may have roots in their childhood as reflected in the qualitative themes. They had a chance to learn the value of the “supportive others” when their parents were unable to satisfy their ongoing emotional and practical needs and help them to develop their social skills.

The importance of a social network and the contribution of extended family members (as presented in Theme 2), and of significant supportive models throughout life (as presented in Theme 3) was evident in the interviews. It may be that the lessons learned in their childhood, of the many channels available for receiving support and how this can be of use to them, are still applied in their present lives.

The interview participants referred to the important role that extended family members continued to play in their lives. They noted the even more significant role that they played in their childhoods (Theme 2), and in helping them become the people they ultimately became. Whether grandparents, aunts, uncles or even cousins, the underlying fact was that the children of PWD had positive significant adult figures in their lives: this made all the difference then, and continues to do so. Shlomit, for instance, described her uncle by saying that “he's like a father to me.”

In the absence of functioning supportive parental figures, the extended family stepped in to fill this gap. “I was missing support,” Shay noted; “and when it was difficult and I didn't have a mother I could talk to...I turned to the family – my grandmother, my cousins, my aunt.” Boss (1999) proposes the term “ambiguous loss” to describe a state in which a loved one is present physically but psychologically absent. This confusing situation is a cause of great grief and possible trauma, as there is no opportunity for resolution or a closure, as exists with other forms of loss – the loved one is there but not all there (Boss, 2009). Similarly, for the children of PWD, the parents are both present and absent. They exist and have a title, but do not fully function as parents. Parents with a MD were at times absent physically, due to hospitalization; or mentally, due to a diminished mental state for periods of time. In the case of IDD, the parents themselves might have required ongoing support and care, and would have been incapable of placing their children’s needs ahead of their own. In such situations, members of the extended family often stepped up to take over the care of the children thus

impacted. This show of support may have been the life lesson that accompanied them into the present; as a result, they now surround themselves with people they can count on. Those participants who have living grandparents or other relatives speak of them as their main safety net today. As Jo described them: “My grandparents are my extra set of parents...they looked out for me and do so to this day.”

Other than family, as life progresses the need arises for extended support. The participants all described a specific need, in the main met by the positive figures throughout their lives who believed in their abilities and worth and saw more in them than just being the children of “those parents” (Theme 3). Mostly figures that appeared naturally later in childhood or adolescence and later in life, they constitute the supportive social circles that the children of PWD chose for themselves. These figures that supported them in the past may have served as the model for the people whom they surround themselves with today. “I married the perfect woman and she has a warm loving family,” Ori commented; his wife's family are his support today.

When reflecting on the past, the children of PWD often referred to the people who crossed made a difference in their lives –teachers, coaches, neighbors or friends. Sometimes, even a single who really saw them for who they are – rather than as a function of their parents’ disability – was enough to instill a sense of worth. Naomi explained the significance of her school teacher – with whom she remains in touch – in such terms. “She told me she saw something special in me and wanted to get to know me better.” These are the memories and the people who they turn to today.

Bowlby (1988) argued that the capacity to create strong emotional bonds with other individuals is a basic element in human nature. We seek these interactions wherever we can find them. Research in the developmental fields suggests that a child with one or more caring adult in their lives has a greater prospects for ultimately maturing into a productive adult

(Jekielek et al., 2002; Rhodes, Ebert & Fiscer, 1992; Scales & Leffert, 1999). The offer of social support and connectedness by at least one caring adult present in their lives has been identified as a protective factor for children and adolescents at risk (Fraser, Kirby, & Smokowski, 2004; Rutter, 1987; Werner & Smith, 2001). When these relationships occur in the child's environment naturally, these individuals are termed “natural mentors”. Mentor-like adults can be a meaningful resource of positive well-being for children: these relationships can contribute to social competence and academic success, and effect positive outcomes in their future (DuBois et al., 2002; Murphey et al., 2013). Meaningful encounters such as these may have laid the groundwork for the connections they feel they have today.

Later in life, the supportive figures they chose for themselves are a great comfort. “My friends became something I really lean on” (Lea). They referred to these supportive figures that they chose, and who value as a part of their present. In Martha's words, “my husband is there for me and I have a group of close friends.”

Their childhoods taught them the value of a good support system, a concept they continue to maintain in their lives. Whether it was the extended family in childhood, the natural mentors and supportive figures in adolescence, or the people they chose for themselves and who populate their current lives, this social support was and remains crucial. It is thus clear that the perception of strong social support plays an important role in managing the effects of stress, and in facilitating adjustment and growth, even in the face of adversity.

## **6.6 The role of Self-esteem in Adjustment and Growth**

*“As a child my parents fought and I was the bridge between them...I later went on to study psychology and was officially the house therapist” (Martha)*

The moderating contribution of self-esteem on the effects of perceived stress on the mental health and personal growth of those raised by PWD was, surprisingly, not found to be significant (Hypothesis 6). With that said, the relatively high levels of self-esteem found for both the research participants raised by PWD and those that were not, is in itself an interesting finding. In addition to this, positive associations were evident between high self-esteem and high levels of personal growth and mental health, while a negative correlation was found with perceived stress.

All these findings imply that the benefits of high self-esteem cannot be disregarded – prompting the question regarding what indeed may be the element promoting the high levels of self-esteem in the research participants who were raised by PWD. It may be that self-esteem is singly an asset not intrinsically connected to stress or variations in parental rearing.

Self-esteem applies to the appraisal and evaluation of one's worth (Leary & Baumeister, 2000; Orth, Robins & Widaman, 2012). Much has been written of self-esteem: its origins in childhood (Jordan, Zeigler-Hill & Cameron, 2015; Neiss, Sedikides & Stevenson, 2002); the functions of high self-esteem in promoting stress resistance (Cohen & Edwards, 1989; DuBois & Flay, 2004); its help in successful coping with negative life events (Brown, 2010; Spencer, Josephs & Steele, 1993); and its contribution to positive adjustment (Brandtstädter & Renner, 1990; Charles & Carstensen, 2010; Rosenberg, 1965; Swann et al., 2007).

Self-esteem is assumed to have strong foundations in childhood experiences (Jordan, Zeigler-Hill & Cameron, 2015); it is influenced by the surrounding environment (Neiss, Sedikides & Stevenson, 2002), and evolves as a criterion of social inclusion (Leary & Downs, 1995). All in all, the ability to feel good about oneself and one's abilities depends, at least in part, on feeling part of a supportive network and being valued within that network (Holmes, 2001).

The importance of a supportive network in moderating perceived stress and its contribution to mental health and growth have been addressed in this paper. I would also like to suggest that a further contribution to the sense of self-worth and esteem possessed by the children of PWD are linked to the critical functions that they inevitably fulfilled within the family unit from a very young age, due to their parent's disability. They began to play these roles they started playing at a young age, and indeed some still do; this may have fed into their feelings of competence in the present.

These adult roles expected and at times demanded of them, by their parents and extended family members, was a main theme that emerged from the interviews (Theme 5). “Mom and Dad are disabled, you need to help them... it was always there in what was said and what we evolved into”: Jo, repeating her grandparent's mantra, said over and over to her and her siblings. They are the children of PWD: everybody was overjoyed when they were born, and born “normal”. They will be able to take over the care of their parents when they grow up. But even as young children, they were obliged to bear the burden of being the responsible adult. They dealt with the many household responsibilities that children are usually blissfully unaware of; they were the house therapists and administrators; they looked after their parents and protected them. They didn't always understand why it was their role, but they nevertheless carried it out as best as they could. As Shay remarked, “When I was young and my mom said ‘help me’ I didn't get it...over time I understood more and was able to support her.”

Children of PWD tend to develop coping strategies that feed into stronger levels independence, autonomy, and self-reliance, relative to their developmental stage (Klein, 1990). The parent-child roles tend to shift occasionally or even permanently from a very early age creating a heightened sense of responsibility (Bleuler, 1978; Brown, 1981; Greer, 1985; Hoffmeister, 1985; Klein, 1990; Royster, 1981). This sense of responsibility and competence –

with the intimation that they are needed and important to the family's success – may form the basis of the high sense of self-esteem they possess as adults, given that they succeeded in carrying out the responsibilities thrust upon to them. Taking all this into account, the positive association between self-esteem and problem-focused coping, with perceived social support, and with mental health and personal growth, as identified in this study, is not surprising.

## **6.7 The role Coping Strategies play in Adjustment and Growth**

*“As a child it was very difficult for me when my mother would say ‘help me’... I couldn't understand it. With time you understand more and are more supportive”*

*(Shay)*

Coping styles were considered in this study as possible moderators of the stress that being raised by a PWD placed on the growth and mental health of the children as they transitioned into adulthood (Hypothesis 4).

The mediation of perceived stress on mental health was higher when lower levels of problem focused coping were found. In other words, the perceived stress that results from being raised with PWD has a greater negative effect on the mental health of individuals with low problem-focused coping capacities.

When addressing the personal growth of children of PWD, emotion-focused coping came into play. The mediation of perceived stress on personal growth was higher at high levels of emotion-focused coping, suggesting that the more one relied on emotion-focused coping, the higher the negative effects of perceived stress on growth. In addition a positive association was found between problem-focused coping and mental health, and a negative association between emotion-focused coping and personal growth. To recap: it appears that

greater reliance on problem-focused coping, and less on emotion-focused coping, plays an important role in supporting better mental health and growth in this case.

The ability to cope with various life situations is an important contributor to positively managing stress. Problem-focused coping is associated with addressing the source of stress; emotion-focused coping, for its part, seeks to address the feelings and thoughts associated with this stress (Folkman & Lazarus, 1985). While emotion-focused coping allows for the regulation of stressful emotions, problem-focused coping addresses the source of the stress and not necessarily the emotions it generates (Folkman, 2008; Folkman et al. 1986; Lazarus & Folkman, 1985; Park & Folkman, 1997; Aldwin, 2007). This suggests that the use of problem-focused coping is usually effective in situations where something can be done, while emotion-focused coping is suited for situations that have to be accepted “as is”. Positive emotions may serve to sustain distress, motivating coping in the process and restoring coping resources (Lazarus, Kanner, & Folkman, 1980) but positive emotions are harder to accomplish and maintain when dealing with a stressful situation. High emotional arousal and a pre-occupation with one's deficiencies undermine effective use of one's competencies and are ineffective in the coping process (Bandura, 1982). Thus emotional focused coping in the face of life-long stressors may be an unstable and ineffective strategy sustaining the long term growth process.

When addressing the need to learn to stay functional, the association with descriptions of their extended roles in the household (Theme 5 – discussed earlier) are explicit. The parent-child roles in the case of children raised by a PWD tend to shift occasionally or even permanently from a very early age, creating a heightened sense of responsibility (Bleuler, 1978; Brown, 1981; Greer, 1985; Hoffmeister, 1985; Klein, 1990; Royster, 1981). Children with extended family responsibilities tend to develop coping strategies, which feed into greater

levels of independence, autonomy and self-reliance relative to their developmental stage (Klein, 1990).

Because they don't have any say in a situation that confronts them at a young age, without preparation or guidance, there's no feasible (active) option other than to adjust to it. In this case, problem-focused coping may be a serviceable asset.

The role of the extended family members in their lives (Theme 2 – discussed earlier) may have also served as an incubator for internalizing a strategy of problem-focused coping. For most of these children, the family as a whole took them on as a mission; they were, at least at a young age, the family's responsibility, in essence a problem to be dealt with. “My grandmother...she took upon herself the control and leadership over the family and us,” Shlomit said by way of explanation. This and other examples of family problem-solving may have inspired the development of this strategy in the children, now manifesting as they reach full maturity.

Their experiences of witnessing their immediate family members (e.g. aunts, uncles, grandparents) being held responsible for the disabled family members behaviors (Van Der Sanden et al, 2014) and the ways they cope with this responsibility is a lesson in problem focused coping in itself. They have learned how to positively cope, and continue to do so; this shed light processes of problem-focused coping, generally found to be negatively associated with perceived stress today and its mediating effect on mental health.

## **6.8 The relationship between Perceived Stress and Adjustment and Growth**

*“I never forget, every time and everywhere – I'm proud of what I was and where I am today” (Shlomit).*

This study's objective was to examine the impact of perceived stress, as an outcome of being raised by a PWD, on the growth and adjustment of their adult children.

As predicted (Hypothesis 3), this perceived stress served as a mediator for lower levels of mental health and growth among those raised by a PWD. Perceived stress was found to have a high negative association with personal growth and mental health; the greater the levels of perceived stress, the lower the levels of growth and mental health reported. Stress inevitably takes its toll on growth and adjustment when viewed through this narrow scope.

As discussed, being raised by a parent with a MD or IDD can place great social and emotional strains on a child, leading to emotional distress manifesting across a wide range of physical and mental disorders, such as anxiety and depression, within maladaptive adjustment (Luhmann et al., 2012; Pakenham et al., 2006; Wallander et al., 1989; Zeidner, 1998). That said, it is important to reiterate that no distinct differences in personal growth were found between those raised by a PWD and those who were not, with both showing relatively high levels of growth. With regards to mental health, a small but distinct difference was found. However, even though the levels of mental health perceived by children of PWD were lower, both groups displayed relatively high levels of mental health.

While the theoretical framework of Wallander et al. (1989) suggests that perceived stress may have detrimental effects on adjustment, it also makes claims for various possible outcomes in accordance with the existence of risk and resistance factors. The risk-resistance model of Wallander et al. (1989) was partially validated in this study, when addressing through the quantitative part of this study.

An analysis of the texts embracing a life view of “the glass half full” (Theme 6), taking together with the quantitative data pertaining to these risk and resistance factors, indicates clearly that the interviewees articulated and displayed high levels of growth and adjustment. As Ori put it: “There is the bottom and only you can rise from there. We were hurt but at some point it becomes a trigger for you.”

In other words, a picture of very resilient individuals emerges from the texts. The term “resilience” applies to a dynamic process of positive adjustment in the context of meaningful hardship and stress (Luthar, Cicchetti & Becker, 2000; Werner & Smith, 1992). This term encompasses two important conditions: the fact that the person has been subjected to a stressful situation; and the actuality of positive adjustment, despite many obstructions to natural processes of development (Masten, Best & Garmezy, 1990; Luthar & Zigler; 1991; Werner & Smith, 1992; Rutter, 1987). Stressors create tension that may be dissipated using the internal or external resistance resources available to the individual. Both risk factors and protective factors are essential for developing resilience (Garmezy, Masten & Tellegen, 1984, Rae-Grant, et al. 1988, Rutter 1985, Werner & Smith 1982, Wyman, et al. 1991). Resilience, is then a resource that can be used to explain individual growth within and out of a stressful situation.

Though perceived stress – in this case as a result of being raised by a PWD – is a risk factor that can contribute to lower levels of personal growth and mental health, in reality a range of protective factors may exist naturally, or maybe instilled in these children’s lives. These include lessons in gaining social support, examples of positive coping strategies, and instilling the high self-esteem that allows for a resilient end result. In Alex's words: “I have a really good life and I feel I deserved it...I worked hard for this life.”

## **7. Theoretical Implications of the Study**

This study brings to light a group that has not been sufficiently recognized and addressed in research until now. Even though research regarding people with disability – including parents – within have gained traction over recent years, their children and their unique life experiences have been largely neglected. There is insufficient literature at the present time about the discrete issue of parents with a disability; less so about their children, and hardly

any considering the child's perspective, whether present experiences or retrospective assessments. Their voices are important, and it is important to incorporate them into the research literature.

This research allows for a deeper understanding of the inner lives of a group of such children, now adults themselves, and who they grew up to be within the context of being raised by a parent with a disability. In the study, perceived stress was identified as positively associated with being raised by a PWD was in turn found to be associated with lower levels of mental health and personal growth. However, it was equally evident that other factors may, and in the case of the participants in the qualitative stage of this research, did –make a difference in the journey to adulthood. All in all, they presented as functioning resilient adults, and in most aspects fare equally well as people raised by a parent without a disability. This finding in itself allows for a new and profound vantage point regarding children of PWD. It seems that the result of this upbringing is not as irretrievably bleak as the scant literature available at the moment suggests (Benjet, Azar & Kuersten-Hogan, 2003; Proctor & Azar, 2013; Feldman, McConnell & Aunos, 2012).

As discussed here, the children of PWD evinced lower levels of parental care and higher levels of parental overprotection, with the emphasis on the possibility of greater paternal care in mediating the possible detrimental effect of stress on mental health and growth. This is an important issue to note, as the role of fathers – specifically, the contribution of the bonding patterns they form with their children – had not been established previously. The shame that they reported feeling during their formative years, and the mixed feelings they retain for their parents, may have had an impact on the bond that developed between them and their parents.

Avoidant attachment orientation was found to mediate the effects of perceived stress on mental health; the stronger the manifestation of avoidant attachment orientation, the

higher the levels of mental health reported. The need to constantly conceal the family secret of disability, and the need to battle the stigma they faced, may have contributed to the further development of these avoidant patterns.

The children of PWD are functional, and cope with life's demands by using a more problem-focused coping strategy. This was found to serve as a moderator of the effects of stress on mental health while emotion focused coping strategies were found to have a negative effect on personal growth. This understanding that specifically problem-focused coping, as opposed to an emotion-focused coping, can contribute to their mental health while not compromising their growth process is central to understanding the strategies that enables personal development and functioning on an ongoing basis. The extended roles they played in the household from a young age may have served to incubate this capacity for coping. The extended family, and the example that they set when taking them on as a “mission to be dealt with” may have provided a further lesson in problem-focused coping.

## **8. Limitations**

This study was based on self-reports at one point across the life span, and thus serve as a snapshot of sorts: a unique and important, but also narrow perspective of the experience of being raised by a PWD. It can only tell the story of their attitudes, feelings and attributes at this point in time. The phenomena that this study seeks to explicate, however, is a lifelong developmental one. Due to the complexity of the study's target and the mediating attributes of many of the variables research allowing for more points or reference during the lifespan may be of great asset.

This study is based on quantitative questionnaires and qualitative interviews, yielding a limited amount of data specific to a single encounter with the study population. Long-term research approaches may be a useful multi-dimensional approach to the topic. These could include meeting with participants across several points in time; and focus groups, which allow for many voices to be heard at once (and possibly catalyzing suppressed memories or experiences etc.). These could prove to be an invaluable asset in developing a comprehensive understanding of their life experiences. The contribution of qualitative data, added at a later part of this study, proved to be of the utmost importance and had a vast contribution to understanding the findings. Combining a more substantial amount of qualitative data in studies such as this has the potential of allowing for a wealth of data to be considered and a greater understanding of life experiences of new populations explored.

The generalization of the findings is limited to children with parents having one of the two disabilities chosen (either MD or IDD) with other parental disabilities not accounted for. Furthermore many familial structures may exist, with either one or both parents having a disability, and possibly both having different disabilities. These situational nuances are not reflected in this study. Researching and comparing those growing up with parents with various disabilities may shed a more distinct light on similar or different experience. In

addition, the significance of various familial structures, parental disability combinations and forms of habitations as well as order of birth was not addressed in this study and may be another aspect worth looking into in the future.

This study is limited in the amount of participants and thus points of view it represents. Recruiting participants for this study proved as the main challenge. This is a population that has not been studied thoroughly before. Most of these now adult children are not known to the social service systems, and are not always aware themselves of being a part of a larger group. For these reasons they were extremely hard to reach and recruit as participants. In addition, as most of them have not “come out” as the children of PWD, and have never had the opportunity to explore the topic with professional guidance, the issues brought forward by the study and the scope of subject encompassed proved difficult (as was reported by some of the participants). Also important to suggest is that those who were willing participants in this study may represent a group that is at peace with how their lives turned out and thus willing to share their life's experiences.

Finally, a wider view of this phenomenon would contribute greatly to the understanding of all the complexities it entails- including family members, supportive professionals and other key figures across the life span may yield a broader picture.

This study allows for new and important knowledge and yet much more is yet to be discovered. Hopefully, this knowledge will be used to develop much needed professional frameworks and support systems. Suggestions for these as arise from this study will be brought in the recommendations.

## **9. Recommendations**

The findings of this study can be adapted for future consideration and practice on two levels – fundamental and practical.

On the fundamental level:

- First and foremost, it is necessary to acknowledge that this population – people with distinct needs, due to their connection to PWD – exist. There needs to be an understanding of the fact that this is not only a limited phenomenon but a large and rapidly growing group in need of professional attention. The first step on the way to improvement is gauging the actual realm of this population.
- This phenomenon needs to be brought further into the light. As we keep promoting discussion on PWD we will allow for dispelling the anonymity of their children. Promoting an open discourse on this population may allow for less concealment and the feelings of shame arising from it, allowing for more children and adults to come forth and seek assistance and support.
- As this study has shown, the children of PWD feel that beyond the hardships and challenges, they gained great assets from their unique parents and homes. Further research into the concept of resilience and the role it plays in these children's future lives may be an important perspective of inquiry. Furthermore, allowing for a shift in the discussion of if PWD can and should be parents to what type of support they may need to improve their parental abilities is an important step in realizing their rights as granted in the convention on the rights of people with disabilities (U.N., 2006).

- As discussed, the stress related to having a PWD is exacerbated by the need to keep the parent's disability secret – compounded by a lack of full understanding of the full import of this this secret. The further impact of this stress can be mitigated by providing children with honest and open explanations (Manby et al., 2014). An important conclusion arising from a former study on this issue (Weshler, 2009) was the importance of professional support for these children as well as their family members in helping them get a clearer understanding of their situation, of their parents' disability and its meaning and especially to help them understand that they are not alone in their situation by opening communication channels relevant to their varying developmental stages.

On the practical level:

- It goes without saying that the earlier the interventions, the higher the success rate when working with children at risk. An offer for support and planned interventions at as early an age as possible with both parents, their supportive family members and the children themselves may be significant for these children's future. Allowing a family with a PWD help and support so life tasks do not fall at the feet of their children is necessary.
- It has been shown that parenting intervention programs contribute to promoting the mental health and emotional well-being of both the children and the parents themselves (Olds, Sadler & Kitzman, 2007). Programs designed to guide and support these parents from an early stage are essential. As most people with a disability are known to the social systems, planned parenting or the reality of pregnancy should be raised with current or future PWD and their family members as needed. For the

children of PWD, there is no single solution; the variations in their childhood experiences, and of the people who help raise them, are great. In most cases the parent/s will need support and assistance to negotiate the challenges of parenthood. It is important to understand the form of assistance needed, what can be done to support the child in receiving the best care possible within the family, and what can be done to support the family members involved.

- As was evident in this study, a caring relationship with one's father can play a significant role in reducing the effect of stress for children raised by PWD. This merits deeper consideration when constructing working models for fathers in families where there is a PWD (even if he is not the parent with a disability). Many barriers exist in engaging fathers in parenting interventions – mostly due to the undervaluing their role, and how these interventions are designed to focus on the mother as prime care-takers. There is an urgent need for re-evaluating the design of such interventions (Panter- Brick et al, 2014).
- The contribution of an affiliation group, one that they felt a part of, was a recurring idea in the participant interviews. For most of these individuals, a support group made up of other children/adults dealing with similar challenges would have been helpful on many levels, especially as a reminder that they are not alone in their experience. Counseling from a young age – both individual and in a group setting – can create a safe zone within which they can express themselves, make sense of the conflicted feelings they have for their parents, and to work through them (Weshler, 2009).

- Being raised by a PWD may be a very unstable life experience, both emotionally and practically. It demands the ability to constantly adjust to events at home and demands from the wider environment. The children who succeed in remaining focused and organized, addressing these issues less emotionally, will ultimately be the better for this. The main challenge is that both practical problem-solving skills and emotion management are life lessons that need to be taught and modeled – an experience not always readily available to the children of PWD. Personal programs aimed at teaching and training these skills, helping the children of PWD to express and sort through the complex emotions they carry, would be an important asset.
- Rabbi Shlomo Carlibach articulated a life-affirming concept in saying "*All a child needs is one adult to believe in him*". We all wish for someone to see us as we are, and believe in our potential. We need someone to judge our book, not by its cover but by the texts that construct our life stories – and to believe that investing in the stories that make up the person would ultimately be worthwhile. This, in essence, describes what the participants of this study identified as making a significant difference in their lives. It is important for every child, especially those who lack support and positive models at home, to have an adult that sees them and believes in them – a mentor. Whether chosen by them or for them, whether they are the natural mentors who already form a part of their lives, or formal mentors matched with them: this appears to have been a vital asset in these children's lives.

## **10. Concluding Remarks**

Imagine a childhood memory. Who helped you with homework? Who sat by your bedside when you were sick? Who came to cheer at your first sports game? Who did you consult when you had a problem? For most of us, our parents were the ones who were there for these crucial moments, and many more besides. For the children of a PWD, these memories are complex; quite often, they involve people other than their parents.

After many years of struggling to convince policy makers and professional field workers that there are actually a vast number of people in the general population who were – or continue to be – raised by a PWD, I truly hope that at least this point is now obvious. I believe there is much more to be learned about this issue, especially at a time when the rights of people with a disability to be parents is being asserted, through changes to human rights and (hopefully) primary legislation. I believe that the number of these children that we still don't know about exceeds those who we do. These children exist and their numbers will keep growing, emphasizing the urgency to further look into the components constructing their lives, their needs, the needs of their parents and those of the family members supporting them.

The reasons for the isolation that many children of PWD grow up with and carry on to adulthood is that to this day, no one talks publicly about such experiences. Consequently, the phenomenon is assumed to be not as widespread as it actually is (Ronai, 1997). It is not yet considered a big enough issue to deal with – to research, write, and talk about. These are ideas that hopefully this study and its findings make worth considering and addressing. Being raised by a PWD is presented in this study as a source of stress affecting all life domains; however, the voices of these children shows a possibility of bright futures nonetheless.

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## Appendix

### Item 1- Research questionnaires- English (original scales)

#### The Perceived Stress Scale (PSS: Cohen, Kamarck, & Mermelstein, 1983)

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate by circling *how often* you felt or thought a certain way in the last month.

	In the last month	Never	Almost never	Somewhat	Fairly often	Very often
1	How often have you been upset because of something that happened unexpectedly?	1	2	3	4	5
2	How often have you felt that you were unable to control the important things in your life?	1	2	3	4	5
3	How often have you felt nervous and “stressed”?	1	2	3	4	5
4	How often have you felt confident about your ability to handle your personal problems?	1	2	3	4	5

5	How often have you felt that things were going your way?.	1	2	3	4	5
6	How often have you found that you could not cope with all the things that you had to do?	1	2	3	4	5
7	How often have you been able to control irritations in your life?	1	2	3	4	5
8	How often have you felt that you were on top of things?	1	2	3	4	5
9	How often have you been angered because of things that were outside of your control?	1	2	3	4	5
10	How often have you felt difficulties were piling up so high that you could not overcome them?	1	2	3	4	5

**Experience in Close Relationships scale (ECR: Brennan, Clark & Shaver, 1988)**

The statements below concern how you feel in emotionally intimate relationships. We are interested in how you generally experience relationships, not just in what is happening in a current relationship. Respond to each statement by circling a number to indicate how much you agree or disagree with the statement.

		Very much agree		Equally agree and disagree			Very much disagree	
		1	2	3	4	5	6	7
1	I would rather not show other people how I feel inside	1	2	3	4	5	6	7
2	I'm worried I will be abandoned	1	2	3	4	5	6	7
3	I feel uncomfortable in other people's presence	1	2	3	4	5	6	7
4	I worry about my relationships	1	2	3	4	5	6	7
5	I steer away when people try to get close to me	1	2	3	4	5	6	7
6	I worry that people won't care about me as much as I care about them	1	2	3	4	5	6	7
7	I feel uncomfortable when people want to get close to me	1	2	3	4	5	6	7

8	I worry that I will lose those close to me	1	2	3	4	5	6	7
9	I don't feel comfortable opening up to people	1	2	3	4	5	6	7
10	I would like others feelings for me to be as strong as my feelings towards them	1	2	3	4	5	6	7
11	I want to be close to other people but I keep pulling away	1	2	3	4	5	6	7
12	I often want to fully merge with others and it pushes them away	1	2	3	4	5	6	7
13	I become tense when others get to close	1	2	3	4	5	6	7
14	I'm afraid of being alone	1	2	3	4	5	6	7
15	I feel comfortable sharing my thoughts and feelings with other people	1	2	3	4	5	6	7
16	My desire to be very close sometimes scares people away	1	2	3	4	5	6	7
17	I try to avoid getting to close to others	1	2	3	4	5	6	7
18	I need many reassurances from those close to me	1	2	3	4	5	6	7

19	I feel it's easy for me to get close to others	1	2	3	4	5	6	7
20	I feel I sometimes make people show more feelings and commitment	1	2	3	4	5	6	7
21	It's hard for me to depend on others	1	2	3	4	5	6	7
22	I don't often worry about being abandoned	1	2	3	4	5	6	7
23	I would rather not be close to other people	1	2	3	4	5	6	7
24	If I can't make other people show interest in me I get angry or frustrated	1	2	3	4	5	6	7
25	I open up to those close to me	1	2	3	4	5	6	7
26	I feel other people don't want to be as close as I would like	1	2	3	4	5	6	7
27	I usually discuss my problems and worries with those close to me	1	2	3	4	5	6	7
28	When I'm not in a relationship I feel anxious and insecure	1	2	3	4	5	6	7
29	I feel comfortable being dependent on others	1	2	3	4	5	6	7

30	I get frustrated when others aren't around as much as I would like	1	2	3	4	5	6	7
31	I don't mind approaching others for comfort, advice or aid	1	2	3	4	5	6	7
32	I get frustrated when others aren't as available when I need them	1	2	3	4	5	6	7
33	It helps me to approach others in times of need	1	2	3	4	5	6	7
34	When others don't validate me I feel bad about myself	1	2	3	4	5	6	7
35	I approach others about many things including comfort and validation	1	2	3	4	5	6	7
36	It makes me resistant when those close to me spend time away	1	2	3	4	5	6	7

**Posttraumatic Growth Inventory (PTGI: Tedeschi & Calhoun, 1996)**

Childhood experiences vary from family to family. Indicate for each of the statements below the degree to which you experienced each feeling in your life as a result of the childhood in your home, using the following scale.

		Not at all	Very little	somewhat	Moderately	Very much	Greatly
1	I changed my priorities about what is important in life.	0	1	2	3	4	5
2	I have a greater appreciation for the value of my own life.	0	1	2	3	4	5
3	I developed new interests.	0	1	2	3	4	5
4	I have a greater feeling of self-reliance.	0	1	2	3	4	5
5	I have a better understanding of spiritual matters.	0	1	2	3	4	5
6	I more clearly see that I can count on people in times of trouble.	0	1	2	3	4	5
7	I established a new path for my life.	0	1	2	3	4	5

8	I have a greater sense of closeness with others.	0	1	2	3	4	5
9	I am more willing to express my emotions.	0	1	2	3	4	5
10	I know better that I can handle difficulties.	0	1	2	3	4	5
11	I am able to do better things with my life.	0	1	2	3	4	5
12	I am better able to accept the way things work out.	0	1	2	3	4	5
13	I can better appreciate each day.	0	1	2	3	4	5
14	New opportunities are available which wouldn't have been otherwise.	0	1	2	3	4	5
15	I have more compassion for others.	0	1	2	3	4	5
16	I put more effort into my relationships.	0	1	2	3	4	5

17	I am more likely to try to change things which need changing.	0	1	2	3	4	5
18	I have a stronger religious faith.	0	1	2	3	4	5
19	I discovered that I'm stronger than I thought I was.	0	1	2	3	4	5
20	I learned a great deal about how wonderful people are.	0	1	2	3	4	5
21	I better accept needing others.	0	1	2	3	4	5

**Rosenberg self-esteem scale (RSES: Rosenberg, 1965)**

Below is a list of statements dealing with your general feelings about yourself.

Please indicate how strongly you agree or disagree with each statement.

		Strongly agree	Agree	disagree	Strongly disagree
1	On the whole, I am satisfied with myself.	1	2	3	4
2	At times I think I am no good at all.	1	2	3	4
3	I feel that I have a number of good qualities.	1	2	3	4
4	I am able to do things as well as most other people.	1	2	3	4
5	I feel I do not have much to be proud of.	1	2	3	4
6	I certainly feel useless at times.	1	2	3	4
7	I feel that I'm a person of worth, at least on an equal plane with others.	1	2	3	4
8	I wish I could have more respect for myself.	1	2	3	4
9	All in all, I am inclined to feel that I am a failure	1	2	3	4
10	I take a positive attitude toward myself	1	2	3	4

**The Mental Health Inventory (MHI: Veit & Ware, 1983)**

The following statements are about how you feel and how things have been for you during the past month.

For each statement choose the description that represents to how you feel.

		All the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
1	How much of the time, during the past month, has your daily life been full of things that were interesting to you?	1	2	3	4	5	6
2	Did you feel depressed during the past month?	1	2	3	4	5	6
3	During the past month, how much of the time have you felt loved and wanted?	1	2	3	4	5	6
4	How much of the time, during the past month, have you been a very nervous person?	1	2	3	4	5	6

5	During the past month, how much of the time have you felt tense or “high-strung”?	1	2	3	4	5	6
6	During the past month, have you been in firm control of your behavior, thoughts, emotions or feelings?	1	2	3	4	5	6
7	During the past month, how often did you feel that you had nothing to look forward to?	1	2	3	4	5	6
8	How much of the time, during the past month, have you felt calm and peaceful?	1	2	3	4	5	6
9	How much of the time, during the past month, have you felt emotionally stable?	1	2	3	4	5	6
10	How much of the time, during the past month, have	1	2	3	4	5	6

	you felt downhearted and blue?						
11	How much of the time, during the past month, were you able to relax without difficulty?	1	2	3	4	5	6
12	How often, during the past month, have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
13	During the past month, how much of the time have you felt restless, fidgety, or impatient?	1	2	3	4	5	6
14	During the past month, how much of the time have you been moody or brooded about things?	1	2	3	4	5	6
15	How much of the time, during the past month, have you felt cheerful, lighthearted?	1	2	3	4	5	6

16	During the past month, have you been anxious or worried?	1	2	3	4	5	6
17	During the past month, how much of the time were you a happy person?	1	2	3	4	5	6
18	During the past month, how much of the time have you been in low or very low spirits?	1	2	3	4	5	6

**The Coping Orientation to Problems Experienced (COPE: Carver et al., 1989)**

The following statements examine how people respond to difficult or stressful situations in their daily lives.

Please select the number you feel represents how much you use each strategy.

	When I encounter a stressful situation in my daily life I:	Not at all	A little bit	A medium amount	A lot
1	Tried to get advice or help from other people about what to do	0	1	2	3
2	Look for something good in what happened	0	1	2	3
3	I put my faith in god	0	1	2	3
4	Turned to work or other activities to take my mind off things.	0	1	2	3
5	I admit to myself that I can't handle it and stop trying	0	1	2	3
6	I refuse to believe this is happening	0	1	2	3
7	I force myself to wait for the right time to do something	0	1	2	3
8	Use alcohol or other drugs to make myself feel better.	0	1	2	3
9	Make jokes about it	0	1	2	3
10	I feel great distress and express this feeling	0	1	2	3
11	Learn to live with it	0	1	2	3
12	I try to prevent other things from interrupting me from handling it	0	1	2	3

13	Try to get comfort and understanding from someone	0	1	2	3
14	I think how I can handle things better	0	1	2	3
15	I do what needs to be done step by step	0	1	2	3
16	I focus my strengths to do something	0	1	2	3
17	I form a plan of action	0	1	2	3
18	I accept the fact that it is happening and it's changeable	0	1	2	3
19	I'm moody and unaware of it	0	1	2	3
20	I talk to someone about my feelings	0	1	2	3
21	I put other issues aside to focus on solving the problem	0	1	2	3
22	I try to limit the amount of effort I put into solving the problem	0	1	2	3
23	I sleep to much	0	1	2	3
24	I pray a lot	0	1	2	3
25	I try to talk to someone who can do something about it	0	1	2	3
26	I learn something from the experience	0	1	2	3
27	I make jokes about the situation	0	1	2	3
28	Use alcohol or other drugs to help myself get over it	0	1	2	3
29	Stop myself from reacting to early	0	1	2	3
30	Pretend as if it never happened	0	1	2	3

**The Multidimensional Scale for Perceived Social Support (MSPSS: Zimet et al., 1988)**

The following statements are about your relationships with family and friends in your life.

For each statement choose how much it is true for you today.

		Not very much		Somewhat			Very much	
		1	2	3	4	5	6	7
1	There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2	There is a special person with whom I can share joys and sorrows	1	2	3	4	5	6	7
3	My family really tries to help me.	1	2	3	4	5	6	7
4	I get the emotional help & support I need from my family	1	2	3	4	5	6	7
5	I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6	My friends really try to help me.	1	2	3	4	5	6	7
7	I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8	I can talk about my problems with my family.	1	2	3	4	5	6	7
9	I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10	There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7

11	My family is willing to help me make decisions.	1	2	3	4	5	6	7
12	I can talk about my problems with my friends.	1	2	3	4	5	6	7

**Parental Bonding Instrument** (PBI: Parker, Tupling & Brown, 1979)

This questionnaire lists various attitudes and behaviors of parents. Choose for each sentence how much it represented your mother and fathers behavior toward you in your childhood.

Please answer for each parent separately.

In this questionnaire answer about your childhood feelings towards **your mother**

		Very unlike	Moderately unlike	Moderately like	Very like
1	Spoke to me in a warm and friendly voice	1	2	3	4
2	Helped me as much as I needed	1	2	3	4
3	Let me do those things I liked doing	1	2	3	4
4	Seemed emotionally cold to me	1	2	3	4
5	Appeared to understand my problems and worries	1	2	3	4
6	Was affectionate to me	1	2	3	4
7	Liked me to make my own decisions	1	2	3	4
8	Wanted me to grow up	1	2	3	4
9	Tried to control everything I did	1	2	3	4
10	Invaded my privacy	1	2	3	4
11	Enjoyed talking things over with me	1	2	3	4

12	Frequently smiled at me	1	2	3	4
13	Tended to baby me	1	2	3	4
14	Seemed to understand what I needed or wanted	1	2	3	4
15	Let me decide things for myself	1	2	3	4
16	Made me feel I wasn't wanted	1	2	3	4
17	Could make me feel better when I was upset	1	2	3	4
18	Talked with me very much	1	2	3	4
19	Tried to make me feel dependent on her	1	2	3	4
20	Felt I could not look after myself unless she was around	1	2	3	4
21	Gave me as much freedom as I wanted	1	2	3	4
22	Let me go out as often as I wanted	1	2	3	4
23	Was overprotective of me	1	2	3	4
24	Praised me	1	2	3	4
25	Let me dress in any way I pleased	1	2	3	4

If you chose not to answer questions about your mother please state why:

- I did not know my mother
- My mother was not a part of my life
- Other: \_\_\_\_\_

In this questionnaire answer about your childhood feelings towards **your father**

		Very unlike	Moderately unlike	Moderately like	Very like
1	Spoke to me in a warm and friendly voice	1	2	3	4
2	Helped me as much as I needed	1	2	3	4
3	Let me do those things I liked doing	1	2	3	4
4	Seemed emotionally cold to me	1	2	3	4
5	Appeared to understand my problems and worries	1	2	3	4
6	Was affectionate to me	1	2	3	4
7	Liked me to make my own decisions	1	2	3	4
8	Wanted me to grow up	1	2	3	4
9	Tried to control everything I did	1	2	3	4
10	Invaded my privacy	1	2	3	4
11	Enjoyed talking things over with me	1	2	3	4
12	Frequently smiled at me	1	2	3	4
13	Tended to baby me	1	2	3	4
14	Seemed to understand what I needed or wanted	1	2	3	4
15	Let me decide things for myself	1	2	3	4

16	Made me feel I wasn't wanted	1	2	3	4
17	Could make me feel better when I was upset	1	2	3	4
18	Talked with me very much	1	2	3	4
19	Tried to make me feel dependent on her	1	2	3	4
20	Felt I could not look after myself unless she was around	1	2	3	4
21	Gave me as much freedom as I wanted	1	2	3	4
22	Let me go out as often as I wanted	1	2	3	4
23	Was overprotective of me	1	2	3	4
24	Praised me	1	2	3	4
25	Let me dress in any way I pleased	1	2	3	4

If you chose not to answer questions about your father please state why:

- I did not know my father
- My father was not a part of my life
- Other: \_\_\_\_\_

## **Personal background questionnaire**

1. **Gender:** M/F
2. **Year of birth:**\_\_\_\_\_
3. **Country of birth:** Israel/other:\_\_\_\_\_
4. **Year of immigration to Israel:**\_\_\_\_\_
5. **Religion:** Jewish/Muslim/Christian/ Other\_\_\_\_\_
6. **Religious affiliation:** Secular/conservative/Religious/ Orthodox
7. **Do you have a disability?** Yes/No

**If answered Yes is your disability:** Physical/Mental/Intellectual/ other

8. **Familial status:** Single/ Married-in a relationship/ Widower/ Divorced
9. **Does your partner (past or present) have a disability?** Yes / No

**If answered Yes what disability:** Physical/Mental/Intellectual/ other

10. **Number of children (if relevant):**\_\_\_\_\_
11. **Does one or more of your children have a disability?** Yes/ No

**If answered Yes what disability:** Physical/Mental/Intellectual/ other

12. **How many siblings do you have?** \_\_\_\_\_
13. **What is your place in the birth order?** Oldest / Middle / Youngest
14. **Does one of your siblings have a disability?** Yes/ No

**If answered Yes what disability:** Physical/Mental/Intellectual/ other

15. **Does one of your parents have a disability?**
  - None of my parents have a disability
  - My father has a disability- Physical/Mental/Intellectual/ other
  - My mother has a disability- Physical/Mental/Intellectual/ other
16. **Where did you spend most of your childhood?**
  - In my parents' home

- Childcare placement or foster family
- With extended family members (grandparents/uncles/aunts..)

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

- 8 years
- 12 years
- Higher education
- Academic

**18. Are you currently employed? Yes/No**

**If answered Yes are you:** Independent/ hired

**If answered Yes do you work:** part time/full time

**If answered Yes how satisfied are you with your job?** Very satisfied/ Partially satisfied/

Not satisfied

**If answered Yes how satisfied are you with your connection to your co-workers?** Very satisfied/ Partially satisfied/ Not satisfied

**If answered No why are you not working?** I don't have a profession/ I can't find work / I was fired / I would rather spend my time doing other things /I can't find work that interests me/ other \_\_\_\_\_

**19. Socio-economic status: what is the net income of your family?** Below average /

average / above average

**20. What are your income sources (you may choose more than one answer)?**

Disability allowance / personal salary / help from family and friends / partners salary / savings /other\_\_\_\_\_

## **Item 2- Interview manual (translated from Hebrew)**

Open the interview with a short explanation on the study and its goals.

### Opening question:

Please tell me about yourself / tell me your life story

### Steering questions:

- What do you remember of how you viewed your parents as a child? How did you view your mother/father?
- When/how did you first understand that there is something in your parents different?
- How did you understand this? Was there a specific moment/ event you remember?
- Can you give examples of the meaning of this difference?
- Describe your relationship with your parents.
- How do you feel your childhood experiences shaped the person you are today?
- What was the role of your extended family in your life?
- Were there other meaning figures you remember from your childhood?
- Do you view your parent differently today than you did during your childhood?
- What responses do you encounter (today or in the past) from society as to people with a disability / your parents?
- What is your position regarding the rights of people with disabilities to have and raise children?

## נולדו לאתגר

**הסתגלות וצמיחה אישית של בוגרים**

**שגדלו עם הורה עם מוגבלות נפשית או שכלית**

חיבור לשם קבלת התואר "דוקטור לפילוסופיה"

**מאת: דורית ושלר**

**בהנחיית: פרופ' ליאורה פינדלר**

עבודת גמר המוגשת כמילוי חלק מהדרישות  
לקבלת התואר "דוקטור"  
בביה"ס לעבודה סוציאלית, אוניברסיטת בר-אילן



מחקר זה נערך בסיוע מענק מחקר מקרן שלום  
הקרן לפיתוח שירותים לאדם עם מוגבלות שכלית התפתחותית  
ברשויות המקומיות

**2019**

**קרן שלום/2019/640**

## **תמצית**

ההתקדמות בשיח ובחקיקה בתחום הזכויות עבור אנשים עם מוגבלות, הובילה רבים מהם לממש את זכותם בתחומי חיים רבים וביניהם הזכות להינשא וללדת ילדים. רוב המחקר עד כה התמקד בחוויית ההורות של אנשים עם מוגבלות, בעוד שהשלכות הורות זו על ילדיהם לאורך חייהם ונקודת המבט של הילדים עצמם זכו להתייחסות מועטה.

מטרתו של מחקר זה הייתה לבחון את תרומתם של משאבים תוך-אישיים (אוריינטציית התקשרות והערכה עצמית), גורמים חברתיים-אקולוגיים (תמיכה חברתית) ואסטרטגיות התמודדות המייצגים גורמי הגנה, להסתגלות (בריאות נפשית) ולצמיחה אישית של בוגרים אשר להוריהם מוגבלות נפשית או שכלית (גורם סיכון המיוצג במחקר זה כדחק נתפס וקשר עם הורה בילדות). בחינה זו נעשתה בהשוואה לאוכלוסיית ביקורת של בוגרים שגדלו עם הורה ללא מגבלה .

מילות חיפוש : הורים עם מגבלה, מגבלה שכלית התפתחותית, מגבלה נפשית, הסתגלות, צמיחה, שוויון זכויות לאנשים עם מוגבלויות.

## תקציר

ההתקדמות בשיח ובחקיקה בתחום הזכויות עבור אנשים עם מוגבלות, הובילה רבים מהם לממש את זכותם בתחומי חיים רבים וביניהם הזכות להינשא וללדת ילדים. רוב המחקר עד כה התמקד בחוויית ההורות של אנשים עם מוגבלות, בעוד שהשלכות הורות זו על ילדיהם לאורך חייהם ונקודת המבט של הילדים עצמם זכו להתייחסות מועטה.

לאור המודל התאורטי של וולנדר ושותפיו (Wallander et al., 1989), מטרתו של מחקר זה הייתה לבחון את תרומתם של משאבים תוך-אישיים (אוריינטציית התקשרות והערכה עצמית), גורמים חברתיים-אקולוגיים (תמיכה חברתית) ואסטרטגיות התמודדות המייצגים גורמי הגנה, להסתגלות (בריאות נפשית) ולצמיחה אישית של בוגרים אשר להוריהם מוגבלות נפשית או שכלית (גורם סיכון המיוצג במחקר זה כדחק נתפס וקשר עם הורה בילדות). בחינה זו נעשתה בהשוואה לאוכלוסיית ביקורת של בוגרים שגדלו עם הורה ללא מגבלה.

מאתיים וחמישה עשר בוגרים בגילאי 25-55 השתתפו במחקר הנוכחי: 100 שגדלו להורה/ים עם מוגבלות ו-115 שגדלו להורים ללא מגבלה. גיוס המשתתפים נעשה באמצעות מסד הנתונים של הבטוח הלאומי וכן באמצעות פניה לאנשי מקצוע ופרסום ברשתות החברתיות.

מחקר זה נערך בגישה משולבת. חלקו הראשון של המחקר היה כמותי ועשה שימוש בכלים הבאים: דחק נתפס- PSS (Cohen, Kamarck, & Mermelstein, 1983); התקשרות להורים- PBI (Parker, Tupling & Brown, 1979); אוריינטציית התקשרות ECR - (Brennan, Clark & Shaver, 1988); הערכה עצמית- RSIS (Rosenberg, 1965); תמיכה חברתית- MSPSS (Zimmet et al., 1988); אסטרטגיות התמודדות- COPE (Carver et al., 1989); רווחה נפשית- MHI (Veit & Ware, 1983) וצמיחה אישית- PTGI (Tedeschi & Calhoun, 1996).

בשל גוף הידע המועט הנוגע לאוכלוסיה זו נעשה בנוסף שימוש במתודה איכותנית בכדי לאפשר נקודת מבט נוספת וידע מעמיק יותר על תופעה ייחודית זו. תשעה ממשותפי השלב הכמותי של המחקר, אשר גדלו עם הורים עם מגבלה, לקחו חלק בראיונות עומק.

בשלב הכמותי של מחקר זה השערות המחקר אוששו בצורה חלקית. כמשוער, ילדים להורים עם מוגבלות דווחו על רמות דחק גבוהות יותר בהשוואה לאלו אשר גדלו עם הורים ללא מגבלה. בנוסף, הדחק זוהה

כמתווך משמעותי של הקשר בין ילדות להורה עם מגבלה לבין בריאות נפשית וצמיחה אישית של משתתפי המחקר.

## **מבוא**

בישראל חיים כיום כ-1.5 מיליון אנשים (כ-18% מהאוכלוסייה) המוגדרים כאנשים עם מוגבלות (Central Bureau of Statistics, 2017), מתוכם 700,000 מבוגרים (18-64) המוגדרים כבעלי מגבלה (Myers- Brookdale, 2018). בין מבוגרים אלו כ-7.5% מאובחנים עם מגבלה נפשית וכ-4.2% עם מגבלה שכלית התפתחותית. על אף שהוכרו כשוות בחוק ובוססו בעקבות שיח ומאבק ציבורי באמנת האו"ם (Commission of Equal Rights of Persons with Disabilities, 1998) במשך שנים רבות זכויותיהם ורצונותיהם של אנשים עם מגבלה נותרו לא ממומשות במספר תחומים וביניהן נושאי המיניות וההורות (Asch & Fine, 1985; Schaaf, 2011).

מידע לגבי ילדיהם מוגבל וחסר בין היתר לאור העובדה שעד היום טרם נעשתה בחינה והערכה ממוקדת בנושא. מיקודו של מחקר זה הוא ילדים אלו, בחייהם הבוגרים. מטרת המחקר לבחון את ההסתגלות והצמיחה האישית של ילדים שגדלו להורה/ים עם מגבלה שכלית או נפשית.

## **סקירה**

### **היקף האוכלוסייה**

ילדים להורים עם מגבלה, גם היום, נמצאים ברוב המקרים מתחת לראדר של שרותי הרווחה ואנשי המקצוע בשטח. הבנת היקף התופעה היא חיונית בעיני להערכה של הצרכים של אוכלוסייה זו והבנת החשיבות של פיתוח מענים חיוניים לרווחתם. מבט על ראשוני על אוכלוסייה מתאפשר במחקר זה הודות לאגף המחקר של המוסד לביטוח לאומי.

**טבלה 1- מספר הורים עם מגבלה וילדיהם\***

מספר ילדים של מקבלי קצבה	מספר מקבלי קצבה שהינם הורים	מספר מקבלי קצבה	מגבל ההורה
15,353	5,394	33,207	שכלית
115,021	36,431	77,357	נפשית
35,993	9,877	14,966	חושית
301,326	84,334	109,898	פיזית
467,693	136,036	235,428	

\*נתונים נכונים לינואר 2017 על פי דיווח של המוסד לביטוח לאומי

הורים עם מגבלה

איכות ההורות נחשבת למשתנה משמעותי באיכות חייו העתידית של הילד. הורות טובה בחובה טווח רחב של התנהגויות ואסטרטגיות ועם זאת קיימת הסכמה כללית כי הורות טובה ואפקטיבית מתאפיינת בקבלה, חום, הקניית מבנה ועידוד לאוטונומיה מותאמת גיל (Maccoby & Martin, 1983; Skinner, Johnson, & Snyder, 2005). תפקודים הוריים עשויה להוות אתגר עבור הורים עם מגבלה. נכון להיום הדעות בדבר כשירותם ההורית של אנשים עם מגבלה מגוונות. מחקרים בדבר הורים עם מוגבלות עד כה נגעו בעיקר בלקויות בתפקודיהם הלקויים ובסיכון האפשרי שהם מהווים להתפתחות ילדיהם.

ילדות להורה עם מגבלה

ההשלכות של ילדות להורה עם מגבלה עשויות להיות השלכות ברמה הרגשית, המשפחתית ובהתפתחות החברתית. ברמה הרגשית החששות הנוגעות לילדים להורים עם מגבלה שכלית או נפשית קשורות בעיקר ביכולת המוגבלת של הורים אלו לספק את הצרכים הרגשיים של הילד, להגן עליו, להציב גבולות ולספק לו מבנה חיים יציב (Ackerson, 2003; Feldman & Aunos, 2010; Jacobsen & Miller, 1998).

ברמה המשפחתית מחלה או מגבלה של הורה עשויה לפגוע בתפקוד התא המשפחתי ולהוות עול מוגבר על בני המשפחה המורחבת ועל הילדים עצמם ולהוות מקור למתח ודחק שעשויים להוביל להזנחה

ופגיעה (Pakenham & Cox, 2011; Leverton, 2003; Meadow-Orlans, 2002; Dearden & Becker, 1995; Lackey & Gates, 2001 ) .

ברמה החברתית האחריות הנלווית המוטלת על ילדים אלו עשויה להגביל את הזדמנויות שלהם בתחום הפנאי ויצירת חברויות, להגביל את חשיפתם לאחרים ושיתוף בחוויותיהם ולעורר רגשות של בושה ומבוכה תוך פחד מתמיד מהתערבות הרשויות והסיכון לפירוק המשפחה ולהיות הבסיס לעיכובים התפתחותיים ברמה האקדמית, ההתנהגותית ובהסתגלותם הכוללת (Atkin, 1992; Banks et al., 2002; Meadow-Orlans, 2002; Pakenham et al., 2006).

### צמיחה והסתגלות בצל דחק

דחק עשוי להוביל למצוקה רגשית אשר עשויה להתבטא בטווח רחב של הפרעות פיזיות ונפשיות ולפגוע ברווחה האישית ובצמיחה. הסתגלות מוצלחת בבגרות מאופיינת ברמות גבוהות של בריאות נפשית, התאמה לשלבי התפתחות מקובלים וביסוס ותיחזוק מערכות יחסים (Zeidner, 1998; Luhmann et al., 2012).

היכולת להתעלות על אתגרי החיים השונים עשויה לתרום לצמיחה אישית גבוהה (Tedeschi & Calhoun, 1995; 2004). חמישה תחומי חיים זהו כאפשריים לצמיחה אישית בצל דחק ובהם: העצמת מערכות היחסים הבין אישיות והערכת האחר, שינוי חיובי בתפיסה העצמית, הערכה מחודשת של פילוסופיית החיים האישית, הערכה מחודשת של החיים וכינון סדרי עדיפויות חדשים.

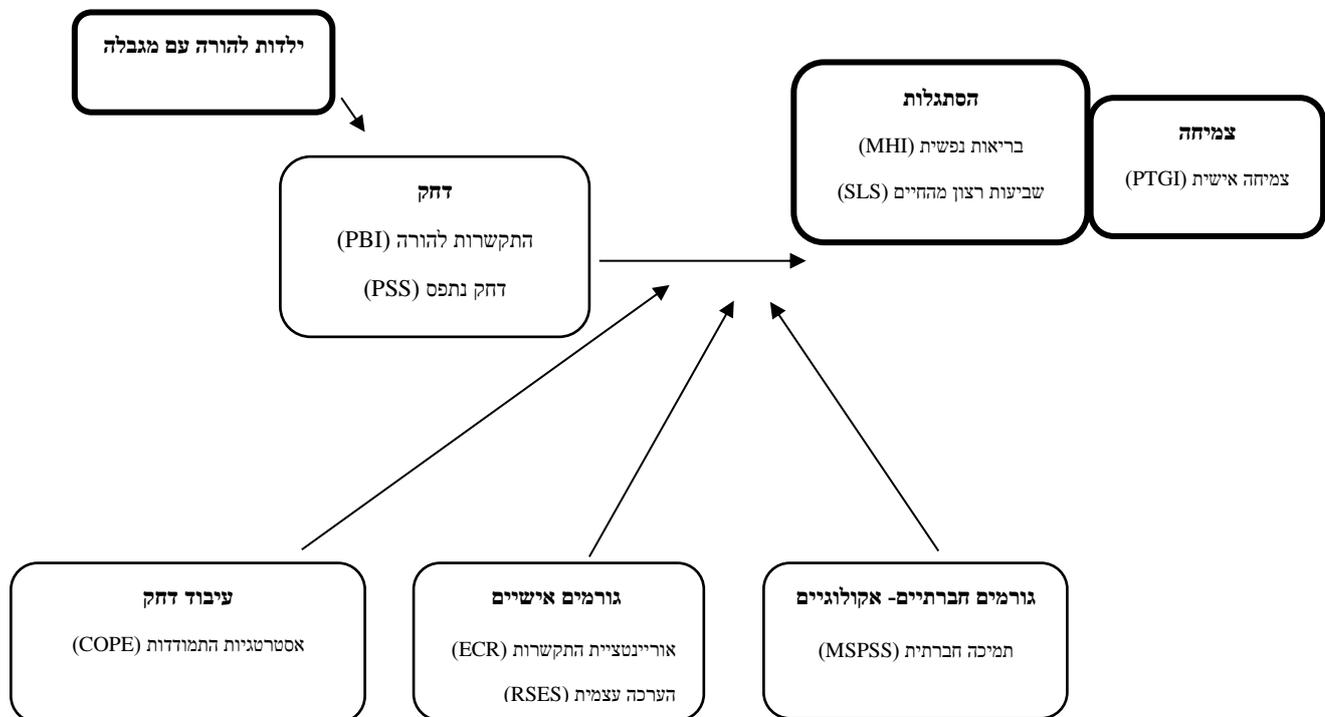
### שיטת המחקר

לאור המודל התאורטי של וולנדר ושותפיו (Wallander et al., 1989), מטרתו של מחקר זה הייתה לבחון את תרומתם של משאבים תוך-אישיים (אוריינטציית התקשרות והערכה עצמית), גורמים חברתיים-אקולוגיים (תמיכה חברתית) ואסטרטגיות התמודדות המייצגים גורמי הגנה, להסתגלות (בריאות נפשית) ולצמיחה אישית של בוגרים אשר להוריהם מוגבלות נפשית או שכלית (גורם סיכון המיוצג במחקר זה כדחק

נתפס וקשר עם הורה בילדות). בחינה זו נעשתה בהשוואה לאוכלוסיית ביקורת של בוגרים שגדלו עם הורה ללא מגבלה .

מאתיים וחמישה עשר בוגרים בגילאי 25-55 השתתפו במחקר הנוכחי: 100 שגדלו להורה/ים עם מוגבלות ו-115 שגדלו להורים ללא מגבלה. גיוס המשתתפים נעשה באמצעות מסד הנתונים של הבטוח הלאומי וכן באמצעות פניה לאנשי מקצוע ופרסום ברשתות החברתיות.

מחקר זה נערך בגישה משולבת. חלקו הראשון של המחקר היה כמותי ועשה שימוש בכלים הבאים: דחק נתפס- PSS (Cohen, Kamarck, & Mermelstein, 1983); התקשרות להורים-PBI (Parker, Tupling); הערכה אוריינטצית התקשרות ECR - (Brennan, Clark & Shaver, 1988); הערכה עצמית- RSIS (Rosenberg, 1965); תמיכה חברתית- MSPSS (Zimmet et al., 1988); אסטרטגיות התמודדות- COPE (Carver et al., 1989); רווחה נפשית- MHI (Veit & Ware, 1983) וצמיחה אישית- PTGI (Tedeschi & Calhoun, 1996).



מודל המחקר לאור מודל סיכון-עמידות של וולנדר ושותפיו (Wallander et al., 1989)

בשל גוף הידע המועט הנוגע לאוכלוסיה זו נעשה בנוסף שימוש במתודה איכותנית בכדי לאפשר נקודת מבט נוספת וידע מעמיק יותר על תופעה ייחודית זו. תשעה ממשותפי השלב הכמותי של המחקר, אשר גדלו עם הורים עם מגבלה, לקחו חלק בראיונות עומק.

## ממצאים

משתתפים עם הורים עם מגבלה דיווחו על רמות נמוכות יותר של טיפול אבהי ואימהי לעומת אלו שגדלו עם הורה ללא מגבלה. ממצאי המחקר עלו הבדלים בסגנונות ההורות בין שתי קבוצות אלו כך ילדים להורים עם מגבלה דיווחו על רמות גבוהות יותר של דפוס של שליטה ללא חיבה (affectionless control) לעומת דפוס של הורות אופטימלית שהציגו אלו עם הורים ללא מגבלה. הילדים שגדלו עם הורים עם מגבלה דיווחו על רמות נמוכות יותר תמיכה חברתית ושל בריאות נפשית בהשוואה למי שגדלו עם הורים ללא מגבלה.

האפיונים המשותפים לקבוצות אלו מעניינים ומפתיעים ועלו על הציפיות כפי ששוערו במחקר. השערות המחקר הניחו שהבדלים יימצאו בין הקבוצות בכל משתני המחקר אך בפועל לא נמצאו הבדלים ברמות ההערכה העצמית, אסטרטגיות התמודדות, אוריינטציית התקשרות וצמיחה אישית בין מי שגדלו עם הורה עם מגבלה לאלו שגדלו עם הורה ללא מגבלה.

שש התמות שזוהו בשלב האיכותני של המחקר והתייחס אך ורק למשתתפים אשר הוריהם עם מגבלה הן: מיעוט המידע לגבי מגבלת ההורה ומשמעותה, והצורך להתמודד עם עמימות בנוגע למידע זה; תפקידם של בני המשפחה המורחבת בילדותם ובחייהם בהווה כמטפלים וכהורים חליפיים; החיפוש המתמיד אחר דמויות בוגרות משמעותיות כמודלים לחיקוי; התחושות המעורבות שהם נושאים כלפי ההורה הנתפס גם כנטל; חילופי התפקידים בגיל צעיר והעול המוטל עליהם במהלך חייהם כתוצאה מכך; השאיפה המתמדת להצליח כנגד כל הסיכויים ולהוכיח את ערכם לעולם. במחקר הנוכחי נערך שילוב בין תמות אלו שעלו במחקר האיכותני לבין ממצאיו של המחקר הכמותי, שילוב אשר איפשר הבנה מעמיקה יותר של החוויות של ילדים אשר נולדו להורה עם מגבלה.

ראייה משולבת של תוצאות החלק הכמותי והאיכותני של המחקר מאפשרת הבנה מעמיקה של חייהם הייחודיים של ילדים להורה עם מגבלה.

בנוגע להתקשרות להורה (PBI) טיפול אבהי נמצא כממתן את הקשר בין ילדות להורה עם מגבלה ודחק נתפס. ממצא זה מדגיש את תפקידם החשוב של אבות ושל הקשר אב-ילד וההתייחסות הנדרשת לקשר זה, התייחסות החסרה לאור המשקל המשמעותי יותר המושם לרב בעולם המחקר והטיפול דווקא על הקשר בין הילד לאמו. תחושות הבושה המלוות את היותם ילדים להורה עם מגבלה כפי שהם מתארים אותן והתחושות המעורבות אשר הם חשים כלפי ההורה עשויות היו גם לשחק תפקיד בקשר שהתפתח עם ההורה.

נמצא כי אוריינטציית התקשרות נמנעת מתווכת את הקשר בין דחק נתפס ובריאות נפשית כך שככל שההתקשרות הנמנעת חזקה יותר רמות הבריאות הנפשית גבוהות יותר. הצורך המתמיד להסתיר את "הסוד" המשפחתי שהוא ההורה עם המגבלה, בשילוב תפיסות חברתיות שליליות לגבי מגבלה עשוי היה לתרום להתפתחות דפוסי הימנעות אלו.

תמיכה חברתית לא נמצאה כמתווכת את הקשר בין דחק לצמיחה אישית ובריאות נפשית על אף שבשתי הקבוצות במחקר דווח על רמות גבוהות של תמיכה חברתית. בקרב אלו שגדלו עם הורה עם מגבלה התפיסה של מערכת חברתית תומכת בחייהם היום עשויה להיות תוצר של שיעור החיים החשוב שרכשו מהליווי של בני המשפחה המורחבת ודמויות בוגרות משמעותיות בחייהם.

בדומה, גם הערכה עצמית לא נמצאה כממתנת את הקשר בין דחק לצמיחה אישית ובריאות נפשית אך רמות גבוהות של הערכה עצמית דווחו גם על ידי מי שגדלו עם הורה עם מגבלה וגם על ידי אלו שגדלו עם הורים ללא מוגבלות. המקור להערכה עצמית גבוהה של מי שגדלו להורה עם מגבלה עשויה להימצא בתחומי האחריות הנרחבים והתפקידים שמילאו מגיל צעיר, התמודדויות בהן עמדו בהצלחה.

התמודדות ממוקדת בעיה נמצאה כמתווכת בקשר בין דחק לבריאות נפשית כאשר ככל שהיכולת להפעיל אסטרטגיות פתרון בעיות גבוהה יותר, הבריאות הנפשית טובה יותר. התפקידים הנוספים שמילאו בבית מגיל צעיר אלה אשר גדלו להורה עם מגבלה עשויים להוות בסיס לפיתוח יכולות אלו של התמודדות. ייתכן שהמשפחה המורחבת אשר היוותה דוגמא להתגייסות למשימה של תמיכה וליווי בילדותם גם היא מהווה מקור לגישה מעשית לפתרון בעיות. התמודדות ממוקדת רגש הראתה תוצאות הפוכות כאשר הדחק

הנתפס כתוצאה מהילדות להורה בעל מגבלה היה בעל השפעה גבוהה יותר על צמיחה אישית עבור מי שהפעילו יותר אסטרטגיות התמודדות ממוקדות רגש. ממצא זה תואם את נטייתם לכיוון התמודדות ממוקדת בעיה. החוויה של ילדות להורה עם מגבלה היא מקור לדחק נתפס גדול יותר אשר אותותיו ניכרים בדפוסי ההתקשרות להורה, בתפיסת התמיכה החברתית וברמות הבריאות הנפשית. עם זאת, בכל יתר התחומים לילדות להורה עם מגבלה לא היו השלכות משמעותיות כפי ששוער. דבר זה יכול להיות סמן להשפעות של חוויות חיים מגוונות, בשלבים שונים בהתפתחות וההתבגרות על ההסתגלות והצמיחה האישית ובעיצוב המבוגרים אשר הפכו להיות.

ממצאי מחקר זה יתרמו להעמקת ההבנה של קובעי המדיניות בתחום הזכויות של אנשים עם מוגבלויות בכלל ובפרט בתחום ההורות. מחקר זה מפנה זרקור לצרכיהם הייחודיים של מי שנולדו להורים עם מגבלה ובני משפחותיהם ועשוי לסייע בפיתוח תוכניות מותאמות להתמודדות עם האתגרים העומדים בפניהם.

## המלצות

מספר המלצות שעלו במחקר זה ברמה העקרונית והיישומית:

### ברמה העקרונית:

- ישנה חשיבות ראשית כל להכיר בקיומה של אוכלוסייה זו וצרכיה. נדרשת הבנה שזו אינה תופעה מצומצמת ונקודתית אלא אוכלוסייה רחבה ההולכת וגדלה ונדרשת לתשומת לב מקצועית. השלב הראשון בכך הוא ביסוס אומדן אמתי על היקף האוכלוסייה בפועל.
- יש צורך לשפוך אור על תופעה זו. ככל שאנשי מקצוע יפעלו לקידום השיח בנושא הורים עם מוגבלות תתאפשר חשיפתם של ילדיהם. קידום שיח פתוח על אוכלוסיה זו יאפשר לצמצם את ההסתרה והבושה המלווים את חייהם ובכך לאפשר להם להגיע ולצרוך את הסיוע והתמיכה לה הם זקוקים.
- כפי שמחקר זה הראה, מעבר לאתגרים הרבים להיות ילדים להורים עם מגבלה טומנת בחובה גם הזדמנות לנכסיי חיים רבים ומועילים. מחקר נוסף אשר יבחן עמידות וחוסן ואת תפקידיהם בעתיד ילדים אלו הינו כיוון חקירה חשוב ומשמעותי להבנה עמוקה יותר של תופעה זו. מעבר לכך, הסתת הדיון לכוזה הבוחן לא את כשירותם להורות של אנשים עם מגבלה אלא את התנאים והתמיכה היכולים לאפשר הורות מיטיבה עבור ילדיהם הינו צעד חשוב במימוש זכויותיהם של אנשים עם מגבלה כהורים.

- כפי שנידון במחקר זה, הדחק המקושר לילדות להורה עם מגבלה מועצם בשל הצורך לשמור את מגבלת ההורה בסוד וחוסר הבנתם באופן מלא של המצב והסיבה לסודיות זו. שיח פתוח והסבר ברור על מצבם של הוריהם עשוי לאפשר הקלה בדחק זה (Manby et al., 2014). מסקנה חשובה נוספת אשר עלתה ממחקר קודם בנושא (Weshler, 2009) הייתה החשיבות של פתיחת ערוצי התקשורת והתמיכה המקצועית לילדים אלו ובני המשפחה המורחבת בהבנת המצב לעומקו וההכרה כי אינם לבדם בהתמודדות זו.

#### ברמה היישומית:

- ברור ושריר כי ככל שהתערבויות יתקיימו בשלב חיים מוקדם יותר כך יגדל הסיכוי להצלחתן כאשר מדובר במענה לילדים בסיכון. הצעה לתמיכה, התערבויות מתוכננות למן הרגע הראשון עם ההורים עם המגבלה, עם ילדיהם ועם בני המשפחה המורחבת המסייעים בגידולם הינה חיונית להבטחת עתידם. אלמנט חיוני הוא סיוע שיסיר את עומס הטיפול והתפעול של חיי היום יום מכתפיהם של הילדים.
- הוכח כי תוכניות התערבות להורים תורמות לקידום רווחתם הנפשית והרגשית של ההורים וילדיהם (Olds, Sadler & Kitzman, 2007). תוכניות אשר מכוונות לתמיכה והנחיה של ההורים אלו משלבים מוקדמים הינן חיוניות. לאור העובדה שרוב האנשים עם המוגבלות מוכרים למערכות הרווחה או הבריאות התערבויות מסוג זה יכולות להתקיים כבר בשלבים מוקדמים עבור הורים אלו, ילדיהם ובני המשפחה המורחבת התומכים בהם.
- כפי שעולה מחקר זה, מערכת יחסים המכילה דאגה של האב עשויה להיות מכרעת בצמצום השפעת הדחק על ילדים להורים עם מגבלה. נושא זה מצריך שיקול ובחינה מעמיקים בכדי לייצר מודלים לעבודה עם אבות במשפחות בהן יש הורה עם מגבלה. ישנם מחסומים רבים בגיוס אבות לתוכניות התערבות הוריות בעיקר לאור התאמתם לאימהות אשר נתפסות לרב כמטפלות העיקריות והגדרת תפקידם של האבות פעמים רבות כמשני בחשיבותו לרווחת הילד. ישנו צורך להעריך מחדש תוכניות אלו ולהתאימן לשילוב מיטבי של אבות.
- תרומתה של קבוצת השתייכות, כזו שבה הם מרגישים חלק, עלתה כנושא חוזר בראיונות במחקר זה. עבור רבים מהמשתתפים קבוצת תמיכה המורכבת מילדים/בוגרים כמוהם אשר מתמודדים עם אתגרים דומים עשויה הייתה להיות משמעותית וחיונית ברבדים רבים. בעיקר חסרה להם התחושה כי הם אינם לבד בחוויותיהם. תמיכה וליווי מגיל צעיר, באופן פרטני וקבוצתי עשויה

לתרום לביסוס מרחב בטוח בו יוכלו להביע את עצמם ולהתעמת עם השאלות והתחושות שיש להם לגבי הוריהם (Weshler, 2009).

- ילדות להורה עם מגבלה עשויה להוות חוויה בלתי יציבה הן מעשית והם רגשית. היא דורשת מהילד להתאים עצמו שוב ושוב לדרישות המשתנות של בבית והן של החברה. אלו הצולחים אתגר זה, שמצליחים להישאר ממוקדים ולפעול בצורה יותרת שכלתנית ופחות רגשנית יצאו לבסוף מחוזקים מילדות זו. האתגר המרכזי במצב זה הוא כי אסטרטגיות לפתרון בעיות והתנהלות רגשית הינם כישורי חיים אותם יש ללמוד אך השיעורים החשובים הללו לא תמיד זמינים לילדים אלו מצד הוריהם. תוכניות התערבות אישיות המכוונות להקניית כישורים אלו עשויים לסייע באופן משמעותי לילדים להורים עם מגבלה.
- רבי שלמה קרליבך באמירתו כי "כל ילד זקוק למבוגר אחד שיאמין בו" היטיב לתבוע רעיון חשוב זה. כולנו מייחלים למישהו שיראה אותנו באמת, על כל מרכיבינו ויאמין בפוטנציאל הגלום בנו. אנו זקוקים לאנשים שיראו לא רק את הקנקן שאנו אלא יגדילו לראות את התוכן שלנו- את סיפור החיים שלנו על מלואו ויאמינו שהשקעה בנו היא בעלת ערך משמעותי. זהו תמציתו של ההבדל שעשו דמויות משמעותיות בחייהם של משתתפי המחקר. כל ילד זקוק למנטור שיראה אותו, וודאי אותם ילדים אשר בחייהם חסרות דמויות חיוביות ומשמעותיות. בין אם נבחר עבורם או על ידיהם, בין אם דמויות משמעותיות טבעיות שנמצאות בסיבתם או דמויות רשמיות שמונו לתפקיד זה לדמויות אלו ניכר כי הן נכס שלא יסולא בפז ויש להן תפקיד משמעותי בעיצוב זהותם העתידית.

## **סיכום**

דמיין זיכרון ילדות. מי היה שם לסייע בהכנת שיעורי הבית? מי ישב ליד מיטתך כאשר חלית? עם מי נועצת כאשר נתקלת בבעיה? עבור רובינו הורינו הן הדמויות אשר היו שם ברגעים המשמעותיים האלה ואחרים. עבור הילדים להורים עם מגבלה זיכרונות אלו הם מורכבים יותר ולרוב משלבים דמויות שאינן בהכרח הוריהם.

בזמנים אלו, בהם מתבססות עוד ועוד זכויותיהם של אנשים עם מוגבלויות ובהן הזכות להורות נושא זה בעל חשיבות גדולה להבנה. אחרי שנים של עיסוק בתחום זה, אני מאמינה כי יש לנו עוד הרבה מה ללמוד על אוכלוסיה זו של ילדים שגדלו, או גדלים היום עם הורים עם מוגבלות. מספרם המוערך גדול יותר מהנתונים הידועים לנו בפועל והוא רק הולך וגדל, נתון המדגיש עוד יותר את הצורך להבין את צרכיהם, צרכי הוריהם ואלו של בני המשפחה המורחבת התומכים בהם.

המיעוט בשיחה הציבורי בנושא הוא אחת הסיבות המרכזיות לבידוד של ילדים רבים הגדלים עם הורה עם מגבלה ואשר אותו הם נושאים הלאה לחייהם הבוגרים. ככל שנרבה לשאול, לחקור, לכתוב ולדבר על הנושא כך נקדם פיתוחם של מענים נחוצים לאוכלוסייה זו. כולי תקווה כי מחקר זה יהווה מקפצה חשובה לשיח זה. הילדות להורה עם מגבלה מובאת במחקר זה כמקור לדחק הנוגע בכל תחומי החיים ואם זאת קולותיהם של ילדים אלו משקפים את האפשרות לעתיד בהיר וחיובי, לצמיחה והסתגלות לצד אתגרים אלו.

#### אנשי מקצוע להם מחקר זה רלוונטי

1. עובדים סוציאליים במחלקות הרווחה
2. סטודנטים לעבודה סוציאלית
3. מפקחי משרד הרווחה
4. חוקרים בתחום המוגבלויות
5. אנשי טיפול במסגרות בקהילה
6. אנשי חינוך

#### המלצות למחקרי המשך

1. חוויותיהם של ילדים צעירים להורים עם מגבלה
2. סקירת המענים הקיימים להורים עם מגבלה
3. הערכת היקפי האוכלוסייה
4. בחינת מרכיבי החוסן של ילדים להורים עם מגבלה
5. קווי דמיון/שוני בין ילדים להורים עם מגבלות שונות

## נספחים

### שאלוני המחקר

שלום רב,

המחקר בו אתה משתתף מתנהל בבית הספר לעבודה סוציאלית ע"ש גבי ולואיס וייספלד באוניברסיטת בר-אילן.

המחקר עוסק בהסתגלות לחיים הבוגרים של אנשים שגדלו במשפחות שונות- מי עם הורה בעל מגבלה ומי עם הורה שאיננו בעל מגבלה, במטרה להבין את הגורמים השונים התורמים להסתגלות זו. המחקר מיועד לאנשים בגילאי 25-50.

לפניך מספר שאלונים. השאלונים מנוסחים בלשון זכר אך פונים לנשים וגברים כאחד.

עבור כל שאלון מצורפות הנחיות למילוי השאלון. אנא עקוב אחר ההנחיות והשלם את השאלון. זמן מילוי השאלון הוא כ-20 דק'.

אנו מודים לך על נכונותך להשתתף במחקר זה ולתרום להרחבת הידע בנושא. המחקר חסוי ונערך תוך שמירה על סודיות מרבית, ולא ייעשה שימוש בפרטים מזהים במחקר.

ניתן לסרב למלא את השאלונים או להפסיק את מילוי השאלונים בכל עת ללא השלכות אישיות עבורך כתוצאה מכך.

מענה על השאלון מהווה הסכמה להשתתפות במחקר.

באם השאלונים עוררו אי-נוחות והנך זקוק לתמיכה, ובכל שאלה נוספות ניתן לפנות אל:

דורית ושלר- החוקרת: [mehkarhistaglut1@gmail.com](mailto:mehkarhistaglut1@gmail.com)

ד"ר ליאורה פינדלר- המנחה המקצועית- [findler@biu.ac.il](mailto:findler@biu.ac.il)

**The Perceived Stress Scale (PSS: Cohen, Kamarck, & Mermelstein, 1983)**

לפניך מספר שאלות על הרגשתך ומחשבותיך בחודש האחרון. לגבי כל שאלה סמן בבקשה באיזו מידה הרגשתה או חשבת כך בחודש האחרון.

הרבה מאוד	לעיתים קרובות	לפעמים	לעיתים רחוקות	אף פעם		
5	4	3	2	1	1	בחודש האחרון, באיזו מידה התרגזת בגלל משהו שקרה באופן בלתי צפוי?
5	4	3	2	1	2	בחודש האחרון, באיזו מידה הרגשת חוסר שליטה בדברים החשובים בחייך?
5	4	3	2	1	3	בחודש האחרון, באיזו מידה הרגשת עצבני ולחוץ?
5	4	3	2	1	4	בחודש האחרון, באיזו מידה הרגשת בטוח ביכולתך לטפל בבעיותיך האישיות?
5	4	3	2	1	5	בחודש האחרון, באיזו מידה הרגשת שדברים מתפתחים בהתאם לרצונותיך?
5	4	3	2	1	6	בחודש האחרון, באיזו מידה גילית שאין ביכולתך להתמודד עם כל הדברים שעליך לעשות?
5	4	3	2	1	7	בחודש האחרון, באיזו מידה הצלחת לשלוט בדברים מטרידים בחייך?
5	4	3	2	1	8	בחודש האחרון, באיזו מידה הרגשת שאתה שולט במצב?
5	4	3	2	1	9	בחודש האחרון, באיזו מידה התרגזת בגלל דברים שאינם בשליטתך?
5	4	3	2	1	10	בחודש האחרון, באיזו מידה הרגשת שהקשיים מצטברים עד כדי כך שלא יכולה להתגבר עליהם?

**Experience in Close Relationships scale (ECR: Brennan, Clark & Shaver, 1988)**

המשפטים שלפניך מתייחסים לאופן שבו אתה מרגיש במערכות יחסים קרובות עם אנשים אחרים. המונח 'אנשים אחרים' מתייחס לאנשים הנמצאים ביחסים קרובים אתך. אנו מתעניינים בדרך שבה אתה חווה בדרך כלל מערכות יחסים. התייחס לכל משפט על ידי דרוג עד כמה אתה מסכים או אינך מסכים אתו.

		מסכים ולא מסכים					מאוד	
		מסכים					מסכים	
		במידה שווה					מסכים	
7	6	5	4	3	2	1		
7	6	5	4	3	2	1	.1 אני מעדיף לא להראות לאנשים אחרים כיצד אני מרגיש בפנים	
7	6	5	4	3	2	1	.2 אני מודאג מכך שאנטש	
7	6	5	4	3	2	1	.3 אני מרגיש בנוח להיות קרוב לאנשים אחרים	
7	6	5	4	3	2	1	.4 אני דואג לגבי מערכות היחסים שלי	
7	6	5	4	3	2	1	.5 אני מתרחק כאשר אנשים מתחילים להתקרב אלי	
7	6	5	4	3	2	1	.6 אני דואג שלאנשים אחרים לא יהיה אכפת ממני באותה מידה שבה לי אכפת מהם	
7	6	5	4	3	2	1	.7 אני מרגיש לא נוח כאשר אנשים רוצים להיות קרובים אלי	
7	6	5	4	3	2	1	.8 אני דואג מכך שאאבד את האנשים הקרובים לי	
7	6	5	4	3	2	1	.9 אני לא מרגיש נוח להיפתח לאנשים אחרים	
7	6	5	4	3	2	1	.10 הייתי רוצה שרגשותיהם של אנשים אחרים כלפי יהיו חזקים כמו רגשותיי כלפיהם	
7	6	5	4	3	2	1	.11 אני רוצה להתקרב לאנשים אחרים אבל אני ממשך לסגת מהם	
7	6	5	4	3	2	1	.12 לעתים קרובות אני רוצה להתמזג באופן מוחלט עם אנשים אחרים, וזה לפעמים מרחיק אותם ממני	

7	6	5	4	3	2	1	13. אני נעשה מתוח כאשר אנשים אחרים מתקרבים אלי יותר מדי
7	6	5	4	3	2	1	14. אני חושש מלהיות לבד
7	6	5	4	3	2	1	15. אני מרגיש נוח לחלוק את המחשבות והרגשות הפרטיים שלי עם אנשים אחרים
7	6	5	4	3	2	1	16. הרצון שלי להיות מאוד קרוב, לעתים מרחיק ממני אנשים
7	6	5	4	3	2	1	17. אני מנסה להימנע מלהתקרב יותר מדי לאנשים אחרים
7	6	5	4	3	2	1	18. אני נזקק להרבה אישורים לכך שאני אהוב על ידי אנשים הקרובים לי
7	6	5	4	3	2	1	19. אני מרגיש שקל לי יחסית להתקרב לאנשים אחרים
7	6	5	4	3	2	1	20. לפעמים אני מרגיש שאני מכריח אנשים אחרים להראות יותר רגשות ויותר מחויבות
7	6	5	4	3	2	1	21. קשה לי להיות תלוי באנשים אחרים
7	6	5	4	3	2	1	22. אינני דואג לעתים קרובות מדי מכך שינטשו אותי
7	6	5	4	3	2	1	23. אני מעדיף שלא להיות קרוב מדי לאנשים אחרים
7	6	5	4	3	2	1	24. אם אינני מצליח לגרום לאנשים אחרים להראות בי עניין, אני נעשה כועס או מתוסכל
7	6	5	4	3	2	1	25. אני מספר לאנשים הקרובים לי הכל
7	6	5	4	3	2	1	26. אני מרגיש שאנשים אחרים אינם רוצים להתקרב כפי שאני הייתי רוצה
7	6	5	4	3	2	1	27. בדרך כלל אני דן בבעיות ובדאגות שלי עם אנשים הקרובים לי

7	6	5	4	3	2	1	כאשר אני לא מעורב במערכת יחסים, אני מרגיש חרדה וחוסר בטחון מסוים	.28
7	6	5	4	3	2	1	אני מרגיש נוח להיות תלוי באנשים אחרים	.29
7	6	5	4	3	2	1	אני נעשה מתוסכל כאשר אנשים אחרים לא נמצאים אתי במידה בה הייתי רוצה שיהיו	.30
7	6	5	4	3	2	1	לא אכפת לי לפנות לאנשים אחרים על מנת לבקש נחמה, עצה או עזרה	.31
7	6	5	4	3	2	1	אני נעשה מתוסכל אם אנשים אחרים אינם זמינים כאשר אני זקוק להם	.32
7	6	5	4	3	2	1	זה עוזר לפנות לאנשים אחרים ברגעים שאני זקוק להם	.33
7	6	5	4	3	2	1	כאשר אנשים אחרים אינם נותנים לי אישור, אני מרגיש ממש רע לגבי עצמי	.34
7	6	5	4	3	2	1	אני פונה לאנשים אחרים בקשר להרבה דברים כולל נחמה ואישור	.35
7	6	5	4	3	2	1	זה מעורר בי התנגדות כאשר אנשים קרובים לי מבליים זמן רחוק ממני	.36

**Posttraumatic Growth Inventory (PTGI: Tedeschi & Calhoun, 1996)**

חווית הילדות שונה מבית לבית וממשפחה למשפחה. אנא ציין את המידה בה חשת את כל אחת מן התחושות הבאות, בעקבות הילדות בבית בו גדלת

במידה רבה מאד	במידה רבה	במידה בינונית	במידה מועטה	במידה מועטה מאד	בכלל לא	
5	4	3	2	1	0	1. פיתחתי סדרי עדיפויות משלי לגבי מה חשוב לי בחיי
5	4	3	2	1	0	2. יש לי הערכה רבה יותר לגבי החשיבות והערך של חיי
5	4	3	2	1	0	3. פיתחתי תחומי עניין ייחודיים
5	4	3	2	1	0	4. יש לי תחושה חזקה שאני יכול לסמוך על עצמי
5	4	3	2	1	0	5. יש לי הבנה טובה יותר של נושאים רוחניים
5	4	3	2	1	0	6. נוכחתי שאני יכול לסמוך על אנשים אחרים בעתות מצוקה
5	4	3	2	1	0	7. עיצבתי מסלול ייחודי לחיי
5	4	3	2	1	0	8. יש לי תחושה חזקה יותר של קירבה לאחרים
5	4	3	2	1	0	9. אני מוכן יותר לבטא את רגשותיי
5	4	3	2	1	0	10. אני בטוח יותר שאני מסוגל להתמודד עם קשיים

במידה רבה מאד	במידה רבה	במידה בינונית	במידה מועטה	במידה מועטה מאד	בכלל לא	
5	4	3	2	1	0	11. אני מסוגל לעשות דברים טובים יותר עם חיי
5	4	3	2	1	0	12. אני מסוגל לקבל טוב יותר את האופן בו דברים מתנהלים בחיי
5	4	3	2	1	0	13. אני מסוגל להעריך יותר כל יום בחיי
5	4	3	2	1	0	14. אני חש כי נפתחו בפני הזדמנויות חדשות שלא היו מתרחשות לולא הילדות בחיק משפחתי הייחודית
5	4	3	2	1	0	15. יש לי אהדה גדולה יותר לאחרים
5	4	3	2	1	0	16. אני משקיע יותר ביחסים בין-אישיים
5	4	3	2	1	0	17. אני נוטה יותר לשנות דברים שצריך לשנותם
5	4	3	2	1	0	18. יש לי אמונה דתית חזקה יותר
5	4	3	2	1	0	19. גיליתי שאני חזק יותר מאשר חשבתי
5	4	3	2	1	0	20. גיליתי עד כמה אנשים יכולים להיות נהדרים
5	4	3	2	1	0	21. אני מקבל יותר את הצורך שלי באחרים

**Rosenberg self-esteem scale (RSES: Rosenberg, 1965)**

לפניך רשימה של תיאורים העוסקים בהרגשתך לגבי עצמך. לגבי כל אחד מהם סמן את הספרה המייצגת עד כמה אתה מסכים או לא מסכים עם התאור.

מסכים מאוד	מסכים	לא מסכים	מאוד לא מסכים	
4	3	2	1	1. באופן כללי אני מרוצה מעצמי
4	3	2	1	2. לפעמים אני חושב שאני כלל לא טוב
4	3	2	1	3. אני מרגיש שיש לי מספר תכונות חיוביות
4	3	2	1	4. אני מסוגל לעשות דברים היטב כמו רוב האנשים
4	3	2	1	5. אני מרגיש שאין הרבה דברים שאוכל להתגאות בהם
4	3	2	1	6. אני בהחלט מרגיש לפעמים חסר תועלת
4	3	2	1	7. אני מרגיש בעל ערך ברמה שווה לאחרים
4	3	2	1	8. הייתי רוצה שיהיה לי יותר כבוד לעצמי
4	3	2	1	9. באופן כללי אני נוטה להרגיש כישלון
4	3	2	1	10. הגישה שלי כלפי עצמי חיובית

**The Mental Health Inventory (MHI: Veit & Ware, 1983)**

השאלות הבאות מתייחסות להרגשתך ולאופן שבו התנהלו הדברים לגבייך במשך החודש האחרון. לגבי כל שאלה סמן את הספרה הקרובה ביותר לדרך שבה אתה מרגיש.

אף פעם לא	חלק קטן מהזמן	חלק מהזמן	חלק ניכר מהזמן	רוב הזמן	כל הזמן		
6	5	4	3	2	1	1.	באיזה חלק מהזמן, במשך החודש האחרון, היו חיי היום-יום שלך מלאים באירועים, שהיו מעניינים עבורך?
6	5	4	3	2	1	2.	האם הרגשת מדוכא במשך החודש האחרון?
6	5	4	3	2	1	3.	במשך החודש האחרון, באיזה חלק מהזמן הרגשת אהוב ורצוי?
6	5	4	3	2	1	4.	באיזה חלק מהזמן, במשך החודש האחרון, היית אדם עצבני מאוד?
6	5	4	3	2	1	5.	במשך החודש האחרון, באיזה חלק מהזמן הרגשת מתוח ונוח לכעוס?
6	5	4	3	2	1	6.	במשך החודש האחרון, האם הייתה לך שליטה על התנהגותך, מחשבותיך, רגשותיך ותחושותיך?
6	5	4	3	2	1	7.	במשך החודש האחרון, באיזו תדירות הרגשת שאין לך למה לצפות?
6	5	4	3	2	1	8.	באזה חלק מהזמן, במשך החודש האחרון, הרגשת נינוח ושליט?
6	5	4	3	2	1	9.	באיזה חלק מהזמן, במשך החודש האחרון,

						הרגשת יציב מבחינה רגשית?	
6	5	4	3	2	1	.10 באיזה חלק מהזמן, במשך החודש האחרון, הרגשת עצוב ועגום?	
6	5	4	3	2	1	.11 באיזה חלק מהזמן, במשך החודש האחרון, היית מסוגל להירגע ללא קושי?	
6	5	4	3	2	1	.12 באיזו תדירות, במשך החודש האחרון, הרגשת, שאתה נתון במרה שחורה עד כי דבר לא היה יכול לעודד אותך?	
6	5	4	3	2	1	.13 במשך החודש האחרון, באיזה חלק מהזמן הרגשת חסר מנוחה, חסר שלווה או חסר סבלנות?	
6	5	4	3	2	1	.14 במשך החודש האחרון, באיזה חלק מהזמן היית מצוברח או שקוע בהרהורים?	
6	5	4	3	2	1	.15 באיזה חלק מהזמן, במשך החודש האחרון, הרגשת מעודד?	
6	5	4	3	2	1	.16 במשך החודש האחרון, באיזו תדירות נעשית מבולבל, חסר שקט או מעוצבן?	
6	5	4	3	2	1	.17 במשך החודש האחרון, באיזה חלק מהזמן היית אדם מאושר?	
6	5	4	3	2	1	.18 במשך החודש האחרון, באיזה חלק מהזמן היית במצב רוח מדוכדך?	

**The Coping Orientation to Problems Experienced (COPE: Carver et al., 1989)**

לפניך שאלות הבוחנות כיצד אנשים מגיבים למצבים קשים או לחוצים בחיי היום יום. אנא בחר את הספרה המייצגת עד כמה אתה משתמש בכל דרך התמודדות.

במידה רבה	במידה בינונית	במידה מועטה	בכלל לא	כאשר אני נתקל במצב של לחץ בחיי היום יום אני :	
3	2	1	0	אני מנסה לקבל ייעוץ ממישהו כיצד לפעול	1
3	2	1	0	אני מחפש משהו טוב בדברים שקרו	2
3	2	1	0	אני שם את אמוני באלוהים	3
3	2	1	0	אני פונה לפעילות חלופית כדי להסיח את דעתי מהמצב	4
3	2	1	0	אני מודה בפני עצמי שאיני יכול לטפל במצב ומפסיק לנסות	5
3	2	1	0	אני מסרב להאמין שזה קורה	6
3	2	1	0	אני מכריח את עצמי לחכות לזמן המתאים כדי לעשות משהו	7
3	2	1	0	אני משתמש באלכוהול או בתרופות הרגעה על מנת להרגיש טוב יותר	8
3	2	1	0	אני מספר בדיחות בנוגע למצב	9
3	2	1	0	אני חש מצוקה נפשית רבה ומוצא את עצמי מבטא זאת במידה ניכרת	10
3	2	1	0	אני לומד לחיות עם זה	11
3	2	1	0	אני מנסה למנוע מדברים אחרים להפריע למאמצי לטפל במצב	12
3	2	1	0	אני מנסה לקבל תמיכה רגשית מחברים או קרובי משפחה	13
3	2	1	0	אני חושב איך אוכל להסתדר עם המצב בצורה הטובה ביותר	14
3	2	1	0	אני עושה מה שצריך לעשות צעד אחר צעד	15

במידה רבה	במידה בינונית	במידה מועטה	בכלל לא	כאשר אני נתקל במצב של לחץ בחיי היום יום אני :	
3	2	1	0	אני מרכז את כוחותיי כדי לעשות משהו	16
3	2	1	0	אני קובע תוכנית פעולה	17
3	2	1	0	אני משלים עם העובדה שזה קורה ושזה ניתן לשינוי	18
3	2	1	0	אני מצוברח ואני מודע לכך	19
3	2	1	0	אני מדבר עם מישהו על רגשותיי	20
3	2	1	0	אני שם בצד דברים אחרים כדי להתרכז במצב	21
3	2	1	0	אני מצמצם את כמות המאמץ שאני משקיע בפתרון הבעיה	22
3	2	1	0	אני ישן יותר מדי	23
3	2	1	0	אני מתפלל הרבה	24
3	2	1	0	אני מנסה לדבר עם מישהו שיכול לעשות משהו ממשי ביחס למצב	25
3	2	1	0	אני לומד משהו מההתנסות עם המצב	26
3	2	1	0	אני מתבדח ביחס למצב	27
3	2	1	0	אני משתמש באלכוהול או בתרופות הרגעה כדי לעזור לעצמי לעבור את המצב	28
3	2	1	0	אני עוצר בעד עצמי מעשיית משהו מוקדם מדי	29
3	2	1	0	אני מתנהג כאילו זה כלל לא קרה	30

**The Multidimensional Scale for Perceived Social Support (MSPSS: Zimet et al., 1988)**

השאלות הבאות עוסקות בהרגשתך לגבי מערכות יחסים עם בני המשפחה וחברים בחיך. קרא כל משפט וציין באיזו מידה הוא מתאים להרגשתך כרגע.

		לא מתאים במידה רבה מאוד			מתאים ולא מתאים במידה שווה			מתאים במידה רבה מאוד	
		7	6	5	4	3	2	1	
1.	יש אדם קרוב הנמצא בקרבתך כאשר אני זקוק לו	7	6	5	4	3	2	1	
2.	יש אדם קרוב שאני יכול לשתף בצער ובשמחה	7	6	5	4	3	2	1	
3.	משפחתי מנסה באמת לעזור לי	7	6	5	4	3	2	1	
4.	אני מקבל ממשפחתי את העזרה והתמיכה הרגשית שאני זקוק לה	7	6	5	4	3	2	1	
5.	יש אדם קרוב אלי המהווה עבורי מקור עידוד	7	6	5	4	3	2	1	
6.	חבריי מנסים באמת לעזור לי	7	6	5	4	3	2	1	
7.	אני יכול לסמוך על חבריי כאשר מתעוררות בעיות	7	6	5	4	3	2	1	
8.	אני יכול לשוחח על בעיותיי עם משפחתי	7	6	5	4	3	2	1	
9.	יש לי חברים שאותם אני יכול לשתף בשמחתי ובצערי	7	6	5	4	3	2	1	
10.	יש אדם קרוב לי שרגשותיי באמת חשובים לו	7	6	5	4	3	2	1	
11.	משפחתי מוכנה לעזור לי לקבל החלטות	7	6	5	4	3	2	1	
12.	אני יכול לדבר על בעיותיי עם חבריי	7	6	5	4	3	2	1	

**Parental Bonding Instrument (PBI: Parker, Tupling & Brown, 1979)**

לפניך רשימה של משפטים. ציין באיזו מידה מתאר כל משפט את התנהגותם של אמך ושל אביך כלפיך  
**בילדותך**. מלא עבור כל הורה את השאלות בנפרד בטור המתאים.

בשאלון זה ענה על תחושותייך לגבי **אמך** בילדותך

דומה מאד לאמי	דומה במקצת לאמי	לא דומה במיוחד לאמי	לא דומה כלל לאמי	
4	3	2	1	1. דיברה אלי בקול חם וידידותי
4	3	2	1	2. עזרה לי ככל שזקקתי
4	3	2	1	3. הרשתה לי לעשות דברים שאהבתי לעשותם
4	3	2	1	4. הייתה קרירה ברגשותיה כלפי
4	3	2	1	5. הבינה את בעיותיי ודאגתיי
4	3	2	1	6. התייחסה אלי בחמימות
4	3	2	1	7. אהבה שאקח החלטות בעצמי
4	3	2	1	8. רצתה שאתבגר
4	3	2	1	9. ניסתה לשלוט בכל דבר שעשיתי
4	3	2	1	10. פלשה לתוך הפרטיות שלי
4	3	2	1	11. נהנתה לשוחח איתי
4	3	2	1	12. חייכה אלי לעיתים קרובות
4	3	2	1	13. נטתה להפוך אותי לתינוק
4	3	2	1	14. גילתה הבנה לרצונותיי וצרכי
4	3	2	1	15. הניחה לי להחליט באופן עצמאי
4	3	2	1	16. גרמה לי להרגיש לא רצוי

4	3	2	1	יכולה הייתה לגרום לכך שארגיש טוב יותר כשהיית מתוסכל	.17
4	3	2	1	דיברה איתי הרבה	.18
4	3	2	1	ניסתה להפוך אותי לתלוי בה	.19
4	3	2	1	הרגישה שאינני מסוגל להסתדר בעצמי	.20
4	3	2	1	נתנה לי חופש ככל שרציתי	.21
4	3	2	1	הניחה לי לצאת ככל שביקשתי	.22
4	3	2	1	הגנה עלי יותר מדי	.23
4	3	2	1	נהגה לשבח אותי	.24
4	3	2	1	הניחה לי להתלבש כמו שרציתי	.25

אם בחרת לא לענות על השאלות הנוגעות לאמך אנה ציין מדוע:

לא הכרתי את אימי

אימי לא נחכה בחיי כלל

אחר

בשאלון זה ענה על תחושותייך לגבי **אבין** בילדותך

דומה מאד לאבי	דומה במקצת לאבי	לא דומה במיוחד לאבי	לא דומה כלל לאבי	
4	3	2	1	.1 דיבר אלי בקול חם וידידותי
4	3	2	1	.2 עזר לי ככל שנזקקתי
4	3	2	1	.3 הרשה לי לעשות דברים שאהבתי לעשותם
4	3	2	1	.4 היה קריר ברגשותיו כלפי
4	3	2	1	.5 הבין את בעיותיי ודאגותיי
4	3	2	1	.6 התייחס אלי בחמימות
4	3	2	1	.7 אהב שאקח החלטות בעצמי
4	3	2	1	.8 רצה שאתבגר
4	3	2	1	.9 ניסה לשלוט בכל דבר שעשיתי
4	3	2	1	.10 פלש לתוך הפרטיות שלי
4	3	2	1	.11 נהנה לשוחח איתי
4	3	2	1	.12 חייד אלי לעיתים קרובות
4	3	2	1	.13 נטה להפוך אותי לתינוק
4	3	2	1	.14 גילה הבנה לרצונותי וצרכי
4	3	2	1	.15 הניח לי להחליט באופן עצמאי
4	3	2	1	.16 גרם לי להרגיש לא רצוי
4	3	2	1	.17 יכול היה לגרום לכך שארגיש טוב יותר כשהיית מתוסכל
4	3	2	1	.18 דיבר איתי הרבה

4	3	2	1	ניסה להפוך אותי לתלוי בו	.19
4	3	2	1	הרגיש שאינני מסוגל להסתדר בעצמי	.20
4	3	2	1	נתן לי חופש ככל שרציתי	.21
4	3	2	1	הניח לי לצאת ככל שביקשתי	.22
4	3	2	1	הגן עלי יותר מדי	.23
4	3	2	1	נהג לשבח אותי	.24
4	3	2	1	הניח לי להתלבש כמו שרציתי	.25

אם בחרת לא לענות על השאלות הנוגעות לאביך אנא ציין מדוע:

לא הכרתי את אבי

אבי לא נכח בחיי כלל

אחר

## שאלון רקע אישי

1. מין: ז/נ
2. שנת לידה: \_\_\_\_\_
3. ארץ לידה: ישראל / אחר \_\_\_\_\_
4. שנת עלייה: \_\_\_\_\_
5. דת: יהודי / מוסלמי / נוצרי / אחר: \_\_\_\_\_
6. נטייה דתית: חילוני / מסורתי / דתי / חרדי
7. האם יש לך מגבלה כלשהיא? כן/לא **אם כן באיזה תחום המגבלה:** פיזי/נפשי/שכלי/אחר
8. מצב משפחתי: רווק / נשוי או בזוגיות משמעותית / אלמן / גרושה
9. האם לבן/בת זוגך (בעבר או בהווה) יש מגבלה כלשהיא? כן/לא  
**אם כן באיזה תחום המגבלה:** פיזי/נפשי/שכלי/אחר
10. מספר ילדים (אם יש): \_\_\_\_\_
11. האם לאחד או יותר מילדיך יש מגבלה? כן/לא  
**אם כן באיזה תחום המגבלה:** פיזי/נפשי/שכלי/אחר
12. כמה אחים/אחיות יש לך: \_\_\_\_\_
13. מה מיקומך בסדר הלידה: בכור / אמצעי / הכי צעיר
14. האם לאחד או יותר מאחידך יש מגבלה? כן/לא.  
**אם כן באיזה תחום המגבלה:** נפשי/שכלי/פיזי/אחר
15. האם לאחד או יותר מהורידך יש מגבלה:
  - אין לאף אחד מהורי מגבלה
  - לאבי יש מגבלה - נפשית/שכלית/פיזית/אחרת
  - לאמי יש מגבלה - נפשית/שכלית/פיזית/אחרת
16. היכן גדלת בילדותך?
  - גדלתי במשך כל ילדותי בבית הורי
  - גדלתי ברוב ילדותי במסגרת פנימייה/משפחת אומנה
  - גדלתי במשך רוב ילדותי בקרב המשפחה המורחבת (סבים/דודים..)
17. מה היא השכלתך:
  - עד 8 שנות לימוד
  - תיכונית
  - על תיכונית/לימודי תעודה
  - אקדמית
18. האם אתה עובד כעת? כן/לא  
**אם אתה עובד כעת - האם אתה:** שכיר/עצמאי  
**אם אתה עובד כעת – מהו היקף המשרה?** משרה חלקית/משרה מלאה  
**אם אתה עובד כעת - באיזו מידה אתה מרוצה מעבודתך:** מרוצה מאד / מרוצה במידה בינונית / לא מרוצה כלל

**אם אתה עובד כעת - באיזו מידה אתה מרוצה מהקשר שלך עם השותפים לעבודה? מרוצה**

מאד / מרוצה במידה בינונית / לא מרוצה כלל

**אם אינך עובד כעת – מדוע?**

- אין לי מקצוע
- לא מקבלים אותי לעבודה
- פוטרתי מעבודתי
- אני מעדיף לנצל את הזמן לדברים אחרים
- לא מצאתי עבודה שמעניינת אותי
- אחר: \_\_\_\_\_

**19. מצב סוציו אקונומי-מה ההכנסה של התא המשפחתי שלך? מתחת לממוצע / ממוצע / מעל**

הממוצע

**20. מהם מקורות הכנסה שלך (ניתן לבחור ביותר מתשובה אחת)?**

- קצבת נכות
- משכורת אישית
- עזרה ממשפחה/חברים
- משכורת בן/בת הזוג
- חסכונות
- אחר: \_\_\_\_\_

**תודה על השתתפותך!**

**המחקר בו השתתפת הינו חסוי ופרטייך יישארו אנונימיים אלא אם כן תבחר אחרת**

נודה לך מאוד באם תסכים להשאיר את פרטייך בכדי שנוכל במידת הצורך ליצור קשר עם שאלות נוספות בנושא מחקר זה בעתיד.

שם פרטי: \_\_\_\_\_

שם משפחה: \_\_\_\_\_

טלפון ליצירת קשר: \_\_\_\_\_

דואר אלקטרוני: \_\_\_\_\_