

- 🌀 **Name of the study:** Born To Challenge- Adjustment and Personal Growth of Adults Raised by a Parent with a Mental or an Intellectual Disability
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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.



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