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Fathering Children with Disabilities

New Perspectives on
Disability Studies and
Family Care

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From: It is the mother who 'produces' the infant, it is she who 'gives' it birth. If 'the product' turns out to be defective, the mother is likely to perceive this as a defect in something she has labored to produce.... (Smith & Neisworth, 1975, in: Ferguson et al., 2020)

Over: ... The most important thing that happens when a child with disabilities is born is that a child is born. The most important thing that happens when a couple becomes parents of a child with disabilities is that a couple becomes parents... (Ferguson & Ash, 1989, 108)

To: Is there any place within the society where inclusion already exist, full-blown? And the answer is: yes! It exists within a lot of families.... (Douglas Biklen in: Including Samuel, documentary of film maker Dan Habib)

Preface

When I told people that I was preparing a booklet on fathers of children with disabilities, some of them raised their eyebrows. These are the friends and colleagues who quickly refer to the (extensive) sociological research that has been done for years on the division of labor in families.

I knew the trends, didn't I? One very influential piece of research talked about 'the second shift' (Hochschild & Machung, 1989) to show that if women were already working outside the home, when they came home, they were working much more (the second shift) than their partners were. Yes, I knew what the trends were.

Indeed, I know that despite changing perceptions about gender, work, and domestic tasks, several researchers (see e.g. Glorieux et al., 2015; Audenaert, 2023) seem to come to the same conclusions: despite increasingly involved fathers, and despite the increase in families where both partners work from home, and despite policies that should allow for a more balanced division of labor, and despite changing perceptions (especially among the highly educated), statistics show that women even if they have a job in society still spend much more time—the studies we refer to for Flanders speak of twice or at least one and a half times as much time—on housework and childcare than men. It is striking that these trends appear to be similar over time (see Bianchi et al., 2000) and across countries (see Craigh & Mullan, 2011 for international comparisons).

In fact, the conclusion is: ‘Fathers have started to contribute slightly more to childcare and domestic work, but the distribution remains unequal...’ (Audenaert, 2023).

And yet. I was looking for the father’s perspective.

When I told people that I was preparing a booklet on fathers of children with disabilities, some others also raised their eyebrows. These are the friends and colleagues who quickly refer to the (extensive) psychopathological research that has been done for years on families with children with disabilities.

Many psychopathological studies have been conducted on fathers and mothers raising children with disabilities. More recent studies have also focused very specifically on the (mental) health of the fathers (no longer as a comparison for the situation of the mothers) and also on their (un) healthy lifestyle. A more recent study in the context of Bourke-Taylor et al. (2021) used a number of online questionnaires and a few open-ended questions to address the fathers in their study. The three instruments used—the Depression Anxiety Stress Scale (DASS), the Health Promoting Activities Scale (HPAS-M), and the Fathers of Children with Developmental Challenges (FCDC) scale—already say a lot about the hypotheses from which they started. The latter scale was developed ‘...to assess fathers’ perceptions of the supports and challenges to their efforts to be involved in their children’s parenting...’ (Ly & Goldburg, 2014).

The results of this study show that fathers reported high depressive, anxious, and stress-related symptoms. Fathers were found to have low levels of participation in health-promoting activities. Fathers felt inhibited in their careers because of the care required by their child with disabilities. Fathers reported that, despite caring for their children, they received little support from services (which were mainly focused on mothers).

And yet. I was looking for the father’s perspective.

Is this a naive attempt to contradict those who raise their eyebrows? Is it a search for the one white blackbird that throws all international (research) trends off the table? Or is it an attempt to learn from the father’s perspective about the caring of men?