Research in Developmental Disabilities 35 (2014) 833–848

Contents lists available at ScienceDirect

Research in Developmental Disabilities

Resilience in families raising children with disabilities and behavior problems

David McConnell[a,*], Amber Savage[a,1], Rhonda Breitkreuz[b,2]

[a] *Family and Disability Studies Initiative, Occupational Therapy, Rehabilitation Medicine, University of Alberta, 3-66 Corbett Hall, Edmonton, AB, Canada T6G 2G4*
[b] *Gender, Family, & Policy Studies, Human Ecology, University of Alberta, 330 Human Ecology, Edmonton, AB, Canada T6G 2N1*

ARTICLE INFO

Article history:
Received 19 November 2013
Received in revised form 6 January 2014
Accepted 9 January 2014
Available online 1 February 2014

Keywords:
Family
Disabilities
Resilience
Social ecology
Behavior problems

ABSTRACT

The purpose of this study was to investigate the resilience displayed by families raising children with disabilities and behavior problems. The question is why do some families do well when others, exposed to similar stressors, struggle to keep their family life running? A stratified (by child age group) random sample of 538 families raising children with disabilities in Alberta, Canada took part. Participants completed the Family Life Survey, which incorporated measures of child behavior problems, social–ecological resources and family-level 'outcomes'. Families raising children with disabilities and behavior problems 'do well' under conditions of high social support and low financial hardship. In contrast, families with low levels of social support and high levels of financial hardship typically struggle, even when the number or intensity of child behavior problems is low. The study findings are consistent with the view that 'resilience' has more to do with the availability and accessibility of culturally relevant resources than with intrinsic, individual or family factors. With respect to family-level outcomes, strengthening social relationships and ameliorating financial hardship may be more important than behavior modification.

Despite well-documented challenges, most families bringing up children with disabilities 'do well'. However, child behavior problems increase the risk of poor family outcomes. Behavior problems can disrupt family routines and relationships, and tax family adaptive resources. Arguably, families who do well despite the stressors associated with bringing up a disabled child with behavior problems display 'resilience'. A challenge for family researchers is to account for such resilience: *why do some families do well when others, exposed to similar stressors, struggle to keep their family life running?* In this study we investigate the proposition that such resilience is context-bound. Our principal hypothesis is that families of disabled children with behavior problems do well, or at least better, under conditions of high social support and low financial hardship.

1. Background

Families of children with disabilities have to contend with many out-of-the-ordinary challenges. Some challenges may be directly related to the child's condition. Other challenges and hardships have little or nothing to do with the child's condition

---

[*] Corresponding author. Tel.: +1 780 492 7475.
E-mail addresses: david.mcconnell@ualberta.ca (D. McConnell), amsavage@ualberta.ca (A. Savage), rhonda.breitkreuz@ualberta.ca (R. Breitkreuz).
[1] Tel.: +1 780 492 5997.
[2] Tel.: +1 780 492 8568.

0891-4222/$ – see front matter © 2014 Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.ridd.2014.01.015

per se, but are rather caused by negative social responses and social arrangements that do not take their needs, interests and circumstances into account (Dowling & Dolan, 2001; Green, 2007; Olsson, 2008; Resch, Benz, & Elliott, 2012; Ryan & Runswick-Cole, 2008). Many parents and siblings, for example, feel the sting of social stigma attached to disability (Farrugia, 2009; Francis, 2012; Gill & Liamputtong, 2011; Green, 2007; Voysey, 1972); some parents struggle to retain meaningful employment and in turn, an adequate standard of living due to a lack of reasonable workplace accommodations and/or inclusive childcare arrangements (Freedman, Litchfield, & Warfield, 1995; Gordon, Rosenman, & Cuskelly, 2007; Owen, Gordon, Frederico, & Cooper, 2002; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001; Warfield, 2001); and, many are overwhelmed by the challenges involved in accessing and navigating fragmented, inflexible and/or poorly resourced service systems (Browne et al., 2013; McManus et al., 2011; Reichman, Corman, & Noonan, 2008; Rodger & Mandich, 2005).

In view of these and other challenges, heightened levels of maternal and family distress might be expected. Recent population-based studies and systematic reviews confirm that mothers of children with disabilities are two to three times more likely than mothers of non-disabled children to report clinically significant levels of depression, anxiety and/or stress (Bailey, Golden, Roberts, & Ford, 2007; Emerson, Hatton, Llewellyn, Blacker, & Graham, 2006; Emerson et al., 2010; Montes & Halterman, 2007; Singer & Floyd, 2006; Totsika, Hastings, Emerson, Lancaster, & Berridge, 2011; Vermaes, Janssens, Bosman, & Gerris, 2005; Yirmiya & Shaked, 2005). However, the *absolute risk* of such negative psychological conditions may not be as high as many people may think: a large majority of mothers and families bringing up children with disabilities appear to 'do well' (Baker, Blacher, & Olsson, 2005; Blacher & Baker, 2007; Carnevale, Alexander, Davis, Rennick, & Troini, 2006; Green, 2007; Glidden & Jobe, 2006; Olsson, 2008; Olsson, Larsman, & Hwang, 2008; Seltzer et al., 2001; Ylvén, Björck-Åkesson, & Granlund, 2006). In the United Kingdom, for example, Emerson et al. (2010) conducted secondary analysis of data from the Millennium Cohort Study and found that fewer than 25% of mothers of children with early cognitive delay were at risk of psychiatric disorder. Similarly, in the United States, Montes and Halterman (2007) conducted secondary analysis of the 2003 National Survey of Children's Health and found that fewer than 20% of mothers of children with an autism spectrum disorder (ASD) reported poor mental or emotional health.

Less research attention has focussed on fathers, siblings and the family as a whole, and the limited available data are equivocal. Several studies have found little or no significant difference between families with and without children with disabilities on measures of father, sibling and/or family wellbeing (Glidden, Bamberger, Turek, & Hill, 2010; Hatton, Emerson, Graham, Blacher, & Llewellyn, 2010; Herzer et al., 2010; Lundeby & Tøssebro, 2008; McCoyd, Akincigil, & Paek, 2010; Risdal & Singer, 2004; Rodrigues & Patterson, 2007; Walsh & O'Leary, 2013). However, other studies have found marked differences (Al-Krenawi, Graham, & Al Gharaibeh, 2011; Hartley et al., 2010; Gau et al., 2012; Higgins, Bailey, & Pearce, 2005; Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010; Neece, Blacher, & Baker, 2010; Pousada et al., 2013; Wymbs, Pelham, Molina, & Gnagy, 2008). Hartley et al. (2010), for instance, employed survival analysis to investigate prevalence and risk of divorce in a matched sample of families with and without children with ASD and found that the prevalence of divorce was higher in the ASD group (24% vs. 14%), and the risk remained relatively high over an extended period.

To explain the observed variation in outcomes among families with disabled children, a great deal of research attention has focused on child-specific factors. One of the most consistent research findings is that risk of poor outcomes increases as the number and/or intensity of child behavior problems increase (Barker et al., 2011; Blacher & McIntyre, 2006; Eisenhower, Baker, & Blacher, 2005; Gray et al., 2011; Hastings, Daley, Burns, & Beck, 2006; Herring et al., 2006; Lecavalier, Leone, & Wiltz, 2006; Orsmond, Seltzer, Krauss, & Hong, 2003; Raina et al., 2005). Indeed, studies have consistently found that maternal and other family outcomes are more strongly associated with child behavior problems than with diagnosis or disability severity. Baker, Blacher, Crnic, and Edelbrock (2002), for example, found that developmental delay in preschool age children did not contribute to maternal stress after controlling for child behavior problems. Similarly, Herring et al. (2006) found that early behavioral and emotional problems in children with disabilities contributed more to later maternal stress and family dysfunction than diagnosis or delay.

The relationship between child behavior problems and parent and family wellbeing is generally thought to be bidirectional (Hastings & Beck, 2004; Lecavalier et al., 2006; Olsson, 2008): In a downward spiral, child behavior problems may heighten parent–carer stress and family dysfunction which, in turn, may lead to ineffective coping and/or parenting practices which, in turn, may increase child behavior problems, and so on. However, the available evidence is not entirely consistent with this view. For example, in a longitudinal study of preschoolers with developmental delays, Eisenhower, Baker, and Blacher (2009) found that child behavior problems, measured at age three, predicted maternal health at ages four and five, but maternal health, measured at age three, failed to predict child behavior problems at ages four and five. Totsika et al. (2013) also found a unidirectional relationship between behavior problems and maternal wellbeing. However, they found that the 'arrow of causality' ran in the opposite direction: maternal wellbeing contributed to later behavior problems in young children with ASD, but early behavior problems did not contribute to maternal wellbeing over the long term.

1.1. Explaining resilience

Positive family adaptation in response to, or despite, the stressors associated with bringing up a child with disabilities and behavior problems may constitute evidence of resilience. The challenge for researchers lies in explaining such resilience: why do some families do well and not others? Early theories posited that family resilience was determined by within-family factors. McCubbin and McCubbin (1988), for instance, defined the study of resilience as the search for "characteristics, dimensions, and properties of families which help families to be resistant to disruption in the face of change and adaptive in