Curr Dev Disord Rep (2015) 2:100–109
DOI 10.1007/s40474-015-0040-z

INTELLECTUAL DISABILITY (R DIDDEN, SECTION EDITOR)

Stress and Resilience Among Families Caring for Children with Intellectual Disability: Expanding the Research Agenda

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Abstract Parents of children with intellectual disability (ID) tend to report higher-than-average rates of stress, anxiety and depression. Chronic psychological distress may place parents at increased risk of marital disruption, family dysfunction, and for a number of physical and mental health conditions. The prevailing approach in the literature starts from the premise that (the care needs of) the child with ID is the stressor and, in doing so, equates resilience with the successful adaptation of families *to* caring for a child with ID. This approach naturally leads to proposals for special services aimed at modifying or reforming the individual child, caregiver and/or family. In this paper, we highlight some of the limitations of a research programme that frames the problem as *family adaptation to* caring for a child with ID. We argue for expanding the research agenda to consider *the adaptation of families* caring for children with ID through greater understanding of the social-ecological constraints on families and the resources needed to meet the 'normal', everyday adaptive challenges they face.

Keywords Intellectual disability · Stress · Resilience · Ecocultural theory · Family life

Introduction

There is an extensive literature on family adjustment and adaptation to caring for a child with intellectual disability (ID). The dominant approach to research in this field starts out from the assumption that (the care needs or daily hassles associated with caring for) the child with ID is a 'stressor', defined as a threat, challenge or demand that taxes or exceeds an individual's capacity to adapt [1]. Researchers then focus on stress and coping processes and what are usually presumed to be outcomes for parents and other family members, including psychological distress and family dysfunction. This research has had a number of positive impacts. It has, for instance, helped justify services such as in-home help, psycho-educational programmes for parents and respite care. In this paper, some of the key messages from this research are reviewed. The primary purpose of this paper, however, is to highlight some of the limitations of a research programme that frames 'the problem' as *family adaptation to* caring for a child with ID. We argue that the research agenda must expand to advance understanding of *the adaption of families* caring for children with ID. Underpinning this argument is the basic premise that parents of children with ID confront the same central adaptive challenge as families with non-disabled children: they are families first. Like other parents, they have to weave together varied family interests and activities into a sustainable daily routine, i.e., a routine that satisfactorily answers the question: *How are we to reconcile what we want for our children, ourselves and our family with what is possible given our circumstances*?

Stress

Numerous studies have found higher than 'population normal' rates of psychological distress among mothers and, less consistently, fathers of children with ID. Recent population-based studies and systematic reviews confirm that mothers of pre-adult children with ID are two to three times more likely than mothers of typically developing children to report clinically significant levels of stress, anxiety and depression [2, 3, 4•, 5].

This article is part of the Topical Collection on *Intellectual Disability*

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Parents of adult children with ID may enjoy better mental health [6, 7, 8••]. However, there is some albeit limited evidence that mothers of adult children with ID are at increased risk for physical health conditions that are etiologically associated with chronic stress, such as obesity, cardiovascular disease, auto-immune diseases and gastro-intestinal disorders [8••, 9, 10••, 11]. Chronic stress may also underlie the (marginally) increased risk for families of children with ID of marital disruption and family dysfunction (e.g., low cohesion, emotional withdrawal, relationship conflict and child maltreatment) [12–18]. Selected recent study findings are summarised in Table 1.

Over the last two decades, researchers have opened the 'black box',[1] that is, to consider mechanisms or mediators that might explain the association between child ID and what are presumed to be negative psychological impacts or outcomes. A key research finding is that (a) children with ID are more likely to exhibit internalising and externalising behaviour problems in comparison with typically developing children, and (b) in the absence of significant child behaviour problems, parents of children with ID do not, on average, report heightened levels of distress [4•, 16, 27, 28]. Furthermore, several prospective studies have found that child behaviour problems predict later parent stress, and this may mediate the relationship between child behaviour problems and family dysfunction [29–33]. Baker et al. [13], for example, found that the behaviour problems of children with Fragile X had an indirect effect on family cohesion and marital satisfaction by way of maternal internalising symptoms. Of course, this body of research does not really explain why certain behaviours are problematic or stressors for parents and families.[2] Moreover, parent distress may be the antecedent rather than the outcome of child behaviour problems: High parent distress is associated with less optimal parenting and more negative parent-child interaction which, in turn, predicts child behaviour problems. However, the relationship between child behaviour problems and parent distress is generally considered transactional [29, 31, 33, 34].

When children with ID (or the behaviour problems they exhibit) are conceptualised as stressors, the inclination to interpret parental distress and family dysfunction as stress reactions or negative impacts may be irresistible, yet the vast majority of studies in the field are correlational, and plausible alternative explanations have not been ruled out. First, it is possible that the association between child ID and parent psychological distress is the result of psychological distress increasing the risk of ID in children. There is compelling evidence that poor parental mental health can have an impact on the cognitive development of children, for example, by way of unresponsive care (low investment) or negative parent-child interactions [35–37]. Second, the association between child ID and parent psychological distress may be explained by a third (confounding) variable. Socioeconomic disadvantage, for example, is causally related to (mild) ID *and* parental mental health, as well as child behaviour problems and family dysfunction [23, 38••, 39–41]. The higher-than-population normal levels of psychological distress found among families of children with ID might therefore be attributable to pre-existing socioeconomic disadvantage (the distal cause), rather than child ID per se. Notably, a series of population-based studies over the last decade have found that the increased risk of parental psychological distress associated with child disability is markedly attenuated when socioeconomic disadvantage is adequately taken into account [42–44]. Emerson et al. [38••], for example, conducted a secondary analysis of the Millennium Cohort Study in the UK and found that after matching on socioeconomic variables, probable psychiatric disorder was no more likely to be found among fathers of children with early cognitive delay, and the strength of this association for mothers was substantially diminished.

Another possibility is that the higher-than-normal levels of distress and dysfunction found among families of children with ID are the product of disablism, rather than any characteristic of the child. Researchers and parents themselves have challenged the (usually) tacit assumption that having a child with ID is inherently, essentially or inevitably negative [45–48]. Some researchers have focused attention on the harmful consequences of culturally ubiquitous prejudices: Disability is generally assumed to be aberrant, tragic and pitiable [49–52]. Such cultural beliefs reify parent grief and parent efforts to normalise their child, often at great personal cost [53–56]. Further, owing to such beliefs, parents may feel the sting of social stigma attached to disability and suffer the hurt of social exclusion [57, 58•, 59, 60]. Other researchers have focused attention on socioeconomic deprivations. For example, the opportunity for parents of children with ID to participate in the workforce and generate income is limited by inflexible employment conditions (e.g., inflexible work hours) and unequal access to childcare resources [7, 61–63]. Formal and informal childcare are recognised as essential for many parents (with or without a disabled child)—enabling them to juggle work and family demands—but inclusive childcare settings are in short supply [64, 65]. Such inequitable access to resources may explain, at least in part, why four out of ten parent carers in Canada report reducing their work hours and why one in five have quit work altogether [66]. In turn, reduced workforce participation may explain, at least in part, why families of children with ID are more likely to be exposed to adverse socioeconomic conditions [62, 67].

Out-of-the-ordinary time demands may further stack the odds against families of children with ID. Time-use studies

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[1] 'Black box epidemiology' is a derogatory label given to the simple identification of exposure-disease relationships [26]

[2] Behavior problems may demand a higher degree of vigilance on the part of parents (which may exhaust self-regulatory resources) and are a potential threat to a family's social respectability and inclusion.

Table 1 Selected comparison studies, 2010–2015

	Design/sample	Primary measure(s)	Outcomes
Parental distress and physical well-being			
[19]	Cross-sectional design Clinical sample: Australia Parent carers aged 55–64 years ($n=20$), 65–74 ($n=25$) and 75+ ($n=14$) of an adult child with ID compared to age-matched population norms	MOS SF-12 Physical Component Scale (PCS) and Mental Component Scale (MCS)	PCS: mean; higher score indicates better health 55–64=44.6, AUS norm=46.6 [*ns*] 65–74=42.3, AUS norm=42.8 [*ns*] 75±=35.9, AUS norm=38.5 [*ns*] MCS: mean; higher score indicates better health 55–64=36.5, AUS norm=50.8 [$p<0.05$] 65–74=47.7, AUS norm=51.3 [*ns*] 75±=48.6, AUS norm=51.8 [*ns*]
[8••]	Longitudinal secondary data analysis Population sample: USA Parent carers of an adult child with IDD ($n=220$) and TCG ($n=1042$). Analysis completed at midlife and again at early older age, comparing those co-residing (*r*) and not co-residing (nr) with their adult child	Center for Epidemiologic Studies Depression Scale (CES-D) Self-rated health, BMI, cardiovascular impairment, Health Utility Index (HUI)	At midlife CES-D: mean (SD); risk of clinical depression (score >15) IDD(r)=8.8 (8.2), IDD(nr)=9.2 (7.8), TCG=8.1 (7.1) [*ns*] Self-rated health: mean (SD); higher score=better health IDD(r)=4.1 (0.68), IDD(nr)=4.2 (0.57), TCG=4.2 (0.64) [*ns*] Parents of grown children with IDD(r) had more cardiovascular problems than TCG [ES=0.24]. At early older age CES-D: IDD(r)=8.8 (8.8), IDD(nr)=7.7(7.3), TCG=6.5(6.6), IDD(r) differed significantly from TCG [ES=0.30] Self-rated health: IDD(r)=3.8(0.83), IDD(nr)=3.8 (0.95), TCG=3.9 (0.85) [*ns*] HUI: Parents of adult children with IDD had significantly poorer HUI scores than TCG [IDD(r) ES=0.40; IDD(nr) ES=0.24] BMI: Parents of adult children with IDD(r) had a significantly higher BMI than IDD(nr) [ES=0.34] and TCG [ES=0.35]
[4]	Cross-sectional secondary data analysis Population sample: UK Mothers of a child aged 5–16 years with ID ($n=590$), ASD ($n=47$), ID and ASD ($n=51$) and TCG ($n=17{,}727$)	General Health Questionnaire (GHQ-12)	GHQ-12: % Probable emotional disorder (score >2) ID=32 %; ASD=44 %; ID and ASD=44 %; TCG=24 % [$X^2=40.12$, $p<0.001$. ES=0.047] Controlling for child age and gender, socioeconomic disadvantage and child problem behaviours, ASD significantly increased the odds for maternal emotional disorder (OR=1.82), while ID did not (OR=1.02)
[20]	Cross-sectional design Clinical sample: India Mothers of a child aged 3–6 years with ID living in urban India ($n=47$) compared to population norms	Parenting Stress Index (PSI-SF)	PSI-SF: mean (SD); clinically significant stress (score >90) 104.69 (22.54) 77 % reported clinically significant stress Scores were significantly higher than those reported by comparable mothers in Canada [95.9 (17.2), $t=2.80$, $p=0.006$], the UK [95.4, 20.3, $t=2.09$, $p=0.04$] and the USA [68.5 (29.3), $t=5.71$, $p<0.001$]
[21]	Cross-sectional design Clinical sample: Turkey Mothers of a child with ID attending special education ($n=75$), not attending special education ($n=70$) and TCG ($n=75$)	The Beck Depression Inventory (BDI) State-Trait Anxiety Inventory (STAI)	BDI: mean (SD); Turkish depression cutoff (score >17) ID attending special education=15.92 (5.8), ID not attending special education=17.61 (6.6), TCG=14.77 (6.9) [$p=0.031$] STAI mean (SD); above normal anxiety (score >60) ID attending special education=52.79 (8.7), ID not attending special education=56.73 (13.7), TCG=49.87 (6.5) [$p<0.001$]
[22]	Cross-sectional design Clinical sample: UK	MOS SF-36 Physical Component Scale (PCS) & Mental Component Scale (MCS)	PCS: mean (SD); higher score indicates better health. UK norm=50 65–74=55.31 (10.68), 75–84=50.26 (5.73), 85+=41.25 (8.41) MCS: mean (SD); higher score indicates better health.UK norm=50 65–74=32.03 (9.48), 75–84=37.26 (7.02), 85+=37.99 (9.00)

Table 1 (continued)

	Design/sample	Primary measure(s)	Outcomes
	Parent carers aged 65–74 ($n=60$), 75–84 ($n=33$), and 85+ ($n=7$) of an adult child with ID compared to population norms		
[9]	Cross-sectional secondary data analysis Population sample: Ireland Parents of a 9-year-old child with DD ($n=627$) and TGC ($n=7941$)	BMI, Prevalence of chronic conditions / disease	BMI: % considered obese DD=24.5 %, TCG=19.6 % [$p=0.005$] Chronic condition(**s**): DD=16.6 %, TCG=13.5 % [$p=0.03$] Musculoskeletal disease: DD=35.6 %, TCG=22.8 % [$p=0.003$] Respiratory disease: DD=25 %, TCG=16.2 % [$p=0.02$]
Family functioning			
[12]	Cross-sectional design Clinical sample: Israel Parents of a child <22 years with ID ($n=300$) and TCG ($n=100$)	McMaster Family Assessment Device (FAD) General Functioning Subscale	FAD: mean (SD); higher score indicates poorer functioning ID=3.12 (0.52), TCG=2.30 (4.30), $p<0.01$ No significant association was found between socioeconomic factors (parental education and source of income) and family functioning
[23]	Cross-sectional design Clinical sample: Australia Primary carers of a child aged 4–25 years with Down syndrome ($n=224$) compared to population norms	McMaster Family Assessment Device (FAD) General Functioning Subscale	FAD: mean (SD); unhealthy functioning (score >2) 1.93 (0.39); middle ($p=0.018$) and high ($p=0.009$) income groups had significantly better family function than the low-income group
[16]	Cross-sectional design Clinical sample: USA Parents of children aged 1–19 years with Smith Magenis Syndrome (SMS) and a mean IQ of 69.96 ($n=25$) compared to population norms	McMaster Family Assessment Device (FAD) General Functioning Subscale	FAD: mean (SD); unhealthy functioning (score >2) 3.3 (0.4); parent stress due to child behaviour problems were significantly reduced in families that functioned well as a unit [(F[3, 22]=7.2, $p<0.01$)]
[24]	Cross-sectional design Clinical sample: Taiwan Parents of children aged 4–17 years with Down Syndrome ($n=80$ mothers, 75 fathers) compared to population norms	McMaster Family Assessment Device (FAD) General Functioning Subscale	FAD: mean (SD); unhealthy functioning (score >2) 2.08 (0.45); social support significantly predicted family functioning ($B=-0.32$, $p<0.001$) and partially mediated the relationship between family demands and family functioning
[25]	Cross-sectional design Clinical sample: Iran Parents of a school aged child with ID ($n=115$) or ASD ($n=121$)	McMaster Family Assessment Device (FAD) Full Scale	FAD: mean (SD): Higher score indicates poorer functioning ASD=21.24 (5.46), ID=14.50 (5.91) [$p<0.001$]. Family functioning was significantly linked to informal social support ($r=-0.318$, $p<0.001$)

TCG typical comparison group, *ID* intellectual disability, *DD* developmental disabilities, *ASD* autism spectrum disorder, *IDD* intellectual and developmental disabilities, *NS* not significant, *ES* effect size, *SD* standard deviation, *OR* odds ratio have found that parents of children with disabilities devote considerably more time than parents of typically developing children to ordinary childcare tasks [68]. In addition, parents may invest considerable time and energy in the challenging process of accessing and navigating supports: Service discontinuity places a strain on families of children with disabilities [55, 69, 70], and then there is the expectation that parents will invest considerable time, energy and financial resources in the amelioration of their child's impairment (e.g., keeping appointments with professionals, implementing home programmes and so on). In a recent study, McConnell et al. [54] investigated the relationship between parent-mediated intervention for children with disabilities and family well-being. The study found that parents cut back on employment-related activities, personal leisure and family time in order to create a slot in the daily routine for the implementation of prescribed therapeutic activities. The number of cutbacks (i.e. level of parent sacrifice) was found to be positively associated with time spent implementing prescribed therapeutic activities, but negatively associated with family well-being. Notably, the observed effect of parent cutbacks on family well-being was larger than the observed effect of child characteristics, including adaptive behaviour deficits. The investigators conclude that rehabilitation professionals must weigh up the pros and cons of parent-mediated intervention and look to enfolding therapeutic activities for children with disabilities into the everyday family routine.

Locating the problem in contemporary social arrangements—rather than the child—leads to the conclusion that interventions to build resilience in families of children with ID, with the goal of helping them *beat the odds*, are insufficient. What's required is intervention at a higher level: sociopolitical action and policy reform to *change the odds* for families of children with ID.

Resilience

A point of consensus among researchers in the field is that families of children with ID face adversity, or in the very least, significant, out-of-the-ordinary adaptive challenges. Another point of consensus is that while many may struggle, most families of children with ID fare well. Although researchers have consistently found higher-than-usual rates of psychological distress among parents of children with ID, the absolute risk of psychiatric disorder may not be as large as many might think. The majority of parents caring for a child with ID are not depressed [5, 7, 71]. Furthermore, most families of children with ID report positive impacts. McConnell et al. [72•] recently surveyed a robust sample of primary parent carers of pre-adult children with disabilities in Alberta, Canada, and found that two thirds agreed or strongly agreed with the statement: "Overall, having a child with disabilities has been positive for our family". More than four out of five parents in the study reported benefits including but not limited to perspective transformation (e.g., "We have learned what is really important in life") and the strengthening of family relationships (e.g., "Our family has emerged stronger"). From a stress and coping theory perspective, such parent-reported benefits may be conceptualised as 'positive illusions' which help fuel parent efforts at coping. However, the current evidence suggests that parent-reported benefits are better viewed as veridical (i.e. corresponding to fact) accounts of positive impact and transformation [47, 48, 72•, 73].

Given the challenges and hardships faced by families of children with ID, those who fare well, in whatever way this is operationally defined, might be described as resilient. Just how much adversity a family must face before successful adaptation can be regarded as a demonstration of resilience is however a topic of debate [74]. Patterson [74] suggests that families demonstrate resilience when, despite adversity, they are competent in performing (one or more of) four core family functions including membership and family formation; economic support; nurturance, education and socialisation; and protection of vulnerable members. Ecocultural theory suggests that a sustainable daily routine may be the *sine qua non* of resilience [75, 76]. A sustainable daily routine is viable (i.e. fitted to the local ecology and family resource base) and congruent with the family's values and goals and with the needs, interests and competencies of family members [77, 78]. In most studies, however, it seems resilience among parents and families of children with ID is implicitly defined as the absence of psychological distress or family dysfunction.

The study of resilience is the search for an explanation of why it is that some families overcome adversity when others, faced with the same or a similar set of circumstances, buckle. In the family and disability field, this search has, for the most part, been enabled and constrained by psychological models of stress and coping. By starting out from the premise that (the care needs of) the child with ID is a stressor, studies informed by stress and coping theory equate resilience with the successful adaptation of families to caring for a child with ID. Although stress and coping theory is ostensibly transactional (outcomes are the product of continuous interaction over time between intrinsic and extrinsic factors), the bulk of this research has focused on intrinsic factors [e.g., 28, 61, 79–81]. This is consistent with McCubbin and McCubbin's [82] early definition of 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 the face of crisis situations" (p. 247). A number of studies have looked at the stress-buffering role of social support. However, as Emerson et al. [38••] observe, "…aspects of social context have often been relegated to the status of background noise" (p. 31).

This literature on the resilience of families caring for a child with ID has been reviewed by Grant et al. [79] and most recently by Peer and Hillman [83]. Grant et al. [79] identify three core resilience processes. These are the search for meaning (in which cognitive coping is key), maintaining a sense of control (i.e. managing difficult situations as an adjunct to making sense of them) and maintaining valued social identities (e.g., effectively combining care-giving with employment and other group memberships). Peer and Hillman [83] reviewed qualitative and quantitative articles written in English and published between 1986 and 2012 and identified three empirically supported resilience factors: dispositional optimism, problem-focused coping (including 'positive reappraisal') and social support. Dispositional optimism is the tendency to look for the positive and expect positive outcomes when confronting problems in life. Problem-focused coping involves altering internal or external situational demands and (planful) problem-solving to prevent a stressful situation from recurring. This form of coping may be juxtaposed with emotion-focused/escape-avoidancecoping strategies. The third factor, social support, may be enacted or perceived and formal or informal. The evidence suggests that it is the perception of social support from informal sources (and the feeling of belonging) that may be most uplifting [24, 25, 84–86]. An unresolved question is whether social support is a moderating factor (stress-buffer) and/or acts more directly on parent and family well-being.

A potential concern is that (1) by framing the problem as one of family adaptation to caring for a child with ID and (2) by treating the social and ecological context in which families live as a background given, research on the resilience of families caring for a child with ID has certain predictable outcomes. To some extent, the sorts of problems that are identified and, in turn, the sorts of solutions that are proposed are pre-determined. Specifically, psychological models of stress and coping quite naturally lead to proposals for 'special services' aimed at modifying or reforming the individual child, caregiver and/or family. Less consideration may be given to social-ecological constraints and resources that families of children with ID may need in order to meet the normal, everyday adaptive challenges they face. As discussed above, families of children with ID no doubt need, but have unequal access to the kinds of resources that all (or most) families need in order to successfully juggle work and family demands, such as meaningful and flexible employment and affordable childcare options.

Intervention studies offer a potentially powerful means of testing ideas about the underlying mechanisms or 'causes' of psychological distress and dysfunction among families of children with ID. If, for example, child behaviour problems explain heightened levels of psychological distress and coping strategies explain or contribute to resilience, then interventions that effectively ameliorate behaviour problems and/or equip parents with effective coping strategies should reduce psychological distress and family dysfunction. Singer et al. [87] conducted a meta-analytic review and compared outcomes across three categories of intervention for parents of children with developmental disabilities: behavioural parent training (BPT), cognitive behaviour therapy (CBT) and multi-component interventions (BPT + CBT). The authors do not report on child behaviour change but note that "…in every instance there was a significant improvement in adaptive behavior or decreases in problem behavior" (p. 363). On measures of parent distress, the average-weighted effect sizes for BFI and CBT interventions were statistically significant but small. A substantially larger average effect size was found for multi-component interventions. The investigators draw the conclusion that there are established evidence-based interventions for reducing psychological distress "…at least in middle-class mothers in the short term" (p. 357). These findings raise a number of questions including: Do risk and resilience factors vary depending on socio-economic position? Perhaps, families who are exposed to socio-economic adversity require different or additional supports.

Ecocultural theory offers an alternative theoretical approach to conceptualising and investigating the resilience of families caring for a child with ID. The theory is not inimical to stress and coping theory. Rather, it encompasses and contextualises stress and coping processes. Ecocultural theorists may argue—along with Ungar [88] and Masten et al. [89], among others—that resilience has more to do with the availability and accessibility of culturally relevant resources than with individual or intrinsic factors: If reasonably good (social and economic) resources are present, then outcomes are likely to be good. A central tenet of ecocultural theory is that all families everywhere face the same central adaptive challenge. That is, sustaining a meaningful daily routine. The theory therefore lends itself to the study of *the adaptation of* families caring for a child with ID, although researchers have applied ecocultural theory to the study of *family adaptation to* caring for a child with ID [76]. The process of sustaining a daily routine involves fitting the routine to the local ecology and family resource base. Resource fit, when family resources roughly match and support the activities the family weaves into a daily routine, is a necessary but insufficient condition for sustainability. In addition, parents try to organise their daily routine in a personally meaningful and socially respectable way. This involves fitting the daily routine to the family's values and goals and effectively juggling the varied and inevitably competing needs and interests of family members. Ecocultural theory posits that a daily routine that holds little meaning and/or revolves around the needs of any one family member is a less sustainable daily routine [76, 78, 90].

Ecocultural theory was recently applied in a multi-method study to identify predictors of resilience among families caring for children with disabilities [91]. Resilience was operationally defined as family life congruence (i.e. the extent to which the daily routine was congruent with the family's values and goals and the needs and interests of family members). A stratified random sample of 538 families caring for children with disabilities in Alberta, Canada, took part. The majority of research subjects were mothers, and most were caring for a child with ID and/or an autism spectrum disorder (ASD). The first finding of this study was that family life congruence was a stronger predictor of family propensity to place their disabled child out of home (e.g., in state care) than a widely used measure of family functioning. A second finding, which is consistent with previous research, was that parents of children with ASD, on average, reported the lowest level of family life congruence. A third finding, also consistent with previous research, was that controlling for the number and intensity of child behaviour problems [measured using the Developmental Behavior Checklist; 92] reduced the strength of the association between impairment type (diagnosis) and family life congruence to non-significance. The main hypothesis of the study, however, was that families caring for disabled children exhibiting behaviour problems 'do well' (i.e. demonstrating resilience) under conditions of high social support and low financial hardship. This hypothesis was well supported: Families with high levels of social support and low levels of financial hardship typically enjoyed average or above average family life congruence even when the number and intensity of child behaviour problems were high. While one in three families caring for a disabled child exhibiting behaviour problems reported above average family life congruence, fewer than 1 in 100 did so in the absence of high social support and low financial hardship. The study also found that families who experienced low levels of social support and high levels of financial hardship usually struggled, even when the number and intensity of child behaviour problems were low. The authors conclude that there is a need to broaden the research and policy agenda: A balanced agenda will address the social and ecological determinants of resilience, along with intrinsic factors.

There is a paucity of research evaluating interventions targeting social-ecological factors associated with psychological distress and dysfunction among families of children with intellectual or other disabilities. Peer support (parent-to-parent) interventions have perhaps received the most research attention to date. Shilling et al. [93•] have conducted one recent systematic review of this literature. A Cochrane review is also proposed [94]. Shilling et al. report that the results of qualitative and quantitative evaluations of peer support interventions confirm that these can have a positive effect on the psychological health of caregivers, although the findings are not entirely consistent. Based on a synthesis of qualitative findings from ten studies, Shilling et al. identify four themes related to benefits. The most common benefit identified was 'finding a shared social identity with other parents'. In a group with experientially similar others, parents found understanding and acceptance, which reduced their sense of isolation and enabled them to feel better able to cope. The second benefit identified was 'learning from the experience of others'. Peer support interventions can facilitate the exchange of useful, practical information, and parents learn from the experience of other parents. The third theme related to benefit is 'personal growth'. Parents report having gained strength through peer support: They were more accepting of themselves and felt more confident and in control. The fourth benefit is 'the opportunity to support others'. In several studies, parents reported that the opportunity to share their experience and support others validated their expertise as parent carers, giving them an increased sense of self-worth. Shilling et al. suggest that there is a need for more robust evaluations to enable parents and service providers to make informed decisions about the potential benefits and costs of peer support 'services'. To this, we would add that there is an urgent need for research evaluating interventions that focus on equalising economic opportunity for families of children with ID including, for example, flexible work and inclusive childcare policies.

Conclusions

In summary, caring for a child with ID is associated with an increased risk of psychological distress among parents and family dysfunction. Despite the proliferation of studies investigating what are usually presumed to be negative impacts of caring for a child with ID, the underlying mechanisms remain poorly understood. Some researchers have investigated the potentially mediating role of child characteristics. These studies have produced evidence consistent with the thesis that child behaviour problems explain the higher-than-population normal rates of psychological distress and dysfunction found among families caring for a child with ID. The implication is that strategies to ameliorate the behaviour problems exhibited by children with ID may close the well-being gap. The study of family adaptation to caring for a child with ID further suggests that parents may benefit from interventions such as behavioural parent training and cognitive behaviour therapy, which can equip them with effective coping strategies, including skills in positive reappraisal and solution-finding. Such strategies may help families 'beat the odds'.

In this paper, we have argued in favour of expanding the research agenda to consider *the adaptation of families*, and not merely *family adaptation to* caring for a child with ID. Ecocultural theory, with its focus on the universal adaptive challenge (i.e. sustaining a meaningful daily routine), may be useful in this regard. Such an orientation may help researchers and policymakers avoid the pitfalls of a research approach that builds on the dubious assumption that having a child with ID is a threat. Such pitfalls include the fundamental attribution error, which is the tendency to overestimate the impact of individual-intrinsic factors, and underestimate the influence of situational-contextual factors on behaviours or outcomes. This program of research would give equal attention to intrinsic family factors and disabling social conditions. Our own position is that there is nothing natural or inevitable about the heightened levels of psychological distress and dysfunction found among families of children with ID: These are the result of institutionalised patterns of social value (devaluing persons with disability) and contemporary social arrangements that do not take the needs, interests and circumstances of these families into account. To close the well-being gap, we think that sociopolitical action and policy reform aimed at *changing the odds*, that is by equalising opportunities for families of children with ID to sustain a meaningful daily routine, are as vital, if not more so, than interventions designed to help these families *beat the odds*.

Compliance with Ethics Guidelines

Conflict of Interest David McConnell and Amber Savage declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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- • Of importance
- •• Of major importance

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