



Family Wellness in Intellectual and Developmental Disabilities: a Balanced Approach

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Abstract

Purpose of Review The current review explores the state of the literature on wellness among families living with intellectual or developmental disability (IDD).

Recent Findings Though wellness is often defined as a process of striving for and achieving positive health, quality of life and subjective wellbeing, much of the literature on wellness in IDD has centred on struggle and negative outcomes, including experiences of stress, crisis, and mental health problems. More recent work reveals that families living with IDD are not simply fraught with negativity, and that positive experiences, such as hope, optimism, and cohesiveness, are important aspects of wellness.

Summary Many promising interventions have emerged to support the mental health of families, ultimately approaching wellness in a manner that contains both adaptive and maladaptive processes and outcomes. The current review provides an overview of this literature, describes evidence-based interventions in this context, and highlights areas for future research.

Keywords Intellectual disability · Autism · Developmental disability · Family · Wellness · Mental health

Abbreviation

IDD Intellectual and developmental disabilities

Family Wellness in IDD: a Balanced Approach

There has been considerable research examining the wellness of families where at least one member has an intellectual or developmental disability (IDD). Wellness has been defined as a multidimensional *state* that reflects positive health, quality of life and an experience of wellbeing [1], along with the “realization of the fullest potential of an individual physically, psychologically, socially, spiritually and economically, and the fulfilment of one’s role expectations in the family, community, place of worship, workplace and other settings” [2]. Others have asserted

that wellness is a *process*, where we take steps to balance these multiple domains over time in a way that enhances quality of life [3]. Wellness is closely tied to experiences of wellbeing, often with terminology used synonymously. Within the context of IDD, the discourse on wellness has traditionally focussed on characterizing and understanding the processes that explain a lack thereof, or the presence of negative experiences. There are many constructs that can fall within this program of study on pathology and maladaptation, including examinations of stress, mental and physical health problems, burden, crisis, marital discord, and poor quality of life. Research has also largely focussed on parents specifically (and mostly mothers), rather than on other members of the family (such as siblings, grandparents, or extended family members) or family systems as a whole. More recently, a focus on understanding and promoting family wellness has included the study of strengths, including constructs of growth, positive gains, hope, and positive mental health and quality of life. There has also been a diversification of interventions directed specifically at improving family wellness, often with a focus on parents. The current review provides an overview of this literature, including the study of negative and positive outcomes for families, describes evidence regarding interventions that either directly or indirectly

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improve family wellness, and highlights areas of future research.

Research on family wellness has long been characterized by the study of family struggle. Parent stress is arguably the most commonly studied construct in the negative domain, with a recent review suggesting that as a group, parents of children with IDD report greater stress compared to those without IDD, from infancy to adolescence, and that stress increases over time [4••]. Crnic and colleagues [4••] further suggest that stress is consistently associated with child clinical needs, including physical and behavioural problems or overall caregiving demands, as well as with broader ecological stressors, such as service-related issues, financial burden, and a lack of social support. Others have documented similar patterns in families caring for adults with IDD [5]. Other variables, beyond stress, further portray families of people with IDD as failing to achieve wellness. Community-based surveys of parents of people with autism, for instance, reveal that 16% report being close to or in crisis, and that negative events, mental health problems, and burden are associated with this level of family distress [6]. More recent population-based studies suggest a more nuanced dynamic between wellness and caring for someone with IDD. Totsika et al. [7•] found that after controlling for differences between groups in demographic characteristics and caring load, being informal caregivers of people with IDD was associated with poorer health status, but not with poorer quality of life. The authors suggest that reduced health status experienced in families living with IDD may be associated with socioeconomic factors (subjective poverty) and caregiving load, rather than to the presence of IDD specifically [7•].

Hastings [8••] points out that there are several important methodological issues that can lead to considering wellness in only a negative light, or to concluding that families of people with IDD do not achieve similar levels of wellness as do other families. One issue involves the kinds of questions that respondents are asked: If they are asked only about negative constructs, we are bound to only reflect on negative occurrences. Another issue involves the lack of consistent, valid measurement of constructs (or even study of consistent constructs) across studies. In a recent scoping review aimed at summarizing the conceptualizations, measures, and results of the family wellbeing literature as it pertains to families with an autistic¹ family member, Tint and Weiss [11••] suggest that the term *wellbeing* has been used interchangeably with synonyms of related outcomes, including adjustment, stress, health, depression, and quality of life. They point out that these inconsistencies can be a major barrier to developing policies focused on improving family outcomes [12]. Third, studies

¹ We recognize that there are many viewpoints with respect to selecting terms and language to describe autism and other disabilities. We use identity-first language here to reflect the preference of many autistic adults and their family members [9, 10]. At other times, we use person-first language (i.e., people with IDD), and do so equally with respect.

often lack meaningful norms with which to compare responses, failing to provide context behind what the numbers may actually mean. Lastly, there is considerable sample bias in most of these studies, including small sample sizes, convenience sampling, poor response rates, and a lack of understanding about the motivations to participate in the research.

Family life is not simply fraught with challenges and negativity. In fact, family wellness, when described in positive terms, may be as high for families of people with IDD as for those without. Hastings [8••] reanalyzed population-based data of negative outcomes for parents of children with IDD [13]. When he only examined endorsements of positive mental health, by looking at items that reflected positive outcomes (e.g., “Have you recently felt capable of making decisions about things?”), he found similar levels for families with and without IDD. Other studies document wellness as the presence of hope [14], eudaimonic wellbeing (i.e., based in meaning, self-realization) [15], optimism [16] and life satisfaction [17], revealing that many families report high levels of these constructs when adequate and appropriate supports and strategies are in place. A substantive body of work, using disability-specific questionnaires, has focussed on operationalizing and measuring the positive contributions that are made to families by having a family member with an IDD (such as the Positive Gain Scale [18]). It is important to note that the clinical characteristics and systemic factors associated with negative outcomes in parents of people with IDD are not consistently associated with positive outcomes (e.g., [19]).

Frameworks of Family Wellness in IDD

The reality of understanding wellness in the context of IDD is that it contains both adaptive and maladaptive processes and outcomes. A qualitative studies of parents reveal the kinds of rich experiences that in fact constitute wellness, which can include life enrichment, positive emotions, spirituality, and improved marital relations, as well as emotional difficulties, relationship issues, and strain [20]. Theoretical frameworks to organize and define research efforts can be useful to bring together these positive and negative elements to our discourse on wellness. Perhaps the most commonly cited framework is the Double ABCX Model [21]. This model proposes that adaptation to stressors depends on the objective characteristic of the stressor and the proliferation of other stressors (aA), family resources and supports (bB), family perceptions of the stressors (cC), and coping strategies (coping), all of which interact to adapt (xX) in a dynamic process. Despite being framed as a stress-response model, studies in the IDD literature have also used this framework to explore positive outcomes that reflect aspects of wellness. For example, Pozo, Sarriá, and Brioso [22•] investigated positive adaptations to stressors in parents of children with autism and reported that social support was associated with improved quality of life. The Family

Adjustment and Adaptation Response (FAAR) Model [23] extends the Double ABCX Model by emphasizing a family's ability to draw on their capabilities (family resources, coping behaviour) to balance the demands (stressors, ongoing family tensions, daily hassles) placed on the family unit. This model predicts periods of stability and "bonadaptation" when demands and capabilities are well balanced, as well as periods of instability, when demands outweigh the capabilities of the family [24]. One important limitation of both the Double ABCX and the FAAR Models is the focus on stressors and negative outcomes. Perry [25] proposed a model in which both positive and negative outcomes are possible, even at the same moment. This model incorporates four main components: stressors (minor and major stressors in families' lives), resources (personal and family resources), supports (from immediate family, informal social networks, formal support services), and both positive and negative outcomes. The model further asserts that although the influences of stressors are primarily negative, there is also potential for positive impact, and although the impact of resources and supports are primarily positive, there is also the potential of negative influence. Ultimately, the model is one that allows for a balanced notion of family adjustment, with potentially different processes leading to independent positive and negative outcomes. To illustrate, Minnes et al. [26••] measured parent distress and positive gain in 155 mothers of children with IDD, and investigated correlates of each, including financial hardship, coping strategies, family resources, and child characteristics. Parent coping strategies (i.e., use of reframing, parent empowerment) were found to be significant predictors of parent perceived positive gain, whereas family financial hardship and lower parent empowerment were found to be significant predictors of parent distress.

Interventions that Improve Wellness in Families

There is an emerging literature on interventions to promote wellness in families. Interventions fall into two overarching categories: those that are focussed on the child, thus indirectly improving family wellness, and those focussed on parent training aiming to directly improving family wellness. The latter type of interventions includes parent training, formal and informal supports, and mindfulness- and acceptance-based strategies.

Child-Focussed Programs

Given the inherent link between child functioning and the broader family system, it stands to reason that interventions that improve outcomes for people with IDD will indirectly promote and potentially improve family wellness. Studies have supported this hypothesis, demonstrating that community-based programs (e.g., Special Olympics) and

behavioural interventions targeting a range of skills (e.g., sleep, challenging behaviour, communication, play, sport) in people with IDD also have collateral benefits for the family unit [27–32]. Of interest, some of these community programs are designed to improve child wellness rather than to address a child's clinical challenges per se, such as with Special Olympics' focus on health, access to recreation and leisure, social inclusion, and acceptance. Findings suggest that families of children with IDD who participate in these programs exhibit reductions in negative experiences, such as stress [27, 29, 31] or parental depression [28]. Although less studied, gains in positive functioning, such as increased perceived parental control, have also been reported [32]. For example, one study examined the benefits of family recreation, where youth with IDD and their families participated together, indicating improvements in a broad range of quality of family life indicators (i.e., unity, satisfaction, health) [33]. Positive impact on family wellness has also been reported in studies using cognitive behaviour therapy to address emotional problems in children with autism who do not have an intellectual disability [34–37].

Parent-Focussed Programs

Parent Training Programs

Parent training can be broadly defined as interventions to improve parenting skills that promote the health, safety, and development of children [38]. The content of the training typically includes a broad range of activities, such as psychoeducation, coping skills development, and behaviour management. The latter involves some combination of cognitive (e.g., cognitive restructuring, goal setting) and behavioural techniques (e.g., reinforcement, extinction, contingency contracting). These interventions aim to empower parents with the knowledge and skills to help manage and improve their child's behaviour. A substantive body of literature supports their simultaneous effect on the family unit (e.g., improved parent-child interactions, family dysfunction, parent competency, parent self-efficacy) and on parent mental health (e.g., reduced depression, stress) [4••, 37, 39–43]. For example, the Incredible Years Parent Training Program (IYPT [44]) and the Stepping Stones Triple P Program (SSTP [45]), document improvements in child behaviour as well as improvements in parent affect, parent-child interactions [42], parenting styles, satisfaction, and adjustment [40, 46]. Similarly, training programs targeting parents' self-efficacy [47, 48] and problem-solving skills [49] report improvements in parents' competency, stress, and depressive symptoms.

Formal and Informal Supports

Other researchers have examined the relationship between family wellbeing and formal/informal supports for

parents, aiming to address key family needs. Emerging evidence suggests that access to formal and informal supports, such as parent information groups, social supports, and respite care, may lead to reductions in parent stress, improvements in parent wellbeing, and greater family empowerment [50–54]. For example, in a study of parents of adolescents with severe intellectual disabilities, parents' ratings of the helpfulness of informal supports (e.g., spouse, family, friends), and to a lesser extent, practical supports, were associated with improved parent wellbeing [54]. Similarly, in a study examining the effect of informal and formal social supports on subjective (self-rated health, daily somatic symptoms) and objective measures (immune dysregulation measured through blood concentration of C-reactive protein; CRP) of health in parents of children with autism, researchers found that improved parent-reported health, fewer physical symptoms, and lower CRP was associated with a higher number of formal social supports (physical therapy and respite care [55]). Gouin and colleagues [55] also reported lower levels of CRP in families with a higher number of informal social supports. In contrast, some studies of parents of children with IDD describe professional supports as unhelpful, noting a lack of expertise, poor service coordination, difficulty accessing services, and parent-professional conflict as barriers to support [56–59]. Parents described characteristics of effective professional supports as those that were easily accessed, flexible, proactive, involved collaborative partnerships between parents and healthcare professionals, and used a family-centred approach [56–59]. Parents in studies of peer support groups also expressed mixed feelings, with dissatisfaction most often related to group identity dynamics (e.g., difficulty sharing personal information with strangers, fear of comparing their child to other children, mismatch between group content and need) [60]. Positive peer support experiences, by contrast, occurred when there was shared social identity among group members (e.g., children facing similar challenges), leading parents to feel a sense of belonging/normalcy, understanding, empowerment, and personal growth [60–62].

Another emerging area of study in the IDD wellness literature is the application of positive psychology to parent wellbeing. For example, positive adult development (PAD), a parent course based on the principles of positive psychology, aims to help reduce stress among parents of children with IDD [63]. Results of a randomized controlled trial (RCT) comparing mindfulness-based stress reduction (MBSR) to PAD, demonstrated that mothers of children with disabilities who participated in both groups reported significant reductions in stress, depression, anxiety, and insomnia. There were also specific benefits to MBSR, discussed below.

Mindfulness- and Acceptance-Based Supports

Given the established research demonstrating the benefits of mindfulness-based and acceptance-based therapies to address mental health in the general population [64, 65], it is not surprising that there is an emerging literature applying these techniques to improve the wellness of families where one member has an IDD. Mindfulness-based interventions involve training in mindfulness, described as the act of intentionally and non-judgmentally attending to the present moment [66]. Interventions typically involve weekly sessions or daylong retreats, where participants are led through guided meditations and engage in daily home practices [67]. For parents of children with IDD, several mindfulness-based intervention studies have demonstrated efficacy in improving parents' mental health [51, 63]. In the RCT comparing MBSR to PAD, the MBSR group demonstrated greater improvements in sleep, anxiety, and depression [63]. More recently, Lunsky and colleagues [51] compared the effects of a 6-week mindfulness group to a 6-week support and information group for 50 parents of children with IDD. While parents in both groups reported satisfaction with the interventions, significant reductions in psychological distress were only observed in the mindfulness group [51]. For parents of children with autism specifically, several studies have demonstrated the efficacy of mindfulness-based interventions in terms of increasing parents' psychological wellbeing (i.e., psychological flexibility, quality of life), improving parent-child interactions, and reducing parental stress [68, 69].

A related set of interventions involves the application of acceptance and commitment therapy (ACT) to parents of people with IDD. The ACT model aims to help individuals accept and develop awareness of their emotions, thoughts and private experiences, and to clarify and make progress toward personal values and goals [70]. As an intervention, ACT is typically offered over 6–10 weekly sessions or as a condensed, 2-day workshop. For example, Blackledge and Hayes [70] delivered ACT to parents of children with autism through a 2-day (14-h) intervention. The workshop involved experiential exercises and meditation to help facilitate acceptance of difficult emotions/cognitions, clarification of values, and commitment toward personal goals. Post-intervention, parents reported reductions in depression and psychological distress, as well as improvements in cognitive fusion (i.e., separating thoughts from reality) and experiential avoidance. Improvements in parents' wellbeing and ability to cope with stress were reported in a shorter workshop in which ACT was delivered over two 4-h sessions, 1 week apart [71]. When delivered with an additional 1-month "refresher" session, ACT has been shown to improve mothers' perceptions of their physical health and social isolation, in addition to reducing stress and depression [72], and improving psychological flexibility, cognitive fusion, and values-consistent activities [73]. Going forward, it

will be important to further explore the effects of mindfulness- and acceptance-based supports among different participants (e.g., mothers, fathers, siblings, grandparents, family unit, caregivers of children with different types of IDD), led by different kinds of facilitators (e.g., clinicians, parents), and using more robust methodologies.

Conclusions

Previous reviews of the IDD wellness literature have identified a number of key considerations to improve the research landscape on wellness in families [8••, 11••]. This includes that (1) Most families living with IDD may not experience significant chronic distress as a result of raising a child with IDD; (2) Many family members express positive perceptions and experience positive outcomes; and (3) When families are experiencing significant stressors, in many cases, the underlying reasons for those stressors are contextual, such as poverty, which can be addressed with proper supports and policies. However, as Hastings [8••] points out, these findings are based on studies which are mostly conducted in English-speaking high-income countries, drawing attention to the need to extend research to low- or middle-income, and non-English-speaking countries to determine if these current conclusions can be generalized.

In terms of future research, this review highlights a number of areas for future study. First, it is important to consider and directly report on the perspectives of individual family members (e.g., individuals with IDD, siblings, mothers, fathers, grandparents), as well as the family unit as a whole, the latter potentially occurring through the adoption of social-ecological models of family wellbeing [8••, 11••]. Second, studying differences in these experiences across the lifespan and among different disability subgroups (e.g., autism, down syndrome, cerebral palsy) continues to be important, to understand what commonalities and differences may exist. Third, research can expand the measurement of wellness to include constructs found within the broader literature on positive psychology, such as happiness, self-determination, resilience, optimism, and thriving [74]. Fourth, although there is an emerging evidence base for interventions targeting (directly or indirectly) wellness in parents and individuals with IDD, there is a need for diverse, large-scale studies that evaluate the feasibility, efficacy, and sustainability of these interventions [4••]. The resulting understanding and evidence base can lead to broader shifts in policy and in ways that improve wellness of individuals and families alike.

Compliance with Ethical Standards

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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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