Current Developmental Disorders Reports (2018) 5:165–196
https://doi.org/10.1007/s40474-018-0146-1

INTELLECTUAL DISABILITY (Y LUNSKY, SECTION EDITOR)

Examining Wellness in Children and Youth with Intellectual and Developmental Disabilities: a Scoping Review

Yani Hamdani[1,2] · Tamara Yee[3] · Emily Rowland[2] · Amy C. McPherson[1,2,4]

Abstract

Purpose of Review This review explored the literature on wellness in children and youth with intellectual and developmental disabilities (IDD). We asked the following: (1) how is wellness conceptualized?; (2) what contributes to a sense of wellness?; (3) what is the current state of wellness research for this population?; and (4) what recommendations are there for clinical practice?

Recent Findings Wellness has been conceptualized as having multiple, overlapping dimensions (e.g., physical, psychological), which can contribute to an overarching sense of wellness when combined and balanced. Most of the wellness literature on children and youth with IDD focus on particular aspects of wellness (e.g., physical activity).

Summary Thirty-seven wellness articles related to children and youth with IDD were identified. Only two defined wellness. Most focused on physical wellness while others addressed multiple wellness dimensions, but none examined wellness comprehensively. Further research can explore what wellness interventions are relevant to children and youth themselves.

Keywords Wellness · Wellbeing · Health promotion · Intellectual and developmental disabilities · Children · Youth

Introduction

Wellness is an important concept for children and youth with intellectual and developmental disabilities (IDD), given the health inequities that exist within this population. For example, they are more likely to develop health problems (e.g., co-occurring chronic disease and/or mental illness) and experience significant challenges accessing healthcare services compared to youth without IDD [1–3]. Children and youth with IDD are more likely to experience diminished wellness as they age, as well as have an increasing number of chronic conditions and lower socioeconomic status than their nondisabled peers [4••]. In a large population-based survey of youth aged 12 to 17 years, those who were older, had specialized healthcare needs and lower socioeconomic circumstances, and had a parent with fair to poor mental health reported lower wellness across several dimensions (e.g., physical, intellectual, social, emotional) [5]. Given the recognized health disparities and prevalent secondary conditions that exist for individuals with IDD, "health" may not be the only construct to view one's existence and sense of well-being [6, 7]. Moreover, there is growing interest in approaches beyond traditional perspectives of health that focus predominantly on physical or mental health.

Wellness is a relatively abstract concept compared to health and has a number of possible meanings. It has been described as living one's life beyond conventional notions of health as the presence or absence of disease [8] and affords opportunities for "a good life" [4••, 9, 10]. Wellness has been conceptualized as having multiple, overlapping dimensions, including physical, social, psychological, emotional, spiritual, and intellectual dimensions [11]. An overarching sense of wellness can be optimized when these dimensions are combined and balanced in a person's life. Conversely, overall wellness can be compromised if a person experiences suboptimal wellness in one or more dimensions [11]. In addition, wellness

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

✉ Yani Hamdani
yhamdani@hollandbloorview.ca

[1] Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, 150 Kilgour Road, Toronto, Ontario M4G 1R8, Canada

[2] Dalla Lana School of Public Health, University of Toronto, Toronto, Ontario, Canada

[3] Cumming School of Medicine, University of Calgary, Calgary, Alberta, Canada

[4] Rehabilitation Sciences Institute, University of Toronto, Toronto, Ontario, Canada

promotion interventions for children and youth need to consider the role families play in fostering health and well-being [12]. If multiple dimensions are not considered, interventions and/or programs of research may not target the most relevant components of wellness for children and youth with IDD.

Despite this, many literature reviews have focused on a single aspect of wellness for children with disabilities (e.g., physical activity, nutrition) [13–16], or psychosocial interventions [17]. However, their links to other wellness dimensions and to an overarching sense of wellness have not been described explicitly. Understanding what contributes to an overarching sense of wellness can potentially enhance how we promote and support children and youth with IDD to live healthily and well and prevent long-lasting impacts of health inequities. The purpose of this scoping review was therefore to explore the available literature explicitly related to wellness for children and youth with IDD. The objectives were to understand the following: (1) how wellness related to children and youth with IDD is conceptualized in the literature; (2) what contributes to their experiences of wellness; (3) the current state of research on wellness for this population; and (4) recommendations for clinical practice.

Methodology

This scoping review followed the methodology proposed by Arksey and O'Malley [18], with updates from Levac, Colquhoun, and O'Brie [19], ensuring that we followed a rigorous process to complete a knowledge synthesis and comprehensively map and identify literature gaps [20]. The processes of identifying and screening for eligibility and inclusion/exclusion of articles in the review are described below and summarized in Fig. 1 [21].

Stakeholder Engagement

To ensure relevance and translation of the findings, a group of stakeholders including young people with IDD and their parents, managers of community programs addressing wellness, program delivery staff, and researchers were consulted to identify the wellness dimensions relevant specifically to young people with IDD based on their daily life or work experiences. Wellness dimensions drawn from the broader wellness literature were presented, namely physical, spiritual, psychological, social, emotional, and intellectual wellness dimensions [11]. Through consensus, the group decided that spiritual wellness and intellectual wellness were not primary concerns for young people with IDD, instead proposing occupational wellness and community participation. Table 1 provides descriptions of the wellness dimensions identified as relevant to young people with IDD.

Search Methods

Search terms including diagnostic labels (e.g., Down syndrome, autism spectrum disorder) and wellness-related terms (e.g., health promotion, well-being, social participation) generated from previous literature and with stakeholders were mapped and organized into subject headings with the assistance of a health sciences research librarian to ensure comprehensive scope of the literature. Medline, PsycINFO, Embase, and CINAHL databases were searched. Gray literature searches using Google Scholar included conference proceedings, books, and archived dissertations.

In addition, TY completed a manual searching of 10 peer-reviewed journals (e.g., *Developmental Disabilities Research Reviews*, *International Journal of Wellbeing*, *Journal of Applied Research in Intellectual Disabilities*, *Journal of Policy and Practice in Intellectual Disabilities*, *Research in Developmental Disabilities*). Reference lists of reviews were also hand searched for potentially relevant articles.

Screening

TY and ER reviewed articles for inclusion and data extraction based on criteria described below; AM acted as a third reviewer to reconcile any disagreements. Inter-rater reliability was calculated.

Inclusion and Exclusion Criteria

To be included in the review, articles had to (1) focus on children and/youth with IDD up to 25 years old (at least 50% or more of the participants); (2) focus on wellness, well-being, or one or more of the wellness dimensions described in Table 1; and (3) be published between January 2006 and January 21, 2017 (including early online articles). Articles were excluded for the following reasons: (1) non-English publication and/or (2) unable to be retrieved.

Data Extraction

To address our objectives, the following information was extracted from articles meeting the inclusion criteria: (1) definition of wellness; (2) wellness dimensions addressed; (3) study type and research design; (4) study objective; (5) sample characteristics; (6) description of intervention (where relevant); (7) outcome measures used; (8) findings; (9) limitations; and (10) recommendations for clinical practice. See Table 2 for the extracted data.

Results

After de-duplication, a total of 11,658 articles were screened by title and abstract and 128 full-text articles reviewed for

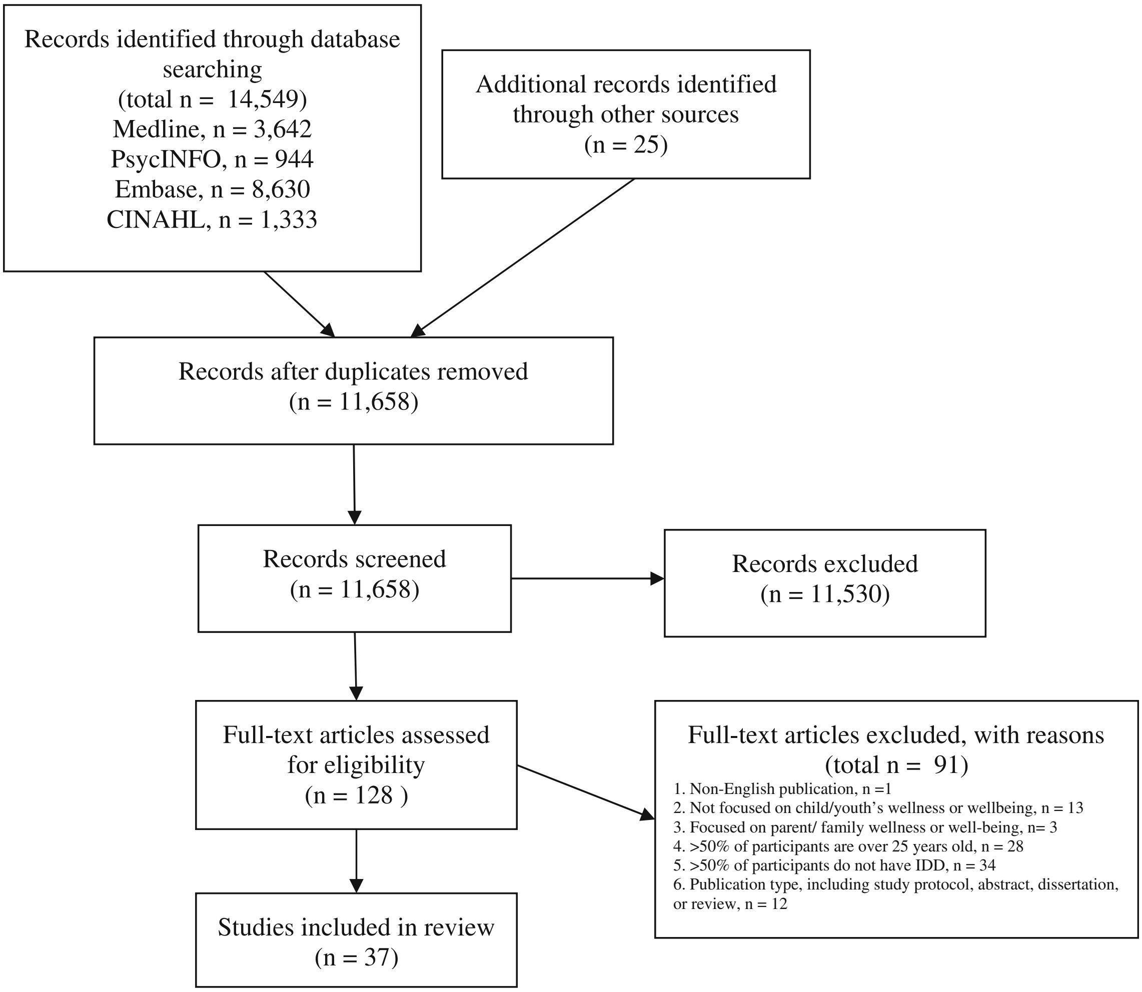

Fig. 1 Process of identification, screening, eligibility, and inclusion of studies in scoping review

inclusion. A total of 37 articles were included in this review. Independent inter-rater agreement was 83.33% for determination of inclusion/exclusion criteria for full-text assessment.

Table 2 provides details of the included studies. The majority of papers were from the USA (*n* = 10), followed by the UK (*n* = 6) and Canada (*n* = 5). There were two articles each from Australia, China, India, South Africa, and Taiwan. The rest were from France, Serbia, Iran, Italy, the Netherlands, and New Zealand. They were published between 2006 and 2016. Collectively, the articles included the following diagnostic labels: autism, cerebral palsy, developmental delay, Down syndrome, fragile X syndrome, intellectual disability (ID), and Prader-Willi syndrome (PWS); and participants in the age range of 4 to 35 years. The majority of articles (*n* = 19) focused on physical wellness (e.g., physical activity, nutrition), followed by psychological (*n* = 14), community participation (*n* = 10), emotional (*n* = 10), occupational (*n* = 2), social (*n* = 7), or other wellness dimensions (e.g., thriving) (*n* = 8). Many of the studies (*n* = 16) could be classified under more than one wellness dimension (e.g., Foley et al. [30]), but none comprehensively examined all wellness dimensions. In what follows, we highlight key findings related to wellness conceptualizations and what contributes to an overarching sense of wellness organized under the wellness dimensions identified with stakeholders (see Table 1) and provide examples from the included articles.

Conceptualizing Wellness

Wellness was explicitly conceptualized or defined in two studies [30, 58]. Foley et al. described wellness as "a good life" [30, p., 378] for their qualitative study that explored the meaning of well-being for children and youth with disabilities (e.g., autism, IDD). Yousefi, Mozaffari, Sharif, and Sepasi described personal well-being as "how people feel about their lives" [58, 68, p.], including their emotional responses, satisfaction with life domains, and global judgment of quality of life. Their study assessed the Personal Wellbeing Index-Cognitive Disability and found it to be reliable and valid for measuring personal well-being of students with ID (age range 9 to 21 years). Wellness conceptualizations were not explicitly

Table 1 Descriptions of wellness dimensions

Wellness dimension	Description
Physical	A positive perception and expectation of physical health or having a healthy body. Commonly associated with physical activity, healthy eating, etc.*
Occupational	Engaging in essential daily life and meaningful activities, such personal self-care and hygiene, taking care of health and household tasks, volunteering.$^+$
Psychological	A general perception that one will experience positive outcomes to daily life events and circumstances. Commonly associated with an optimistic disposition, happiness, hardiness, or resilience.*
Emotional	Having a positive sense of self-identity or image of oneself. Commonly associated with positive self-regard, self-esteem, feeling good about oneself, etc.*
Social	The perception of having supports available from family or friends and reciprocally valued as a support provider. Commonly associated with interdependence, interpersonal supports with friends and other people.*
Community participation	Participating or spending time in the community and/or spaces that make one feel happy, involved, and/or included. Commonly associated with participating in public spaces outside of the home and spending time with friends for fun (not for the purpose of support).$^+$

*Descriptions adapted from Adams et al. [11]

$^+$ Descriptions informed by stakeholder engagement

described in the remaining articles. However, some focused on related concepts, such as quality of life [34, 39, 57] and thriving [54••].

Physical Dimension

Physical wellness (e.g., physical activity, nutrition, weight) was the focus of the majority of articles (*n* = 19). In a commentary, Buckley [22] discussed the need to emphasize the benefits of a healthy lifestyle, and particularly physical activity, for children with Down syndrome. In a mixed methods study, Curtin et al. [28] developed a structured interview to assess the physical activity participation of adolescents with IDD. These examples reflect the relative importance attributed to the physical activity participation of children and youth with IDD in promoting wellness.

Several studies focused on physical activity and exercise and their effects on common physical health indicators (e.g., body mass index (BMI), weight), comparing differences before and after an exercise program or differences between young people with and without ID. For example, Davis [29] found no significant differences in BMI in grade 2 students with ID (mean age of 9.7 years) before and after an adapted exercise program, but significant differences on measures of strength and flexibility (e.g., medicine ball throw, sit-and-reach). In a single-case study, Singh et al. [51] examined the effectiveness of regular exercise alone compared to regular exercise with healthy eating education and then with healthy eating education and mindfulness strategies on weight reduction for a young man with PWS (age 17 years). While weight reduction was achieved over 3 years, the component(s) that contributed to this result was inconclusive. Similarly, Hinckson et al. [38] examined the effects of a 10-week school-based physical activity and healthy eating program on the weight and health behaviors of youth with ID or autism (mean age of 14 years) with overweight or obesity, and found minimal changes on indicators such as weight and waist circumference between pre- and post-evaluation at 24 weeks. However, youth and their family members described overall health and social gains through participation in a program tailored to this population. Salaun and Berthhouze-Aranda [50] used physical health status indicators to compare the health-related fitness between adolescents with ID and their peers without disabilities, as well as between those with and without obesity. They found significant differences on physical fitness tests between adolescents with ID and those without ID, as well as between those with and without obesity. The authors suggest that adolescents with ID experience fatigue sooner than their peers because they are not participating in regular physical fitness activities. Combined, these studies suggest that children and youth with ID score lower on conventional physical fitness indicators than their peers without disabilities, but can improve with specific targeted exercises. However, if weight loss is the desired outcome, then two studies found that physical activity interventions had little impact on weight and/or obesity. Nevertheless, young people with IDD may achieve other positive outcomes of physical activity programs, such as an overall sense of health and social wellness.

The importance of families' influences on physical wellness was highlighted in two studies. George, Shacter, and Johnson [32] found high correlations between the BMI of both adolescents with ID (age range 13 to 20 years) and their parents, and their beliefs, attitudes, and behaviors related to physical activity and nutrition. Lin et al. [42] examined the prevalence of physical activity and its determinants for adolescents with ID and found that 29.9% of the 351 adolescents with ID who participated in the study had regular physical activity. In addition, boys were more likely than girls to have a preference for physical activity, and adolescents whose caregivers had post-secondary education were more likely to participate in regular physical activity than those whose caregivers had primary school education or below. Together, these studies suggest that physical activity promotion is needed for children,

Table 2 All included articles

Article	Wellness or well-being defined?	Wellness dimensions included	Study type and research design	Objective	Sample characteristics
Buckley, 2007, UK [22]	No.	Physical	Commentary, not applicable.	To highlight the importance of physical activity for individuals with Down Syndrome (DS) across the lifespan with support from family, community organizations, and professionals.	Not applicable
Burrows, Adams, and Spiers, 2008, Canada [23]	No.	Psychological other, sense of security	Qualitative, ethological	(1) To determine and describe the behaviors/relationship between the service dog, child with autism, and family members; (2) draw conclusions about the organization, function, and significance of this behaviour	10 families, including 7 boys and 3 girls with autism, 2 of the families had a 2nd child with autism. Age range: 4.5 to 14 years old (at time of service dog placement) Parents were primary dog handlers and, thus, primary informants. 9 mothers and 1 father participated over 6 months.
Caliandro et al., 2007, Italy [24]	No.	Physical Emotional Social	Quantitative, prospective, multi-centered	(1) To investigate the quality of life of children with Prader-Willi syndrome (PWS) by using validated patient-oriented tools; (2) to evaluate the relationship between quality of life and the child's clinical presentation.	40 participants, 26 female and 14 males Mean age: 21.68 years (range 5–35 years; SD: 8.53 years)
Carvalho et al., 2014, Canada [25]	No.	Community participation	Quantitative, sub-set data analysis	To examine child characteristics and contextual factors related to overall social inclusion within community settings.	27 participants; 63% boys; 48% had intellectual/developmental disabilities (IDD); 43% had IDD and autism spectrum disorder (ASD); 9% had ASD with no IDD Age: 6 to 17 years old
Choi and Cheung, 2016, China [26]	No.	Physical Psychological Social	Quantitative, quasi-experimental pre-post test	(1) To identify the effect of a group-based 8-week structured physical activity program on psychosocial behaviors; (2) to investigate generalization of those behaviors.	30 participants, all grade 2 students with mild intellectual disability (ID) (18 as training group and 12 as control group); 22 boys and 8 girls; 60% also had ASD

Table 2 (continued)

Article	Wellness or well-being defined?	Wellness dimensions included	Study type and research design	Objective	Sample characteristics
					Age: 7 or 8 years old (mean = 7.39 years; SD = 0.5 years)
Cooney et al., 2006, UK [27]	No.	Emotional	Quantitative, between-subjects design	To compare the impact of segregated schooling on young people with ID's reports of stigmatized treatment, social comparison with peers and future aspirations.	60 participants with mild to moderate ID; 31 males (52%) Age: 15–17 years old
Curtin et al., 2016, USA [28]	No.	Physical	Mixed methods, measure development	To develop and establish reliability of a structured interview to assess physical activity	15 adolescents with ID, 6 males (40%), 13 white (87%) Mean age = 16.7 years (SD = 1.5 years)
Davis, Zhang, and Hodson, 2011, USA [29]	No.	Physical	Quantitative, prospective, cross-sectional intervention	To determine if the implementation of a 30-min/day exercise program has an effect on the health-related fitness of students with mild-to-moderate ID.	25 elementary school youths, 16 males, BMI 19.9 (SD = 5.9 kg/m^2) Age: 9.7 years (SD = 1.2 years),
Foley et al., 2012, Australia [30]	Yes. Well-being is defined as "a good life" (p. 378).	Physical Emotional Community Participation Psychological Social	Qualitative, semi-structured interviews	To describe the meaning of well-being for children and youth with disabilities, including ID, from their own perspectives.	9 girls, 11 boys; 3 with DS, 7 with ASD, 6 with CP, 1 with vision impairment, and 3 with ID. Age range: 8 to 16 years old
Fourie and Theron, 2012, South Africa [31]	No.	Emotional Community Participation Social	Qualitative, single-case study	(1) To understand resilience in a young woman with fragile X syndrome (FXS); (2) shed light on what those protective processes are towards of resilience.	16-year-old female with FXS. Author described this young woman as cheerful and forward-looking, despite many physical, mental, and emotional challenges
George, Shacter, and Johnson, 2011, USA [32]	No.	Physical	Survey, descriptive, cross-sectional	(1) To evaluate the beliefs, attitudes, and behaviors associated with nutrition and physical activity of parents with adolescents with ID; (2) to investigate relationship between these variables in relation to body mass index (BMI) of adolescents and parents; (3) to investigate if parents' perceptions	*n* = 207 parents, 84% female, mean BMI 25.4 (SD = 6.7) Age range: 13–20 years old, mean age = 16.8 years (SD = 1.8 years) Parents had mean age = 45.6 (SD = 7.1); 62% of parents were employed; 69% of parents were

Table 2 (continued)

Article	Wellness or well-being defined?	Wellness dimensions included	Study type and research design	Objective	Sample characteristics
				of child's weight status was accurate.	overweight or obese; mean BMI = 28.5 (SD = 6.4)
Ghosh and Datta, 2012, India [33]	No.	Community participation Physical	Mixed methods, cross-sectional design	To determine if sports activities have been detrimental in improving functional ability in sample of children with ID	26/31 were in special education classes specific to children with mild to moderate ID (IQ within 45–58 band) Age range: 2–18 years old, mean age = 15.09 years, SD = 2.3 years
Golubovic and Skrbic, 2013, Serbia [34]	No.	Other, quality of life	Quantitative, cross-sectional, observational	To examine the agreement of quality of life assessments made by adolescents with disability and their parents compared with assessments made my adolescents without disability and their parents.	67 adolescents, 35 males/32 females with ID; no. of mild ID = 62, no. of moderate ID = 5 Mean age of youth = 15 years, 10 months (SD = 14.74 years); mean age of parent = 44.3 years
Grandisson, Tetreault, and Freeman, 2012, Canada [35]	No.	Community Participation Physical	Qualitative, exploratory, and descriptive	(1) Document adolescents' and parents' perceptions about the outcomes of sports participation for adolescents with ID, including integrated sports; (2) gain an understanding of facilitators and barriers to the integration of adolescents with ID	Total of 79 participants; adolescent with ID (*n* = 20) (age range 12–19 years old), their parents (*n* = 20) and staff working with individuals with ID (*n* = 39)
Hall and Theron, 2016, South Africa [36]	No.	Psychological	Qualitative, exploratory, and descriptive	To explore resiliency, specifically why some young people with ID cope well despite these risks associated with ID (e.g., social and language skills)	24 participants as primary informants; 18 teachers as secondary informants
Hassiotis and Turk, 2012, UK [37]	No.	Psychological	Survey, cross-sectional	Prevalence and predictors of mental health needs and service use in adolescents with ID	75 adolescent participants Age range 12–19 years, mean age = 15.4, SD = 2.1); 48 males (64%), mild ID: 10, moderate: 23, profound: 42 most attended special schools (67.9%)
Hinckson et al., 2013, New Zealand [38]	No.	Physical	Mixed methods, pre-post cohort intervention	To determine the effectiveness of an intervention program in managing weight through	*n* = 17 participants Age = 14 years (SD = 4), BMI = 31 (SD = 8)

Table 2 (continued)

Article	Wellness or well-being defined?	Wellness dimensions included	Study type and research design	Objective	Sample characteristics
				changes in physical activity and nutrition behaviors in overweight or obese children and youth with ID or autism	
Hsieh et al., 2013, Taiwan [39]	No.	Community Participation Psychological Other, quality of life	Quantitative, cross-sectional, observational	To evaluate the quality of life and health of children with unclassified developmental delay and the impact this had on family	DD age = 4 years, 2 months (SD = 0.2 months), 60 children with DD matched with 56 TD children
Kumar et al., 2011, India [40]	No.	Psychological Emotional Occupational Social	Quantitative, prospective pre-post cohort experimental	To evaluate the effect of a psychosocial interview on disability grades and quality of life for adolescents with mental disabilities.	103 students, 70 males (68%) Age range: 12–18 years old, mean age = 14.8 years
Li et al., 2006, China [41]	No.	Community participation	Qualitative, ethnography	To explore participant's life story, and then personal strategies and external resources to enable success.	10 participants with ID, 4 males/6 females, none married and all lived with families; age range = 14–31 years old; 4 in special school, 1 in vocational training, 4 sheltered workshop worker, and 1 worked full-time non-sheltered workshop
Lin et al., 2010, Taiwan [42]	No.	Physical	Quantitative, cross-sectional observational	To describe the regular physical activity prevalence and examine its determinants among adolescents with ID in Taiwan	351 participants with ID; age mea*n* = 17.06 (SD = 0.76; range = 16–18); no. of males = 211; no. of females = 139; no. with ID = 214; multiple = 112 BMI; 51 underweight; 87 normal weight; 21 overweight; 73 obese
Marquis and Baker, 2015, USA [43]	No.	Physical Psychological Other, sport participation	Quantitative, 2-year cohort observational	(1) To explore differences in sports participation between young children with DD vs age-matched peers on 3 dimensions: no. of sports, relational nature of sports, and consistency of participation; (2) what other child or parent	DD sample ONLY no. of participants = 63; 36 males

Table 2 (continued)

Article	Wellness or well-being defined?	Wellness dimensions included	Study type and research design	Objective	Sample characteristics
				variables are related to sports participation.	
Menear, 2007, USA [44]	No.	Physical Community participation	Qualitative, exploratory	To understand parents' perceptions of health and physical activity needs of their children with DS	21 parents (5 dads); 21 children (13 males); age range of children with DS = 3–22 years old
Messersmith et al., 2008, USA [45]	No.	Physical	Quantitative, observational case report	To demonstrate interdisciplinary behavioral rehabilitation for life-threatening obesity in adolescent female with PWS	15 years old, female, Caucasian, PWS, moderate mental retardation
Pikora et al., 2015, Australia [46]	No.	Physical Community Participation Psychological	Survey, 1-time cross-sectional observational	(1) Examine the prevalence of medical conditions and health service use by adolescents and young persons with DS; (2) describe the impact of these conditions on the individual's life; (3) explore relationship between the presence of medical conditions and level of functioning in daily life	Of 223 families invited to participate, 197 responded; 110 were males, median age = 23.6 years (range 16.3–31.9 years); 164 lived with parents; no. of health current medical conditions ranged from 0 to 11.
Rimmer et al., 2010, USA [47]	No.	Physical Psychological	Survey, cross-sectional	(1) Examine the prevalence of medication conditions and health service use by adolescents and young persons with DS; (2) describe the impact of these conditions on the individual's life; (3) explore relationship between the presence of medical conditions and level of functioning in daily life	461 parents of adolescents with IDD (e.g., DS, autism) (mean = 14.9 years, SD = 1.9)
Roizen et al., 2014, USA [48]	No.	Physical	Survey, cross-sectional	To determine the frequency of medical problems in a large population of children with DS	440 participants; 406 were white; 318 with at least 1 educated parent; mean child age = 7.5 years (SD = 3.1; range 3–13); 227 were males
Roush et al., 2007, USA [49]	No.	Emotional Community Participation Occupational Social	Qualitative, exploratory	To describe experiences of young adults with developmental disabilities (DD) who were living in the community with support from government services.	16 participants, 6 males/10 females, mean age = 24 years
Salaun and Berthouze-Aranda, 2012, France [50]	No.	Physical	Quantitative, cross-sectional observational	(1) To investigate health-related fitness in adolescents with ID; (2) to analyze various	87 participants with mild to moderate ID (only 3 had DS; otherwise etiology

Table 2 (continued)

Article	Wellness or well-being defined?	Wellness dimensions included	Study type and research design	Objective	Sample characteristics
				performances in physical fitness tests according to degrees of obesity	unknown re: ID); mean age = 14.24 (SD = 1.48)
Singh, et al., 2008, USA [51]	No.	Physical Psychological	Quantitative, ABCD single-case	To evaluate effectiveness of regular exercise alone, regular exercise plus healthy eating, and mindfulness-based strategies combined with exercise and healthy eating to an adolescent with PWS	17 years old, male, PWS, mild IDD (IQ = 75); weight between 250 and 260 lb, height 4 ft, 8 in., morbidly obese, BMI = 57.2 presentation of hyperphagia, food-seeking behaviors, challenging behaviors (e.g., tantrums, impulsively), parent reports typically unhappy, low self-esteem, and socially withdrawn
Skotko, Levine, and Goldstein, 2011, USA [52]	No.	Emotional	Survey, cross-sectional	To explore self-perceptions of individuals with DS to share with new and expectant parents of children with DS.	266 participants, mean age = 23.4 years (SD = 8.9; range: 12.1–51.9); 54% were male, 64% were 12–25 years old
van Gameren-Oosterom, et al., 2011, Netherlands [53]	No.	Physical Emotional Psychological Other, quality of life	Quantitative, cross-sectional observational	To investigate levels of development, problem behavior, and health-related QoL in a population sample of Dutch 8-year-old children with DS.	337 participants, mean age = 8.1 years (SD = 0.15, range 7.8–9.1); 52% were boys, 94.6% were Dutch origin. Above 90% were diagnosed/treated for co-occurring conditions, including but not limited to: visual impairment, chronic airway infection, heart defect, or hearing impairment
Weiss and Burnham Riosa, 2015, Canada [54••]	No.	Emotional Other, thriving	Quantitative, cross-sectional	To examine individual and contextual correlates of thriving in 330 youth with IDD and ASD compared to youth with ID only.	Combined: 330 (203 males), age = 16.78 years (SD = 2.92), 45% training 1–4× per month
Weiss, Ting, and Perry, 2016, Canada [55]	No.	Psychological Social	Survey, cross-sectional observational	To identify the child, family, and psychosocial characteristics that were associated with the presence of psychiatric diagnoses and maladaptive behavior in youth with severe ID	141 parents of youth with severe or profound ID, 4 to 18 years old mean age = 11.04 (SD = 3.38); 68% male; 39% with ASD

Table 2 (continued)

Article	Wellness or well-being defined?	Wellness dimensions included	Study type and research design	Objective	Sample characteristics
Whitt-Glover, O'Neill, and Stettler, 2006, USA [56]	No.	Physical	Quantitative, cross-sectional observational	To describe physical activity patterns of children with DS compared to unaffected siblings	~ 7.1 years old, equal no. of males and females; children with DS were younger, weighed more, were shorter, and had higher BMI than their unaffected siblings ($p < 0.05$). No. of children with DS = 28; no. of children without DS (unaffected siblings) = 30
Wilson, Wiersma, and Rubin, 2016, USA [57]	No.	Other, quality of life	Quantitative, cross-sectional observational	(1) To evaluate the Peds QL4.0 to assess quality of life in children with PWS; (2) compare difference with parent and child report as well as between children with PWS and without PWS	Children with PWS ($n = 44$), average age = 11.0 years (SD = 2.4 years); average 46.8% of body fat (SD = 9.5%). Mostly mothers participated ($n = 39$, 92.9%); comparison sample ($n = 66$) who were obese, parents were included. Children were avg. = 9.7 (SD = 1.1 years), had a body fat% of 44.6% (SD = 5.8%); parents were mostly mother $n = 58$; 87.9%
Yousefi et al., 2013, Iran [58]	Yes. Wellness is how people feel about their lives, includes emotional responses, satisfaction with life domains and global judgment of life quality, p. 68.	Emotional Psychological Social	Quantitative, cross-sectional observational	To assess the reliability and validity of the "Personal Well-Being Index - Cognitive Disability" on students with ID	200 students with ID; mean age = 14.49 (SD = 2.66); 100 male/100 female

Article	Intervention	Outcome measures	Findings	Limitations	Implications for clinical practice
Buckley, 2007, UK [22]	Not applicable.	Not applicable.	Not applicable.	Not applicable.	There is a need for a stronger focus relating to healthy

Table 2 (continued)

Article	Intervention	Outcome measures	Findings	Limitations	Implications for clinical practice
					lifestyles, particularly physical activity, in formative years (i.e., preschool years) to have a multitude of benefits in the long term (e.g., friendships).
Burrows, Adams, and Spiers, 2008, Canada [23]	Not applicable.	Not applicable.	(1) Sentinel of safety (including home, especially routines and during the night, car rides, and community); (2) child companionship and learning new skills; (3) shifting the focus from autistic child to service-dog companion; (4) individual respite, relaxation, and family recreation; (5) enhancing the family's social status; (6) facilitating awareness and education about autism	Although the service dog is intended to directly serve and support the child with autism, the children with autism in this study could not be directly interviewed due to significant communication challenges (e.g., non-verbal).	Further research should include follow-up of experiences for individuals with autism and their families beyond 6 to 12 months. This may be of particular importance near the end of the service dog relationship, especially as the service dog nears retirement, becomes ill, or dies.
Caliandro et al., 2007, Italy [24]	Not applicable.	(1) Child Health Questionnaire-Parent Form-50 (CHQ-PF50) for participants < 14 years old. (2) Short Form-36 (SF-36) for participants > 14 years old	For participants > 14 years old, authors reported significant differences between group and Italian norms existed between the means of: physical functioning, role-physical, bodily pain, general health, social functioning, role-emotional, and mental health. For participants < 14 years old, authors reported significant differences between group and Italian norms existed between the means of: general health, physical functioning, role-emotional behavior, role-physical, behavior emotional, global behavior emotional, mental health, self-esteem, general health, change health, parental emotional, parental time,	Not discussed.	None reported for use of research or areas of future research.

Table 2 (continued)

Article	Intervention	Outcome measures	Findings	Limitations	Implications for clinical practice
			family activity, physical score, and psychosocial score.		
Carvalho et al., 2014, Canada [25]	Not applicable.	(1) Vineland Adaptive Behavior Scales-Second Edition Socialization Domain (2) Scales of Independent Behavior-Revised Adaptive and Maladaptive sections (3) Mullen Scales of Early Learning or Stanford Binet Fifth Edition (4) Receptive and Expressive One-Word Picture Vocabulary Tests 4th Edition (5) Playground of Peer Engagement	Three moderate to strong correlations with social inclusion were present: (1) social age, (2) adaptive age, and (3) mental age. In community settings, coders rated children with DD as moderately to highly socially included.	Small sample and limited measures	(1) Determine frequency and quality of actual interactions; (2) understand the role of the adults in the environment; (3) larger and broader sample to increase representativeness of sample
Choi and Cheung, 2016, China [26]	Over 8 weeks, matched a psychosocial behavior (e.g., pairing up in teams, give high fives) with motor skills and play behaviors	(1) Checklist for Pupil Evaluation (observational evaluation on a Likert scale completed by 2 observers)	(1) Significant differences exist on emotional self-control and social interaction within training context; (2) no significant difference on emotional or social interaction within classroom context.	(1) Difficult to evenly distribute 3× per week sessions over 8 weeks as planned due to school holidays and special school events; (2) difficulty in obtaining adequate sample size; (3) random sampling approach could not be utilized; (4) limitations of school schedule did not allow study to be extended for a longer period of time.	(1) Increase length of intervention in future studies, especially if large proportion of sample includes participants with ASD; (2) include non-randomized studies, of high quality for future demonstration of effectiveness given that children with ID have limited opportunity for physical activity; (3) include physical activity as part of special education, in addition to providing after-school programs/opportunities.
Cooney et al., 2006, UK [27]	Not applicable.	(1) British Picture Vocabulary Scale – Revised	Participants from mainstream school had significantly higher IQ than segregated	Half of individuals approached did not participate. Socio-	Students with ID maintain a positive internal view of

Table 2 (continued)

Article	Intervention	Outcome measures	Findings	Limitations	Implications for clinical practice
		(2) Adapted Social Comparison Scale (3) Modified Life in School Checklist - Junior School Version (4) Experience of Stigma Checklist (5) Future Aspirations Checklist	schooling. Significant differences between groups re: self-report of stigmatized treatment. No significant differences on social comparison with peer with a more severe ID between groups. No significant differences on social comparisons with peer without disability between groups. No significant differences on future aspirations between groups	demographic differences exist between mainstream and segregated groups; only a single-point in time captured	themselves in comparison to non-disabled peers, and their future. Students remain resilient even though could recall negative stigma treatment and experiences. Further research needed to examine what positive supports facilitate optimism and emotional well-being.
Curtin et al., 2016, USA [28]	Not applicable.	(1) Demographics (2) Kaufman Brief Intelligence Test 2nd Edition (KBIT-2) (3) Vineland Adaptive Behavior Scales II (VABS-II) (4) Structured interview re: physical activity (reliability and validity established in this study)	(1) 14 questions (42%) had substantial reliability, (2) 10 questions (30%) had almost perfect agreement between adolescents with ID and typically developing (TD), (3) 8 questions did not meet the criteria for reliability or agreement	(1) Did not conduct the interviews with parents and caregivers to assess convergence/divergence; (2) interview did not contain redundant questions to verify responses; (3) unable to determine the extent to which individuals with ID understood the questions asked	Future research could explore the extent/experiences of social exclusion related to physical activities, barriers, and facilitators of sedentary over active leisure time.
Davis, Zhang, and Hodson, 2011, USA [29]	Over 8-week period, participants completed a 30 min/day, 5 days/week activity program.	(1) Body mass index (BMI); (2) Progressive Aerobic Cardiovascular Endurance Run (PACER); (3) modified curl-up; (4) medicine ball throw; (5) sit-and-reach right; (6) sit-and-reach left	(1) BMI—no statistical difference, delta = 0.01 (very trivial effect in favor of program); (2) PACER—significant difference, delta = 0.55 (medium-sized positive effect); (3) modified curl-up—significant difference, delta = 0.42 (medium-sized positive effect); (4) medicine ball throw—significant difference, delta = 0.42 (medium-sized positive effect); (5) sit-and-reach right—significant difference, delta = 0.42 (very large positive effect); (6) sit-and-reach left—significant	(1) Lack of criterion-referenced standards available at certain age levels for students with disabilities; (2) measurements (e.g., medicine ball throw) lack reliability and validity; (3) lack of control group; (4) limited to generalize findings to larger group	Future research needs to focus on relationship between health-related fitness and on-task behavior, motivation to exercise, examining nutrition/caloric intake using longitudinal follow-up studies.

Table 2 (continued)

Article	Intervention	Outcome measures	Findings	Limitations	Implications for clinical practice
			difference, delta = 0.42 (very large positive effect)		
Foley et al., 2012, Australia [30]	Not applicable.	Not applicable.	(1) "Having things to do," including involvement, to feel belonged, meaningful things to do; (2) "The most important thing is good friends," including people you can trust and close friends, acceptance; (3) "You know home is where the heart is," including family, parents, and siblings as a sense of support, but also source of annoyance; (4) "Nothing seems to stick in my brain," including anxiety underperforming academically, stress, worry, and anxiety; (5) "You need some way to cool down," including resiliency, coping strategies, and hardiness re: bullying and/or negative experiences; (6) "Feeling good about yourself," including personal development and growth, goal-setting, striving to do one's best and facing fears.	(1) Unable to cover all topics as proposed in "Mapping terrains" report; (2) not able to generalize findings to the wider population of children	(1) Continue including the direct perspectives of children and youth with ID re: their own wellness; (2) further consultation to develop best ways of translating perspectives into measurable indicators
Fourie and Theron, 2012, South Africa [31]	Not applicable.	Not applicable.	(1) Intrapersonal agency, including determination and motivation, assertiveness, being socially inclined, sunny temperament, and meaningful pastimes; (2) unconditional positive acceptance and belonging, including familial acceptance, acceptance by the religious community, friendships with youth with disabilities, and community acceptance; (3) support towards mastery, including	Single case—potentially limited transferability	(1) Contributes to the limited available literature on woman with FXS reporting positive traits; (2) discourages blind stereotyping of young woman with FXS as at risk only; (3) provides encouragement for carers to co-collaborate and co-promote their resilience.

Table 2 (continued)

Article	Intervention	Outcome measures	Findings	Limitations	Implications for clinical practice
			practical support, supportive medical interventions, motivational support, and opportunities to experience mastery.		
George, Shacter, and Johnson, 2011, USA [32]	Not applicable.	(1) The Healthy Buddies Parent Nutrition and Physical Activity Survey; (2) body mass index	Many correlations between BMI, factors, and specific questions. Highlights: (1) youth's with low BMI more likely to agree about parental role ($r = -0.17$, $P < 0.025$); (2) parents with low BMI more likely to agree about family health habits ($r = -0.15$, $P < 0.047$)	(1) Height and weight were self-reported and could have been limited accuracy; (2) diagnosis not specifically assessed; (3) limited to those in Best Buddies program; (4) surveys sent home with students (and not mailed, may have had a higher response if mailed)	(1) Need to focus on health disparities for children and youth with ID, particularly obesity; (2) need to explore parent education in this area, barriers to healthy lifestyles, addressing limitations specific to ID, and impact of peer relationships on healthy lifestyles
Ghosh and Datta, 2012, India [33]	Not applicable.	WHODAS 2.0	(1) For 10 of 11 attributes, values of $R^2 > 0.70$ (indicates over and above 70% in the variation in the dependent variables are explained by independent variables—thus proves relationship between); (2) no. of years in sports not statistically significant for 3 attributes (walking a long distance, washing whole body, getting dressed); (3) no. of years in school statistically significant for all attributes, (4) age of respondent not statistically significant for any attributes	(1) Relationships may exist between child, teacher, coach, learning ability of child that may have influenced results; (2) no screening norms available for sample	For low-income and indigenous populations, sports would be an appropriate inexpensive rehabilitation measure to promote health and well-being of persons with disabilities in the community.
Golubovic and Skrbic, 2013, Serbia [34]	Not applicable.	PedsQL 4.0 Generic Core Scale for adolescents aged 13–18 years old	(1) Significant differences between adolescents with ID and parents in physical health, psychosocial health, emotional functioning, social functioning, and school functioning; (2) low correlation for physical health and emotional	(1) Did not consider cognitive level influencing level of agreement; (2) study was limited to 1 geographic area	Need to follow-up on applied treatments and determine further guidelines in working with children with ID

Table 2 (continued)

Article	Intervention	Outcome measures	Findings	Limitations	Implications for clinical practice
			functioning; moderate correlation for psychosocial health, social functioning, and school functioning		
Grandisson, Tetreault, and Freeman, 2012, Canada [35]	Not applicable.	Not applicable.	Outcomes of sports participation by adolescents with ID: (i) health improvement, self-esteem development, increased social inclusion, development of motor, social, and cognitive abilities, and opportunity to have fun. Factors associated with integration: (i) environmental factors, including social dimension, political economic factors, physical dimension, (ii) personal factors	(1) Limits to generalization of study findings due to sampling decisions	(1) Need for consistent messaging that integration of adolescents with ID into sports benefits everyone; (2) health authorities have a mandate to decrease health inequalities for everyone, including promoting health and social inclusion of individuals with ID; (3) need pilot projects to address the factors addressed herein, including support and assistance, and information sessions and training
Hall and Theron, 2016, South Africa [36]	Not applicable.	Not applicable.	2 interrelated themes: (1) their being embedded in a supportive social ecology, (2) as cooperative members of this ecology	(1) Challenges with gaining perspectives of cognitive and expressive-language-related difficulties for some participants to verbalize their experiences; (2) focused on individuals in special school setting; (3) advisory panel may have only nominated those who are atypically resilient	(1) Future exploration needed to understand the impact of environment, and resiliency on individual's health and well-being
Hassiotis and Turk, 2012, UK [37]	Not applicable.	Vineland Adaptive Behaviour Scale (VABS: survey form); Developmental Behaviour (DBC) Checklist (primary carer and teacher version); socio-demographic data; service utilization	(1) On DBC questionnaire, 38 adolescents identified; (2) during clinical interview 50 were identified; (3) agreements between parent report and clinical interviews were moderate (Cohen's kappa = 0.518); (4) no	(1) Lacks a matched comparison group; (2) no independent clinical assessment re: diagnosis or inclusion of additional gold standards/criteria	(1) Understand mental health and psychopathology for individuals with ID, specifically in adolescents; (2) need consider social adversity, carer

Table 2 (continued)

Article	Intervention	Outcome measures	Findings	Limitations	Implications for clinical practice
			significant relationship between DBC identification vs clinical interview re: adaptive functioning; (5) 68% of parents reported > 3 visits to GP in last years; (6) 43 participants were on medication		burden, and QoL with emphasis on transitions
Hinckson et al., 2013, New Zealand [38]	10-week school-based program consisting of 18 sessions focusing on physical activity, healthy eating, and motivation. Program was facilitated by PT, dietician with support from teacher and teacher's aide.	1) Six-minute walk test; (2) body fatness via waist circumference and BMI; (3) physical activity and nutrition changes measure by proxy report and interviews	(1) Possibly positive changes between baseline and follow-up at 24 weeks at six-minute walk-test (participants walked 51 m further); (2) most results were unclear or trivial in findings; (3) qualitative themes: (i) health gains, (ii) social gains, and (iii) program that fits	(1) Sample size was small; (2) baseline measures were conducted in summer and follow-up was in winter (may account for no findings as lower physical activity in winter months); (3) no control group	(1) Need for program specific to population with ID; in consultation with families, builds on school/community relationships; (2) special needs school to include healthy living as part their curriculum
Hsieh et al., 2013, Taiwan [39]	Not applicable.	(1) PedsQL - Generic Core Scale (proxy report for child); (2) Pediatric Outcomes Data Collection Instrument (proxy report for child); (3) WHO - Quality of Life Brief version (self-report); (4) PedsQL - Family Impact Module (self-report); (5) Hospital Anxiety and Depression Scale (self-report); (6) PedsQL - Health satisfaction	(1) DD had significantly different QoL (psychological, physical, total) compared to TD; (2) DD had significantly different function (upper extremity and physical functioning, transfer and basic mobility, sports and physical functioning, pain and comfort, happiness, global functioning) compared to TD	(1) Measures originally developed by Western world, required translation. May not be able to rule out cross-cultural differences; (2) proxy report rather than child's self-report may be different; (3) sample is diverse group	(1) Increase attention to psychological/ socio-economic factors that impact families of children with DD; 2) need to improve QoL and health status for children with DD
Kumar et al., 2011, India [40]	4-month program teaching life skills, emotional regulation, and social skills.	(1) Indian Disability Evaluation Assessment Scale (IDEAS) (2) WHO QOL BREF; structured self-report interview schedule	(1) Mental disability among participants—mean scores in self-care, interpersonal activities, communication and understanding and work were significantly different pre/post intervention; (2) quality of life among participants—mean scores in physical, psychological, social, and environmental	None reported.	To implement intervention over long term in schools, in collaboration of teachers and aides, for long-term benefit. Also, to facilitate learning through multi-media methods compared to more traditional learning methods in schools.

Table 2 (continued)

Article	Intervention	Outcome measures	Findings	Limitations	Implications for clinical practice
Li et al., 2006, China [41]	Not applicable.	Not applicable.	(1) Positive personality (including motivation and perseverance); (2) involvement in volunteer service; (3) supportive family; (4) support from school	Not reported.	(1) Positive personality and role modeling by parents are 2 important factors for achievement; (2) needs for ongoing support and counseling need to be available to support parents to facilitate child's success; (3) important for collaboration to occur across community, school, and family for a higher level of social integration
Lin et al., 2010, Taiwan [42]	Not applicable.	(1) Demographics (e.g., disability, gender); (2) BMI; (3) regular physical activity (preference, prevalence, frequency)	(1) 29.9% of ID had regular physical activity habits (e.g., walking, sports, and jogging; (2) male adolescents with ID had positive preference towards physical activity; (3) caregivers with university education, adolescents were more like to have regular PA compared to caregivers with primary school or less	Not reported.	Need to initiate appropriate interventions to motivate participation in physical activity for adolescents with ID
Marquis and Baker, 2015, USA [43]	Not applicable.	(1) Demographics, plus sports participation variables (at 6 and 8 years); (2) child factors (at 6 and 8 years); (3) maternal factors (at 6 and 8 years)	(1) No. of sports—children with DD participated in fewer sports than TD on average at 6 years; no longer present at 8 years; (2) highest relational sport—higher relational sports associated with child TD status, higher social skills, and at trend level, better child health at 6 years; no longer present at 8 years; (3) no. of consistent sports—for 6 and 8 years, higher among TD children and children with better health, mothers worked fewer hours	(1) As part of other studies, unable to link potential other barriers to account including distance to facilities, transportation, and skill level; (2) previously collected data; some variables lacked specificity or detail for deep understanding	(1) Continue to work towards nuanced understanding of DD sports participation disparities; (2) develop interventions to effectively address barriers re: benefit of sports participation for physical/mental health of youth with ID

Table 2 (continued)

Article	Intervention	Outcome measures	Findings	Limitations	Implications for clinical practice
			and displayed negative parent during home observations		
Menear, 2007, USA [44]	Not applicable.	Not applicable.	(1) Physical activity has immediate and long-term positive health impacts on child with DS, and child could benefit from being more active; (2) child participated in physical activity for social reasons (e.g., be with peers w/ or w/o DS, siblings) and w/o such motivation would select sedentary activities; (3) parents of teens identified a need for child to learn individualized sports to have sporting opportunities that do not require ability-matched teammates/opponents; (4) parents recognize need for PA specialists, through parent-education re: home-based programs or increase in appropriate community-based PA programs	Not reported.	(1) Educators, recreation specialists, and therapists should assist children/ youth in acquisition of skills for individuals and dual sports; (2) need for programs that address location/time/ cost for implementation —perhaps inclusion of home programs in addition to community-based programs
Messersmith et al., 2008, USA [45]	Behavioral intervention—5 months in-patient, including environmental destruction of food, low-calorie diet, staff and family training, daily occupational and physical therapy, and highly structured behavior management program. In addition, 25 weeks out-patient treatment with behavioral structure program, and nutrition. 2 years post-discharge, therapist follow-up with	(1) BMI; (2) supplemental oxygen requirement; (3) mobility; (4) tantrums	(1) BMI—decreased from 84.3 at admissions to 59.8 at discharge; (2) supplemental oxygen requirement—decreased to > 95% on room air during day and decreased supplemental (1 L of O_2 per min) during sleep; (3) mobility—tolerance improved significantly, including ambulate independently, move from floor to stand with no supports, ascend/ descend stairs without railing, inclusion of exercise and walking regime; (4) tantrums—gradually	Statistical generalization limited by design of a single-case study	(1) Early intervention from interdisciplinary team that addresses medical, behavioral, physical, and developmental needs; (2) maintain effective/ same results from in-patient to out-patient, as well as ongoing caregiver training is essential

Table 2 (continued)

Article	Intervention	Outcome measures	Findings	Limitations	Implications for clinical practice
	school and family twice per year.		decreased to zero per week prior to discharge		
Pikora et al., 2015, Australia [46]	Not applicable.	(1) Demographics; (2) information related to use of health services; (3) body weight; (4) Index of Social Competence; (5) family characteristics	(1) Overall, no. of participants with: eye/vision (143), muscle/bone (140), menstrual (50 out of 87), body weight (113), skin (110), ear/hearing (88), respiratory (71), mental health (62), bowel (56), thyroid (52), heart (50), and diabetes (30); (2) level of functioning and health conditions—adjusting for gender and age, DS with mental health were more likely to have lower communication, community skills, and self-care skills; (3) most common acute illnesses within 12 months were cold, influenza, or ear infection. 37 individuals had at least 1 hospital admission within 12 months. 174 had visited a GP, 20 a psychologist, 14 a mental health doctor within 12 months.	(1) As questionnaire was long, respondent fatigue may have occurred; (2) recall error with retrospective reporting	(1) Monitoring and screening for health conditions in this population is important due to no. of conditions; (2) develop management plans and strategies to avoid long-term consequences of conditions (to ensure they do not act as barriers to participation in employment/social activities)
Rimmer et al., 2010, USA [47]	Not applicable.	Web-based survey including demographics, disability status and health conditions, body weight status, obesity-related health conditions	(1) Significant difference in weight, height, and BMI across gender and disability groups. Youth with ASD significantly heavier and taller than other disability groups; youth with CP were light than other groups with the exception of spina bifida and mean BMI was lower than any other group; (2) youth with ASD were more likely to be obese and overweight compared with youths without IDD; youths with DS were also more likely to be obese and overweight	(1) Over representation of families with more education, higher SES, limiting to primarily white population with higher education; (2) limited participation by minority population groups; (3) limited in survey time; only 15 major secondary conditions presented; (4) BMI may not be adequate estimate of adiposity; (5) self-report of height, weight to underreporting; (6) not	(1) Need to develop and test interventions that are effective in reducing/managing obesity among youth with IDD; (2) focus our emphasis on decreasing incidence of obesity, secondary conditions, and improve lifestyle health behaviors

Table 2 (continued)

Article	Intervention	Outcome measures	Findings	Limitations	Implications for clinical practice
			compared to youths without IDD; and youths with spina bifida were more likely to be overweight than non-disabled; (3) overweight youth with cognitive disability reported a higher prevalence of secondary conditions (e.g. high blood cholesterol, diabetes, preoccupation with weight, and early maturation) compared to healthy weight youth. Overweight youths with IDD had significantly higher prevalence of high blood pressure compared to physical disabled who were in healthy weight category. In physical disability group, overweight youths tended to show higher trend for each secondary condition.	possible to assess level of severity	
Roizen et al., 2014, USA [48]	Not applicable.	(1) Medical History Questionnaire; (2) Modified Checklist for Autism in Toddlers;(3) Social Communication Questionnaire	(1) 3 most common medical problems were: heart disease (55.2%), vision problems (56.8%), and hearing problems (39.3%); (2) only 32 children (7%) reported none of the 10 medical problems listed on questionnaire; (3) sex not associated with co-morbid medical conditions with exception of heart disease (more frequent in females) and asthma (more frequent in males).	(1) Under ascertainment of DS cases, as registry estimated to include 88% of population; (2) 22 participants were recruited outside of NYCMR, making it not purely population based; (3) parent recall bias	(1) Primary care providers of children with DS need to monitor for the secondary conditions; (2) implications for long-term health of individuals with DS, important to enhancing health into adulthood
Roush et al., 2007, USA [49]	Not applicable.	Not applicable.	(1) Home life; (2) relationships; (3) health and healthcare; (4) personal growth and accomplishments; (5) occupation; (6) transportation. Positive experiences	(1) Although saturation was reached; need larger sample size; (2) interview time did not allow for participants to reflect upon topics or be	(1) Need to understand the dynamics of community integration of young adults with DD; (2) need to identify techniques to

Table 2 (continued)

Article	Intervention	Outcome measures	Findings	Limitations	Implications for clinical practice
			associated with integrated, comprehensive, timely services delivered by knowledgeable/sensitive service providers—strong parental advocacy facilitated these features	considered in larger context; (3) recency/unreliable memory may have impacted responses; (4) only explored young adults receiving state-support; those without support may have difference experiences	improve lives of persons with DD
Salaun and Berthouze-Aranda, 2012, France [50]	Not applicable.	(1) EUROFIT physical fitness test; (2) height; (3) waist circumference; (4) BMI; (5) waist-to-height ratio; (6) bio-impedancemetry	(1) Significant differences on EUROFIT physical fitness test between adolescents with ID vs TD (including lower no. of endurance laps for boys and girls; low cardiorespiratory fitness compared to standard VO_2max); (2) strong correlations between % body fat and waist circumference for boys and girls; (3) significant differences between "non-obese" and "obese" boys according to %BF on standing board jump test; 10*5 agility shuttle run, sit-and-reach test, sit-up test, shuttle run test; and between "normal" and "obese" girls for plate tapping, sit-ups, 10*5 agility shuttle run and shuttle run test; (4) overweight boys better performance than obese boys in sit-up, sit-and-reach test, and standing broad jump test; (5) correlation analyses between %BF and WC in less active adolescents	(1) Limited by EUROFIT physical fitness test; may not be appropriate for individuals with ID (even though modifications were made to the measure); (2) absence of control group; (3) low number of participants in study	(1) Adolescents with ID are easily tired, due to low physical fitness and not physically active enough; (2) ongoing investigation into the habits of adolescents towards a more active lifestyle; (3) development of Adapted Physical Activities programs for adolescents with ID
Singh, et al., 2008, USA [51]	An ABCD design, with 3-year follow-up A = baseline B = exercise alone (12 months) C = exercise plus food awareness program,	(1) Weight; (2) BMI	(1) Weight—reduction from 57.2 to 42.8 at 36-month follow-up; 2) BMI—reduction from 256.3 to 190.7 lb	(1) Case report; thus cannot be generalized; (2) multi-component intervention; thus, not sure what the	Use of multi-component intervention to impact those identified as obese or morbidly obese

Table 2 (continued)

Article	Intervention	Outcome measures	Findings	Limitations	Implications for clinical practice
	using visuals (12 months) D = exercise plus food awareness program, and mindfulness training. Parents provided training directly, with therapist at a distance to provide instruction and encouragement re: implementation, measurement			"active" ingredient may be re: effectiveness	
Skotko, Levine, and Goldstein, 2011, USA [52]	Not applicable.	Authors developed survey, piloted with persons with DS, established construct validity and test-retest reliability.	(1) 99% of participants are happy with lives, 97% like who they are, 96% like how they look, 4% are sad about their lives; all positive feelings of self-worth were positively correlated; (2) easy to make friends 86%, feel like they help other people 85%, love your family 99%, like siblings 97%, siblings are good friends 89%, parents pay more attention to siblings than you 15%; (3) fondness of siblings associated in part with race and geographic location; (4) those who did not make friends easily were more likely to be living in a group home; (5) qualitative re: new mom/dad with baby with DS—love your baby/your baby loves you 61%, life is good 60%; (6) qualitative re: MDs re: your life with DS—life is good 85%, please take care of our medical needs 50%	(1) Selection bias, only families on non-profit DS organizations sampled; (2) non-response bias (17% response rate is within acceptable range 15–25%); (3) small SD on survey; respondents had similar opinions; (4) parents may have influenced results, (5) lack of ethnic diversity	(1) Need to capture and share perspectives of persons with DS as part of informed, non-judgmental family planning; (2) provide educational information to health professional students
van Gameren-Oosterom, et al., 2011, Netherlands [53]	Not applicable.	(1) McCarthy Scales of Children's Ability; (2) Child Behaviour Checklist; (3) TNO-AZL Children's Quality of Life	(1) Mean developmental age (8.1 years, SD = 15) was substantially lower than calendar age (3.9 years, SD = 0.87); (2) mean developmental age	(1) Not able to carry out a non-response analysis; (2) parents of children with more serious developmental problems may have refused to	(1) Provide reference information re: expected development of a child with DS; (2) assist in giving parents realistic

Table 2 (continued)

Article	Intervention	Outcome measures	Findings	Limitations	Implications for clinical practice
			significantly lower among boys (3.6 years, SD = 0.85) than girls (4.2 years, SD = 0.82) ($p < 0.001$); (3) compared to general population, children with DS had more emotional/behavioral problems ($p < 0.001$); (4) children with DS less anxious/depressed than general population ($p < 0.001$); (5) significantly lower HRQoL for gross motor skills, autonomy, social functioning, and cognitive functioning ($p < 0.001$); (6) no significant differences between physical complaints, positive, and negative emotions	participate (under-estimation of difficulties faced by population)	expectations of future for children
Weiss and Burnham Riosa, 2015, Canada [54••]	Not applicable.	(1) Waisman Activities of Daily Living Scale; (2) Socio-communicative abilities—combining set of items measuring social and communicative functioning; from National Longitudinal Transition Study-2; (3) Functional Cognitive Ability—from NTYS2; (4) Participation and Environment Measure—Child and Youth version (PEM-CY); (5) Thriving - parent scale of six Cs of positive youth development	(1) Youth with ASD + ID reported to thrive less than peers with ID only; (2) group differences in socio-communicative abilities and school participation mediated the relationship between ASD and less thriving	(1) Cross-sectional design of study limits inferences regarding the casual relationships; (2) measures lack established psychometrics; (3) results solely based on parents' report; (4) limited to SO, may not reflect those outside of the organization	Consider contextual factors (e.g., family social support, connection with peers, community cohesion or acceptance, SES) related to thriving in youth with ASD
Weiss, Ting, and Perry, 2016, Canada [55]	Not applicable.	Online survey on child and family characteristics, negative life events, family QoL, and own mental health	(1) Youth with IDD and a psychiatric diagnosis had higher levels of adaptive behaviors and experienced more negative life events than youth w/o psychiatric diagnosis; (2) presence of	(1) Sample size limited statistical power of analysis; (2) proxy respondents (typically mothers); (3) retrospective reported re: negative	Need a combination of child- and family-based interviews plus policies that address larger systemic issues to promote mental health

Table 2 (continued)

Article	Intervention	Outcome measures	Findings	Limitations	Implications for clinical practice
			clinically significant maladaptive behavior was related to higher levels of adaptive behavior, parents' mental health, and lower family QoL; (3) child age, gender, ASD status, and financial hardship were not related to either outcome variable.	life events; (4) cannot infer directionality or casualty in this design and analysis of results	and treat psychopathology
Whitt-Glover, O'Neill, and Stettler, 2006, USA [56]	Not applicable.	(1) Descriptive characteristics (including BMI); (2) accelerometers	(1) Children with DS were younger (6.6 vs 7.1 years) and heavier (BMI 18.4 vs 16.7) than siblings ($p < 0.05$); (2) children with DS had less vigorous activity ($p < 0.04$) and shorter bouts ($p < 0.01$), but similar amount of time in moderate/low intensity physical activity	(1) Data collected in a single 7-day period, which may not account for usual physical activity patterns or seasonality of activity participation; (2) parents may have biased results; as were aware of what was being measured; (3) children with DS may have gait differences that may impact PA; (4) qualitative data may have added useful info to identify what type of low, moderate, and high PA engaged in; (5) differences may have been underestimated between DS and non-affected sibs given exclusion criteria of co-morbidities	As children with DS are more likely to be obese, increasing vigorous physical activity may be appropriate for prevention of obesity and promotion of life-long health
Wilson, Wiersma, and Rubin, 2016, USA [57]	Not applicable.	Peds QL4.0	(1) PedsQL 4.0 showed acceptable internal consistent for child report (alphas > 0.72) and acceptable for 4 out of 6 scales for parent report (alphas > 0.66); (2) test-retest reliability coefficients support for reliability (ICCs > 0.64); (3) parents	(1) Limited ability to generalize to broader population of children with PWS and those who are obese; (2) test-retest may have been influenced by other tests completed as part of this study	Given the different reports of parents and children, two forms of reports do not appear to be interchangeable

Table 2 (continued)

Article	Intervention	Outcome measures	Findings	Limitations	Implications for clinical practice
			perceived lower QL than children with PWS; (4) children with PWS showed lower QL than children without PWS		
Yousefi et al., 2013, Iran [58]	Not applicable.	Personal Well-Being Index - Cognitive Disability	(1) Internal consistency: all items were correlated with the total score and their score averages were similar to each other; (2) reliability criteria; Cronbach's alpha coefficient the seven items on the index between 0.56–0.62; (3) coefficients test-retest using Pearson correlation were significant 0.001	Limited number of students with ID enrolled; cannot be generalized	Index has benefit to identifying well-being in students with ID

youth, *and* their families, and that further work is needed to understand gender differences in the physical activity interests of children and youth with IDD.

Several studies examined the influence of physical wellness on other dimensions (e.g., psychological, social). Caliandro et al. [24] investigated the relationship between quality of life and physical, emotional, and social clinical presentations of youth with PWS. They found significant differences between youth with PWS and Italian norms for their age group on several clinical indicators (e.g., physical functioning, social functioning, mental health). In a study to examine the effects of an 8-week physical activity program on motor skills and psychosocial behaviors, Choi and Cheung [26] found significant changes in emotional self-control and social interaction of grade 2 students with IDD (ages 7 to 8 years). However, these changes did not generalize to their classroom contexts. These studies suggest that interventions addressing multiple, overlapping wellness dimensions are important to consider in practice and future research.

Occupational Dimension

Two articles described studies related to community and life skills of young people with IDD, which we classified as occupational wellness. Kumar et al. [40] found significant differences in self-care, interpersonal activities, communication, and work of students with ID (the term "mental disabilities" was used in the article) (ages 12 to 18 years) after a 4-month program focused on teaching life skills, emotional regulation, and social skills. In an exploratory study, Roush et al. [49] showed that integrated, comprehensive, and timely government services delivered by knowledgeable and sensitive service providers were associated with positive community living experiences of young adults with IDD (mean age of 24 years), improved health and healthcare access, and personal growth and accomplishments. These articles direct attention to the need for interventions that address occupational wellness (e.g., self-care, daily living skills) but also home and community services to support young people with IDD in their daily lives in order to foster an overarching sense of wellness.

Psychological Dimension

Two studies aimed to understand the resiliency of young people with IDD. Resiliency or the ability to recover or adjust from misfortune or change can contribute to experiences of psychological wellness. In a single-case study, Fourie and Theron [31] found that (1) intrapersonal agency (e.g., motivation, being socially inclined, and having a "sunny" temperament and meaningful pastimes) and (2) unconditional positive acceptance and belonging contributed to the resiliency of a young woman with fragile X syndrome (age 16 years). In an exploratory study, Hall and Theron [36] found that being embedded in a supportive and cooperative social ecology contributed to the resiliency of young people with ID. Together, these studies suggest that attributes of both the person and their social contexts contribute to resilience in young people with IDD.

Several articles examined mental health problems of children and youth with IDD. We categorized these articles under the psychological dimension because mental health most closely aligned with the description of psychological wellness as being "a general perception that one will experience positive outcomes" (see Table 1). For example, Van Gemeren-Oosteremo et al. [53] found that children with Down syndrome (DS) (age range 7 to 9 years) had more emotional and behavioral problems but less anxiety and depression compared to children without IDD. In addition, there were no significant differences in experiences of positive and negative emotions between children with DS and their nondisabled peers. Other articles examined child, family, and psychosocial factors associated with mental health problems in children and youth with DD. Regarding child-related factors, Pikora et al. [46] found that youth with DS (age range 16 to 31 years) with co-occurring mental health conditions were more likely to score lower on tests for communication, self-care, and community skills. In another study, Weiss, Ting, and Perry [55] conducted an online survey of parents of youth (age 4 to 18 years old) with severe or profound levels of ID to identify child, family, and psychosocial characteristics associated with psychiatric diagnoses and maladaptive behaviors (e.g., hurting oneself, destroying property). They found that youth who experienced psychosocial stressors (e.g., transition to a new school) were more likely to have reported mental health problems than youth without such stressors. In addition, youth with ID and a psychiatric diagnosis had higher levels of adaptive behaviors and experienced more negative life events (e.g., housing problems, family health issues) than their peers with ID without psychiatric diagnoses. Moreover, clinically significant maladaptive behavior was related to parents' mental health and lower family quality of life. These studies suggest that efforts to address the mental health and quality of life of both children and youth with DD and their families can play a role in preventing mental health problems, thus potentially optimizing their psychological wellness. However, we recognize that mental health and psychological wellness may be related but distinct concepts, much like physical health may be conflated with physical wellness, which warrants further exploration for conceptualization.

Emotional Dimension

On a survey to examine self-perceptions, Skotko et al. [52] found that the vast majority of participants (young people with DS aged 12 to 25 years old) responded that they were happy with their lives, liked who they are, and liked how they looked. This study suggests that the participants had a positive self-regard and self-esteem and felt good about themselves, which aligns with our description of the emotional dimension of wellness. In addition, young people with DS may have their own perceptions about their emotional wellness, which may be more positive than other people's perceptions or expectations. Similarly, Hsieh et al. [39] found that children labeled with unclassified developmental delay self-reported higher quality of life and health status than their parents' proxy reports. These studies suggest that young people with DD may have their own perceptions of experiencing good quality of life, health status, and emotional wellness, which may not align with social assumptions about the negative impact of DD on experiences of health, wellness, and quality of life.

Social Dimension

Eight studies included aspects of social dimensions of wellness as defined in Table 1, but none focused specifically on social wellness (e.g., Caliandro et al. [24], Foley et al. [30]). Two studies found that social contextual factors (e.g., experiencing acceptance and trust of friends, family, and community members) contributed to a sense of belonging in a family and community [30, 55], suggesting the importance of interpersonal supports in the everyday lives of children and youth with DD in order to foster social wellness. In a qualitative study, Rhoush et al. [49] described positive experiences of community living for young people with IDD when services were integrated, comprehensive, and timely and delivered by knowledgeable and sensitive service providers. Collectively, these studies underpin that social contextual factors (e.g., perceptions of being supported and valued by family, friends, and service providers) can contribute to experiences of social wellness.

Community Participation Dimension

Three studies were classified under the dimension of community participation. They focused on the notion of experiencing social inclusion in public places and spaces. Carvalho et al. [25] examined social inclusion of children with IDD and ASD (ages 6 to 17 years old) in community settings in relation to child characteristics and contextual factors. They found that 70% of children in their sample ($n = 27$) were rated as being moderately to highly socially included in integrated and mixed community settings compared to segregated settings by coders trained to use a social inclusion measure. The authors suggested that this finding contrasts some studies that have found low participation of this population in community activities. In general, the so-called high-functioning children were more likely to be included, but child characteristics (e.g., adaptive, social, and mental age) were not associated with social inclusion based on the coders' observations of different types of community settings. However, the nature of the interactions between children with IDD and ASD and their typically developing (TD) peers and/or adults in these settings was unclear (e.g., does the physical presence of TD peers or facilitation of interactions by adults in a setting count as social inclusion?). Both Ghosh and Datta [33], and Grandisson, Tereault, and Freeman [35] examined participation in community sports activities and the impact on daily life functioning and social inclusion for young people with IDD. Ghosh and Datta found that participation in sports activities developed specifically for young people with ID (e.g., Special Olympics) was linked to increased functioning in daily life activities for young people with ID (ages 2 to 18 years) and increased experiences of social inclusion compared to mainstream sports and other community activities. Likewise, Grandisson, Tetreault, and Freeman found that sports participation contributed to increased perceptions of social inclusion, as well as health improvement, self-esteem development, development of motor, social, and cognitive skills, and opportunities for fun for adolescents with ID aged 12 to19 years old. These studies suggest that participation in community sports activities can have an impact on multiple dimensions of wellness, including community participation, occupational, and social wellness.

Nature of Research on Wellness for Children and Youth with IDD

Articles in this review included a commentary ($n = 1$), web-based surveys ($n = 7$), quantitative ($n = 17$), qualitative ($n = 10$), and mixed methods ($n = 2$) studies. The majority of studies focused on youth (i.e., individuals with IDD > 12 years old; $n = 16$), followed by studies that included children and youth ($n = 11$), then studies focused on children only ($n = 5$) or did not report on age clearly ($n = 5$).

From the qualitative studies, particularly exploratory studies, the combined findings are potentially transferable for developing our understandings of what constitutes and contributes to an overarching sense of wellness for children and youth with IDD more broadly. Of the quantitative studies, the study designs ranged from a single case-controlled study to before and after cohort studies, which often lacked a control group. In addition, sample sizes were small, which potentially limits the statistical generalizability of results to a broader population of children and youth with IDD. For the most part, the outcome measurement tools for wellness were completed by a parent or guardian as a proxy, rather than by children and youth themselves. This suggests that further research should explore methods for gaining the perspectives of children and youth in order to understand what wellness means to them and how they experience it.

Comparisons across studies were difficult to make because IDD is an umbrella term for a wide range of diagnostic labels. People with IDD are a diverse group, considering diagnostic labels, levels of adaptive functioning and social circumstances. Moreover, wellness can have multiple, co-existing meanings; thus, conceptualizations of wellness need to be broad, yet flexible, in order to capture what wellness means for each person and for a variety of stakeholders. Some of the studies examined or focused on concepts such as quality of life, participation, health, and thriving, which can be considered similar to, but not necessarily the same as, wellness. The measurement tools used often focused on "proxy" concepts, which may not measure wellness or its dimensions, or may be conflated with measuring wellness. However, collectively, these studies can inform future research that aims to gain in-depth understandings of the multiple, overlapping wellness dimensions, which can inform conceptualizations of wellness for this population, as well as the development and evaluation of wellness interventions and measures.

Informing Wellness Promotion Research and Practice

Young people with IDD experience suboptimal wellness across several dimensions compared to their peers without IDD and interventions are needed to target multiple dimensions at once. Many of the articles alluded to wellness as the ultimate goal for children and youth with IDD, although wellness itself was not clearly defined or explored. This posed a challenge for categorizing the articles, even with the wellness descriptions on Table 1 to guide us. For example, we had challenges distinguishing between psychological and emotional wellness, particularly in relation to articles focused on mental health. Further work is needed to explore how wellness and wellness dimensions are conceptualized in relation to one another, and in relation to conventional notions of health. A wellness approach recognizes that interventions focused on addressing deficits will have limited impact on the overall health and wellness of children and youth with IDD over the lifespan. However, research that can inform interventions focused on promoting and supporting wellness across multiple dimensions can potentially contribute to an overarching sense and experience of wellness for this group.

Wellness promotion programs for children and youth with IDD should be to be tailored to them—their bodies, learning styles, and ways of communicating and functioning, rather than being framed around typical bodies, development, and functioning. A sense of wellness from the perspectives of young people with IDD can and should be understood and valued in their own right. In addition, wellness programs for this group can target multiple, overlapping dimensions. For example, physical activity programs can play a role in fostering not only physical wellness, but also social wellness and community participation. Whether or not gains are made in improving physical health indicators, there may be valuable gains such as connecting with others, having a sense of belonging, and participating in programs at a local community center that can contribute to an overarching sense of wellness. It is also important to address the barriers and inequitable access to wellness-promoting programs and services that were highlighted in these studies. This means developing programs and services if they do not exist, or tailoring/adapting existing wellness programs in health, education, and social services to meet the needs of children and youth with IDD. This includes programs that target family caregivers as wellness role models who can promote wellness experiences and life-long wellness behaviors in their children and youth with IDD. Moreover, programs can promote family wellness more broadly by taking a family systems approach [59•].

Wellness interventions require a multi-disciplinary approach: Wellness promotion does not rest on one profession or discipline given that it covers an array of dimensions and can be experienced in a variety of daily life contexts. This suggests the need for comprehensive and coordinated services and care that spans across health, education, and social services. Moreover, wellness care and pathways ought to be personalized, as what constitutes and contributes to wellness may be different for each person at different life stages and in social contexts that shift over the life course. However, identifying a service provider who can assist young people and their families in navigating services and opportunities to foster wellness could be a valuable service in itself.

Conclusion

Wellness for children and youth with IDD marks a shift in perspective from a health-only model to including physical, psychological, emotional, occupational, and other dimensions that impact on a person's sense of wellness. The emerging wellness literature, as well as the interest of stakeholders involved in informing this scoping review, illustrates that wellness is an important and emerging topic of interest for children and youth with IDD and their families. Rethinking approaches to the health and well-being of children and youth with IDD can place more emphasis on promoting an overarching sense of wellness and on the perspectives of children and youth with IDD themselves on what contributes to their wellness across multiple dimensions.

Acknowledgments We sincerely thank our partners Special Olympics Canada and Special Olympics Ontario for supporting this work. YH and TY were supported by Mitacs Elevate Postdoctoral Fellowships.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no competing interests.

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.

References

Papers of particular interest, published recently, have been highlighted as:
- • Of importance
- •• Of major importance

1. Ali A, Scior K, Ratti V, Strydom A, King M, Hassiotis A. Discrimination and other barriers to accessing health care: perspectives of patients with mild and moderate intellectual disability and their carers. PLoS One. 2013;8(8):e70855.
2. Hamdani Y, Lunsky Y. Health and health service use of youth and young adults with intellectual and developmental disabilities. Curr Dev Disord Rep. 2016;3(2):97–103.
3. Thomas K, Bourke J, Girdler S, Bebbington A, Jacoby P, Leonard H. Variation over time in medical conditions and health service utilization of children with Down syndrome. J Pediatr. 2011;158(2):194–200.
4.•• Menear KS, Preskitt JK, Goldfarb SS, Menachemi N. Correlates of wellness among youth with functional disabilities. Disabil Health J. 2015;8(2):223–30. **This study explored overall wellness and its subdimensions experienced by youth with functional limitations (ages 12 to 17 years) and directs attention to family involvement and comprehensive supports as wellness-promoting interventions.**
5. Preskitt JK, Menear KS, Goldfarb SS, Menachemi N. Wellness among US adolescents ages 12–17 years. Child Care Health Dev. 2015;41(6):1207–15.
6. Rimmer JH. Health promotion for people with disabilities: the emerging paradigm shift from disability prevention to prevention of secondary conditions. Phys Ther. 1999;79(5):495–502.
7. Rimmer JH. Building a future in disability and public health. Disabil Health J. 2011;4(1):6–11.
8. Sartorius N. The meanings of health and its promotion. Croat Med J. 2006;47(4):662–4.
9. Kuijken NM, Naaldenberg J, Nijhuis-van der Sanden MW, Schrojenstein-Lantman de Valk HM. Healthy living according to adults with intellectual disabilities: towards tailoring health promotion initiatives. J Intellect Disabil Res 2016;60(3):228–241.
10. Rodogno R, Krause-Jensen K, Ashcroft RE. 'Autism and the good life': a new approach to the study of wellbeing. J Med Ethics. 2016;42(6):401–8.
11. Adams T, Bezner J, Steinhardt M. The conceptualization and measurement of perceived wellness: integrating balance across and within dimensions. Am J Health Promot. 1997;11(3):208–18.
12. Saul J, Rodgers RF. Wellness, not weight: changing the focus in children and adolescents. J Am Acad Child Adolesc Psychiatry. 2016;55(1):7–9.
13. Brooker K, Van Dooren K, McPherson L, Lennox N, Ware R. Systematic review of interventions aiming to improve involvement in physical activity among adults with intellectual disability. J Phys Act Health. 2015;12(3):434–44.
14. Johnson CC. The benefits of physical activity for youth with developmental disabilities: a systematic review. Am J Health Promot. 2009;23(3):157–67.
15. Maïano C, Normand CL, Aimé A, Bégarie J. Lifestyle interventions targeting changes in body weight and composition among youth

with an intellectual disability: a systematic review. Res Dev Disabil. 2014;35(8):1914–26.

16. McPherson AC, Keith R, Swift JA. Obesity prevention for children with physical disabilities: a scoping review of physical activity and nutrition interventions. Disabil Rehabil. 2014;36(19):1573–87.
17. Tint A, Thomson K, Weiss JA. A systematic literature review of the physical and psychosocial correlates of Special Olympics participation among individuals with intellectual disability. J Intellect Disabil Res. 2017;61(4):301–24.
18. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol. 2005;8(1):19–32.
19. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. Implement Sci. 2010;5(1):69.
20. Colquhoun HL, Levac D, O'Brien KK, Straus S, Tricco AC, Perrier L, et al. Scoping reviews: time for clarity in definition, methods, and reporting. J Clin Epidemiol. 2014;67(12):1291–4.
21. Moher D, Liberati A, Tetzlaff J, Altman DG, Prisma Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med. 2009;6(7):e1000097.
22. Buckley S. Increasing opportunities for physical activity. Down Syndr Res Pract. 2007;12(1):18–9.
23. Burrows KE, Adams CL, Spiers J. Sentinels of safety: service dogs ensure safety and enhance freedom and wellbeing for families with autistic children. Qual Health Res. 2008;18(12):1642–9.
24. Caliandro P, Grugni G, Padua L, Kodra Y, Tonali P, Gargantini L, et al. Quality of life assessment in a sample of patients affected by Prader–Willi syndrome. J Paediatr Child Health. 2007;43(12):826–30.
25. Carvalho M, Perry A, Bebko J, Minnes P. BRIEF REPORT: social inclusion of Ontario children with developmental disabilities in community settings. J Dev Disabil. 2014;20(3).
26. Choi PH, Cheung SY. Effects of an 8-week structured physical activity program on psychosocial behaviors of children with intellectual disabilities. Adapt Phys Act Q. 2016;33(1):1–4.
27. Cooney G, Jahoda A, Gumley A, Knott F. Young people with intellectual disabilities attending mainstream and segregated schooling: perceived stigma, social comparison and future aspirations. J Intellect Disabil Res. 2006;50(6):432–44.
28. Curtin C, Bandini LG, Must A, Phillips S, Maslin MC, Lo C, et al. Including youth with intellectual disabilities in health promotion research: development and reliability of a structured interview to assess the correlates of physical activity among youth. J Appl Res Intellect Disabil. 2016;29(4):378–86.
29. Davis K, Zhang G, Hodson P. Promoting health related fitness for elementary students with intellectual disabilities through a specifically designed activity program. J Policy Pract Intellect Disabil. 2011;8(2):77–84.
30. Foley KR, Blackmore AM, Girdler S, O’donnell M, Glauert R, Llewellyn G, et al. To feel belonged: the voices of children and youth with disabilities on the meaning of wellbeing. Child Indic Res. 2012;5(2):375–91.
31. Fourie CL, Theron LC. Resilience in the face of fragile X syndrome. Qual Health Res. 2012;22(10):1355–68.
32. George VA, Shacter SD, Johnson PM. BMI and attitudes and beliefs about physical activity and nutrition of parents of adolescents with intellectual disabilities. J Intellect Disabil Res. 2011;55(11):1054–63.
33. Ghosh D, Datta TK. Functional improvement and social participation through sports activity for children with mental retardation: a field study from a developing nation. Prosthetics Orthot Int. 2012;36(3):339–47.
34. Golubović Š, Škrbić R. Agreement in quality of life assessment between adolescents with intellectual disability and their parents. Res Dev Disabil. 2013;34(6):1863–9.
35. Grandisson M, Tétreault S, Freeman AR. Enabling integration in sports for adolescents with intellectual disabilities. J Appl Res Intellect Disabil. 2012;25(3):217–30.
36. Hall AM, Theron L. How school ecologies facilitate resilience among adolescents with intellectual disability: guidelines for teachers. S Afr J Educ. 2016;36(2):01–13.
37. Hassiotis A, Turk J. Mental health needs in adolescents with intellectual disabilities: cross-sectional survey of a service sample. J Appl Res Intellect Disabil. 2012;25(3):252–61.
38. Hinckson EA, Dickinson A, Water T, Sands M, Penman L. Physical activity, dietary habits and overall health in overweight and obese children and youth with intellectual disability or autism. Res Dev Disabil. 2013;34(4):1170–8.
39. Hsieh RL, Hsueh YM, Huang HY, Lin MI, Tseng WC, Lee WC. Quality of life and impact of children with unclassified developmental delays. J Paediatr Child Health. 2013;49(2):E116–21.
40. Kumar G, Shekhar A, Unnikrishnan B, Kotian MS. Effect of psychosocial intervention on quality of life and disability grading of mentally disabled adolescents. Curr Pediatr Res. 2011;15(2).
41. Li EP, Liu YM, Lok NC, Lee VW. Successful experience of people with Down syndrome. J Intellect Disabil. 2006;10(2):143–54.
42. Lin JD, Lin PY, Lin LP, Chang YY, Wu SR, Wu JL. Physical activity and its determinants among adolescents with intellectual disabilities. Res Dev Disabil. 2010;31(1):263–9.
43. Marquis WA, Baker BL. Sports participation of children with or without developmental delay: prediction from child and family factors. Res Dev Disabil. 2015;37:45–54.
44. Menear K. Parents’ perceptions of health and physical activity needs of children with Down syndrome. Down Syndr Res Pract. 2007;12(1):60–8.
45. Messersmith NV, Slifer KJ, Pulbrook-Vetter V, Bellipanni K. Interdisciplinary behavioral intervention for life-threatening obesity in an adolescent with Prader-Willi syndrome—a case report. J Dev Behav Pediatr. 2008;29(2):129–34.
46. Pikora TJ, Bourke J, Bathgate K, Foley KR, Lennox N, Leonard H. Health conditions and their impact among adolescents and young adults with Down syndrome. PLoS One. 2014;9(5):e96868.
47. Rimmer JH, Yamaki K, Lowry BM, Wang E, Vogel LC. Obesity and obesity-related secondary conditions in adolescents with intellectual/developmental disabilities. J Intellect Disabil Res. 2010;54(9):787–94.
48. Roizen NJ, Magyar CI, Kuschner ES, Sulkes SB, Druschel C, van Wijngaarden E, et al. A community cross-sectional survey of medical problems in 440 children with Down syndrome in New York state. J Pediatr. 2014;164(4):871–5.
49. Roush SE, Samways KF, Stolgitis J, Rabbitat J, Cardinal E. Self- and caregiver-reported experiences of young adults with developmental disabilities. J Soc Work Disabil Rehabil. 2007;6(4):53–73.
50. Salaun L, Berthouze-Aranda SE. Physical fitness and fatness in adolescents with intellectual disabilities. J Appl Res Intellect Disabil. 2012;25(3):231–9.
51. Singh NN, Lancioni GE, Singh AN, Winton AS, Singh J, McAleavey KM, et al. A mindfulness-based health wellness program for an adolescent with Prader-Willi syndrome. Behav Modif. 2008;32(2):167–81.
52. Skotko BG, Levine SP, Goldstein R. Having a son or daughter with Down syndrome: perspectives from mothers and fathers. Am J Med Genet A. 2011;155(10):2335–47.
53. van Gameren-Oosterom HB, Fekkes M, Buitendijk SE, Mohangoo AD, Bruil J, Van Wouwe JP. Development, problem behavior, and quality of life in a population based sample of eight-year-old children with Down syndrome. PLoS One. 2011;6(7):e21879.
54.•• Weiss JA, Burnham Riosa P. Thriving in youth with autism spectrum disorder and intellectual disability. J Autism Dev Disord. 2015;45(8):2474–86. **This study examines what contributes to thriving in youth with autism and ID, which is a shift in focus compared to research to date that focuses on identifying their deficits as barriers to mental health and wellness.**

55. Weiss JA, Ting V, Perry A. Psychosocial correlates of psychiatric diagnoses and maladaptive behaviour in youth with severe developmental disability. J Intellect Disabil Res. 2016;60(6):583–93.
56. Whitt-Glover MC, O'Neill KL, Stettler N. Physical activity patterns in children with and without Down syndrome. Pediatr Rehabil. 2006;9(2):158–64.
57. Wilson KS, Wiersma LD, Rubin DA. Quality of life in children with Prader Willi syndrome: parent and child reports. Res Dev Disabil. 2016;57:149–57.
58. Yousefi AA, Mozaffari K, Sharif N, Sepasi M. Reliability and validity of the "personal wellbeing index-cognitive disability" on mentally retarded students. Iranian J Psychiatry. 2013;8(2):68–72.
59.• Tint A, Weiss JA. Family wellbeing of individuals with autism spectrum disorder: a scoping review. Autism. 2016;20(3):262–75. **This review is one of the first papers focused on understanding family well-being of people on the autism spectrum**