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RESEARCH ARTICLE

Capacity building for youth with disabilities: principles and key ingredients identified through a scoping review

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ABSTRACT

Purpose: This knowledge synthesis aimed to 1) Map the extent and nature of the literature on capacity building in the field of rehabilitation for transition-age youth with disabilities (12-30 years old) and 2) Describe how capacity building is conceptualized and identify principles and key ingredients underpinning this concept.

Materials and Methods: A scoping review using JBI methodology was employed. A search of six databases resulted in 2169 English documents; 34 were retained. Two reviewers charted and analyzed the data, supported by the third reviewer. Inductive content analysis was used to identify principles and key ingredients.

Results: Seven documents provided explicit definitions of capacity or capacity building. Content analysis revealed four principles describing capacity building as: 1) individualized approach with real-world application 2) fostering a preferred future 3) youth taking ownership for change and 4) an ongoing process. Six key ingredients detail how to build capacity: 1) individualized and flexible approach in natural context 2) shared responsibility 3) use of accessible information and resources 4) cultivate strengths 5) opportunities for full participation and 6) facilitate reflection on experiences.

Conclusion: Clinicians and researchers can draw upon identified capacity building principles and ingredients to support meaningful real-world outcomes for transition-age youth.

IMPLICATIONS FOR REHABILITATION

- Programs and interventions that seek to build capacity of youth with disabilities can consider the identified ingredients to guide the generic rehabilitation process.
- Capacity building approaches address youth's beliefs, knowledge, and skills, related to pursuing their desired goals and problem-solving through barriers in their own changing contexts.
- As our field shifts toward a focus on capacity building approaches; it is important to clearly define this concept within our intervention and outcomes.

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Youth; young adults; capacity building; neurodevelopmental disability; long-term outcomes; problem-solving; environment; transformative learning

Introduction

Capacity building in the context of rehabilitation has been described as a process encompassing change in knowledge and skills with the focus on future growth and development of the client's potential [1]. Capacity building can be difficult to define theoretically and operationally [2] since it is an approach that is transactional, highly dependent on an individual's unique context and focuses on future change. It is necessary to find ways to capture the process and outcomes of capacity building. There is inconsistency in defining and using capacity building as both a process and an outcome in pediatric rehabilitation.

Capacity building is a desired outcome in rehabilitation, which considers the future potential of an individual to adapt to environmental conditions [3]. To illustrate, participation-based approaches are increasingly being used for youth with neurodevelopmental disabilities [4–6] where *building child and family capacity to self-manage disability related situations is an intended outcome*. Interventions such as coaching or participation-based therapies are typically done in natural contexts (involve real life learning) and aim to build the capacity of clients, caregivers, or others in the client's environment to solve their own problems [1,7]. There is also some documented use of capacity building approaches for youth with mental health problems [8,9]. Although capacity building is considered important, as it is commonly used as a desired target end of intervention, the concept of capacity building is also elusive; there is no unified theoretical definition and thus no clear operational definition. While there are emerging capacity building approaches (often embedded within coaching approaches) to improve outcomes in the field of rehabilitation, research is needed to examine sustainability of effects [10]. Examining long-term effects of capacity building

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approaches is challenging given the gap in knowledge about how to operationalize these effects.

Capacity building is important for youth as they transition from adolescence to a more independent adulthood (and adult roles) which includes transitioning to adult health care systems [11]. The United Nations typically defines youth as ranging from age 15-24 years old [12]. In rehabilitation, the preparation for transition to adult care is recognized to start as young as age 12 [13], about the age that youth with chronic conditions start to develop self-management skills [14]. Additionally, this period of emerging adulthood may be a longer process for people with disabilities who often attend secondary school longer than same-age peers and experience delays in finding employment [15]. Therefore, for the purpose of this review, the expanded age range of 12-30 is used to encompass the adolescent period of many youth with disabilities.

A scoping review is used to identify and synthesize existing knowledge to understand how capacity building is framed and used in rehabilitation of youth with neurodevelopmental or chronic disabilities, and/or mental health disorders. A scoping review methodology was selected for several reasons. First, to clarify the concept of capacity building and its related definitions in the literature for rehabilitation, second to identify key characteristics of capacity building, and finally to identify potential knowledge gaps [16]. The scoping review methodology uses an exploratory, descriptive approach allowing for inclusion of studies with different methodological approaches and populations which is useful given the heterogeneity of the emerging literature on capacity building. The goal of a scoping review is to describe concepts, findings, and outcomes rather than to summarize or assess the quality of studies. The research question guiding this review is: How is capacity building framed within the literature for rehabilitation of transition-age youth with neurodevelopmental disabilities and/or mental health problems and/or their caregivers?

Objectives

This knowledge synthesis aimed to 1) Map the extent and nature of the literature on capacity building in rehabilitation for transition-age youth (ages 12-30) with disabilities and 2) Describe how capacity building is conceptualized and identify principles and key ingredients underpinning this concept.

Methods

The scoping review was conducted in accordance with the Joanna Briggs Institute (JBI) methodology for scoping reviews [16]. This methodology builds upon the six-stage methodological framework by Arksey and O'Malley [17] and additional recommendations by Levac et al. [18]. This manuscript follows the Preferred Reporting Items for Systematic reviews and Meta-Analysis extension for Scoping Reviews (PRISMA-ScR) [19], a completed PRISMA-ScR checklist is provided in the supplementary file.

The protocol is registered online with Open Sciences Framework [20]. To ensure the currency of the synthesis an updated search was completed on June 17, 2024. Although an overview of all results is presented in the current manuscript, the qualitative analysis focuses on answering the first subquestion of the protocol: *(a) how is capacity building conceptualized within theoretical and practical models (principles and key ingredients) of rehabilitation for youth?*

Search strategy

The search strategy aimed to identify relevant peer-reviewed articles, book chapters, and dissertations. An academic librarian was involved with developing and implementing a targeted and iterative search strategy. The comprehensive search strategy was used to identify literature that explicitly includes the concept of capacity building, rather than related concepts (e.g., empowerment, self-determination) since this review aims to understand how the term capacity building is used in the literature. To identify literature relevant for the rehabilitation context, diagnoses of youth who typically receive rehabilitation services were included. With the goal of capturing a broad range of disabilities and mental health problems of youth who are serviced by rehabilitation professionals, a comprehensive list was developed through expanding on search terms used in previous scoping reviews. Specifically, the list of search terms used for childhood-onset disabilities in Anaby et al. [21] and mental health problems in Lal et al. [22] were used to build the search since both of these reviews also aimed to develop a broad and comprehensive list of relevant diagnoses. Additional search terms and MeSH headings were also applied to the current search as needed. Finally, the target population (i.e., youth 12-30 years old) was searched broadly based on salient terms and keywords related to capturing 'transition-aged youth'. A full search strategy was developed for OVID Medline (Table 1). The search strategy, including all identified keywords and index terms, was adapted for each included database, allowing a more sensitive search of the literature. The reference lists of all included sources of evidence were hand searched for additional documents.

Studies published in English without any date restraints were included. This scoping review considered all study designs, including experimental, case reports, and qualitative designs. Opinion papers, theoretical papers, book/book chapters, and dissertations were also considered for inclusion. Published abstracts were not included due to the limited information that can be extracted from an abstract.

Six databases were searched (initially on July 14, 2021; and updated on June 17, 2024): Medline (OVID), CINAHL (EBSCO), ERIC (EBSCO), EMBASE (OVID), PsycInfo (OVID), and ProQuest (for dissertations). These databases were selected to search for information from a combination of fields (i.e., health, education, psychology) for broader results which may be relevant for the rehabilitation context.

Source of evidence selection

Following the search, all identified citations were collated and uploaded into EndNote X9.3.3 and duplicates removed. Specific eligibility criteria for including documents were defined according to population, concept, and context.

Population

The target population of interest was youth receiving rehabilitation services as they transition from adolescence to a more independent adulthood (or their caregivers). Documents were included if the population was: 1) Youth with persistent or chronic physical disabilities, neurodevelopmental disorders, and/or mental health problems who typically receive rehabilitation services OR their parent(s)/caregiver(s) AND 2) The adolescent, youth, or young adult(s) were within the transition-age range of 12-30 years old. Documents were excluded if: 1) The specified median age of youth sample was outside of the 12-30 years old range OR 2) The age was not specified but was focused on "early intervention" or "young children."

Table 1. Search strategy for OVID Medline.

Participants: Transition-age Youth
Pediatric Filter: (child* or pediatric* or pediatric* or prematur* or preterm* or perinat* or neonat* or neo nat* or newborn* or new born* or infan* or baby* or babies or toddler* or boy* or girl* or kid$1 or school* or juvenil* or underage* or under age* or teen* or minor$1 or youth$1 or adolescen* or pubescen* or puberty).mp.
OR
(neonat* or infan* or child* or adolescen* or pediatric* or pediatric*).jw.
OR
young adult*.mp.
OR
MeSH Headings:
exp infant/ or exp child/ or adolescent/ or exp pediatrics/
Young Adult/
Transition to Adult Care/
Students/
AND
Concept: Capacity Building
(Capacity adj3 build*).mp. OR Self-capacit*.mp.
AND
Context: Rehabilitation of Youth with Neurodevelopmental Disabilities or Mental Health Problems
(Cerebral Palsy, Spina Bifida OR myelomeningocele OR meningocele, Down syndrome, Attention Deficit Disorder OR ADD OR Attention Deficit/hyperactivity disorder OR ADHD, Developmental Coordination Disorder, Communication Disorder OR DCD OR developmental dyspraxia OR Motor coordination disorder OR clumsy child syndrome, Eating disorder OR disordered eating, Orthopedic Muscular Dystrophies (OR … Duchenne's, Spinal Muscular Atrophy), Congenital deformity, Brachial Plexus injury, Epilepsy OR seizure disorder, Movement disorder, Autism OR autistic disorder* OR Autism spectrum disorder OR ASD OR Pervasive Developmental Disorder OR PDD OR PDD-NOS, Sensory disintegrative disorder OR sensory defensiveness OR sensory processing disorder, Anxiety, Global developmental delay, Fine motor dysfunction, Acquired brain injury OR traumatic brain injury OR brain injury OR head injury Learning Disability, Non-verbal learning disabilities/disorder, Cleft lip and palate (OR cleft lip; cleft palate; cleft lip and palate; orofacial cleft), Juvenile adj3 arthritis).mp.
OR
(Physical disability or physical handicap or neurodevelopmental disorder).mp
OR
(Mental* ill* person* or Mental health* or Psychiatric diagnosis or Psychotic disorder* or Brief reactive psychosis or Schizoaffective disorder* or Schizophreniform disorder* or Psychosis or Schizophrenia or Schizophrenic disorder* or Bipolar disorder* or Bipolar depression or Manic disorder* or Manic state* or Mania or Bipolar affective psychosis or Anxiety or Depression or Substance* abuse* or Substance* related disorder* or Eating disorder* or ASD or Autism or DSM).ab,kf,kw,ti.
OR
MeSH Headings:
Cerebral Palsy/ or Spinal Dysraphism/ or Spina Bifida Occulta/ or Meningomyelocele/ or Meningocele/ or Down Syndrome/ or Attention Deficit Disorder with Hyperactivity/ or Motor Skills Disorders/ or exp Communication Disorders/ or exp Developmental Disabilities/ or Apraxias/ or Neuromuscular Diseases/ or Duchenne/ or Scoliosis/ or Muscular Dystrophies/ or Muscular Atrophy, Spinal/ or Abnormalities, Multiple/ or Birth Injuries/ or Brachial Plexus Neuropathies/ or Epilepsy/ or Movement Disorders/ or Autistic Disorder/ or Asperger Syndrome/ or Autism Spectrum Disorder/ or Child Development Disorders, Pervasive/ or Sensation Disorders/ or Brain Injuries, Traumatic/ or Brain Injuries/ or Craniocerebral Trauma/ or Cleft Lip/ or Cleft Palate/ or Arthritis, Juvenile/ or Disabled Persons/ or Neurodevelopmental Disorders/ or Feeding and Eating Disorders/ or exp Anxiety/ or Learning Disabilities/ or Congenital, Hereditary, and Neonatal Diseases and Abnormalities/ or Disabled Children/

Concept

We were interested in how the concept of capacity building is explicitly used (i.e., when the term capacity building is clearly named) in the literature for transition-age youth who receive rehabilitation services. Documents were included if they: 1) Included capacity building as at least one aspect of the intervention, framework, outcome measured/reported, or findings (i.e., themes) for either the youth or their caregiver. Documents were excluded if they: 1) Focused on capacity building exclusively of staff/service providers at an organizational level.

Context

The aim was to include documents relevant to the rehabilitation context, in any setting (i.e., home, school, community, etc.), without restrictions on geographic location. The World Health Organization's definition of rehabilitation was used to clarify the meaning of rehabilitation context [23]. Documents were included if they: 1) Are within the rehabilitation field including (but not limited to) occupational, physical, or speech therapy, or social work. Documents were excluded if they: 1) Are focused on contexts outside of the rehabilitation of youth such as public health, health behavior change, educational context without mention of a rehabilitation specialist, knowledge translation for health professionals, or youth/family engagement in research.

The eligibility criteria were pilot tested by having two reviewers (M.R. & N.F.) independently screen the first 20 titles and abstracts. With 75% agreement initially, consensus was reached through discussion between the two reviewers and confirmation from a third reviewer (D.A.). All remaining titles and abstracts were then screened by M.R. & N.F. for assessment against the inclusion and exclusion criteria for the review and then compared. Potentially relevant sources were retrieved in full, and their citation details imported into EndNote X9.3.3. The full texts of selected citations were assessed in detail against the inclusion/exclusion criteria by M.R. & N.F. Rayyan [24] was used for blinding decisions made by each reviewer. Reasons for exclusion of sources of evidence screened at the level of the full text were recorded. Disagreements that arose between the reviewers at each stage of the selection process were resolved through discussion, or consultation with

D.A. as needed. A validation process was conducted by D.A. who screened 25% of the excluded documents (every 4th document when listed alphabetically by title). Consensus was reached through discussion. A similar screening process was used for the updated search although screening was completed by M.R. with support from two research assistants. Consensus was reached through discussion with D.A. and M.G. as needed.

Data charting

After collectively developing the data charting form and prior to starting data charting, two reviewers (M.R. & N.F.) independently piloted the data charting form for five documents, comparing afterwards to determine that their approach was consistent with the research question and purpose as recommended by Levac et al. [18]. Each of these two reviewers finished charting data for half of the remaining documents, meeting regularly to discuss the charting process and to confirm all relevant data was included.

The data items charted included publication year and country/location and specific details about the participants (age, diagnoses), concept of capacity building, definitions of capacity or capacity building, context/setting, study methods and key findings relevant to the review questions. Specifically, data was charted about models, theories and frameworks presented in the documents which were relevant for capacity building. Details charted included the title and source/author of the model/theory/framework as well as their key elements (that related to capacity building) and descriptions.

Analysis

Given the variability and emerging use of capacity building in rehabilitation with youth, we anticipated a variety of study designs and research approaches. We did not plan to conduct a critical appraisal of the sources of evidence included in this scoping review. Rather, we aimed to identify the scope and breadth of how capacity building is currently used in the rehabilitation literature for youth to better understand the concept of capacity building and its outcomes in this context and to identify gaps in knowledge.

Charted data about the scope and nature of documents were analyzed descriptively using counts, proportions, and tables. A table was used to organize how capacity building was captured and defined within each document. Data charted about models and frameworks from the initial search were analyzed using qualitative content analysis to describe principles and key ingredients of capacity building. Conventional content analysis, an approach that involves inductive category development [25], was chosen due to the limited existing literature and theory on capacity building. In line with this process, the researchers started by immersing themselves in the data through reading all the data charted relating to models, theories, and frameworks relevant to capacity building. Next, one reviewer (M.R.) color-coded specific words from the charted text that appeared to be important in describing key information about capacity building while also making notes of their initial thoughts/analysis. The initial coding scheme was discussed with the second (N.F.) and third (D.A.) reviewers after coding the first ten documents. Once M.R. completed the coding process, the final list of codes was sent to N.F. The two reviewers independently grouped codes that appeared similar or related to each other to develop emergent categories and suggest potential meaningful clusters to organize the information. M.R. and N.F. each suggested eight categories to group the codes – many of which were similar to one another. D.A. was consulted to discuss the categories and provide input into how to organize them into meaningful clusters. Through discussion and further analysis – data were clustered into a set of four principles, which focus on the overarching ideas describing *what* capacity building is, and six key ingredients that describe more specifically *how* to build capacity. Each principle and key ingredient were then defined, key examples were identified and the list of all references which supported the development of the principle or ingredient was organized. Updated search results were then deductively analyzed according to the identified principles and key ingredients.

Results

Identification of included documents

After removing duplicates, 2169 documents were screened (title and abstract), of which 191 were read in full. Subsequently, 32 documents were identified for inclusion. Based on hand-searching the included documents, two additional relevant documents were identified for a total of 34 documents to be included in the review. The PRISMA-ScR flow diagram is included in Figure 1.

Characteristics of included documents

Documents published in peer-reviewed journals ($n = 31$) included a) three review papers, b) 17 studies presenting original research including 11 studies evaluating a program or service (six qualitative and five mixed methods) and six descriptive qualitative studies, c) eleven perspective papers including seven theoretical manuscripts, three manuscripts that presented a specific capacity building initiative or program (implemented in their local contexts), and one commentary. Additionally, there were two textbook chapters, and one doctoral dissertation included.

Of the 34 included documents, 20% were published between 2006 and 2013, 65% between 2014 and 2020, and 15% within the last three years (2021–2024). Most were published in the United-States (38%) or Canada (38%). Many of the documents (53%) were relevant for a broad rehabilitation context (i.e., not specific to one discipline). The largest represented discipline was Occupational Therapy (OT), 11/34 documents (32%) included an OT context, of which five were OT only, four were OT and Physical Therapy combined, and two were OT with other rehabilitation professionals. One document was specific to speech and language pathology, one specific to vocational rehabilitation, and one specific to therapeutic recreation. The context of four documents were not specified.

Table 2 presents the included documents, the details about their scope and nature, and summary of relevant info extracted that relates to the research question.

Population

With regards to the target population of the included documents, 15 of the documents (44%) addressed capacity building for both youth and their caregiver/family, 10 documents (29%) focused on building capacity of the youth only, and nine documents (27%) were focused more on building the capacity of the youth's caregivers.

Population diagnoses discussed in the selected sources varied. Most documents ($n = 22$; 65%) included a youth population that had more than one diagnoses or were documents that were relevant broadly to youth with disabilities (including eight which did not specify a diagnosis). Whereas 35% of documents ($n = 12$) pertained to one specific diagnosis as follows: cerebral palsy ($n = 3$), brain injury ($n = 2$), developmental coordination disorder (DCD) ($n = 2$), learning disabilities/dyslexia ($n = 2$), autism ($n = 1$), intellectual disability ($n = 1$), and Rett syndrome ($n = 1$). Overall, neurodevelopmental diagnoses were most prevalent with 94% of documents that specified a diagnosis including these conditions. Examples of

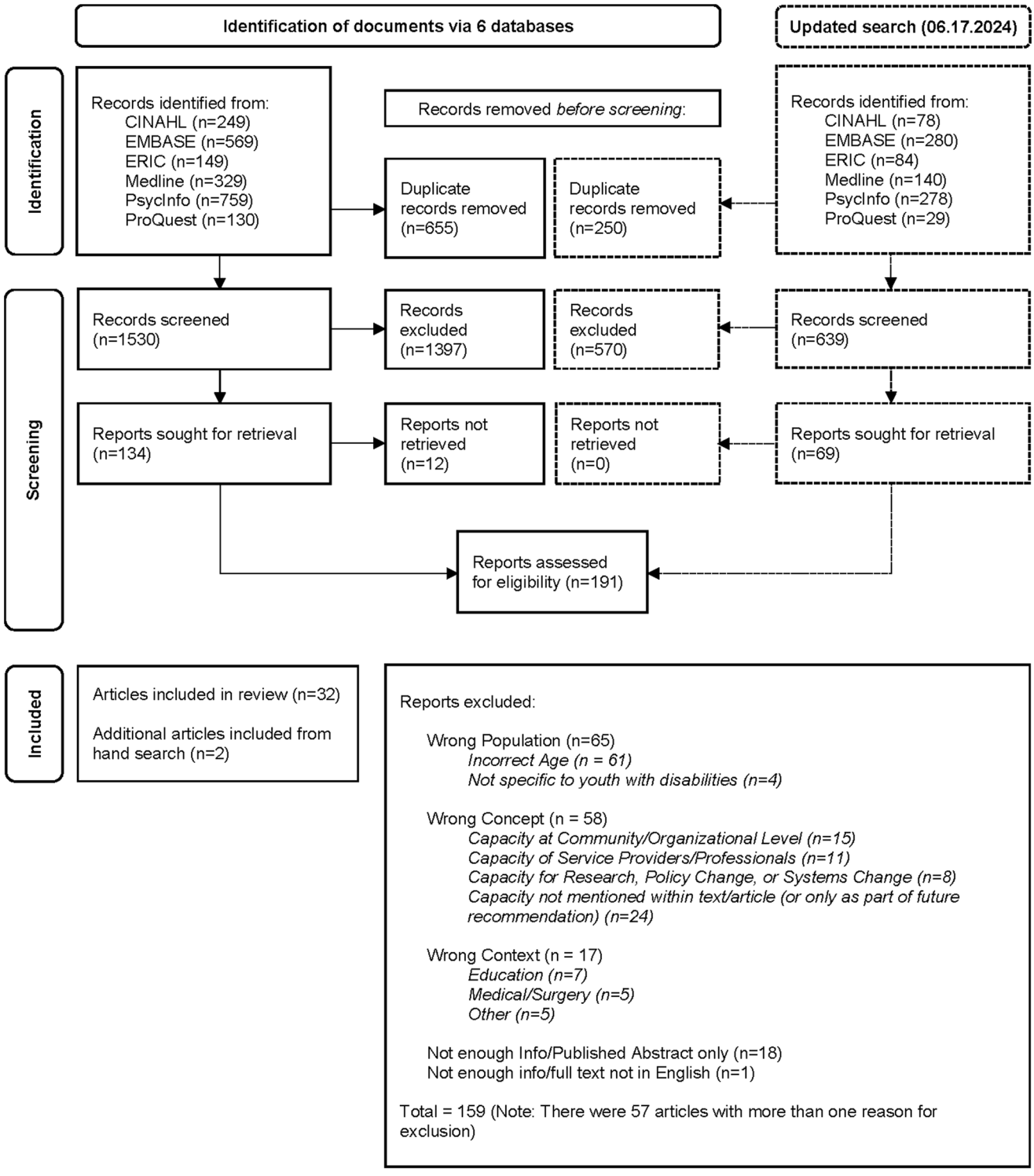

Figure 1. PRISMA flow diagram.

specific neurodevelopmental conditions mentioned were intellectual disability ($n=8$), cerebral palsy ($n=6$), autism ($n=4$), brain tumor/brain injury ($n=3$), learning disorder/dyslexia ($n=3$), seizure ($n=2$), DCD ($n=2$), and ADHD ($n=1$). Other physical/sensory diagnoses were observed/addressed in 21% of the documents: orthopedic/clubfoot ($n=1$), visual/hearing ($n=2$), unspecified physical disability ($n=4$). A few documents ($n=4$; 12%) included mental illness, with only one document specifying the following list of mental health comorbidities: depression, anxiety, bipolar disorder, trauma, post-traumatic stress disorder, eating disorder.

Definitions of capacity building

Seven documents provided an explicit definition of capacity or capacity building (Table 3). The term 'capacity' was described as moving away from traditional skill development in a particular area of function (e.g., physical skills, academic skills), toward addressing future abilities and potential [28,54,57]. Capacity was defined by Stewart as "the ways and means to do what has to be done" [57, p.139]. Capacity building was identified as the *process* of strengthening competencies, knowledge, abilities, resources

Table 2. Included documents.

Authors/ Country	Type of document	Purpose/ Objective	Context	Population	How capacity building was addressed	Relevant models, theories, frameworks
Reviews ($n = 3$)						
Ding, J., Cleary, S., & Morgan, P. [26]. Australia.	Systematic review	To identify evidence of health literacy in young people with cerebral palsy (13–38 years), describe current strategies they use to access and build their health knowledge, and explore associations between health literacy and quality of life (QoL).	Health Literacy (including rehabilitation)	*Studies with participants with cerebral palsy, of any functional or communicative level. Mean age of participants ($n = 363$) across the 11 studies ranged from 16 to 29 years a	Capacity building is captured through the results of the first two aims. Capacity building was identified as a component of health literacy that was evaluated in one study (Aim 1). Capacity building was described within two themes related to strategies (Aim 2): 'The toolkit of essential skills required to build health literacy' and 'Learning experientially through self-reflection, family, peers, and mentors'. In the discussion, capacity building is identified as one of the necessary skills (along with self-efficacy and self-management) to understand and evaluate health information. Authors conclude that "building capacity and empowerment from adolescence can support identification of emerging health literacy needs, and target health literacy development to individuals and their life goals." (p. 10).	N/A
Nguyen, T., Stewart, D., & Gorter, J. W. [27]. Canada.	Narrative review	To reflect on the work conducted by CanChild researchers, in collaboration with stakeholders, about transitions to adulthood for youth and young adults with disabilities since the publication of the best practice guidelines in 2009.	Rehabilitation Sciences	Youth and young adults with disabilities.	Capacity building is a prominent theme throughout the document - and is primarily portrayed as a recommendation for rehabilitation practice. Capacity building is identified as part of intervention approaches and also described in detail within the lessons learned.	The Best Journey to Adulthood
Stewart, D. [28]. Canada.	Review of current evidence	To outline the evidence upon which best practice guidelines for transition to adulthood for young people with physical and developmental disabilities were developed in Ontario, Canada, through consensus activities.	Rehabilitation/ Transition services and care.	Young people with physical and developmental disabilities, in transition from adolescence to adulthood. Participants involved in the documented project: A panel of 'experts' (young people, parents, community members, service providers, consultants) reviewed all of the current evidence about transition to adulthood for young people with disabilities at a consensus conference.	Capacity building is one of the four main areas of recommendations, described in detail through two guidelines developed.	Best practice guidelines for the transition to adulthood for youth with disabilities

(*Continued*)

Table 2. Continued.

Authors/ Country	Type of document	Purpose/ Objective	Context	Population	How capacity building was addressed	Relevant models, theories, frameworks
Primary Studies/Original Research ($n=17$)						
Missiuna, C., Pollock, N., Campbell, W. N., Bennett, S., Hecimovich, C., Gaines, R., DeCola, C., Cairney, J., Russell, D., & Molinaro, E. [29]. Canada.	Mixed-methods/ Feasibility Study	A mixed-methods research design was employed: (1) determining the effectiveness of the OT training on Partnering 4 Change (P4C); (2) testing procedures for documenting therapist activities to assess intervention fidelity; (3) examining the receptivity of teachers and schools to coaching by OTs and the uptake of knowledge around earlier identification and management of children with DCD; (4) examining parent awareness and knowledge uptake; and (5) documenting participant recruitment and retention.	Occupational Therapy	School-age children with Developmental Coordination Disorder (DCD)	The intervention approach (Partnering 4 Change) includes building parent/teacher capacity (i.e., to identify DCD earlier and receive supports). Results from questionnaires and interviews suggest the model increased knowledge and capacity of OTs, teachers, and parents. Parent outcomes included changes in knowledge and empowerment. Some reported increased self-confidence and self-efficacy to advocate on behalf of their child.	Partnering 4 Change (P4C) employs a 'coaching' approach in which OTs collaborate in the classroom to build teacher capacity Adult learning theory Knowledge translation strategies
Bunning, K., Gona, J. K., Newton, C. R., Andrews, F., Blazey, C., Ruddock, H., Hartley, S. [30]. Kenya.	Mixed Methods/ Pre-post	To evaluate impacts associated with the self-help process (i.e., self-help groups) and to identify mechanisms determining the outcome for caregivers of children with disabilities in Kenya.	Mix: self-help groups (SHGs) identified in the 'empowerment' domain of community-based rehabilitation (CBR) matrix and guidelines.	*86 children [female ($n=35$, 41%), age: 0-3 ($n=9$, 11%), age: 4-6 ($n=14$, 16%), age: 7-10 ($n=26$, 30%), age: 11-15 ($n=37$, 43%)] 81 caregivers [age: <20 years ($n=1$, 1%), 21-29 ($n=15$, 19%), 30-39 ($n=27$, 3%), 40+ ($n=38$, 47%)] who cared for a child (0–15 years) that they identified as having a primary condition affecting body function and structure, including intellectual disability, deafness, visual impairment, autistic spectrum condition, cerebral palsy, variously associated with limitations in vision, hearing, mobility, attention, learning and the effects of seizures.	Capacity is included in the description of Empowerment Theory (underlying theory in the introduction). Capacity building itself emerged as part of a theme from caregiver findings defined as "Togetherness and Capacity Building" within the post-intervention which included 'group cohesion', 'business' and 'self-determination'. This theme was categorized under "Agency" in the framework of thematic constructs, reflecting the developing control of the group members and impact on their quality of life. These findings are described in detail in the results section.	Empowerment Theory

(*Continued*)

Table 2. Continued.

Authors/ Country	Type of document	Purpose/ Objective	Context	Population	How capacity building was addressed	Relevant models, theories, frameworks
Pearson, J., Stewart-Ginsburg, J., Malone, K., Manns, L., Martin, D.M., & Sturdivant, D. [31]. U.S.A.	Mixed Methods / Evaluative	Fostering Advocacy, Communication, Empowerment and Supports (FACES) is an advocacy training program with evidence from pilot testing. The purpose of this study was to measure the outcomes of the FACES training on the advocacy capacity among a larger sample of Black parents raising autistic youth, using a quasi-experimental design.	Mix: Professionals with backgrounds in psychology, special education, and mental health counseling were involved with providing the training.	*16 participants: parents/caregivers raising a child with autism. Both the caregiver and the child had to identify as Black or African-American. Two dyads (spouses, and mother/ grandmother) participated in the experimental group. Average age of participants' children was 12.8 years old (range 5.3 − 35.4 years), 81% were male. Two children had co-occurring diagnoses of intellectual disability and attention deficit hyperactivity disorder alongside autism.	The document evaluates outcomes of the FACES program that aims to improve Black parent's capacity to advocate for their autistic children. A definition of advocacy capacity is provided with supporting references, and outlines that advocacy capacity requires knowledge, empowerment, and emancipation. The Special Education Advocacy Scale (SEAS) is used to measure advocacy capacity. Significant change was demonstrated in the experimental group in three of the outcomes measured: family empowerment, perceptions of advocacy capacity (SEAS), and frequency of communication with school-based professionals. However, no significant changes were observed for knowledge of autism and social communication/behavior strategies. The authors therefore suggest "that aspects of advocacy capacity (e.g., empowerment, confidence) may function independently of knowledge" (p.144) and that this may be due to additional social barriers experienced by families in the Black community. Qualitative feedback reflected caregivers' appreciation for the group discussion, mental health and faith content, and IEP information. Aspects of advocacy capacity that demonstrated change (i.e., perceptions of advocacy, overall family empowerment) are discussed in detail through the discussion. The authors conclude that FACES could be used by schools and agencies to build advocacy capacity of Black parents raising autistic youth.	Fostering Advocacy, Communication, Empowerment and Supports (FACES) program developed with: (a) the FACES theory of change (i.e., parent knowledge, parent perceptions, and parent and child outcomes); (b) a simple-to-complex sequence and (c) adult learning theory characteristics.
Daly, L., Sharek, D., Devries, J., Griffiths, C., Sheerin, F., McBennett, P., & Higgins, A. [32]. Ireland.	Mixed Methods / Evaluation of program impact	To report on an evaluation of four family support programmes in Ireland for families of people with a physical or an intellectual disability or autism, to establish whether the programmes had an impact on families' capacity to effectively support their family member.	Not specified	*Family members of a person with disabilities. Persons with disability aged 2-54 (mean 16.5; SD = 12.3), gender distributed evenly, with various disabilities: speech and language difficulties ($n = 19$), behavioral challenges ($n = 17$), physical health problems ($n = 17$), mobility challenges ($n = 17$), feeding or eating problems ($n = 10$), seizures ($n = 8$). 38 family members responded to survey (30 parents, 6 siblings, 1 grandmother, 1 aunt) 21 family members interviewed (18 mothers, 2 fathers, 1 sister)	Capacity building is one of the primary aims and anticipated outcomes of the family support programmes described in detail in the introduction. Within the results, capacity building was described as part of the theme "Making a difference within the family" and more specifically "enrichment of the quality of life of the person living with a disability." Following the programmes, improvement was observed in several aspects of capacity building. Examples included changes in family's worldviews, knowledge and skills related to advocating for their family member to achieve self-determination and experience a meaningful fulfilled life. Linked outcomes for family members (i.e., youth) included increased community involvement, employment, independent living, or socializing for example.	A model to categorize family-oriented supports according to the extent of self-sufficiency and capability assumed

(*Continued*)

Table 2. Continued.

Authors/ Country	Type of document	Purpose/ Objective	Context	Population	How capacity building was addressed	Relevant models, theories, frameworks
Bigby, C., Douglas, J., Smith, E., Carney, T., Then, S., & Wiesel, I. [33]. Australia.	Mixed Methods / Evaluative	A rights perspective proposes supported decision-making as an alternative to substitute decision-making. However, evidence about supported decision-making practice is limited. The aim was to build evidence about building the capacity of decision supporters.	Not specified.	*18 parents ranging in age from 47-74 years (mean = 59). Adults with mild to profound intellectual disability that they supported ranged from 19-39 years (mean =27).	The importance of focusing on the capacity of decision supporters to respect will and preferences is described in the introduction, with supporting legislation in Australia. Building capacity is the primary aim of the training program (based on the La Trobe Framework) provided to decision supporters and evaluated in this study. Three categories are described in the results; two that capture parents' reflections about the training ('*a catalyst for reflecting and rethinking perspectives*' and '*taking a more deliberative approach to supporting participation*') and one reflecting perceived change to the person being supported ('*greater confidence in expressing preferences*'). Capacity building is captured in the discussion, and findings suggest that greater attention could also be given to building capacity of all adults with intellectual disability as a parallel strategy.	La Trobe Support for Decision-making Practice Framework
Burrough, M., Beanlands, C., & Sugarhood, P. [34]. UK.	Qualitative/ Evaluative	To understand experiences of clinicians implementing PREP in a UK clinical context, with a focus on implementation processes and key factors for successful implementation.	Occupational Therapy	*6 female occupational therapists working with children and young people with ABI.	Post-implementation, capacity building was captured as part of one of the qualitative themes "Participation Moves Beyond the OT" described in the results. Therapists felt youth demonstrated more insight into participation challenges and families began to apply problem-solving techniques to other participation opportunities. Ripple effects were also described to reach other members of the multidisciplinary team.	Pathways and Resources for Engagement and Participation (PREP) Person-centered care principles (from NHS England New Care Models)
Ellem, K., Chenoweth, L., & Edwards, R. [35]. Australia.	Qualitative/ Evaluative	To present findings from an evaluation of a family resourcing and capacity building project in New South Wales, Australia.	Disability services	*26 family members interviewed (majority mothers; one father and one sibling), including 16 participants (62%) supporting a person with an intellectual disability as their primary diagnosis, while other family members supported a person with autism, cerebral palsy and brain tumor.	This study describes a capacity building project (Helping Families Project), with the capacity building aims specified in the introduction. Furthermore, the approach which families were trained on (i.e., person-centered planning) are also capacity building approaches themselves. The thematic findings were initially organized into four categories (change in the life of the person with a disability, change in the intentions of families, change in actions of families, barriers faced by families). The findings presented in this manuscript focus on family responsibilities in PCP (overall benefits of participation in workshops, visioning-unpacking psycho-emotional disablism, building commitment through circles of support, asking to be included, employment, service responses, self-directing supports, and tiredness). Recommendations for implementing capacity building initiatives are summarized.	Person-centered Planning (PCP)

(*Continued*)

Table 2. Continued.

Authors/ Country	Type of document	Purpose/ Objective	Context	Population	How capacity building was addressed	Relevant models, theories, frameworks
Hanson, J., Robinson, D., & Codina, G. [36] United Kingdom.	Qualitative / Evaluative	To find out how supported internships for people with learning disabilities helped them to feel like they belong in workplaces and society.	Supported internships (SI) – relevant for rehabilitation.	Young people with learning disabilities *Interviews were conducted with 6 Interns, 3 Graduates, 2 Job coaches, 2 Supervisors, and 1 Colleague	The theoretical framework describes how self-concept is implicated in the development of capacities for participation. Capacities are captured in the theme, 'Expanding horizons: positive self-concept and capacities for participation' (development of self-concept in relation to self-confidence, self-efficacy, and self-determination). In the discussion, authors describe evidence for how self-concept and capacities for participation reinforce one another throughout the lifespan and argue for positive self-concept as a capacity for social inclusion.	Supported Internships (SI) A model for conceptualizing the (a) quantity (breadth), (b) quality (depth) of social inclusion and (c) the role of self-concept as a factor in capacity for participation is presented. An ecosystemic model is used to conceptualize 'breadth' of social inclusion.
Moore, M., Kiatchai, T., Ayyagari, R. C., & Vavilala, M. S. [37]. USA.	Qualitative/ Evaluative	To develop a framework to identify targeted areas for improving health literacy for caregivers after traumatic brain injury (TBI) in the US.	Health literacy after trauma – includes rehabilitation service providers as team members.	*Interviews with 23 caregivers of 22 persons hospitalized with TBI (moderate to severe injuries who had been in the hospital for an average of 12.3 days (SD 8.0) from admission to interview date). Caregivers were mostly female (83%) with an average age of 44 years (SD =19.6).	Capacity building is one of the three main areas of the family-centered care model. It also emerged as a theme within the findings, as families identified the need to improve their capacity to care for their child (as well as service providers and facilities' capacity).	TBI Family Centered Care Model Framework for Improving Health Literacy, Health Communication and Caregiver Capacity after Trauma
Schwellnus, H., Seko, Y., King, G., Baldwin, P., & Servais, M. [38]. Canada.	Qualitative/ Evaluative	To explore perceived impacts of solution-focused coaching in pediatric rehabilitation (SFC-peds) from the viewpoint of experienced therapists.	Occupational Therapy, Physiotherapy	Therapists experienced in delivering SFC-peds.	In the background, the authors describe the alignment between coaching and capacity building approaches. Capacity building is captured in the findings as one of the main themes, "enhanced client capacity" related to solution-focused coaching, described in detail in the results. Three subthemes (client ownership for change, empowered mindsets, and improved parent-child relationship) reflect perceived impacts beyond immediate therapy sessions.	Solution-Focused Coaching - Peds (SFC-Peds) family centered approaches and family centered practice principles Solution-Focused Brief Therapy Conceptual frameworks for pediatric service delivery
Wynn, K., Stewart, D., Law, M., Burke-Gaffney, J., & Moning, T. [39]. Canada.	Qualitative/ Evaluative	To describe a community capacity-building approach to facilitate the transition to adulthood for youth with developmental disabilities and their families in Canada.	Occupational Therapy	*2 youths with disability (not specified), 7 parents (one who was also a service provider), and 8 community members.	Capacity building was the primary objective of the approach used and is described in detail in the introduction Capacity building was also captured through the findings, including the theme "raised awareness about capacities and gifts." Finally, capacity building is addressed throughout the discussion section including recommendations for future initiatives.	Community Capacity Building (CCB) Model
Bagatell, N., Chan, D., Rauch, K. K., & Thorpe, D. [40]. USA.	Qualitative	To explore the transition experiences, perceptions, and needs of young adults with cerebral palsy (CP) living in one state in the southeastern United States.	Mix	*9 persons with Cerebral Palsy (CP), aged 19-33 (mean = 26.2, median = 25), 5 female, 4 males.	Capacity building is mentioned in the discussion and authors conclude that building capacity and empowerment (of youth/young adults) can further support youth/young adults with CP to reach their life goals.	N/A

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Table 2. Continued.

Authors/ Country	Type of document	Purpose/ Objective	Context	Population	How capacity building was addressed	Relevant models, theories, frameworks
Buckley, N., Stahlhut, M., Elefant, C., Leonard, H., Lotan, M., & Downs, J. [41]. Australia.	Qualitative	Caregivers and therapists supporting individuals with Rett syndrome were surveyed, aiming to gather insights on how to support participation in "uptime" activities.	Mix: Physiotherapy, Occupational Therapy, Support worker, Other (teacher, relaxation therapist).	*International sample of parents of children with Rett syndrome. Median age of child with Rett syndrome was 13 (ranging from 2 years to 54 years).	The introduction states how motor impairments and dependence on others challenges the *capacity* of people with Rett syndrome to lead physically active lives. The term building capacity is used in the first theme "Fitness and Function – Evaluate and build capacity for 'uptime'" which includes a list of strategies to promote 'uptime' participation included *building physical capacity* in activities that are enjoyable and motivating.	F-words analogy for the ICF framework.
Palisano, R.J., Di Rezze, B., Stewart, D., Freeman, M., Rosenbaum, P.L., Hlyva, O., Wolfe, L., & Gorter, J.W. [42]. Canada.	Qualitative: Interpretive Description	First, to describe how young adults with cerebral palsy (CP) experience lifecourse health development, and second, to create key messages for pediatric health service providers to promote children's capacities for future adult roles and healthy adult living.	Pediatric health services	*23 young adults with CP (13 male, 10 female), 25–33 years of age (mean 28.2, SD ¼2.4).	Capacities are described in the aim of the study. Furthermore, building capacities are captured in three of the four themes described: 1) Personal lifecourse (personal *capacities* such as being able to self-manage health and adapt to change), 2) Health development through everyday experiences (how transactional relationships take place overtime and *capacities* for current and future living develop), and 3) Healthy living as an adaptive process (reflecting upon and learning from different experiences, to enable development of *capacities* for healthy living). In the discussion, the authors identify 'experiential learning' (and providing opportunities to reflect and learn from experiences) as an important aspect of the adaptive process that builds capacity. Links between the themes and capacity building are further explored through the discussion. Authors suggest a lifecourse health development approach shifts the focus of pediatric health services toward developing health capacities through opportunities and everyday experiences.	Lifecourse Health Development Model
Shimmell, L. J., Gorter, J. W., Jackson, D., Wright, M., & Galuppi, B. [43]. USA and Canada.	Qualitative: Phenomenological	The purpose of the present study was to consult with youth with CP and their parents to identify what they perceive as facilitators and barriers to being physically active.	Occupational Therapy, Physical Therapy	*Youth aged 10-18 (8 male; 9 female) with a classification at level I to V on the Expanded and Revised Gross Motor Function Classification System.	Capacity building is listed within one of the qualitative themes, "Contextual, environmental and personal factors." Capacity building is primarily described in the recommendations provided by authors in their future directions at the end of the manuscript.	Conceptual Development Model ICF & Family Centered theory and family centered services

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Table 2. Continued.

Authors/ Country	Type of document	Purpose/ Objective	Context	Population	How capacity building was addressed	Relevant models, theories, frameworks
Son, J., Debono, D., Leitner, R., Lenroot, R., & Johnson, J. [9]. Australia and USA.	Qualitative	To identify gaps and challenges in care delivery for youth with both intellectual disability (ID) and mental health (MH) disorders (dual diagnosis), and to identify bridges for these and identify what works well in existing services.	Mix: Education, Psychology, Employment, Disability support (case manager/support worker/respite), Health (nurse/ doctor), and Allied Health (Occupational Therapy, Physiotherapy, Speech), and more.	*117 service providers of youth (aged 14-24) with dual diagnoses and Intellectual Disability (ID) and Mental Health (MH) problems. Of the participating service providers: • 92 (79%) female, 22 (19%) male, 3 (2%) unknown • Services provided: Education ($n=39$, 33%), Psychology ($n=16$, 14%), Employment ($n=12$, 10%), Disability support ($n=16$, 16%), Health (nurse/doctor) ($n=6$, 5%), Allied health (OT/physio/speech) ($n=3$, 3%), Student ($n=8$, 7%), Career/Consumer support/Advocate ($n=7$, 6%)	Capacity building was captured as one of the main qualitative themes that emerged, "Capacity building of carers and clients" described in the results. Service providers identified building rapport and collaborative relationships with parents and youth as imperative; and identified the need for more support and education for carers.	N/A
Waite, R., & Tran, M. [44]. USA.	Qualitative: Qualitative Description	To explore the experience of women diagnosed with ADHD who were also engaged in their academic pursuits, aimed to (i) explore women's perspectives about ADHD, (ii) examine women's experiences of how ADHD affected their life course, and (iii) identify comorbidities that women self-reported.	Not specified	*16 female aged (years): 18-25 ($n=5$, 31%), 26-35 ($n=4$, 25%), 36-45 ($n=4$, 25%), >45 ($n=3$, 19%), with ADHD (Inattentive $n=10$, Combined type $n=5$, Hyperactive $n=1$). Comorbidities range of: Depression, Anxiety, Bipolar Disorder, Trauma, Post-traumatic stress disorder, Eating disorder, not specified.	Capacity building emerged in the findings as one of the main themes, "commitment to capacity building" described in detail in the results. Furthermore, authors conclude that building capacity of women with ADHD could facilitate proactive healthy ways to manage and live more effectively with ADHD.	N/A
Perspective ($n=11$)						
Carter, E. W., McMillan, E., & Willis, W. [45]. USA.	Program Description	To describe the origins and organization of the TennesseeWorks program (whose goal is to ensure every youth and young adult with IDD have the aspirations, preparation, opportunities, and supports to access competitive and integrated work), present central components of the approach to systems change, highlight progress and outcomes in each area, and share the program's investment in sustainability.	Vocational Rehabilitation	Youth and young adults with Intellectual and developmental disabilities (IDD).	Building capacity is described as one of the primary approaches and outcomes of the program described in this publication.	TennesseeWorks Partnership

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Table 2. Continued.

Authors/ Country	Type of document	Purpose/ Objective	Context	Population	How capacity building was addressed	Relevant models, theories, frameworks
Green, F., Brown, C., Gordon, E., & Martin, D. [46]. USA.	Program Description	To describe the development of a 15-year community (public school district) and university partnership that was formed based on a shared mission of education and training.	Therapeutic Recreation	High school students with disabilities.	Part of the approach described was to build the capacity of youth to develop and maintain a healthy leisure lifestyle. This is described in some detail in phase three of the project.	The therapeutic recreation continuum of services (model)
Raynor, O., Hayward, K., & Rice, K. [47]. USA.	Program Description	To describe the California Employment Consortium for Youth with IDD ("CECY") and its impact in California.	Not specified, published in Vocational Rehabilitation. "Department of Rehabilitation" one of the participating organizations.	Youth and Young Adults (YYA) (age unspecified) with intellectual and other developmental disabilities (IDD).	Capacity building is part of the overarching mission of the program presented in this publication. Specific goals and approaches related to capacity building are described as part of the program's strategic actions, outcomes and activities.	California Employment Consortium for Youth with Intellectual and Developmental Disabilities ("CECY") Collaborative Leadership Approach
Anaby, D. [48]. Canada.	Commentary	Commentary on the original article by Kramer et al. [49]: Initial evaluation of the effects of an environmental-focused problem-solving intervention for transition-age young people with developmental disabilities: Project TEAM. Author discusses research considerations for participation-based interventions that focus on change in the environment.	Occupational Therapy, Physiotherapy	Children and adolescents with disabilities (mentions CP, Physical Disabilities, and Developmental disabilities).	Capacity building is discussed as an aspect of participation-based intervention approaches.	Participation-based intervention framework Project TEAM (Teens Making Environment and Activity Modifications)
An, M., & Palisano, R. J. [50]. USA.	Theoretical	To formulate principles of collaborative service delivery in pediatric rehabilitation through a 4-step process of implementation, and recommend strategies that professionals can use to foster a collaborative process between families and professionals to optimize outcomes of children with disabilities and their families.	Physical Therapy, Rehabilitation Sciences	Children with disabilities and their families	Capacity building is described as part of the collaborative intervention approach.	Model of family–professional collaboration: a 4-step process of collaborative service delivery

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Table 2. Continued.

Authors/ Country	Type of document	Purpose/ Objective	Context	Population	How capacity building was addressed	Relevant models, theories, frameworks
Camden, C., Leger, F., Morel, J., & Missiuna, C. [51]. Canada.	Theoretical	To propose the Apollo model as an example of an innovative interdisciplinary, community-based service delivery model for children with Developmental Coordination Disorder (DCD) characterized by the use of graduated levels of intensity and evidence-based interventions that focus on function and participation.	Occupational Therapy, Physiotherapy	Children with Developmental Coordination Disorder (DCD).	Capacity building is included as part of the Partnering 4 Change intervention approach.	Partnering 4 Change (P4C) Apollo Model
Chiarello, L. A. [52]. USA.	Theoretical	To explore the complex and multidimensional construct of participation and present recommendations for practice, education, and research to transform pediatric physical therapy service delivery.	Rehabilitation; author is Physiotherapist.	Children with physical disabilities.	Capacity building is identified as one of the 10 'C's of the service delivery approach presented by the author. It is described in relation to participation-based therapy approaches.	Participation-based therapy Pathways and Resources for Engagement and Participation (PREP)
King, G., Graham, F., Ziegler, S.A. [10]. Canada, New Zealand, Switzerland.	Theoretical	This perspectives paper advances understanding of coaching in pediatric rehabilitation. We compare three coaching approaches designed for pediatric rehabilitation.	Coaching in rehabilitation.	Pediatric rehabilitation.	Capacity building is identified as a hypothesized outcome of all three coaching approaches. Throughout the paper, capacity building is linked to supporting long-lasting, sustainable changes. The desired long-term outcomes of coaching (which include capacity building, goal achievement, and empowerment) are described as "coachees' sense of being capable to make decisions and undertake desired actions for themselves." *(p.5)*.	Occupational Performance Coaching (OPC) Solution-Focused Coaching in Pediatric Rehabilitation (SFC-peds).
King, G., Imms, C., Stewart, D., Freeman, M., & Nguyen, T. [53]. Canada.	Theoretical	This article proposes a conceptual framework to bring about a broader awareness of clients' lives and transactional processes of change over the life cours	Pediatric Rehabilitation	Children with neurodevelopmental disorders.	Capacity and capacity building are described as part of the framework presented in this publication.	Framework of transactional processes and adaptive development for pediatric rehabilitation Halfon's Lifecourse Health Development model Developmental Health Model The Integrated Model of Social Environment and Social Context Collaborative practice models: Examples include participation-based intervention models, coaching models, and relational models of client change.

(*Continued*)

Table 2. Continued.

Authors/ Country	Type of document	Purpose/ Objective	Context	Population	How capacity building was addressed	Relevant models, theories, frameworks
King, G., Seko, Y., Chiarello, L. A., Thompson, L., & Hartman, L. [54]. Canada (one author, USA).	Theoretical	To present a resiliency framework to inform pediatric rehabilitation research, service design, and practice.	Pediatric Rehabilitation	Children with disabilities (clinical illustration for 17 year old female with "neurological disability" provided).	Capacity is defined as part of the framework.	A transactional resiliency framework for pediatric rehabilitation
Rappolt-Schlichtmann, G., Boucher, A. R., & Evans, M. [55]. USA.	Theoretical	To first explore the deficit view of dyslexia, and then consider the neurodiversity view of dyslexia as its alternative to support the overall well-being and development of students with dyslexia. To provide practical strategies for applying a strengths-based approach in the speech-language pathologist setting to support students with dyslexia.	Language, Speech, and Hearing Services speech-language pathologists	Students with dyslexia.	Building capacity of students with dyslexia to thrive within education is stated as the main goal from a neurodiversity view. Capacity is discussed in relation to Universal Design for Learning and applied to an example using the neurodiversity view to make science notebooks accessible for students with dyslexia.	Universal Design for Learning
Textbook Chapters ($n = 2$)						
McLeod, H. J., & King, R. [56]. Location unknown.	Textbook Chapter	To describe cognitive remediation.	Cognitive remediation, psychosocial remediation (case manager or rehabilitation worker)	Individuals with mental illness (case example for working-age male with schizophrenia is provided).	Cognitive capacity is mentioned as being targeted by intervention. The authors suggest considering how to generalize capacities to the real-world.	N/A
Stewart, D. [57]. Canada.	Textbook chapter	To describe rehabilitation for transition to adulthood for youth with disabilities. Presents current evidence and provides directions for the future for occupational therapists and other professionals working with children and youth with disabilities.	Occupational Therapy	Transition aged youth with disabilities (textbook chapter presents hypothetical case example of 5-year-old girl with autism).	Capacity Building is primarily and explicitly described as a key component of the intervention approach recommended for use by OTs working with transition-age youth. The chapter offers dedicated sections describing capacity building and outlining strategies.	Community Capacity Building (CCB) Best Journey to Adulthood PEO (Person-Environment-Occupation), strengths-building and asset-building approaches, client and family-centered approaches
Dissertation ($n = 1$)						
Katrikh, R. D. [58]. USA.	Doctoral Dissertation	To review existing literature of OTs' previous and potential role in transition, and to propose a model for an OT-led transition program for use within the Los Angeles Unified School District (LAUSD).	Occupational Therapy	Students with physical limitations or intellectual disabilities aged 18-22.	Capacity building is primarily described through the underlying theories presented in the background of this dissertation. Two models of service delivery are discussed: both which aim to build capacity.	Supporting Opportunities for Adult Readiness (SOAR) (part of ACES program - Advancing Children's Educational Success) Knowledge to Action Framework Direct service models vs collaborative service models

Notes: *actual study population of participants (while the rest are 'target' population); Rows marked in gray indicate evaluative studies.

Table 3. Definitions of capacity or capacity building.

Term	Explicit definitions
Capacity	**"Capacity** is more than just traditional skills such as motor or cognitive skills. **Capacity** includes attributes such as understanding and using one's abilities, problem solving and decision making, being in control of one's life and directing others to provide supports. Everyone, including service providers, need to **build capacity** to promote positive, inclusive adult outcomes for all young people with disabilities" [28, p. 171]. "**Capacity** is described as the 'ways and means needed to do what has to be done'" [57, p. 139]. **"Capacity** represents a shift away from simple skill development in a particular area of function such as physical skills, academic skills, or vocational skills to address the current and future abilities and assets of each individual" [57, p. 139]. **"Capacity**: The ability or power to do, experience, or understand something" [53, p. 1835]. "**Individual capacity** includes knowledge and skills, resources, strengths, and experiences that all contribute to participation in daily life" [57, p. 139]. **"Self-capacity**: potential to develop or potential that an individual can reach in the future" [54, p. 1033]. "**Advocacy capacity** refers to the knowledge and self-efficacy parents need to engage in activities designed to enrich their child's development. **Advocacy capacity** requires: (a) knowledge of service systems (i.e., opportunities and barriers for obtaining support); (b) empowerment (i.e., viewing oneself as an authority); and (c) emancipation (i.e., experiencing freedom from social restrictions." [31, p. 136]
Capacity Building	"**Capacity-building**: Strengthening the skills, competencies, and abilities of people and communities" [53, p. 1835]. "The model outlines **two sets of capacity-building processes**: (a) environment-to-person processes, including resources, supports, and opportunities for experiences, and (b) person-to-environment processes, including choice, collaboration, and active engagement" [53, p. 1832] **"…capacity-building** is the process of ensuring that an individual or organization has the skills, competencies, knowledge, structures and resources to realize their goals effectively. For family support programmes, **capacity building** means first and foremost the provision of relevant and practical materials and skills that can be implemented independently by participants" [32, p. 35-36]. "**Community Capacity Building (CCB)** differs from other approaches to community development as it focuses on identifying and developing a community's capacities as assets to addressing health concerns instead of a focus on risks, needs, or other deficits. A **community's capacities** can include: The extent of community member's participation and leadership in the community, the skills and resources available in the community and the extent of a community's social and interorganizational networks" [39, p. 92].

or structures to realize goals effectively [32,53] and was described by King et al. [53] to be bi-directional: environment-to-person and person-to-environment. Wynn et al. [39] included a definition for Community Capacity Building (CCB) which addresses health concerns through developing a community's capacities as assets rather than focusing on risks, needs, and deficits. Across all documents, capacity building was primarily described or captured as part of an intervention approach ($n = 8$) [10,29,46,48,50–52,57], as part of the objectives/goals ($n = 9$) [31–33,35,39,42,45,47,55], within the findings/results ($n = 9$) [9,26,30,34,37,38,40,41,44], as an identified gap or recommendation ($n = 4$) [27,28,43,56], or as part of the underlying theory ($n = 4$) [36,53,54,58]. A summary about how capacity building was addressed is included in Table 2.

Models, theories and frameworks

Twenty-nine of the 34 documents included a model, theory, or framework related to capacity building. Four of these documents presented real-world (practical) models of capacity building initiatives that were implemented within specific (local) contexts [32,45–47]. There were eleven practice models and two theoretical frameworks identified in the documents that explicitly aimed to build capacity of youth and/or families. Seven of these practice models were specific to the rehabilitation context: 1) Best Journey to Adulthood – An evidence-based Model and Best Practice Guidelines [27,28,57], 2) Partnering 4 Change (P4C) [29,51], 3) Participation-based therapy (including specific examples such as PREP-Pathways and Resources for Engagement and Participation and TEAMS-Teens making Environment and Activity Modifications) [34,48, 52,53], 4) Solution-focused Coaching (SFC) [10,30], 5) Occupational Performance Coaching (OPC) [10], 6) Lifecourse Health Development Model [42] and 7) Model of family-professional collaboration: a 4-step process of collaborative service delivery [50]. Four practice models were situated more broadly (not exclusive to rehabilitation): community capacity building (CCB) [39,57], La Trobe Framework for Decision Making [33], Supported Internships [36], and Fostering Advocacy, Communication, Empowerment and Supports (FACES) [31]. One of the theoretical frameworks was specific to rehabilitation: 1) A transactional resiliency framework for pediatric rehabilitation [54] and the other was broad: 2) Framework for Improving Health Literacy, Health Communication and Caregiver Capacity after Trauma [37]. Additionally, several theories/models were also described as elements underlying capacity building approaches in the documents (e.g., coaching [10,29,38,53], family-centered care [38,43,57], collaborative approaches [47,53,58], person-centered planning/care [34,35], conceptual development model [43], Universal Design for Learning [35]). Furthermore, the FACES program was described to draw upon three underlying theories (i.e., FACES theory of change, a simple-to-complex sequence, and adult learning theory) [31]. Finally, two documents used theoretical frameworks to organize their findings (which were relevant for capacity building) including the ecosystemic model used to conceptualize the breadth of social inclusion [36], and the F-words analogy for the ICF framework [41]. The names of relevant models, theories, and frameworks for which data was extracted and analyzed are included in Table 2. The documents which did not specify a relevant model, theory or framework (marked as N/A in Table 2) were not included in the content analysis for identifying underlying principles and key ingredients.

Principles and key ingredients of capacity building

To answer the question, "How is capacity building conceptualized within theoretical and practical models of rehabilitation with youth?", four principles and six key ingredients were identified through the content analysis of data extracted from 23 of the initial documents relating to theories, models, and frameworks of capacity building. Examples were also added based on deductive analysis of six documents from the updated search which contained relevant theories/models/frameworks. Table 4 presents four overarching principles that define what capacity building is in the

Table 4. Principles of capacity building.

Principle	Description	References
#1 - Capacity building interventions involve meaningful, **individualized approaches** that have **real-world application** for youth now and in the future.	Interventions are delivered in context and are relevant throughout the lifespan of youth.	[*n* = 19; 10,27, 29,33, 35–39,41–43, 46,48, 50–53,55]
#2 - Capacity building fosters youth and/or caregivers' **vision for a preferred future** and cultivates their **ability to problem-solve** through barriers.	Interventions equip youth with the knowledge and skills to overcome barriers. Strategies target a) what youth and/or caregivers *believe* (about themselves and their future) and b) what they *do* (to act on their environment).	[*n* = 21; 10,28, 30–34,36, 38,39,42,45,46,48, 50–55,57]
#3 - In capacity building approaches, youth and/or caregivers have agency and **take ownership for change.**	Through transformative learning processes, youth and/or caregivers are empowered to act.	[*n* = 13; 10,28, 30,34, 38,46, 48,50, 52,54,55,57,58]
#4 - Capacity building is an **ongoing process**, involving **reflection** and learning from experiences.	Youth are supported to problem-solve, try the identified strategies, modify them as needed, and develop new solutions.	[*n* = 11; 10,27, 33,38, 42,50, 52–55,57]

Table 5. Key ingredients of capacity building.

Key ingredient	Examples	Supporting references
#1 - Use an individualized (and flexible) approach embedded in the natural context of the youth/family.	• Focus on client priorities • Address holistic needs • Optimize strategies for natural environment • Embed flexibility and supports	[*n* = 21; 10,27, 29,32–34, 36–38,41–43, 45,46,50–53,55, 57,58]
#2 - Share responsibility for planning and decision making.	• Youth / family active engagement • Collaboration and coaching • Mutually-agreed upon goals • Co-construct manageable plans	[*n* = 19; 10,27, 29,32–34, 38,39,42,43, 45–47,50–53, 57,58]
#3 - Assume youth/families are capable and cultivate their strengths.	• Recognize unique areas of strengths • Build on strengths/abilities • Be solution-focused • Use family and social connections and youths' strengths in everyday environments	[*n* = 15; 10,32, 34,35,38,39, 42,45,46,50, 52,53,55,57,58]
#4 - Share and facilitate the use of accessible and meaningful information, resources, and networks.	• Multiple methods of dissemination • Develop in partnership with youth • Collaborate with others in community • Power of personal relationships	[*n* = 24; 27–32, 35–39, 42,45–48, 50–55,57,58]
#5 - Provide accessible opportunities for full participation in daily environments.	• Remove environmental barriers • Provide contextual supports • Focus on participation-level outcomes • Facilitate experiences that promote self-determination	[*n* = 20; 10,27–29, 34,36–39, 41–43,45, 48,50–53, 55,57]
#6 - Facilitate ongoing learning processes through promoting reflection on experiences.	• Reflection and feedback • Supported problem-solving • Discuss successes, challenges, changes, lessons learned • Share and learn from others' lived experience	[*n* = 12; 10,27, 31,33, 38,42, 47,50–52, 55,57]

context of rehabilitation of youth and the corresponding documents that support them. Table 5 specifies six key ingredients, framed as actionable items with examples, that service providers implement when building the capacity of youth/caregivers. The principles and key ingredients are described in more detail below.

Principles: what is capacity building?

The following four principles describe guiding beliefs about capacity building approaches based on relevant models, theories, and frameworks documented in the literature for rehabilitation of youth. Key references are included which support the underpinning beliefs identified about capacity building.

Principle 1: meaningful, individualized approaches that have real-world application for youth now and in the future. Capacity building focuses on addressing outcomes that are based on individualized goals and driven by youths' needs and preferences [10,33,35,42,50,52,55]. Using an individualized capacity building approach, such as the person-centered planning approaches described in Ellem's qualitative study allows "the person with a disability and his or her allies to come together to determine a better life now and into the future" [35, p. 398]. Several documents described the importance of sustainability of outcomes [38,39], including preventing deterioration [29] and considering healthy lifestyle and development across the lifecourse [37,42,43,46,53,]. Furthermore, the importance of using capacity building approaches to support youth's transition to adulthood with special consideration of the environment was specified in three documents [27,36,48]. Another two documents viewed youths' development as a capacity and lifelong process that considers the complexity of environmental factors and interactions with the individual [37,53]. Strategies to support generalization of learning and application to real-life settings were described in four documents as an integral part of rehabilitation interventions for youth [41,51–53]. The ultimate aim of capacity building, as described by the example in Rappolt-Schlichtmann et al.'s theoretical paper, is to "create the foundation for thriving in learning and life" [55, p. 872].

Principle 2: fosters youth and/or caregivers' vision for a preferred future and cultivates their ability to problem-solve through barriers. Capacity building interventions equip youth with the beliefs, knowledge, and skills to overcome barriers. Approaches described in the literature considered youth's awareness of themselves, youth and/or caregivers' perceived capacity to evoke change, their ability to visualize a preferred future and their application of knowledge and skills to solve problems [10,28, 31,32,38,42,46,50,53,57]. Hanson et al. [36] suggest that self-concept (self-image, self-esteem and self-determination) contributes to (or detracts from) capacities for participation. King et al.'s resiliency framework [54] includes both the capacity to envision a positive future and the capacity to adapt to change across a variety of contexts as important for building resilience in youth with disabilities. Similarly, Schwellnus et al. [38] describe the value of nurturing youth and family's adaptive capacity to changing contexts. Capacity building approaches involved raising expectations and aspirations [45], cultivating youth's perceived competence [30,50], developing their awareness of their own strengths and limitations [28,55], and valuing preferences [33]. Building youth's capacity to problem-solve and overcome barriers

in their environment was discussed in several documents [28,34,39,48 51,52]. Self-efficacy and self-determination were linked to youth's capacity to succeed in five documents [10,28,32,36,55].

Principle 3: youth and/or caregivers have agency and take ownership for change. In capacity building approaches youth were described as actively guided and involved in joint planning and action [52,55]; youth develop a sense of control [30,50,57] and take ownership of goals [10,46]. Central to this principle is the concept of empowerment, which was discussed in several documents [10,28, 34,38, 48,50, 54,55,57,58]. For example, An & Palisano [50] describe a collaborative approach which uses empowering processes through providing opportunities for families to make informed decisions about the intervention. Similarly, participation-based interventions, as discussed by Anaby have the purpose of "…empowering adolescents and families to become problem-solvers and self-advocators. Building the capacity of adolescents by enhancing their knowledge and ability to use solution-based strategies on their own" [48, p. 735]. According to Schwellnus et al. [38], utilizing transformative learning processes could be important for facilitating sustainable changes when building client capacities through promoting ownership for change. The qualitative theme "enhanced client capacity" emerged from therapists who implemented the SFC approach in Schwellnus et al.'s study [38]. This theme describes how 'the seeds of change' were planted within clients (including examples from both youth and families) which led to clients taking ownership for change and developing an enhanced sense of agency.

Principle 4: an ongoing process, involving reflection and learning from experiences. Theories and models involving capacity building approaches were described as ongoing and iterative [42,50,53]. When capacity is built, youth and/or caregivers can identify and try strategies in their everyday life and/or develop new solutions [10,38,52]. Self-capacities (i.e., activity self-efficacy, marshaling resources, life situation adaptability, envisioning a positive future) are described by King and colleagues as part of a transactional framework which are "both proactive and reactive, propelling personal and environmental change as well as being influenced by change. They are seen as interdependent, triggered by adversity…" [54, p. 1034]. Six documents identified that reflection, feedback, and sharing experiences promote learning [27,33,42,52,55,57]. Parents who received decision support training in Bigby et al.'s [33] study reported that the training acted as 'a catalyst for reflection'. As emphasized by Chiarello, "reflections on the intervention approach (what was most helpful, what worked, what did not work) guide the future direction of services as well as provide the family and child with the capacity to realize new participation experiences" [52, p. S18].

Key ingredients: how do we build capacity?

The six ingredients described below outline strategies for building capacity of youth and their families, with supporting references from the literature.

Key ingredient 1: use an individualized (and flexible) approach embedded in the natural context of the youth/family. This ingredient emphasizes the need to consider the youth and family in their broader context [10,27,34,36,37,41–43, 45,50–53,57,58]. First, several documents discussed keeping client priorities at the forefront and offering choices to ensure the intervention is individualized to meet their needs [10,27,32,33,38,45,46,50–53]. Furthermore, through understanding that every individual learns differently and thus flexibility, or the use of differentiated instruction is necessary [29,55]. Use of tiered approaches to learning can be beneficial to implement a combination of strategies such as universal design, differentiated instruction and/or accommodation as described by Camden et al. [51] or ensuring avenues for more individualized or intensive assistance as described by Carter et al. [45]. Shimmel et al. [43] also identify that youth are embedded in the family which is also part of a larger community; thus, elements of both the family and community must also be addressed in interventions with youth. Other documents also indicate the role of contextual factors in interventions and suggest strategies should be optimized for youth's natural environments [34,38,42,52,53]. When using coaching approaches, King et al. [10] describe the role of clinicians in assisting clients and families to "discover solutions that fit their everyday contexts, thus building capacity." (p. 2).

Key ingredient 2: share responsibility for planning and decision making. This ingredient emphasizes youth/family's active investment and involvement throughout the process [10,32,38,42,47,50, 52,58]. Several documents emphasized the importance of 'partnerships' or included the use of collaborative approaches when building capacity of youth/families [10,27,29,38,39,42,43,45–47,50–53,57,58]. Documents emphasized the quintessential role of the partnership between the therapist and youth/family throughout the process as well as the value of building relationships between the youth/family with other stakeholders in the community, researchers, and/or policy makers. Additionally, coaching methods and/or sharing information and working together to engage the youth/family to co-construct manageable goals and plans was also documented [10,29,34,38,39,42,50–52]. Youth/families should be trusted and supported to make informed decisions [32,33] and enabled to discover their own solutions [10,38,52]. Bigby et al. [33] focus on training caregivers in supported decision making that respects the will and preferences of youth with disabilities rather than substitute decision making. Furthermore, Stewart [57] and Raynor et al. [47] both suggest the value of the mutual learning that occurs for individuals involved in capacity building approaches (i.e., both service providers and recipients of care). In their model of family-professional collaboration, An & Palisano [50] offer practical recommendations for how service providers can promote shared responsibility and decision making including specific strategies related to goal-setting, therapy planning, reflecting on the intervention process, and evaluating outcomes.

Key ingredient 3: assume youth/families are capable and cultivate their strengths. This ingredient identifies the importance of having positive beliefs about youth and families' strengths and capabilities and using these as a starting point for development [10,32,38,39,42,46,53,55,57,58]. It is about building and sustaining a relationship grounded in respect [52,55] and using a solution-focused approach that enables youth/families to apply their unique strengths and talents in their everyday environments [10,34,42,50,52]. This can include mobilizing youth's family and social connections [35]. Increasing expectations for competitive work for youth and young adults with intellectual and developmental disabilities was one aim of the multi-faceted capacity building intervention documented by Carter et al. [45], providing an example of an intervention which not only assumed capabilities of youth but aimed to increase these expectations for youth, family and community professionals as part of their

capacity building approach. Stewart suggests that therapists can support youth and families to think first about their strengths, and to view "asking for assistance as a sign of personal strength in knowing what they need and want" [57, p. 146].

Key ingredient 4: share and facilitate the use of accessible and meaningful information, resources, and networks. This ingredient helps to develop youth and/or caregiver's knowledge of their environment and the skills/resources to interact with it [30–32,35,36,38,39,42,45,48,50,51,53–55,57]. Documents highlighted the value of information, resources, training, and relationships which are meaningful and delivered effectively to meet youth and caregiver's needs [27,31,42,45,52]. Pearson and colleagues [31] evaluate a capacity-building program that aims to address barriers and experiences that are unique to Black parents raising autistic youth; sessions included topics such as stigma and disability in the Black community, the role of religious belief and practice in coping, and empowerment (which included a panel of Black mothers raising autistic youth who shared advocacy experiences) for example. Palisano et al. [42] highlight the importance of timing of information provided to youth/families since information needs change over time. Similarly, Moore et al.'s enhanced model of family centered care [37] identified the need for continuity of care communication, as well as earlier discussion and training for families (about how to care for their child). Using multiple methods of communication, representation, or dissemination were also identified as a strategy across several documents [45–47,55]. For example, in the CECY project presented by Raynor and colleagues [47] which focused on systems change to support employment of youth with developmental delays, multiple methods of dissemination were used to build capacity and share information with youth, families, professionals, and providers including presentations, webinars, websites, policy and informational briefs, resource guides, and weekly CECY E-news. Furthermore, the CECY alliance organized two employment strands at an education-sponsored "Bridge to the Future" Transition Institute attended by over 1,000 transition specialists, rehabilitation counselors, families, and youth. In their theoretical paper, Rappolt-Schlichtmann and colleagues [55] recommend using guidelines developed by the Center for Applied and Special Technology (CAST) to design learning experiences from a universal design perspective, which considers multiple ways to demonstrate learning. Nguyen [27] also recommend that information, education and resources be developed in partnership with youth/families and suggest that peer mentors could serve as navigators for youth to navigate complex systems and information. Importantly, community partnerships and relationship-building with stakeholders were described across several documents as necessary to develop a supportive network for youth [28,29,45,47,52,57,58]. For example, in the textbook chapter by Stewart [57], the value of using community capacity building strategies is documented and evidence for offering capacity building workshops for community agencies is highlighted. Stewart suggests that occupational therapists can collaborate with other agencies and community services to increase the understanding and capacity of these services to offer community-based experiences and opportunities for youth.

Key ingredient 5: provide accessible opportunities for full participation in daily environments. This ingredient focuses on the person-environment (or eco-behavioral) interactions and the need to provide real-world experiences for youth [27,28,36,38,39,41–43,48,50–53,55,57]. King et al.'s framework of transactional processes and adaptive development for pediatric rehabilitation [53] proposes that "people build capacity, adapt, and change through transactional opportunities and experiences" [53, p. 1833, Fig. 2]. Several documents outlined the use of a holistic approach that considers contextual barriers and supports in the environment to promote functional outcomes supporting learning and participation [10,27–29,34,37,42,48,51,55]. Furthermore, the literature suggests that providing opportunities for youth to experience true inclusion in the community and promote their self-determination starting in childhood and through adolescence facilitates participation in current and future environments [27,57]. Palisano et al. [42] suggest that providers "pay attention to the timing of opportunities and experiences" (p. 2007) since children and youth learn and develop when they are ready. Similarly, within the context of improving work outcomes for youth in the TennesseeWorks Partnership described by Carter et al. [45] access to competitive and integrative work opportunities as well as early work experiences were emphasized. The literature also suggests that it is also necessary to build capacity not only of youth, but of others in the youth's natural environments to support these opportunities, as summarized in a narrative review by Nguyen and colleagues,

> Capacity building among parents, community members, and policy makers is also key to provide experiences and opportunities for youth and young adults with disabilities that extend beyond health to address their holistic needs including participation and inclusion in communities. [27, p. 86].

Key ingredient 6: facilitate ongoing learning processes through promoting reflection on experiences. This ingredient outlines that capacity-building is an ongoing process involving opportunities to problem-solve, try out and modify strategies as needed, develop solutions, and reflect on experiences [10,33,38,42,47,50,52]. In the context of participation-based approaches, Chiarello outlines in their perspective paper that service providers can involve the youth and family in evaluating processes and outcomes to promote future participation by inviting them to "identify their current participation level across the dimensions relevant to them – performance of the activities, social involvement, enjoyment, and satisfaction as well as what they learned from the experience" [52, p. S18]. A graduated approach can be used to build capacity of youth and families through supported problem-solving and feedback (i.e., discussing what worked, what was most helpful, and what didn't work) [51,52,55]. For example, when designing learning experiences from a universal design framework, Rappolt-Schlichtmann and colleagues [55] describe *'just-in-time feedback'* as a technique that can be gradually withdrawn as learner's expertise increases. The literature suggests that there are also mutual benefits for youth/caregivers in sharing their experiences (e.g., related to transitioning to adulthood), supporting, and learning from others [27,31,57]. Specifically, based on the evidence, Stewart [57] recommends peer mentorship (i.e., encouraging youth in transition to meet with young adults to share lessons learned) and connecting parents of youth in transition with parent networks in the community to build capacity of youth and families. Drawing on the lifecourse health development model, Palisano and colleagues [42] describe this ingredient as *'experiential learning'*:

> -what everyone learns from different experiences. While there is value in participating in everyday experiences, there is a need to provide the opportunity to reflect on, and learn from, these experiences, as this learning builds capacity. (p. 2009)

Evaluative studies and emerging outcomes (n = 11)

The eleven evaluative studies collected data following a program or service (e.g., Helping Families Project [35], family support programmes [32], Community Capacity Building Project [39]). Qualitative methods were employed across all the evaluative studies, with semi-structured interviews being the predominant form of data collection. Interviews were completed with parents and/or family members in five studies [30,32,33,35,37], while Wynn et al.'s participatory action pilot study [39] included perspectives from parents, youth, and community members. Hanson et al.'s [36] exploration of social participation through Supported Internship (SI) involved interviewing graduates/interns (i.e., youth) as well as job coaches and colleagues. Missiuna et al.'s feasibility study [29] interviewed parents, therapists, and teachers, and another study interviewed therapists only [38]. Burrough et al.'s knowledge translation study [34] also focused on the therapists' perspective but used a focus group. Four of these evaluative studies also included quantitative tools, employing a mixed methods approach to evaluation. Within three of these studies, structured questionnaires were designed drawing on items from existing measures to reflect the objectives of the study such as caregiver's perception of their child with disabilities as well as perceived supports [30,32], and therapist/teacher beliefs, knowledge, and skills [29]. Pearson et al.'s [31] quasi-experimental design involved six measures completed by caregivers before and after the FACES intervention which evaluated: knowledge (of autism), empowerment, confidence (in advocating), frequency of communication with school-based professionals, satisfaction with family-professional partnership and perceptions of advocacy capacity (using the special education advocacy scale; SEAS). Caregivers also provided written feedback (i.e., satisfaction, relevance, suggestions) on the intervention sessions.

In several studies, capacity building was captured within themes that emerged through the qualitative analysis. Outcomes of capacity building that were captured for parents included changed perceptions, attitudes, or worldviews [32,38,39], increased knowledge [29,32], improved self-confidence and self-efficacy in advocating for their child [29], an increased capacity for parents to work together with their child [38], prompting helpful reflection and a more deliberate approach to supporting decision-making (of their youth) [33], empowerment and empowered mindsets [29,38], agency and self-determination [30,38], positive changes to self-concept (i.e., self-confidence-socially, self-determination, self-efficacy) and participation [36], as well as skills in advocacy [32] or problem-solving [34,38]. Therapists in two studies perceived impacts for the youth and family beyond therapy sessions [34,38]. Therapists in Burrough et al. [34] perceived these 'ripple effects' for the multidisciplinary team as well (i.e., professionals' attitudinal changes and greater shared management of participation challenges). In Moore et al.'s findings [37], capacity building was identified as an area for recommended improvement in terms of needing to improve capacity of families to care for their child after traumatic brain injury (as well as service provider and facilities' capacities). Findings from Ellem et al.'s 'Helping Families Project' [35] which aimed to build capacity of families to implement person-centered-planning (PCP) approaches revealed that although there was utility in providing these workshops, there were also challenges related to families being able to apply what they had learned due to environmental and social barriers. They recommend that capacity building initiatives for family members must consider cultural nuances, the families' local context, and formal and informal supports [35]. Pearson et al. [31] found significant changes for caregivers who received the FACES intervention on measures of family empowerment, perceived advocacy capacity, and frequency of communication with school-based professionals. In terms of outcomes for youth, therapists in Burrough et al.'s study [34] felt that youth gained insight into their participation challenges (and in one instance a youth began participating in new community experiences beyond the intervention) and families of youth with disabilities in Daly et al.'s parent-focused capacity building intervention [32] reported enriched quality of life for youth through linked outcomes such as improved community involvement, employment, independent living, and socializing. Some parents (of youth with intellectual disabilities) who received decision-support training in Bigby et al.'s intervention perceived greater confidence of their adult children in expressing preferences [33].

Discussion

This review enhances our understanding of how capacity building is framed within the literature of rehabilitation of youth with disabilities. A total of 34 documents were included, of which approximately half were empirical in nature, and the other half consisted of theoretical documents, descriptions of capacity building programs, textbooks, and perspective papers. Results from this review suggest that the term capacity building is being used increasingly in recent years in the rehabilitation literature for youth with disabilities. Historically, capacity building has been the focus of initiatives to support liberation/empowerment of people with disabilities from multi-ethnic populations, typically through community capacity building and/or through building individual's capacity for advocacy [59]. The increasing use of this term more broadly in pediatric rehabilitation is in line with the ongoing paradigm shift in pediatric rehabilitation documented in the literature and described by King and colleagues as, "a movement from therapist-as-expert approaches to those that build empowerment and capacity" [10, p. 1]. Based on the documents included in this review, the concept of capacity building is a universal task for many professional categories and is reflected in the literature in a variety of ways: as a targeted aim of interventions, an outcome captured, a recommendation for future practice, or as part the underlying theory supporting intervention approaches. The four principles and six key ingredients identified contribute to the theoretical definition of the concept including what capacity building is and strategies to build capacity of youth with disabilities and their families. This clarification can support clinicians in the field to identify when they are using capacity building approaches and to articulate the rationale behind their chosen intervention strategies. It can also guide the development of interventions aimed at building capacity and provide guidance on how to operationalize the concept and identify appropriate outcomes of capacity building in research and practice.

Capacity building approaches and emerging outcomes documented in this review drew upon various theories, models, and frameworks. Content analysis revealed the overarching aims of capacity building and the key ingredients that contribute to building capacity of youth in their contexts. Interventions that address capacity building draw on other approaches used in pediatric rehabilitation including family-centered services, collaborative practice, coaching models, environmental/contextual approaches, and participation-based approaches. For example, the notion of respecting, valuing, and collaborating with youth and families which are foundational elements of family-centered services [60] and collaborative practice models [50] was integrated throughout the process of capacity building in the identified principles and

ingredients. In some cases, these other specific underlying approaches used in pediatric rehabilitation (e.g., coaching, participation-based approaches) can facilitate capacity building outcomes on their own, such as the three coaching approaches described by King and colleagues that each have hypothesized long-term capacity building outcomes [10]. Given that capacity building outcomes can be addressed by drawing on several intervention approaches, it is important that service providers and researchers clearly define the intervention and the intended outcomes. Being explicit with how capacity building is defined within the intervention or outcome will help to clarify the use of this concept. The principles and key ingredients in this review offer guidance on the kinds of approaches and interventions that can be used to facilitate capacity building of youth with disabilities to make decisions and pursue their goals for themselves as they move toward adulthood.

Youth with disabilities experience changing social roles, expectations, and needs across contexts over the lifespan (and particularly as they transition to adulthood) [3]. In the framework proposed by King et al. [53] development is also viewed as both a capacity and a lifelong process involving dynamic interaction between youth and their environment and reinforce the need to consider interventions that facilitate long-term capacity building outcomes across changing contexts. This is seen as an 'adaptive process' that occurs within contexts that are multidimensional, transactional, and unique to individuals [42]. Parallels can be drawn between the four principles of capacity building identified and these lifecourse approaches. For example, the principles describe how building capacity of youth has 'real-world application' now and in the future (Principle #1), cultivates youth's ability to problem-solve through barriers (Principle #2), empowers youth to take ownership for change (Principle #3), and is an ongoing process with opportunities for youth to learn and reflect on experiences throughout their life (Principle #4). It is therefore important to consider characteristics of both the person (i.e., self-efficacy, problem-solving) and the context (intervention, professionals, environment, etc.), as well as the interaction between the person and their context, when building youth's capacity.

In recent research in participation, there have been examples of documented strategies used by families' [61,62] and youth [63] to support the participation of children and youth in 'real-world' activities at home and in the community; many of these strategies targeting the environment/context. This scoping review links to this growing body of knowledge, reinforcing the value of therapists supporting youth's problem-solving skills in their own contexts (Key Ingredient #6), believing in their capabilities (Key Ingredient #3), and providing opportunities for shared decision-making (Key Ingredient #2). However, it is also important to consider how to effectively engage youth and families in capacity building interventions without overloading them. For example, in their recent publication, Grandisson and colleagues [64] propose nine principles to build capacities of families (of young children with special needs) without overburdening them. These principles, identified through forums with parents and therapists (e.g., propose flexible conditions, prioritize with the child and their family, take time, highlight the positive, collaborate with the family and different healthcare providers), align with many of the key ingredients of capacity building identified in this scoping review while emphasizing the need to limit burden during capacity building interventions. Similarly, findings of our review also indicate strategies that actively guide and support youth throughout the process such as the need for flexible and individualized supports (Key Ingredient #1), providing accessible and meaningful information (Key Ingredient #4), and ensuring 'real-world' opportunities to participate (Key Ingredient #5) for youth. Existing literature on family engagement in therapy can also provide guidance to support the process of working together with youth and families to promote capacity building outcomes. For example, Phoenix and colleagues offer insights into the conditions in which attendance, participation, and engagement in therapy occur [65] and recommend that service providers understand family composition, ask about parents' mental health, and when multiple services are involved, offer service navigation or a collaborative interprofessional approach to care. In addition to these conditions, The Phoenix Theory of Attendance, Participation, and Engagement in therapy also outlines the process of parent engagement and child, parent, service provider, and organizational factors that impact engagement [66]. In this theory parents' feelings, knowledge, and skills are all identified as elements that can help or hinder the process of attendance, participation, and engagement. These elements (beliefs, knowledge, skills) were also reflected as aspects of capacity building outcomes in the current scoping review.

Principles and key ingredients identified in this review can also provide guidance for researchers about how to capture the process and outcomes related to capacity building. Firstly, existing tools may be available to capture the various strategies (e.g., collaboration, engagement, accessibility of information) used in capacity building processes. For example, King et al. propose an observational tool (PRIME-O) that measures engagement of families and service providers that can provide insight into therapy as a "co-constructed relational and goal-oriented process" [67, p. 96]. Such a tool could facilitate measuring the process or mechanisms contributing to capacity building interventions. More recently, King and colleagues [68] have described four principles of co-constructed engagement when working with youth and identified specific underlying strategies which can help researchers to capture these underlying processes. Furthermore, key ingredients of capacity building identified in this review suggest other potential changes that would come about due to the transactional nature of the process of capacity building. For example, based on *Key Ingredient #4, sharing relevant information, resources and supports* could be observed through an increased number of people supporting the youth (i.e., increase in their network) and potentially measured through the individual's knowledge and use of these resources/supports. Additionally, changes could be observed beyond the person involved (and observed in the environment) such as more opportunities and experiences in real-world settings (Key Ingredient # 5). In terms of designs, mixed methods approaches can offer value in measuring changes of targeted outcomes quantitatively while also including the perceptions of youth, families, and therapists which are crucial to understand whether changes are meaningful to youth, applicable to the real-world setting, and relevant over the long-term. It is also important to consider designs that can evaluate such long-term outcomes. Recommendations documented in a perspective paper by Hsieh and colleagues [69] suggest the use of a follow-up phase after the end of participation-based interventions that aim to build capacity. The follow-up phase can be used to document problem-solving strategies that youth may have learned and/or applied and provide insight into the extent to which youth generalize acquired skills beyond the intervention to new participation experiences. Documenting youths' pursuit of new participation experiences after the intervention, including the level of support and/or strategies used, is one way to examine whether youth were able to act on learned knowledge, suggesting increased capacity to pursue desired goals.

Several gaps were identified through this scoping review. First, only seven documents included an explicit definition of capacity

or capacity building, suggesting there is no unified, consistent definition of the concept. This gap reinforces the importance of clarifying the use of this concept within rehabilitation contexts. Furthermore, given the relatively small number of evaluative documents included, primarily qualitative in nature, it is important that future research focus on developing appropriate methods to evaluate interventions that use capacity building approaches and their impacts. Across documents, qualitative methods such as semi-structured interviews, were seen as valuable tools for capturing capacity building outcomes from the perspective of parents and therapists. Interestingly, most of the evaluative studies that were included focused on building the capacity of parents rather than youth themselves. Further research is needed to evaluate interventions that aim to also build youth's capacity directly. Additionally, included documents were primarily published in North America and focused on youth with neurodevelopmental disabilities. Future research on capacity building should aim to include and report on outcomes specific to youth with disabilities from other marginalized populations such as youth from low-income, indigenous, refugee, or LGBTQI communities.

Limitations and future directions

A comprehensive approach was used to identify documents eligible for inclusion in this scoping review. There are several potential limitations worth discussing. First, in terms of the search strategy and eligibility, only documents published in English were included. Documents published in other languages may have been missed and perhaps the extent of the publications on capacity building of youth may have been limited to English-speaking regions. Furthermore, based on the research objectives, the term capacity building was searched explicitly to clarify the use of this concept. There may have been capacity building outcomes reflected in other interventions which did not use this term within their title/abstract, or whose findings reported on similar interventions or related constructs. For example, a publication by Kramer et al. [49] outlines initial findings from an environmental-focused problem-solving intervention for youth with developmental disabilities, and although strategies and findings are similar to documents found in this review, the term 'capacity building' was not used. Concurrently, such additional publications are unlikely to change the principles derived. Findings from this scoping review can be used to inform future review questions through including other relevant concepts that emerged as related to capacity building (i.e., self-determination, empowerment). This review included dissertations and textbooks, but did not include other grey literature (i.e., other non-peer reviewed documents, websites); other relevant documents could have been missed. For example, when reviewing the citations lists of included documents, one document by Stewart et al. [70] was identified which is the original document outlining the Best Journey to Adulthood model with more details related to the model that supports capacity building of youth. However, aspects of this model were captured through the included documents within the review.

Our process did not include involvement of people with lived experience of disability. This was primarily due to the lack of funding and resources available to meaningfully compensate individuals for the work and time that would be required. For similar reasons, the data extraction was not performed independently by two reviewers, but rather piloted, then divided and reviewed by each of the two team members. This is still in line with minimum requirements recommended for the involvement of two reviewers in the process of extraction [16]. The initial coding of data during content analysis was also completed by only one reviewer yet was reviewed by the second and third reviewer who were also then involved in the development of meaningful clusters and categories leading to the development of the principles and key ingredients. Given the nature of the data that was extracted and the aims of our scoping review, this level of content analysis was considered appropriate for our research objectives. Involving youth with disabilities or their families may have enhanced credibility of these findings, however, all three of the reviewers did have clinical experience working with a range of youth with disabilities and their families. The identified key ingredients in this review identify important considerations when working with youth including the need for individualized and flexible supports, the integral role of family, as well as the value of building community capacity to provide accessible opportunities for youth. Furthermore, few documents implied a bi-directional influence between youth/caregivers and their contexts (including professionals), however little is known about how professionals change (for example) when applying capacity building approaches. Therefore, obtaining perspectives of youth, their families, and other stakeholders involved in supporting capacity building (i.e., service providers, community services, etc.) is an important future direction of research.

Implications for rehabilitation

Therapists servicing youth with disabilities are working within a shifting paradigm that addresses both present and long-lasting/enduring outcomes for youth [69]. Approaches that aim to build capacity of youth consider "the current and future abilities and assets of each individual" [57, p. 139]. The definitions of capacity building extracted from the literature serve as valuable references and examples of how to explicitly define what is meant by the term capacity building. Recognizing and naming the intervention process as capacity building is the first step toward accurately documenting, implementing, and measuring effectiveness of such approaches. The four principles offer clarification about when an intervention/approach can be considered 'capacity building' in terms of supporting youth and families to self-manage their disability-related situations and pursue a meaningful life according to their own visions and goals. Importantly, researchers and clinicians should consider the transactional nature of capacity-building approaches and provide specific details about both the processes and the outcomes of such approaches. Researchers could draw upon these four principles to develop fidelity measures (i.e., a checklist) for interventions that are focused on building capacity. Therapists can implement the key ingredients outlined in this review when working with youth and families to build their capacity toward targeted outcomes of the intervention and beyond.

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