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# Advancing health equity: a scoping review of interventions for multiply marginalized children with disabilities in the United States

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## Abstract

**Background** Multiply marginalized children with disabilities disproportionately experience health disparities resulting from compounding experiences of systemic discrimination and oppression.

**Purpose** To characterize interventions addressing health outcomes or social determinants of health for multiply marginalized children with disabilities in the United States.

**Methods** We conducted a scoping review of peer-reviewed and grey literature. Search results were independently and dually screened by abstract then by full-text for eligibility criteria: available in English; original data from 2014 onward; intervention addressing health outcomes or social determinants of health; multiply marginalized children with disabilities; and US-based. Data were individually abstracted and checked by a second reviewer and narratively summarized.

**Results** Twenty-seven articles from peer-reviewed sources met inclusion criteria. The majority were descriptive or pilot and feasibility studies, with only eight including a control or comparison group. Participants were most often children with intellectual and developmental disabilities ($n=16$) and families with low socioeconomic status ($n=9$). Other marginalized identities and circumstances were rarely represented: immigration status ($n=3$), foster care ($n=2$), justice system involvement ($n=1$), and Black race ($n=1$). No included article reported an intervention for marginalized gender or sexuality. Slightly over half intervened at the level of the individual or caregiver ($n=15$) versus professionals or institutions ($n=12$). Interventions included telehealth integration ($n=2$); interprofessional programs and clinics ($n=3$); supports for system navigation ($n=4$); comprehensive programs for educational and post-secondary attainment ($n=6$); and, most commonly, training interventions for individual agency and skill development ($n=12$). Outcomes evaluated varied from rates of program use to educational attainment and were most commonly intervention acceptability ($n=13$); only one included article measured a health outcome directly. Reported involvement of community partners was limited, most commonly only during evaluation ($n=14$), with three studies reporting involvement across design, implementation, and evaluation.

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**Conclusions** Identified interventions centered on navigating or mitigating the downstream consequences of structural inequity, rather than changing the conditions producing it. Future efforts should prioritize interventions that shift the work of navigating inequitable systems away from families and address the conditions producing disparities, engage multiply marginalized communities as partners throughout design and evaluation, and attend to long-term sustainability from the outset.

**Keywords** Children with disabilities · Intersectionality · Health equity

## Background

All children deserve the chance to be healthy. This is a human right, recognized by the United Nations which calls upon members to progressively realize for all children without discrimination [1]. Despite this international acknowledgement, being healthy is not something everyone has a fair chance to achieve [2, 3]. Children with identities and circumstances marginalized by social systems experience avoidably worse health outcomes, or health disparities [4, 5]. A prospective cohort study of over 400,000 children found those with disability had 34% higher odds of mortality by adulthood than those without [6]. Additionally, a recent meta-analysis reported that children who are Black, compared to children who are White, have 3.2 times higher odds of requiring an emergency department visit and wait times up to 33% longer [7]. These disparities are not inevitable; they result from discriminatory policies, practices, and norms that create pervasive barriers and unjust differences in the distribution of social determinants of health, such as access to health care, education, and housing [8–10]. In other words, social systems do not provide marginalized children with the services and resources necessary to be healthy, and as a result, their health outcomes can be dramatically worse than those of their peers.

For children with multiple marginalized identities or circumstances, social systems disproportionately impose disadvantage, substantially increasing their risk for worse health outcomes [11, 12]. A systematic review of 37 studies spanning 29 years found that among children with physical disabilities, those with minoritized race experience disparities compared to their White peers in health-care access, health outcomes, and mortality rates [13]. Kimberlé Crenshaw's concept of intersectionality explains how overlapping systems of power and oppression create layered and amplified experiences of marginalization [14]. This compounding of discrimination, bias, and oppression is termed multiple marginalization. Health equity solutions must incorporate intersectional approaches to account for the systemic inequities and social injustices that reinforce each other and perpetuate health disparities among multiply marginalized children with disabilities [15, 16].

Notably, interventions designed to reduce health disparities for the most marginalized can improve health outcomes for all children [17]. This framework, Targeted Universalism, is exemplified by the Curb-Cut Effect: an accessibility feature designed for people with disabilities that also improved accessibility for the broader community, including older adults, travelers, and people using strollers [18]. However, justifying equity efforts for their benefit to the majority risks obscuring the civil injustice that necessitates these interventions [17]. Ensuring marginalized children have the opportunity to achieve their best health warrants prioritization on ethical grounds alone [1]. Therefore, the primary aim of this scoping review is to characterize existing interventions that address health outcomes or social determinants of health for multiply marginalized children with disabilities in the United States (US). We direct these findings to the professionals, institutions, and policymakers positioned to change the practices, norms, and policies that produce these disparities.

## Methods

We conducted a scoping review following JBI methodological guidance and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR; available in Additional File 1) [19, 20]. This design was appropriate given the early state of this literature and the dispersion of relevant interventions across health care, education, and social service sectors. It allowed us to address our objective of characterizing existing interventions, including the populations they serve and the outcomes they measure, rather than estimating the effect of a defined intervention on a defined outcome [21]. Consistent with our objective, and with JBI guidance that critical appraisal is optional in scoping reviews, we did not appraise the methodological quality of included sources or assess certainty. Outcomes were not pre-specified and are reported as described by source authors. The protocol was not registered.

### Article search terms

We developed a broad search strategy to identify projects, programs, and/or practices that improve health outcomes for multiply marginalized children with disabilities across social systems, including but not limited to the healthcare system. The strategy included subject terms and keywords in three domains: (1) children with disability, (2) marginalization, and (3) health-care delivery. Particular attention was given to the terminology, recognizing historical and contemporary variations in terminology use and preferences. Additional keywords were included to capture the following core outcomes identified by the Maternal and Child Health Bureau and the National Standards for Systems of Care for Children and Youth with Special Health Care Needs: medical home care; transition to adult healthcare; shared decision-making; early and continuous screening; adequate insurance and funding for services; community-based services; and health information technology.

The search strategy was developed and executed iteratively from September 2022 to July 2023, consistent with guidance for scoping reviews in which terms are refined as familiarity with an emerging literature develops [21]. Refinements included adding synonyms for the key terms as identified during the screening process and incorporating harvested references as the authors screened results, with the final search executed on July 6, 2023. Keywords were searched with the Boolean operator OR between domain-related terms and AND between domains. Searches were performed in PubMed (National Library of Medicine), CINAHL (EBSCO), Academic Search Complete, PsycINFO, and Web of Science.

For grey literature, targeted searches in Google using site:.gov, site:.edu, and site:.org were supplemented with recommendations from members of the Disability Inclusive Vision for Engaged Research and Service for Equity (DIVERSE) Collective and manual searching of websites. Government agencies, foundations, and research networks and institutes with disability in their mission were the basis for manual searching (Table 1). The filters or limiters used were date range (2014-present) and geography (US-based).

Search terms for each domain, along with the final PubMed strategy as executed, are provided in the supplemental materials (Additional File 2). Strategies for CINAHL, Academic Search Complete, PsycINFO, and Web of Science applied the same term sets adapted to each database's controlled vocabulary and syntax.

### Terminology and operationalization

We use person-first language throughout this paper but recognize that many people with disabilities prefer identity-first language and that preference is individual [22]. We conceptualize disability as arising in the interaction between a child's capacities and environments not built for the full range of human variation. Research design and reporting norms, however, frequently describe participants by diagnosis or condition, an approach rooted in the medical model of disability that overlooks the effects of contextual factors [23]. We therefore operationalized disability broadly: articles using disability-specific terminology (e.g., disability, impairment, limitation) were

**Table 1** Sources screened for grey literature

| Government agencies | | |
|---|---|---|
| Agency for Healthcare Research and Quality | Administration for Community Living | Centers for Disease Control and Prevention |
| Centers for Medicare and Medicaid Services | Department of Education, Office of Special Education and Rehabilitative Services | Department of Justice, Office of Juvenile Justice and Delinquency Prevention |
| Department of Labor | Health Resources and Services Administration | National Academies of Sciences, Engineering, and Medicine |
| National Institutes of Health | Office of Women's Health | Substance Abuse and Mental Health Services Administration |
| **Foundations** | | |
| Association of University Centers on Disabilities | De Beaumont | Family Voices |
| Kaiser Family | Lucille Packard | Robert Wood Johnson |
| **Research networks and institutions** | | |
| Children and Youth with Special Health Care Needs National Research Network | Disability Rights Education and Defense Fund | IRIS Center |
| National Academies of Sciences, Engineering, and Medicine | Patient-Centered Outcomes Research Institute | |

eligible on that basis. Those defining their sample by a specific condition were reviewed individually; inclusion was based on severity or functional descriptors in the full text and determined by consensus.

We operationalized multiple marginalization as a child with disability and additional identities or circumstances that experience marginalization (e.g., minoritized race, immigration status). We use the terms identities and circumstances when describing the marginalization, recognizing that intersectionality scholarship includes various terms for these factors, including identity, circumstance, social position, and social status [24].

Table 2 provides operationalization of key terms for inclusion criteria and data abstraction.

## Screening and data abstraction

Results were dually and independently screened by two reviewers, first by title and abstract and then by full text, for the following criteria, applied to both grey literature and peer-reviewed records: U.S.-based, available in English, and including original data from 2014 and onward on an intervention addressing health outcomes or a social determinant of health for children with disability who are multiply marginalized. We limited the search to the US because the policies and financing that enable these interventions, such as Medicaid and Supplemental Security Income, are country-specific, and health equity is defined relative to the inequities of a given system.

Data abstraction was completed using Covidence systematic review software [25]. The abstraction form was piloted and refined using two studies. Two reviewers then independently abstracted 25% of the included articles to confirm consistent application of the form. The remaining articles were individually abstracted and verified against the full text by a second reviewer, such that every article was reviewed by two team members.

Screening and abstraction discrepancies were resolved by consensus in team meetings, held approximately biweekly, with the senior author adjudicating when consensus was not reached. When warranted, discrepancies led to refining definitions of key terms in operation procedures.

Data abstraction included study characteristics, sample description, and details on intervention target (i.e., what the intervention sought to change in order to improve the outcome), design, execution, and outcomes. Study aims are reported as authors described them, marginalized factors are reported using the abstraction categories in Table 2.

**Table 2** Operationalization of key inclusion criteria and data abstraction

| Term | Operationalization |
|---|---|
| ***Inclusion criteria*** | |
| Disability | Participants are described as having a disability, functional impairment, difficulty completing activities of daily living or participating in the home, school, or community, or a condition(s) that may result in functional difficulty, such as paralysis. Health conditions that may or may not be associated with function were included dependent on the description of severity.<br>*Example*: Geenen et al.'s abstract described including "youth in foster care with mental health challenges," and their methods elaborated that this meant youth "identified as experiencing a significant mental health condition," indicated by criteria such as receiving special education services for an emotional disability or taking psychotropic medication. |
| Original data | A study that reports data derived from observation or experimentation that is not reported elsewhere. |
| Health intervention | An intervention that aims to improve health outcomes or social determinants of health for a group or identity that experiences health disparities; includes a policy, procedure, or program that was intentionally designed for and/or evaluated among children with a disability who are multiply marginalized. |
| Multiply marginalized child with disability | Children and youth with both a disability and a second identity or circumstance that experiences marginalization and health disparities. |
| Original data | Findings related to the reported intervention have not been previously published. |
| U.S.-based | Intervention takes place within the United States of America. |
| ***Data abstraction*** | |
| Disability types | *Disability broadly*: When studies did not specify a disability type.<br>*Intellectual and/or developmental*: Originated in childhood, characterized as difficulty or delay in acquiring motor, communication, speech, social, or cognitive skills. Such as autism spectrum disorder, cerebral palsy, and spina bifida.<br>*Mental health*: Mental health diagnoses with severity to limit or prevent the child's functioning, such as obsessive-compulsive disorder and major depressive disorder,<br>*Physical*: Related to body structure, mobility, and activities of daily living difficulty, other than those categorized as developmental. Includes spinal cord injury and muscular dystrophy.<br>*Sensory*: Related to processing sensory information, such as sight, hearing, and touch |
| Intervention target | Who or what the intervention aimed to change to improve outcomes, categorized as 1) *Individual/caregiver*: sought to change the knowledge, skills, behavior, or capacity of the child or caregiver, even when delivered by professionals within a service setting; or 2)*Professional/institution*: sought to change professional practice, provider skills, institutional processes, or the structure of service delivery.<br>*Example*: Carr and Lord tested modifications to an early intervention protocol (in-home sessions, a liberal cancellation policy, shortened duration). Caregivers were the participants and children were the intended beneficiaries, but what changed was the program's delivery, so the target was categorized as professional/institution. |
| Marginalized identities and circumstances | Included minoritized gender (female, transgender, and gender nonconforming), race, and ethnicity; queer sexuality; immigration status; non-English language speaking preference; rural geography; low socioeconomic status; involvement with child welfare or juvenile justice systems; and obesity. |

## Results

Our literature search identified 553 results, of which 27 were removed due to duplication. Screening by title and abstract removed an additional 243 results and the remaining 283 results were screened by full text with 27 meeting the criteria for inclusion in this review (see Fig. 1). All included texts were from peer-reviewed journals. We report our findings in the following order: first, we summarize across all articles the study characteristics and the interventions and outcomes reported. Next, we describe the individual studies within each intervention category, subcategorized by the target level (Individual/caregiver; professional/institution).

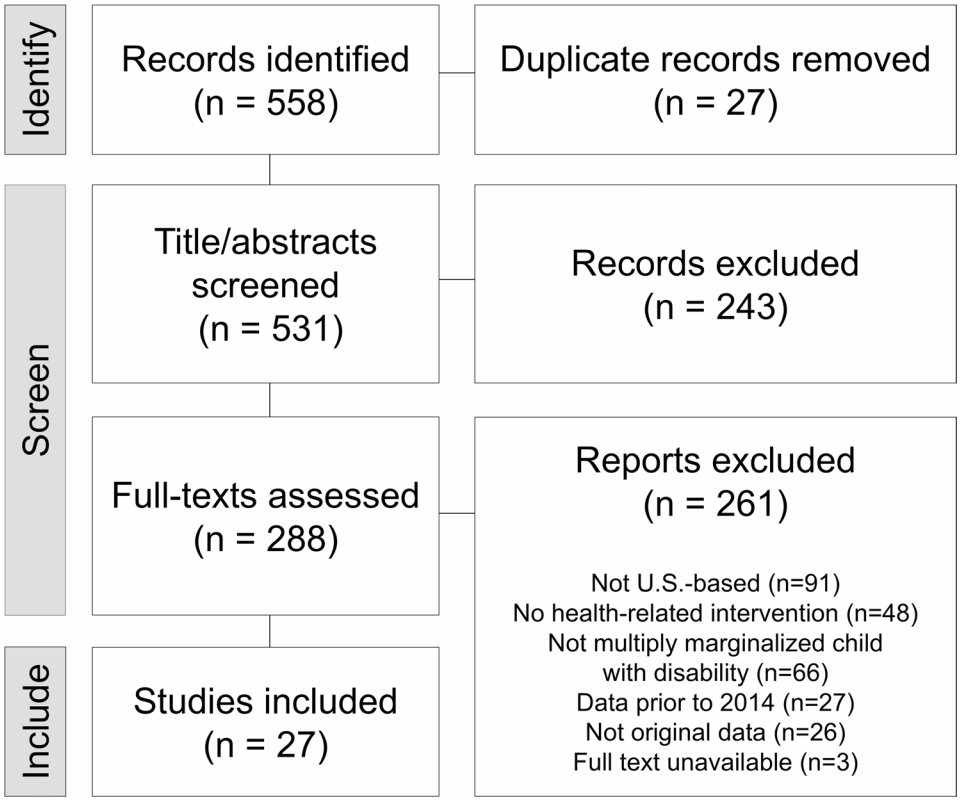



**Fig. 1** Preferred reporting items for systematic reviews and meta analyses (PRISMA) flow diagram

## Study characteristics

Characteristics of the included studies are detailed in Table 3 and briefly summarized below. A third were pilot studies ($n=8$ [30%]), of which two used randomized assignment. Six studies (22%) were experimental or quasi-experimental, including four randomized control trials and two studies with nonrandomized comparison groups. The remaining 13 studies (48%) were descriptive, including one single-case experimental design and one implementation evaluation, and did not include a comparison group.

The locations of recruitment are depicted in Fig. 2.

Sample sizes across studies ranged from 3 to 3,072, with a median (IQR) sample size of 40 (19–170) participants per study. Interventions were most commonly for children or youth with intellectual and developmental disabilities ($n=16$ [59%]) and families with low socio-economic status ($n=9$, [33%]). Figure 3 provides a matrix to depict the intersection of marginalized identities and circumstances with disability types for the participants recruited across included studies. Notably, no interventions included in this review focused on marginalized gender or sexuality and very few on immigration status ($n=3$), foster care ($n=2$), or justice system involvement, ($n=1$). Although 7 studies included children with disability and minoritized race or ethnicity, only 1 focused on children who are Black. The remaining focused on Latinx/Hispanic ethnicity ($n=4$) or were community-based interventions in settings described as having a high proportion of children with minoritized race and/or ethnicity ($n=2$).

## Interventions and outcomes

Half of the interventions included targeted the individual/caregiver as their locus of change for promoting health outcomes ($n=15$) while the remainder targeted the professional or institution ($n=12$). Interventions were grouped by their components, resulting in the following 5 categories: interprofessional programs or clinics (Table 4);

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**Table 3** Characteristics of included studies (W=White; B=Black; O=Other; NR=Not reported), *N*=27

| Author & year | Aim/objective | Marginalized factor(s) | | Design | Sample size | Age in years (mean) | Female (*N*) | Race and ethnicity (*N*) | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Disability | Additional factor (s) | | | | | Non-Hispanic | | | Hispanic |
| | | | | | | | | W | B | O | |
| **Intervention Target: Professional or Institution**, *n*=12 | | | | | | | | | | | |
| Adolphe 2022 | Describe the development and implementation of the *EASE clinic*, a program to improve access to special education services for children with intellectual and developmental disabilities (IDD). | IDD | Low socio-economic status<br>Non-English speaking | Descriptive | 308 | 8.3 | 96 | 178 | 21 | 45 | 64 |
| Blakeslee 2022 | Evaluate a post-secondary support program for enrolled college students with foster care backgrounds and mental health challenges. | Mental health | Foster care involvement | Pilot | 35 | 20.5 | 25 | 21 | NR | 7 | 7 |
| Carr 2016 | Apply empirically supported methods promoting the participation of families with low income and low education levels to an established intervention for children with autism spectrum disorder (ASD). | IDD | Low socio-economic status | Pilot | 8 | 2.6 | NR | 4 | 4 | NR | NR |
| Coleman 2022 | Examine the impact of providing ASD-specific training (FITT) and coaching to rural early intervention providers in an effort to ameliorate barriers for the implementation of ASD-focused early intervention in rural settings. | IDD | Rural residence | Single-case experimental design | 3 | NR | 3 | 2 | 1 | NR | NR |
| Davidson 2022 | Investigate parent and therapist experience and cost savings from the payer perspective associated with a novel telephysiatry program for children living in rural and underserved communities. | IDD | Rural residence | Randomized control trial | 118 | 10.9 | NR | NR | NR | NR | NR |
| Geenan 2015 | Conduct a preliminary efficacy evaluation of the *Better Futures* model, which is focused on post-secondary preparation and participation of youth in foster care with mental health challenges. | Mental health | Foster care involvement | Randomized control trial | 67 | 16.7 | 15 | 28 | 13 | 9 | 3 |
| Hodges 2022 | Determine whether the *ECHO* model could be used to improve the utilization of evidence-based behavioral practices by early childhood educators in rural communities and evaluate the effectiveness of a professional development training designed to increase early childhood care providers' ability to use preventative, positive behavior supports for young children with disabilities. | Disability broadly | Rural residence | Pilot | 18 | NR | NR | NR | NR | NR | NR |
| Hooshmand 2018 | Examine cost, caring, and family-centered care in relationship to pediatric specialty services integrating telemedicine visits compared to traditional face-to-face visits. | Disability broadly | <200% of the Federal Poverty Level<br>Rural residence | Quasi-experimental | 222 | 9.8 | NR | 47 | 101 | 17 | 57 |
| Kendrick-Allwood 2021 | Assess the ability of a medical-legal partnership to benefit pediatric patients with neurodevelopmental disabilities and their families from an urban community and examine legal, social, and health issues addressed and outcomes attained through interprofessional collaboration among health-care providers and lawyers to address health-harming legal issues. | IDD<br>Physical<br>Sensory | <200% of the Federal Poverty Level | Descriptive | 651 | NR | 570 | 139 | 385 | 12 | 85 |
| Mathur 2021 | Explore the effects of *Project RISE* on youth with disabilities and compare outcomes of engagement and recidivism for RISE and non-RISE groups. | Disability broadly | Juvenile justice involvement | Quasi-experimental | 112 | 16.5 | 9 | 35 | 26 | NR | 48 |

**Table 3** (continued)

| Author & year | Aim/objective | Marginalized factor(s) | | Design | Sample size | Age in years (mean) | Female (*N*) | Race and ethnicity (*N*) | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Disability | Additional factor (s) | | | | | Non-Hispanic | | | His-panic |
| | | | | | | | | W | B | O | |
| Matiz 2022 | Evaluate the impact of integrating community health workers into the medical teams of children with hearing loss and identify their social needs at a large urban hospital center. | Sensory | Immigrant<br>Minoritized ethnicity | Descriptive | 30 | 3.4 | 11 | NR | NR | NR | 27 |
| Weier 2017 | Present a case study of care coordination for children and youth with special health-care needs from an exclusively pediatric accountable care organization and compare pre-care and post-care data on their use of inpatient and emergency department services. | Disability broadly | Insured by Medicaid | Descriptive | 3072 | NR | 1747 | NR | NR | NR | NR |
| **Intervention target: Individual or caregiver**, $n=15$ | | | | | | | | | | | |
| Dababnah 2021 | Engage community advisory group in the local adaptation and implementation of *Parents Taking Action* for parents of Black children with ASD in low-income Baltimore neighborhoods and identify participation barriers and facilitators. | IDD | Black race<br>Low socio-economic status | Cultural adaptation and pilot | 7 | NR | 2 | 7 | 0 | 0 | 0 |
| Hartman 2019 | Determine if Wisconsin *PROMISE* had an impact on early educational attainment and employment outcomes of *PROMISE* youth and their family members compared to services as usual. | Disability broadly | <200% of the Federal Poverty Level<br>Receiving SSI benefits | Randomized control trial | 1011 | NR | 374 | 344 | 495 | 51 | 101 |
| Ipsen 2019 | Report preliminary outcomes from the *ASPIRE* consortium, part of the PROMISE Initiative. The PROMISE Initiative includes six demonstration research projects targeting youth with disabilities receiving Supplemental Security Income (SSI). | Disability broadly | Receiving SSI benefits | Randomized control trial | 1429 | NR | 487 | 902 | 190 | 100 | 519 |
| Luelmo 2021 | Examine the effectiveness and feasibility of a low-intensity, low-cost, parent-to-parent advocacy intervention for parents of children with ASD. | IDD | Latinx ethnicity | Pilot | 24 | NR | 23 | NR | NR | NR | 23 |
| Magana 2017 | Examine the feasibility, acceptability, and preliminary outcomes of a culturally derived intervention, *Parents Taking Action*, for 19 Spanish-speaking mothers of children with ASD. | IDD | Immigrant<br>Spanish-speaking<br>Latinx ethnicity | Pilot | 19 | 5.8 | 2 | NR | NR | NR | 19 |
| Martino 2022 | Examine multiple frameworks of disability inclusion that progressively reshaped an existing pediatric obesity intervention program toward improving participation for children with disabilities. | Disability broadly | Obesity | Descriptive | 40 | NR | NR | NR | NR | NR | NR |
| McIntyre 2022 | Evaluate the implementation of a behavioral parent training telehealth intervention for Spanish-speaking parents of preschool children with developmental delay and elevated behavior problems during the pandemic. | IDD | Spanish- speaking | Implement-ation trial | 42 | 4.0 | 12 | NR | NR | NR | 42 |
| Meadan 2020 | Evaluate a parent training and coaching program designed to support English-speaking families, then translated and modified to support Spanish-speaking families of young children with disabilities or speech delays. | Disability broadly | Spanish-speaking | Cultural adaptation and pilot | 7 | NR | NR | NR | NR | NR | 7 |
| Miller 2022 | Trial a novel website and smartphone application designed to aid adolescents and young adults during transition to adult care. | Disability broadly | <247% of the Federal Poverty Level | Pilot | 23 | NR | NR | NR | NR | NR | NR |



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**Table 3** (continued)

| Author & year | Aim/objective | Marginalized factor(s) | | Design | Sample size | Age in years (mean) | Female (*N*) | Race and ethnicity (*N*) | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Disability | Additional factor (s) | | | | | Non-Hispanic | | | Hispanic |
| | | | | | | | | W | B | O | |
| Pearson 2020 | Implement and evaluate a community workshop to connect minority families of children with ASD to services. | IDD | Minoritized race/ethnicity<br>Low socio-economic status | Descriptive | 57 | NR | 45 | 13 | 40 | 6 | 3 |
| Pona 2017 | Assess the effectiveness of a specialized multidisciplinary weight management program for children with disabilities. | IDD<br>Physical | Obesity | Descriptive | 115 | 10.5 | 43 | 66 | 26 | 5 | 18 |
| Schlegelmilch 2021a | Explore Wisconsin *PROMISE* participants' perspectives and experiences receiving an intervention to increase paid employment experiences of youth with disabilities. | Disability broadly | Receiving SSI benefits | Descriptive | 4 | NR | NR | 3 | 1 | NR | NR |
| Schlegelmilch 2021b | Positively change youth readiness to work through the use of Motivational Interviewing, work incentive benefits counseling, financial capability building, shifting expectations, and help navigating transition resources. | Disability broadly | Receiving SSI benefits | Descriptive | 2024 | NR | 804 | 690 | 144 | NR | 113 |
| Suarez-Balcazar 2016 | Implement and examine the benefits of a culturally tailored healthy lifestyle program for Latino youth with disabilities and their families. | IDD | Latinx ethnicity<br>Rural residence | Descriptive | 19 | NR | 6 | NR | NR | NR | 19 |
| Suarez-Balcazar 2018 | Develop a healthy lifestyles intervention in collaboration with Latino immigrant families with youth and young adults with disabilities using a community-based participatory research approach, and examine the impact of the intervention from participants' perspectives. | IDD | Immigrant<br>Latinx ethnicity | Descriptive | 24 | NR | NR | NR | NR | NR | 24 |




**Fig. 2** State-level locations of intervention or recruitment across the 22 articles reporting this information

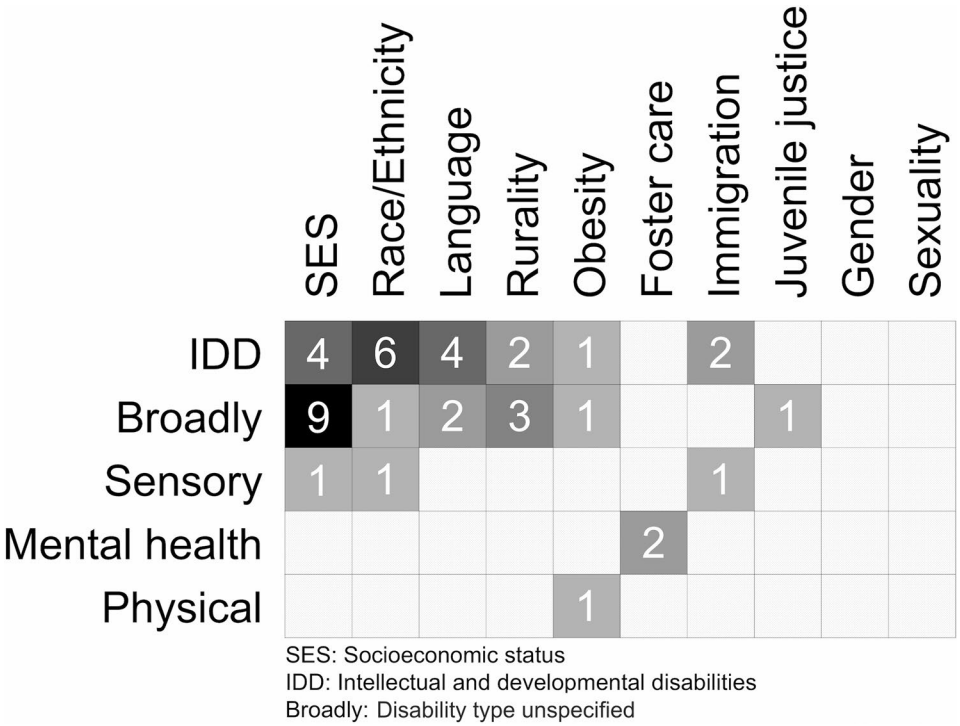



**Fig. 3** Multiple marginalization matrix for participants of included articles; categories are not mutually exclusive

telehealth integration (Table 5); comprehensive programs for educational and post-secondary attainment (Table 6); care coordination and system navigation supports (Table 7); and educational interventions to increase individual agency or skills (Table 8).

The included articles evaluated a wide variety of outcomes, as depicted in Fig. 4. Most examined intervention acceptability or increasing participants' individual agency, such as health-related knowledge, self-determination, and optimism. Only one study included a health outcome directly (body mass index) [26].

Lastly, the extent to which research teams involved multiply marginalized people with disabilities as partners throughout the research process was limited (see Fig. 5). Most commonly, they were involved only in evaluation ($n = 14$ [52%]). Three (11%) reported involvement throughout the design, implementation, and evaluation of the intervention.

**Table 4** Interprofessional programs and clinics, $N=3$

| Author & year | Summary | Components and process | Outcome measures and key findings |
|---|---|---|---|
| **Intervention Target: Professional or Institution, n = 3** | | | |
| Adolphe 2022 | ***The (EASE) clinic*** Interprofessional clinic to improve access to special education services. ***Systems involved*** Education Health care Legal/Justice | Embedded in an existing primary care clinic, three multilingual staff (Haitian Creole, Spanish and English) operate the EASE clinic once a week. The physician, nurse practitioner, and lawyer are funded through insurance reimbursement (CPT codes 99213, 99214, 99215).<br>Enhancements to existing primary care included<br>• Structured, recurring education on community needs, available services, and the special education qualification process<br>• Up-to-date information on available resources<br>• "On-the-fly" consultations during appointments.<br>Families were provided with<br>• Support qualifying for services<br>• A school to health care liaison<br>• In person support for IEP meetings, if needed. | Rates of program use from 2017–2021 including the number of referrals and clinic visits and participant characteristics.<br>• 308 children were referred<br>• 452 clinic visits occurred<br>• Growth was sustained, ≥20 additional referrals each year<br>• Children served were 58% Black and 21% Hispanic. |
| Kendrick-Allwood 2021 | ***The HeLP clinic*** Medical-Legal partnership. ***Systems involved*** Health care Legal/Justice | Embedded in an existing primary care clinic, a collaborative team of lawyers, law students, physicians, and medical students assist families with legal issues. Families were referred to the HeLP clinic during primary care visit or could self-refer for assistance accessing or navigating:<br>• State sponsored health insurance<br>• Disability benefits such as SSI and SSDI<br>• Special education or school disciplinary problems<br>• Employment complications like Family Medical Leave Act benefits or discrimination<br>• Housing conditions and evictions<br>• Public benefits like the Supplemental Nutrition Assistance Program<br>• Permanency planning like wills or guardianship<br>• Family law issues like custody. | Rates of program use, including the number of clients and legal cases, the types of cases assisted with, and financial benefits awarded.<br>• 651 families were served<br>• 898 legal cases assisted<br>o 25% were education related<br>o 21% SSI or SSDI related<br>• $4.9 million in benefits resulted from these cases with an average value of $9,595.93 |
| Mathur 2021 | ***The RISE program*** Adding a transition specialist to support community reintegration after juvenile justice release. ***Systems involved*** Education Health care Legal/Justice Social services | A dedicated transition specialist provides personalized and proactive case management, early individualized goal setting, and long-term review and support during transition.<br>Components of the RISE group (versus traditional services provided to historical controls of youth who did and did not receive special education (SPED) services):<br>• Dedicated Transition Specialist with small caseload of 14 youth (vs. 30 and 80)<br>• Individualized Transitions Plan creation at entry into the facility, including academic, pro-social, and vocational skill building and parole plan (vs. parole planning only at exit)<br>• Proactive, interprofessional coordination and communication with schools, parole officers, service providers, families, and child welfare caseworkers (vs. not provided)<br>• Ongoing, proactive support from Transition Specialist weekly pre-release and every 15 days post for 120 days; parole officer post release (vs. supervision by parole officer, frequency not stated) | Community engagement status at 120 days post-release and recidivism (measured by the number of days post-release that return to custody occurred) were calculated in multi-variable analyses.<br>Compared to control groups, those with and without SPED services, RISE program participants were 385% and 598% more likely to be engaged in the community 120 days post-release, respectively.<br>At 120 days post-release, 88% of RISE youth, 53% of the SPED group, and 45% of the non- SPED group were engaged with their community. Compared to the special education group, those involved in RISE were almost 5 times as likely to be engaged in the community 120 days post-release (OR = 4.85), and 7 times as likely as the non- special education group (OR = 6.98).<br>RISE program participants also had lower levels of recidivism as compared to the special education group and the control group (12% vs. 53% vs. 68%).<br>The rate of recidivism for those engaged in the RISE program was 89% lower than the special education group (HR = 0.11) and 92% lower than the non- special education group (0.08). |

**Table 5** Telehealth integration, $N=2$

| Author & year | Summary | Components and process | Outcome measures and key findings |
|---|---|---|---|
| **Intervention Target: Professional or Institution, $n=2=2$** | | | |
| Davidson 2022 | ***Telehealth*** Physiatry within school-based clinics called Medical Therapy Units in rural or underserved areas. ***Systems involved*** Education Health care | Four school-based Medical Therapy Units provided either in-person or telehealth physiatry visits. Both the patients and a physical or occupational therapist were present at all visits and the physiatrist attended either in-person or remotely via video software and a high-definition camera. After clinics were randomized, clinics alternated between in-person or telemedicine care. | Acceptability was measured by the adapted Consumer Assessment of Health Providers and Systems Hospital Survey and provider skill was measured by the adapted Consumer Assessment of Health Providers and Systems Hospital Survey. Financial impacts were measured by cost to the payer. Telehealth was not inferior to in-person delivery of physiatry, per parent and therapist report of acceptability and provider skill. Telehealth saved payers $100 per day. |
| Hooshmand 2018 | ***Telehealth*** Neurology and nutrition specialists within pediatric specialty clinics in rural, remote, and underserved areas. ***Systems involved*** Health care | Families were able to choose between in-person or telemedicine pediatric specialty appointments. Telemedicine appointments were conducted using Polycom equipment and a nurse or nurse practitioner was present with the family in the clinic. | Health-care access and use was measured using the Caring Professional Scale (CPS) and Measure of Process Care-20 (MPOC-20). Financial impact was measured using the Family Cost Survey. There was no significant difference in families' perceptions of care (CPS score) or in cost to families between telehealth and traditional care. Families rated telemedicine as more family-oriented compared to traditional care ($p=0.003$). |

### Interprofessional programs or clinics

Three studies reported on interprofessional programs or clinics (see Table 4) [27–29], in which professionals from different systems (e.g., health care and law) collaborate to jointly provide services to children and their families. All three studies intervened at the level of the professional/institution, since this intervention changed how professionals work together to provide care, rather than changing the knowledge or behavior of the families. Adolphe et al. reported on the Engagement and Access to Special Education (EASE) clinic, a primary care-embedded, interprofessional clinic situated in an urban health-care center that predominantly serves families that identify as Black or Hispanic, are Medicaid-insured, and living at or below the federal poverty level [27]. The EASE clinic is comprised of a physician, nurse practitioner, and a lawyer, who are multilingual. The aim is to address systemic barriers to special education by providing ongoing education for primary care providers (PCPs) and clinic staff through structured in-services, consultations, and a regularly updated guide on local resources. The EASE clinic also functions as a liaison between the school and PCPs, assisting with the qualifying processes for special education services. Study results were a descriptive analysis of the clinic's patients which included 308 patients served between 2017 and 2021, the majority of which were minoritized race and ethnicities (50% Non-Hispanic Black; 21% Hispanic; 7% White) with public health insurance (80%), and moderate to high complexity of medical needs (33% and 50%, respectively).

Kendrick-Allwood et al. describes the development of a medical-legal partnership within the Children's Hospital of Atlanta's health-care system for families of children and youth with intellectual and developmental disabilities living in poverty. This program provides legal support for addressing needs across the social determinants of health, including access to health care, education, housing, social services, and family law [28]. From 2006 to 2018 this program opened 898 legal cases and obtained or retained $4.9 million in benefits for families.

Project Reentry Intervention and Support for Engagement (RISE) is a juvenile justice program working with education and health-care systems to ensure service needs are met to support community engagement and prevent

**Table 6** Comprehensive programs for educational and post-secondary attainment, $N=6$

| Author & year | Summary | Components and process | Outcome measures and key findings |
|---|---|---|---|
| **Intervention Target: Professional or Institution, $n=2$** | | | |
| Blakeslee 2022 | ***Project Futures*** Post-secondary support program for youth with foster care experience and mental health challenges. ***Systems involved*** Education | Individual near-peer coaching provided twice per month from an upper-level undergraduate or graduate student who has lived experience with foster care and/or mental health challenges. Workshops organized three times each academic year with the involvement of program participants. Topics include self-determination skills, post-secondary experiences, informal networking, and group recreational activities. Campus champions are key administrative and faculty representatives from various departments. They participated in the workshops and were available to answer questions about campus navigation, structure, services, and policies. | Individual agency as measured by the AIR Self-determination scale, Self-determination Score, Career Decision Self-Efficacy-Short Form, Career Goals Exploration, and Youth Efficacy/Empowerment-Mental Health. Educational attainment was measured by ongoing enrollment and self-reported grade point average. Compared to the control group, program participants had statistically significantly higher grade point averages (3.1 vs. 2.6, d = 0.93), college enrollment in the following year (93% v 67%), and self-determination and empowerment scores. Two years post-intervention families reported higher rates of parent encouragement to have a job, youth expectations of working, and participation in employment activities. |
| Geenan 2015 | ***Project Futures*** High school and post-secondary support program for youth with foster care experience and mental health challenges. ***Systems involved*** Education | Participants were randomized to either a control group which received typical services or the experimental group which received access to<br>• The summer institute: a four-day stay at a university campus which included tours and discussions with near-peers about preparation, mental health, accommodation needs, and available resources.<br>• Individual near-peer coaching: twice a month for nine months, focusing on achieving goals and managing barriers, provided by established students with shared experiences in foster care and/or mental health challenges.<br>• Mentoring workshops: five workshops with topics chosen by participants included the college application process, mental health, and transition services. | Educational attainment as measured by graduation rates and post-secondary enrollment and individual agency as measured by self-determination (Arc Self-Determination Scale & AIR Self-Determination Scale), mental health (Youth Empowerment Scale-Mental Health, Mental Health Recovery Measure, & Youth Self-Report), and quality of life (Quality of Life Questionnaire).<br>Compared to the control group, Project Futures participants had significantly higher rates of high school completion (65% vs. 52%) and post-secondary enrollment (65% vs. 24%). Non-significant increases over time were found in self-determination, empowerment, hope, and quality of life. |
| **Intervention target: Individual or caregiver**, $n=4$ | | | |
| Hartman 2019 | ***Wisconsin PROMISE*** One of six federal demonstration sites promoting work readiness and financial self-sufficiency among minors receiving supplemental security income. ***Systems involved*** Social services | Intervention group participants ($n=1,018$) were automatically enrolled in state vocational rehabilitation services and received wraparound case management, employment services including soft skills training and paid work experience, financial coaching, an Individual Development Account, work incentive benefits counseling, and self and family advocacy training. Control group participants ($n=1,006$) continued services as usual. | Workforce integration as measured by administrative wage records, and educational attainment via National Student Clearinghouse data. Youth employment rates rose from 1% in 2013 to 67% in 2018, 10% points higher than the control group. Each service component was positively correlated with employment: 78% of the 535 youth who met with a work incentive benefits specialist had reported wages versus 55% of those who did not; 95% of the 285 youth receiving short-term job supports had a paid job afterward. |
| Ipsen 2019 | ***PROMISE Initiative and the ASPIRE Consortium*** Six demonstration research projects targeting youth with disabilities receiving Supplemental Security Income. ***Systems involved*** Social services | Intervention group participants received case management, self-determination training, transition training for parents/guardians, financial literacy training, benefits counseling, and pre-employment services. Control group participants received standard services offered by their state systems. | Individual agency as measured by the American Institutes for Research Self-Determination Scale, and workforce integration based on self-reported volunteering, looking for work, or working part of full time in past 30-days. Two years post intervention, families reported higher rates of parent encouragement to have a job, youth expectations of working, and participation in employment activities. |

**Table 6** (continued)

| Author & year | Summary | Components and process | Outcome measures and key findings |
|---|---|---|---|
| Schlegelmilch 2021a | ***Wisconsin PROMISE*** Federal research grant intended to promote work readiness in minors receiving supplemental security income. ***Systems involved*** Social services | Participants received soft skills training, financial coaching, work incentive benefits, a savings account, self and family advocacy training, and information intended to promote healthy lifestyle habits. | Individual agency and workforce integration as measured by self-report via interviews. The PROMISE program provided needed employment support and additional services for youth and their families and two of the four participating youth self-reported employment by study end. |
| Schlegelmilch 2021b | ***Wisconsin PROMISE*** Assists youth with disabilities transitioning from high school to adulthood who experience barriers in achieving employment. ***Systems involved*** Social services | Participants received soft skills training, financial coaching, work incentive benefits, a savings account, self and family advocacy, and health promotion. They also received motivational interviewing from case managers to address barriers to employment and empower youth and their families. | Individual agency as measured by the Stages of Change Questionnaire and workforce integration as measured by employment rates. A statistically significant increase both in youth and family member mean Stages of Change score was found following the intervention. Employment rates differed between youth who had large increases, small increases, and decreases in their Stages of Change scores (94% vs. 71% vs. 50%). |

recidivism for children and youth with disabilities receiving special education services [29]. Project RISE uses a personalized and proactive case management approach with a dedicated transition specialist who works with the youth prior to and throughout 120-days post release to set individualized goals and implement action plans. Transition specialists also facilitated communication and service coordination between families, schools, healthcare providers, and social services. Compared to two historical control groups that did and did not receive special education services, Project RISE participants had increased rates of community engagement (88% vs. 53% and 45%) as well as decreased recidivism (12% vs. 53% and 68%) 120 days post release.

### Telehealth Integration

Two (7%) articles evaluated telehealth versus in-person health care to increase access to specialty services in rural areas (see Table 5) [30, 31]. In both, telehealth was provided within an existing clinic space and thus classified as targeting professionals/institutions. Davidson et al. used a noninferiority cluster-randomized crossover design in four school-based clinics and reported that caregiver and therapist perceived quality of care was equivalent to in-person physiatry services and an average savings of $100 per day for the payer, California Children's Services, through avoided physician mileage reimbursement [30]. Hooshmand et al. similarly reported no difference in families' perception of their providers caring, and additionally reported significantly higher scores of family-centered care delivery with telehealth versus in-person nutrition and/or neurology services. However, telehealth was not associated with a significant reduction in families' actual out-of-pocket costs; lower costs were observed only when telehealth costs were compared with families' estimates of what they would have incurred had telemedicine been unavailable [31].

### Comprehensive programs for educational and post-secondary attainment

Six (22%) articles described programs supporting educational and post-secondary attainment, including workforce availability (see Table 6) [32–37]. Programs in this category combined three or more components sustained over an academic year or longer, most commonly one-on-one coaching or case management, structured workshops on self-determination, and formal linkage to education or employment systems. Two (7%) targeted professionals or institutions and four (15%) targeted individuals or caregivers.

**Table 7** Care coordination and system navigation supports, N=4

| Author & year | Summary | Components and process | Outcome measures and key findings |
|---|---|---|---|
| **Intervention Target: Professional or Institution, *n* = 3** | | | |
| Carr 2016 | ***Modification to the Early Social Interaction Project*** Increase engagement in early autism resources by addressing known barriers. ***Systems involved*** Health care | Program modifications were made to address known treatment barriers. For example, in-home treatment sessions were offered, compensation for transportation provided, cancellations and rescheduling permitted, and advocacy training for caregivers added. Families participated in a total of twenty-four twice weekly, sixty-minute sessions where an interventionist worked with the caregiver to improve the social-communication skills of their child. | Acceptability as measured by program attrition and attendance, rates of program use as measured by engagement in study activities, and acquired skills as measured by caregiver adherence to protocol and via caregiver interviews. Intervention length ranged from 3.6 to 9.1 months (M = 6.99, SD = 2.2) and appointment cancellations ranged from 2 to 20 (M = 11.1, SD = 7.0). Outside of treatment appointments, caregivers engaged in study activities from 5.97 to 22.02 h per week (M = 12.8, SD = 4.7). |
| Matiz 2022 | ***Community health workers*** A retrospective chart review of patients with hearing loss receiving community health worker services. ***Systems involved*** Health care | Two community health workers and a community-based organization expert lead the intervention, which supported caregivers navigating social services, education and health-care services. It connects families to resources, accompanies them to medical appointments, and provides advocacy. Children were referred by their pediatrician, audiologist, or education specialist. Follow-ups with families occurred every two to four weeks until transition to pre-school or service establishment in a pre-school setting. | Acceptability as measured by the Distress Thermometer for Parents and health-care access and use based on an intake assessment. At 3-month follow-up, 70% of patients had needed referrals, 89% reported completing goals, and a significant proportion had cochlear implants compared to baseline (33% vs. 20%, $p = 0.017$). No significant differences were found in level of distress or confidence comparing baseline to follow-up data. |
| Weier 2017 | ***Partners for Kids*** A care coordination program funded through Medicaid. ***Systems involved*** Health care | Children were referred to care coordination through direct referral and also by data mining for high-cost or high morbidity patients. Care coordinators developed individualized care plans for each family informed by completion of a Health Risk Assessment and contacted families monthly. In-person visits occurred every ninety days and care plan updates occurred quarterly. | Health-care access and use data obtained from the electronic medical record. Statistically significant reductions pre- and post-enrollment were found for inpatient admissions ($p < 0.001$), bed days ($p < 0.001$), and 30-days readmissions ($p = 0.009$). A non-significant reduction in emergency department visits was also found ($p = 0.07$). |
| **Intervention Target: Individual or caregiver, *n* = 1** | | | |
| Miller 2022 | ***Website and smartphone application*** Designed to aid adolescents and young adults during their transition to adult care. ***Systems involved*** Health care | Customized website and smartphone application designed for user-friendly<br>• Access to transition resources such as help finding health-care providers, employment assistance, local support groups, and post-secondary education information.<br>• Care coordinators in charge of introducing and teaching youth on how to use the website and application.<br>• Storage of personal data.<br>• A reminder system for medication refills and appointments. | Acceptability, individual agency, and health-care access as measured by a study-designed survey and interview.<br>After the intervention, participants demonstrated gains in medical knowledge of their condition (21%), system navigation (15%), having an identified health provider (32%), and awareness of resources (19%). Results support a mobile application's potential to assist with the difficult transition between youth and adult care. |

Both interventions classified as targeting professionals/institutions described near-peer coaching models for youth in foster care with mental health disabilities. Geenen et al. reported on Better Futures, which randomized 67 high school youth to the program or standard school services [32]. The Better Futures group received a multifaceted program consisting of: (1) multi-day college campus experience; (2) five workshops with topics selected by participants and relating to self-care, transition services, and the college application process; and (3) one-on-one coaching with near-peers to identify goals, barriers, strategies, and supports. Importantly, the near-peers received extensive training (about 40 h) in mental health and related support strategies, foster care dynamics, and barriers in higher education [32]. They reported higher rates of high school completion (65% vs. 52%) and post-secondary enrollment (65% vs. 24%) among youth randomized to Better Futures versus standard school services. Blakeslee et al. reported on Project Futures, which adapted the model for students already enrolled at a university and two community colleges and added designated administrative and faculty representatives from various departments tasked with providing specific support and addressing student queries [33]. This pilot randomized

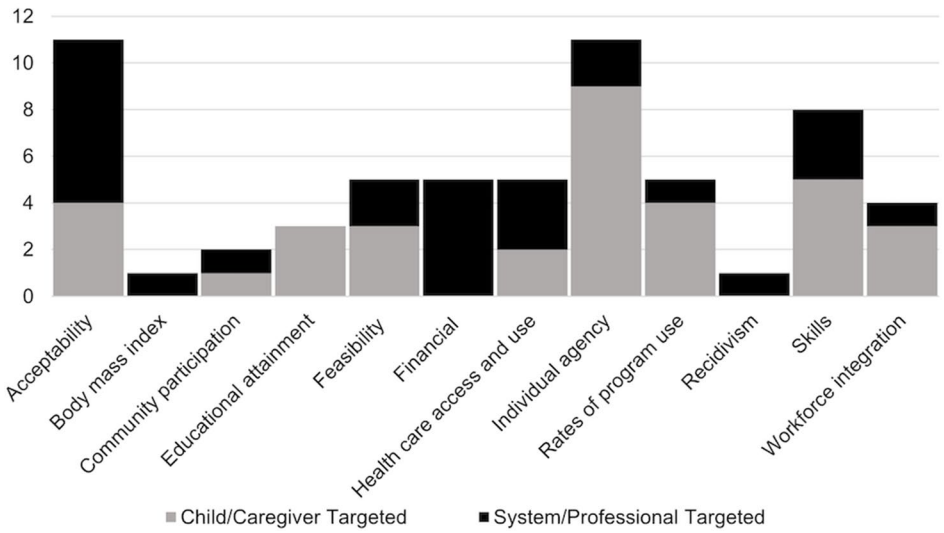



**Fig. 4** Outcomes evaluated by included articles

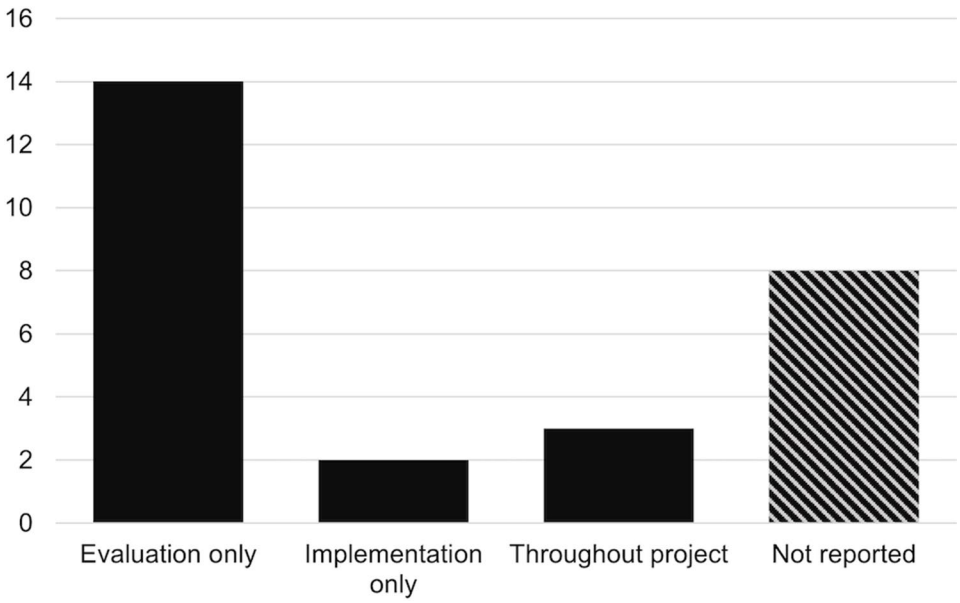



**Fig. 5** Degree of partnership with the multiply marginalized population of interest reported by articles

trial of 35 students reported gains in self-determination, career-related self-efficacy and exploration, and mental health self-efficacy and empowerment.

The four articles classified as targeting individuals or caregivers described the Promoting Readiness of Minors in Supplemental Security Income (PROMISE) program, a federally funded initiative designed to enhance career and education readiness that included case management, employment support, and financial literacy, benefits, and self-determination counseling for youth with disabilities from low-income families across six sites.

Hartman et al. reported on Wisconsin PROMISE, which randomized youth to PROMISE services or usual services [34]. They reported youth employment rising from 1% in 2013 to 67% in 2018, 10% points above the control group. Schlegelmilch et al. reported on work readiness within Wisconsin PROMISE, surveying youth and vocational rehabilitation counselors using a modified Stages of Change scale [35]. They reported increases in work readiness and positive feelings about work from baseline to follow-up, alongside rising employment. In a second article, Schlegelmilch et al. qualitatively evaluated the Wisconsin PROMISE, and reported that service access and paid employment varied considerably across participants, with youth in all four sampling categories

describing a desire to work [36]. Ipsen et al. reported on the Achieving Success by Promoting Readiness for Education and Employment (ASPIRE) consortium, a six-state PROMISE site that randomized youth ages 14 to 16 to intervention or control conditions [37]. At 24 months, they reported gains in parent encouragement about working, youth expectations of working, and participation in employment activities, but not in employment itself.

### Care coordination and system navigation supports

Four articles (15%) evaluated interventions to support low-income families navigating the health-care system (see Table 7) [38–41]. Navigational supports varied and included: care coordinators, community health workers, a mobile app, and changing the process and policies for engaging in early childhood services. Three were classified as targeting professionals/institutions, while one targeted the individual/caregiver.

Among the three targeting professionals/institutions, Carr and Lord (2016) conducted a pilot study to address disparities in early autism intervention by adapting the Early Social Interaction Project for families from low socioeconomic backgrounds [38]. Specifically, they addressed three key barriers: improving access to treatment and assessment, reducing attrition, and fostering sustained caregiver engagement. All treatment sessions were delivered in-home, with transportation assistance or compensation provided for clinic visits for assessment. A flexible attendance policy allowed rescheduling without penalty, ensuring families received all 24 planned sessions regardless of completion time. Of the 13 families initially enrolled, 8 entered the treatment phase, and 7 completed all sessions over an average of 7 months with an average of 11 cancellations per family. Qualitative feedback suggested improved caregiver understanding of autism, greater advocacy skills, and observable positive behavioral changes in children; however, feedback also indicated that the intensity of the program was not feasible for families, with challenges including difficult scheduling, the length of questionnaires, difficulties implementing treatment, and initial discomfort with home visits [38]. Matiz et al. integrated community health workers into the medical teams of 30 children with hearing loss at an urban academic medical center and reported social needs in 93% of families, 70% of referrals completed at three months, and more children obtaining hearing aids or cochlear implants relative to baseline [39]. Weier et al. compared utilization before and after enrollment in Partners for Kids care coordination among 733 children in Medicaid managed care, reporting decreases in inpatient admissions, hospital bed days, and 30-day readmissions [40] .

Miller et al. evaluated the one navigation intervention classified as targeting the individual or family, a website and smartphone application to support the transition from pediatric to adult care for “medically fragile youth” from low-income families [41]. The application centered on improving health and health-system knowledge, self-management and health-care navigation skills, and served as a support tool. The study found the intervention to be acceptable to the 24 youth enrolled and reported increases in self-reported knowledge and skills, and the number of youth with an adult primary care provider identified by 32%.

### Training interventions for individual agency and skills

Twelve articles (44%) evaluated interventions to build individual agency and skills (see Table 8) [26, 42–51]. These primarily focus on improving health-related knowledge and skills, including healthy lifestyle behaviors, condition-specific education, and local resource awareness, with several aiming to strengthen advocacy and caregiving strategies for addressing children’s behavioral and communication needs. Two were classified as targeting professionals/institutions, while ten targeted individuals or caregivers.

Both interventions targeting professionals/institutions delivered remote provider training. Coleman et al. reported that Family Implemented TEACCH for Toddlers (FITT), a remote training model for early intervention providers in rural areas working with children with autism, was feasible and fit existing workflows [42]. Hodges et al. reported that Project Extension for Community Healthcare Outcomes® (ECHO®), a virtual training in Prevent-Teach-Reinforce for professionals supporting children with disabilities and challenging behavior, was acceptable and implementable [43].

**Table 8** Training interventions for individual agency or skills, N=12

| Author & year | Summary | Components and process | Outcome measures and key findings |
|---|---|---|---|
| **Intervention Target: Professional or Institution,*n*=2** | | | |
| Coleman 2022 | ***Family Implemented TEACCH for Toddlers (FITT)*** Remote training for early intervention providers. ***Systems involved*** Health care | Early intervention providers who had on their caseload a toddler with autism-spectrum disorder with an interested caregiver were identified through local clinics, early intervention programs, clinicians, or community programs Participating providers conducted baseline in-home sessions without training or assistance from FITT staff. FITT staff then conducted a two-day training for providers including lectures, video examples, case studies, and Q&A sessions. Providers received the FITT manual, example activities, required forms, and an iPad mini to collect audio and video samples. Thirty-minute weekly FITT coaching sessions followed. Trained early intervention providers then implemented FITT in twenty-four weekly sizty-minute home sessions that emphasize play and routine-based activities. | Feasibility as measured by a fidelity checklist and acceptability to the professional and caregiver as measured by the Social Validity Questionnaire. Using a 5-point Likert scale, the intervention was rated as feasible and acceptable to implement, by early intervention professionals (M=4.3) and they reported that they were likely to continue the intervention in the future (M=4.4). Caregivers also rated the intervention as feasible and acceptable (M=4.1), and that they would likely continue it in the future (M=4.3). |
| Hodges 2022 | ***Project ECHO*** Web-based training of Prevent-Teach-Reinforce for Young Children for professionals working with children with disabilities and challenging behavior. ***Systems involved*** Education Health care | Eight weekly sessions conducted over Zoom for early childhood care providers in a rural area. Content included introductions, announcements, voluntary case presentations from participants, clarifying questions, case recommendations, didactic learning, and closing information guided by facilitators and three Prevent-Teach-Reinforce for Young Children experts. | Acceptability as measured by the Social Validity Questionnaire. Of eighteen participants, five completed all steps. Four of the five reported improved child social skills and decreased child challenging behavior. All participants reported that the ECHO model was acceptable and that they would recommend the format to others. All participants also reported that the Prevent-Teach-Reinforce for Young Children approach was acceptable and that they would be willing to implement what they were taught. |
| **Intervention Target: Individual or**, *n*=**10** | | | |
| Dababnah 2021 | ***Parents Taking Action*** Cultural adaptation of a peer-led caregiver education program for parents raising Black children with autism in low-income Baltimore neighborhoods. ***Systems involved*** Community | A community advisory, including parents and grandparents of Black children with autism, a Black self-advocate, school representatives, and clinicians guided adaptation of the 14-session manualized program. Adaptations included: • Reordering sessions to introduce play and communication content earlier and advocacy content later • Replacing the opening narrative with the story of a young Black man with autism in Baltimore and his mother's experience of diagnostic delay • Re-recording video narration with Black speakers and adding photographs of Black children and families • Adding guidance on police interactions to the advocacy session • Revising language throughout toward child and family strengths and removing text implying children should conform to non-autistic behavior Three Parent Leaders, all mothers of Black children in Baltimore, received two days of group training plus individual training, were compensated, and delivered sessions in participants' homes at mutually arranged times. Delivery shifted to phone and video during the COVID-19 pandemic. | Feasibility and acceptability as measured by session completion, and participation barriers and facilitators identified through interviews with parents and Parent Leaders. Seven mothers enrolled over 20 months; three completed all 14 sessions (mean 9.6 sessions completed). Cancellations and missed appointments were frequent, and no participant qualified for the attendance incentive offered. Financial and material hardship were the dominant participation barriers. Parents described the program as relevant to Black families and valued the peer relationship, with several connecting the program to racial disparities in autism recognition and services. |

**Table 8** (continued)

| Author & year | Summary | Components and process | Outcome measures and key findings |
|---|---|---|---|
| Luelmo 2021 | ***Parent to parent advocacy*** A randomized controlled pilot study examining the effectiveness and feasibility of a low-intensity, low-cost, parent advocacy intervention. ***Systems involved*** Education | Participants were randomized to either a control group provided with intervention materials or the intervention group which was a parent-to-parent individualized education, advocacy, and mentorship program that included • Four experienced Promotoras (community-based, Latinx peer mentors and advocates) recruited from community-based organizations and given twelve hours of additional training. Three individualized, one hour educational sessions delivered to families in Spanish and covering autism spectrum disorder knowledge and individualized education program rights. | Individual agency as measured by a study-created IEP advocacy knowledge scale and the Family Empowerment Scale and acceptability as determined via interview. The intervention group demonstrated greater increase in knowledge gained (8.6 vs. 0.08 points). No significant group differences for confidence in caring were found. Interviews indicated overwhelmingly positive responses to the intervention and one barrier which was scheduling difficulties. |
| Magana 2017 | ***Parents Taking Action*** A culturally derived intervention for Spanish-speaking mothers of children with autism spectrum disorder (ASD). ***Systems involved*** Community | Two consecutive, eight-week modules provided caregivers with education on child development, ASD, and behavior intervention. The program was designed for Latinx families and delivered via Promotoras who completed 48 h of training. Module 1 contained an introduction to the program and information about • Development of skills and communication in young children • Recognizing signs and symptoms of ASD • Dispelling myths • Diagnosis criteria and where to go and how to advocate for diagnosis, supports, and services • How to advocate in the school system • Explaining ASD to others and building social supports • Taking care of oneself Module 2 included • Research-based ASD interventions • Strategies to encourage the child's communication, play, and social skills • The reasons behind problem behaviors • Preventing and addressing problem behaviors Looking ahead. | Feasibility as measured by the Treatment Acceptability Rating Form, individual agency as measured by the Maternal Autism Knowledge Questionnaire and Family Outcome Survey-Revised and rates of program use tracked by a study-created survey. There was an 86% retention rate in module 1 with 84% of mothers then enrolling in module 2. Following module 1, caregivers reported significantly increased advocacy skills and autism spectrum disorder knowledge. Mothers reported increased understanding of the child's needs and strengths, knowledge of their rights, better information of how to help their child learn, knowledge of support systems, and greater access to the community. 88% completed module 2 and reported a significant increase in efficacy in the use of strategies. |
| Martino 2022 | ***Fit Kids for Life*** Reshaped an existing pediatric obesity intervention program toward improving participation for children with disabilities. ***Systems involved*** Health care | A multidisciplinary team of physical therapists, a pediatric cardiologist, registered dietitians, and behavioral psychologists facilitated two hour sessions twice weekly for ten weeks which included exercise, meditation, and nutrition support. Modifications to the existing program included recruiting personnel to support and address the specific needs of participants with disabilities, additional training for staff, changes to the built environment, and policy adaptation. | Acceptability as measured by facilitators and barriers to participation mentioned in interviews. Themes from qualitative interviews suggest the intervention was acceptable and beneficial. A lack of local, accessible fitness sites was cited as a barrier to long-term change. |
| McIntyre 2022 | ***Behavioral Parent Training Program*** Telehealth intervention delivered to Spanish-speaking Latinx parents of children with developmental delay and elevated behavior problems. ***Systems involved*** Education | Ten weekly, 90-minute Zoom meetings facilitated in Spanish by bilingual research staff who completed cultural humility training. Content areas included play, praise, rewards, limit setting, and handling challenging behaviors. Parents read or listened to chapters from the book The Incredible Years between sessions. | Acceptability as measured by the Telehealth Satisfaction Survey, feasibility as measured by the Treatment Fidelity Checklist, and financial implications as measured by implementation cost. • 33% of participants completed all 10 sessions and 52% completed 3 or more. • Over 80% of participants stated that they would participate again online. • The most common barriers were lack of technology and access to childcare. The total cost of the intervention was $609 per family (the cost of the provided tablet and data plan). |

**Table 8** (continued)

| Author & year | Summary | Components and process | Outcome measures and key findings |
|---|---|---|---|
| Meadan 2020 | ***Parent-implemented Communication Strategies*** A parent training and coaching program translated and modified to support Spanish-speaking families with young children with disabilities or speech delays. ***Systems involved*** Community | Seven sessions over ten weeks with follow-up at four weeks post the final session. Both group training and individual coaching occurred with the entire program provided in Spanish by bilingual or bicultural staff. Childcare, transportation, and refreshments were provided at each session. Group training consisted of teaching parents naturalistic communication methods to enhance their child's communication skills and after group training each parent received an individual, 20-minute coaching session. | Acceptability as measured by caregiver interviews, feasibility as measured by parent observation, and skills development as measured by a check-for-understanding questionnaire. Strategy knowledge increased by 13% and fidelity of intervention delivery improved throughout. Caregivers reported high satisfaction and perceived impact with coaching, provision of childcare, and location of the program, all rated as very helpful. Caregivers recommended simplifying the language and terminology use for the interventions, for example "environmental arrangement" should become "organize the room." |
| Pearson 2020 | ***Meeting FACES workshop*** To build partnerships between parents, education, and service providers. ***Systems involved*** Community | A three-hour workshop that included a meet and greet, a resource fair, presentations from service providers, community agencies, and parent advocates, and a Q&A session. Food and childcare were provided. | Health-care access and use as measured by knowledge and use of services and acceptability as measured by satisfaction with the workshop. When shown a list of available services and providers, on average half of parents and a quarter of professionals did not know about them. On average, 30% of parents and 43% of providers did not use the available services or providers and only 15% of parents and 27% of providers endorsed using any of them |
| Pona 2017 | ***Special Needs Weight Management Clinic*** A hospital-based multidisciplinary weight management program for children with disabilities. ***Systems involved*** Health care | The five-visit intervention (baseline, 6 weeks, 3 months, 6 months, 12 months) is staffed by a medical professional, a pediatric psychologist, an occupational therapist, and a registered dietitian. At baseline, a complete history is obtained and treatment goals and recommendations are created for the child. Children are taught balanced eating using the MyPlate guidelines which include making small but noticeable changes, environmental controls, methods to help with acceptance of new healthier foods, and increasing physical activity. Response to the intervention and additional recommendations are assessed at the following sessions. | Body Mass Index (BMI) z-score. Significant reductions of in BMI z-scores each month (0.02) over the course of the treatment were recorded with younger children showing greater reductions than older children. |
| Suarez-Balcazar 2016 | ***Familias Saludables*** Translated Healthy Families, this is a culturally tailored healthy lifestyle program for Latino youth with disabilities and their families. ***Systems involved*** Community | The intervention included a Zumba/dance group, nutrition education, and group discussions and goal setting. It took place for two hours per week over eight weeks and was held twice consecutively to allow families to make up missed sessions. | Acceptability as measured by discussions with families, skills as measured by a goal-setting form adapted from the Health Matters curriculum and Goal Attainment Scaling. Families reported healthy improvements in family routines and habits like less unhealthy snacking and more help with meal prep. They reported high satisfaction with the program, endorsing it as family-centered and solutions-focused, but have concerns about outdoor safety and activity opportunities for youth with disabilities. |
| Suarez-Balcazar 2018 | ***Expansion of Familias Saludables*** A healthy lifestyle program for immigrant Latino youth with disabilities and their families. using a community-based participatory research approach. ***Systems involved*** Community | A community-based healthy lifestyle program that included a Zumba/dance group, nutrition education, and group discussions and goal setting was augmented with culturally tailored adaptations including incorporating foods from participants' culture, choosing Latin music for Zumba and Salsa dancing, offering the program in Spanish, and creating a modified version of the MyPlate graphic. It took place for two hours per week over eight weeks at existing community-based organizations and co-facilitate by mothers in the community who volunteered to teach Zumba classes and help youth make healthy snacks. | Skills development as reported via focus group interviews. Themes included healthy lifestyle components, social learning, inclusion of the whole family, individual agency as measured by peer advocacy and community participation. Families stated that the program met a community need and positively impacted areas such as health behavior, social learning, inclusion, community participation, and peer advocacy. Concerns were expressed about maintaining long-term changes, adults who use food to manage behaviors, and difficulty participating in community activities due to inaccessibility and discrimination. |

Among the ten interventions targeting individuals or caregivers, four addressed physical health. Martino et al. adapted Fit Kids for Life, a 10-week pediatric obesity program, to include children with disabilities, identifying parent and community engagement and diverse staffing as facilitators and stigma and site accessibility as barriers [44]. Across two articles, Suarez-Balcazar et al. implemented and expanded Familias Saludables, an 8-week culturally tailored program for Latinx youth with disabilities, leading to improved health behaviors and high satisfaction [45, 46]. Pona et al. reported on the hospital-based Special Needs Weight Management Clinic which demonstrated significant reductions in BMI z-scores over time in a hospital-based Special Needs Weight Management Clinic [26].

Five delivered caregiver training culturally adapted for Spanish-speaking or Black families. Magaña et al. reported increases in empowerment-oriented outcomes following Parents Taking Action, a psychoeducational program for Spanish-speaking mothers of children with autism delivered by promotoras (community-based Latinx peer mentors trained to provide information, support, and resources) [47]. Dababnah et al. adapted Parents Taking Action for Black mothers in low-income Baltimore neighborhoods, notably the only intervention specifically designed for children with a marginalized race. Mothers found the program relevant and valued the peer relationship, yet only three of seven completed all 14 sessions amid financial and material hardship [48]. Meadan et al. translated a parent coaching program on communication strategies for Spanish-speaking families and added transportation and childcare, reporting gains in caregiver knowledge and strategy use [49]. Luelmo et al. evaluated a three-session special education advocacy program for Latinx, immigrant-origin parents of children with autism delivered by trained parent mentors [50]. McIntyre et al. reported that telehealth delivery of a behavioral parent training program for Spanish-speaking Latinx parents of children with developmental delay was acceptable and feasible [51].

Pearson et al. reported on Meeting Fostering Advocacy, Communication, Empowerment, and Supports (FACES), a community workshop aimed at addressing disparities in access to services for families of children with autism and marginalized race or ethnicity [52]. The program connected families with service providers, facilitated parent education on available autism services, and assessing barriers to care. Participants expressed high satisfaction with the program, emphasizing the value of peer support, community connection, and advocacy training in navigating autism services.

## Discussion

This scoping review characterized health interventions for multiply marginalized children with disabilities. We included 27 articles, all from peer-reviewed sources as no grey literature records met inclusion criteria. Interventions included interprofessional programs and clinics, programs for educational and post-secondary attainment, telehealth integration, systems navigation support, and training to develop individual agency or skills. Articles reported a range of outcomes, spanning intervention acceptability and individual agency, social determinants of health (educational attainment and employment), and system-level measures such as cost savings to payers and reduced recidivism, with one article measuring a health outcome directly. These outcomes describe what was measured among the multiply marginalized children who received the interventions, often without a comparison group. Determining whether disparities narrowed would additionally require comparison with less marginalized peers over time. We also identified gaps: few articles addressed identities and circumstances beyond intellectual and developmental disability and low socioeconomic status, most interventions targeted the child or family rather than systems, and few research teams reported partnering with people with lived expertise. These findings map the available evidence and point to priorities for future research.

Common components recurred across intervention categories. Most notable are the interprofessional models, which brought together health care providers, educators, and legal advocates to address families' interconnected needs across the social determinants of health [27–29]. Other interventions aimed to align care with the needs, values, and experiences of marginalized communities through cultural adaptations of existing programs and peer

navigators, community health workers, and promotoras who foster trust while supporting system navigation [45–51]. Several interventions were delivered in the home or community settings to overcome logistical barriers like transportation and childcare, while others leveraged technology to address geographic barriers to health care and training opportunities for skill development [30, 38, 41–43].

This review illuminates significant gaps in representation of intersectionality, particularly limited attention to sensory and mental health-related disabilities, immigration status, and minoritized race, gender identities, and sexuality. Addressing these gaps requires culturally responsive approaches that acknowledge and integrate the perspectives and diversity of multiply marginalized children and families. Balén et al. highlighted the importance of inclusive approaches when engaging with lesbian, gay, bisexual, transgender, queer/questioning, intersex, asexual, and other identities (LGBTQIA+) youth in sexual health programs [53]. Their randomized controlled trial incorporated plain language, diverse recruitment strategies, and researchers with shared identities, resulting in improved data accuracy and inclusivity. Such strategies offer a model for designing interventions that account for intersectionality and the priorities of communities, both of which are absent from the articles identified in this review.

Our review identified few interventions that addressed the root causes of health disparities. Dismantling health disparities requires transformative policies and sustained, multi-level approaches that address the structural conditions, including racism and ableism, that shape the unjust distribution of the social determinants of health [54, 55]. The complexity of these efforts makes them unlikely to be evaluated within a single intervention, which may explain their limited representation in the included literature [56]. The interventions we identified primarily aimed to remediate health disparities by addressing the downstream consequences of structural inequities, with only a subset having professionals and institutions absorb the work of addressing these barriers and half by the individual or their caregivers. For example, the medical-legal partnership helped families respond to structural inequities through legal recourse to secure housing, disability accommodations, or essential services [28]. While such strategies matter, they operate within systems that continue to produce inequity [55]. Advancing health equity requires confronting and transforming systems, a process that must be rooted in the leadership, lived expertise, and priorities of the communities most affected [56].

As such, engagement of multiply marginalized communities throughout the research and implementation process is essential. While some articles described mechanisms to support participation or sought feedback from participants, only three reported partnership across design, implementation, and evaluation. Without partnership, interventions risk overlooking community priorities, needs, and strengths. In line with disability justice, partnership requires allocating time and resources to center the expertise of multiply marginalized people with disabilities, including shared decision-making, co-design, and joint evaluation of experiences and outcomes [46, 57]. Importantly, researchers and policymakers must attend to the power dynamics driving the historical and ongoing exclusion and harm to marginalized communities, and to establishing trusting relationships [58].

Important to maintaining trust is ensuring sustainability. Discontinuing interventions or programs prematurely erodes community trust, complicating contemporary and future mobilization efforts [56]. Frameworks such as Khalil's Triple C Model, supported by syntheses like Hailemariam et al.'s systematic review, underscore the importance of clearly defining sustainability goals, involving community partners throughout implementation, and standardizing policies and processes to ensure continuity [59, 60]. Embedding sustainability as a core component from the outset establishes partnerships to promote equitable health outcomes beyond the life of a single project.

## Limitations

This study has limitations that should be noted. First, we included articles if they described their intervention as being designed for or evaluated among multiply marginalized children with disabilities rather than requiring an explicit health equity aim, since few interventions in the literature are framed that way. Characterizing these interventions as relevant to health equity therefore reflects our operationalization rather than the stated aims

of the original authors. Second, restricting inclusion to US-based studies means we may have missed relevant approaches from other countries that could inform US practice, and that our findings may not transfer to countries with different disability policies or health-care financing. Third, no grey literature source met eligibility criteria. Our requirement that sources report outcomes may have contributed, as prior methodological work notes that programs delivered in practice settings are often documented without accompanying outcome data [61]. We cannot confirm this, however, as we did not record exclusion reasons separately by source type.

## Conclusion

Identified interventions mitigated the downstream consequences of structural inequity rather than changing the conditions producing it. Less than half of included articles described an intervention that targeted professionals or institutions to mitigate barriers, doing so through approaches such as interprofessional collaboration across systems, flexible attendance policies, and navigators or coordinators to support system navigation. More commonly, interventions aimed to build individual skills for navigating those barriers independently. Representation of marginalized identities and engagement of community partners with lived expertise were both limited. This literature remains at an early stage, with gaps in both the populations represented and the interventions evaluated. Research priority should be given to interventions in which professionals, institutions, and systems prevent or remediate the inequities driving health disparities, developed in partnership with multiply marginalized communities, with sustainability addressed from the onset and evaluating the effect on health equity directly.

**Abbreviations**

| | |
|---|---|
| ASPIRE | Achieving Success by Promoting Readiness for Education and Employment |
| DIVERSE | Disability Inclusive Vision for Engaged Research and Service for Equity |
| EASE | Engagement and Access to Special Education |
| FACES | Fostering Advocacy, Communication, Empowerment, and Supports |
| FITT | Family Implemented TEACCH for Toddlers |
| LGBTQIA+ | Lesbian, gay, bisexual, transgender, queer/questioning, intersex, asexual, and other identities |
| PCP | Primary Care Provider |
| PRISMA-ScR | Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews |
| Project ECHO® | Project Extension for Community Health Outcomes |
| PROMISE | Promoting Readiness of Minors in Supplemental Security Income |
| PTA | Parents Taking Action |
| RISE | Reentry Intervention and Support for Engagement |
| US | United States |

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**Data availability** The data supporting the findings of this review are reported in this article and its supplementary information files. Full-text sources are publicly available from their original publishers. The PRISMA-ScR checklist is provided in Additional File 1, and the search strategy in Additional File 2.

## Declarations

**Ethics approval and consent to participate** Not applicable.

**Consent for publication** Not Applicable.

**Registration and protocol** This scoping review protocol was not registered.

**Competing interests** The authors declare no competing interests.

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