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Scoping Review of Interventions to Promote Social Participation in Adolescents and Young Adults with Neurodisability

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Scoping Review of Interventions to Promote Social Participation in Adolescents and Young Adults with Neurodisability

Abstract

Background: Social participation, described as taking part in, being involvement and engaged with, and doing or being with others, is an important health outcome. Adolescents and young adults with neurodisability are often restricted in their social participation, particularly if they experience social and executive functioning challenges. A scoping review was conducted to examine interventions aimed at improving social participation in adolescents and young adults with neurodisability characterized by these challenges.

Method: The scoping review included peer-reviewed empirical studies published from 1990 to 2016 that employed psychosocial interventions to improve social participation in young people 13 to 24 years of age with acquired brain injuries, autism spectrum disorders, and attention deficit disorders.

Results: Narrative synthesis of 32 included studies highlighted significant variation in both the definition and measurement of social participation outcomes. The lack of RCT studies with large samples was noted, with almost a third of the studies including fewer than 10 participants. The two dominant types of intervention were peer mentoring and social skills training.

Conclusion: There is a lack of rigorously tested interventions that specifically address social participation challenges for individuals with neurodisability. Future research will need to be clearer in how social participation is conceptualized and operationalized to allow for improved measurement and comparison between studies.

Comments

The authors report that they have no conflicts of interest to disclose.

Keywords

acquired brain injury, autism spectrum disorder, attention deficit disorder

Credentials Display

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Social participation plays a critical role in adolescent development (Corsano, Majorano, & Champretavy, 2006; Eriksson, Hochwalder, Carlsund, & Sellstrom, 2012; Waldrup, Malcolm, & Jensen-Campbell, 2008). Alongside its impact on quality of life (Eccles, Barber, Stone, & Hunt, 2003; Larson & Verma, 1999; Levasseur, Desrosiers, & Tribble, 2008; Mahoney, Cairns, & Farmer, 2003) and morbidity (Berkman, Glass, Brissette, & Seeman, 2000), it represents one of the most valued and important rehabilitation outcomes for individuals with neurodisability (Allard et al., 2014). Neurodisability encompasses a wide range of diagnoses covering both congenital and acquired long-term conditions resultant of brain and/or neuromuscular impairment (Morris, Janssens, Tomlinson, Williams, & Logan, 2013). The broad reach of this definition reflects the fact that a specific diagnosis is not required for identification of neurodisability. A systematic review of patient-reported outcome measures in neurodisability by Janssens et al. (2016) identified the most commonly reported neurodisabilities as cerebral palsy (CP), epilepsy, acquired brain injury (ABI), autism spectrum disorder (ASD), and attention deficit hyperactivity disorder (ADHD). While the physical barriers resultant of CP or epilepsy can negatively impact social participation, the current study focused on other conditions, such as ABI, ASD, and ADHD, that are more often characterized by significant social and executive functioning challenges.

Allard et al. (2014) qualitatively examined the health outcomes deemed most important for young people with neurodisability and their parents. Of note was the high degree of perceived interrelatedness of outcomes in terms of how they impacted the lives and experiences of young people. Health outcomes, such as physical impairments, were identified as barriers to more important higher-level outcomes, such as social participation and friendship. Thus, while addressing physical and sensory deficits is an important component of the rehabilitation process, attending to these deficits is a stepping-stone toward the goal of participation, rather than the goal of rehabilitation itself. When further work contrasted 191 health professionals' perceived responsibility toward patients with neurodisability, physical and sensory outcomes were prioritized above aspects of social participation (Janssens, Williams, Tomlinson, Logan, & Morris, 2014). This mismatch reflects a possible overfocus on physical rather than social participation outcomes by clinicians.

The International Classification of Functioning, Disability and Health-Children and Youth Version (ICF-CY) broadly defines participation as an individual's involvement in life situations that can be thought of in terms of a person's ability to engage and interact with society (World Health Organization, 2007). However, while participation can involve a wide range of activities, social participation has been defined as taking part in, or being involved or engaged with, doing or being with others (Bedell, 2012). Levasseur et al. (2010) established the following definition of social participation: "the person's (who) involvement (how) in activities that provided interactions (what) with others (with whom) in society or the community (where)" (p. 2144). The authors further proposed a 6-level hierarchical taxonomy of social activities that includes activities in preparation for connecting with others (Level 1), being alone with others around (Level 2), interacting with others without engaging in a specific activity (Level 3), collaborative activities (Level 4), helping others (Level 5), and contributing to society (Level 6). Noting that the involvement of others is a key facet of social participation, the authors highlighted the benefit of such a structure in differentiating general participation (Levels 1-6) from social participation (Levels 3-6) and social engagement (Levels 5-6). Incorporating the nature or goal of activities in which individuals participate further clarifies the distinction between social participation (activities with others) and social engagement (activities with others for the benefit of others, e.g., volunteering).

The barriers to social participation faced by individuals with neurodisabilities are well documented. A narrative review of 44 studies by van Tol, Gorter, DeMatteo, and Meester-Delver

(2011) examined home, school, and community participation outcomes for children with ABI. While their focus was primarily in examining the tools used to measure participation, the included studies reaffirmed that children and adolescents with ABI routinely experienced participation restrictions, poorer social competence, and fewer friendships than typically developing children. Other reviews, such as that of Tobin, Drager, and Richardson (2014), examined social participation in adults and young adults with ASD. Again, the included studies reflected sparsity in relationships, leading to high levels of loneliness and isolation. A broader review of peer relationships and friendships among children with ADHD reported that between 56% and 76% of children with ADHD had no mutual friendships (Gardner & Gerdes, 2015). The authors noted that peer interaction interventions tended to be secondary to behavior modification programs, and these were often grouped in multicomponent treatment programs that may improve ADHD symptomology without demonstrating improvements in social participation.

There is a clear need for further investigation into social participation interventions for these three groups. In addition to representing a key rehabilitation goal for individuals with neurodisability (Allard et al., 2014), social participation is vital to reducing loneliness, exclusion, and victimization among children and young people with ABI, ASD, and ADHD (Gardner & Gerdes, 2015; Tobin, Drager, & Richardson, 2014; van Tol, Gorter, DeMatteo, & Meester-Delver, 2011). Without interventions to address the social difficulties resultant of these three conditions, difficulties may persist into adulthood with peer relationship difficulties predictive of future negative outcomes, such as delinquency, substance abuse, and psychopathology (Hoza, 2007).

Past reviews of interventions to promote social participation among persons with neurodisabilities have tended to focus on specific types of interventions, such as peer mentoring (Morris, Fletcher-Smith, & Radford, 2017), community integration (Agnihotri, Keightley, Colantonio, Cameron, & Polatajko, 2010), or social skills groups (Bellini, Peters, Benner, & Hopf, 2007; Storebø et al., 2010) for specific diagnoses. This is limiting both in terms of contrasting differences between intervention designs and outcomes, as well as identifying generalizable interventions that can be adapted to a range of diagnoses. It is necessary to recognize the overlap in social participation impairments between diagnoses and focus intervention efforts toward such overlapping impairments rather than toward specific conditions. The purpose of this study is to expand on previous work by reviewing interventions to improve social participation outcomes for adolescents and transition-age young adults with ABI (inclusive of traumatic brain injury), ASD, and ADHD and to provide recommendations for future work in the area.

Method

Six electronic databases, EMBASE, PubMed, CINAHL, Web of Science, Medline, and PsychInfo, were searched between March 14th and 16th, 2017. Keywords were developed through examination of literature relevant to the aim of this study. Databases were then searched using combinations of the keywords: Intervention, Social Participation, Child, Adolescent, Young Person, Brain Injury, ASD, and ADHD. Articles from each database were then compared and duplicates were removed. Screening for inclusion was conducted by the first author, with title and abstract review of all screened articles conducted by the second author. In a similar way, with full text articles, 25% of full text articles assessed by the first author were reviewed by the second to ensure inter-rater reliability. In cases of disagreement the third author was available to arbitrate, though this was not required. The reference lists of the included studies were hand searched for relevant literature alongside other known studies of youth participation.

Inclusion and Exclusion Criteria

Peer-reviewed empirical studies, excluding review papers, published in English from 1990 to 2016 were included in this review. The population of interest was adolescents and young adults 13 to 24 years of age (though studies could also include some participants outside of this age range) with ABI, ASD, or ADHD. No restriction was placed on study design, although studies with only one participant were excluded because of an inability to compare between participants in the study. Because of the broad definition of social participation, we limited our inclusion to studies aimed at promoting social participation, interaction, or use of social skills in natural contexts (e.g., among peers in school). In this way, social participation was operationalized as Levels 3 and 4 of the Levassuer hierarchical taxonomy: interacting with others without engaging in a specific activity (Level 3) and collaborative activities (Level 4). Further, pharmacological and physical interventions were also excluded, as our primary interest was in psychosocial interventions. Psychosocial interventions were defined as interventions with specific social and executive functioning components and were chosen because of their focus on psychological, problem-solving, and social needs rather than biological or physical. While interventions, such as social skills groups, often address deficits in this area, such studies were only included if a clear outcome measure of social participation, social interaction, or generalization of social skills to natural contexts was used. While explicit measures of social participation exist, subsections of other measures can also implicitly examine this construct (Bedell & Coster, 2008). Studies using such implicit measurement were only included if they provided a clear breakdown of the social participation subsection of their outcome measures. Figure 1 shows a search strategy flow diagram of the included papers.

Quality Appraisal

Because of the heterogeneity of the included studies, appraisal was conducted using an adapted version of the Mixed Methods Appraisal Tool (MMAT) (Pace et al., 2012). This tool allows for appraisal of qualitative, quantitative, and mixed method studies using two general screening questions, coupled with between four to 11 design specific questions. The number of criteria differs by study design, with total scores presented in percentage form for ease of comparison (i.e., 12/16, 75%; 7/9, 78%). The amended version replaces the two general screening questions with five more focused questions relating to: reporting of the research question/aim, definition of study population and recruitment of sample, specification of inclusion and exclusion criteria, and participation rate of eligible persons. Data extraction was conducted using an adapted data extraction tool employed previously in a systematic review (O'Rourke, Linden, Lohan, & Bates-Gaston, 2016). The tool, which covers demographics of participants, study design, outcome measures, study findings, and limitations, was adapted to include three intervention specific questions: intervention type (e.g., 1:1, group, telehealth), description of the intervention, and length of the intervention. All data extraction and quality appraisal were conducted by the first author, with a proportion (15%) checked for accuracy by the second author. As with the screening process, divergence in appraisal scores were discussed between the first two authors with the third author available to arbitrate. However, consensus was achieved without the need for arbitration by the third author.

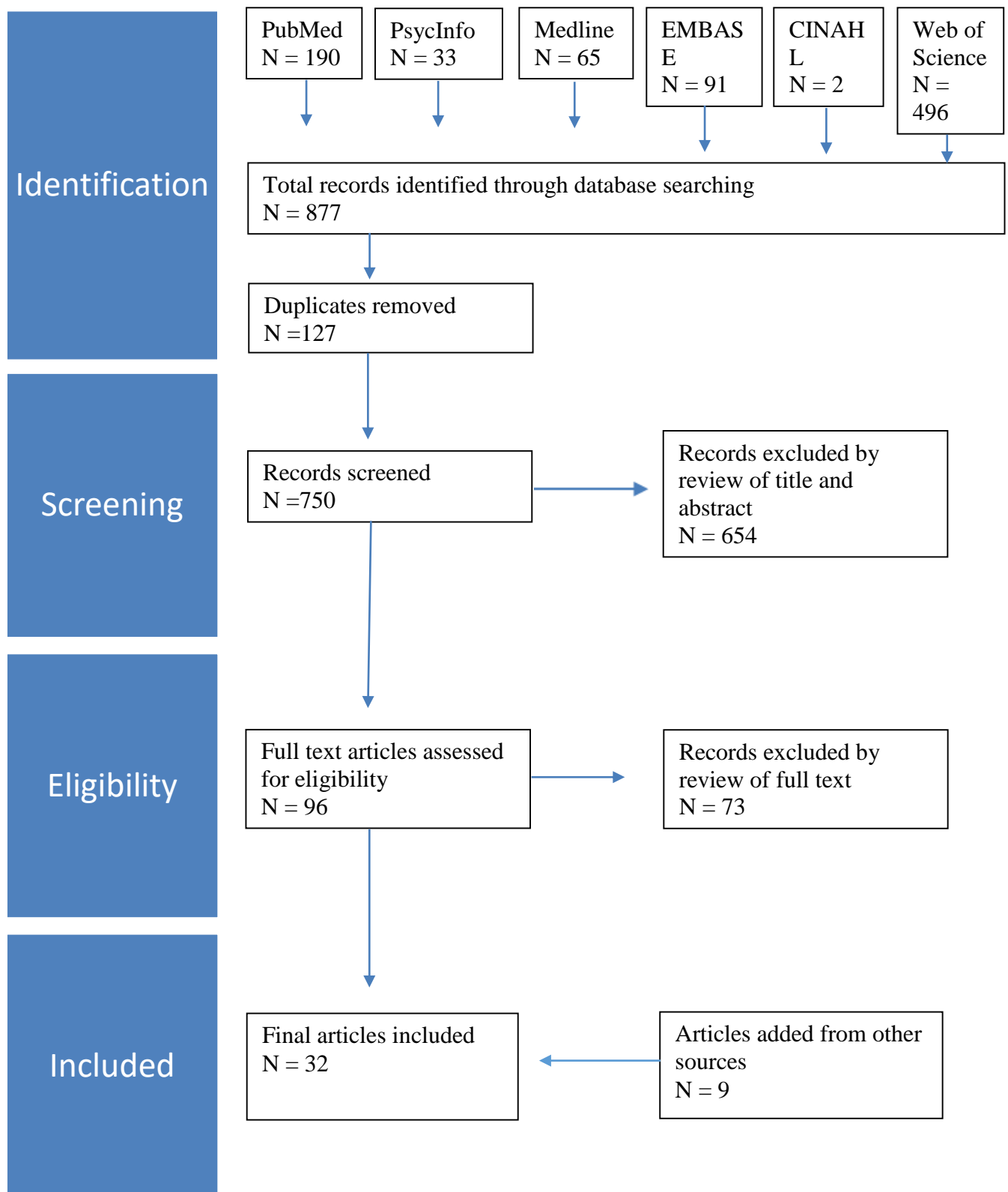


Figure 1. Search strategy flow diagram.

Results

Thirty-two intervention studies were included in this review; 23 from database searches and nine from hand searches of study reference lists. Among the excluded studies, common reasons for exclusion included a focus on community or recreation participation such that social interaction and engagement were not measured. In a number of school-based interventions, focus was placed on behavior or academic engagement instead of social interaction and participation. Only eight RCTs

and three quasi-experimental designs were identified, with 20 studies lacking control groups. Age ranges varied between studies (with some including ranges as wide as 17 to 86 years of age), as did sample sizes, which ranged from two to 178 participants.

Summaries of the included studies are displayed in the Appendix, categorized by intervention type and appearance in the results sections. Given the number of studies and the number of outcome measures used in each, changes to social participation outcomes are indicated by either a + (significant statistical/clinical improvement as indicated by author) or a – (non-significant/negative change) symbol. Interventions are summarized below under four main headings: group skills training, peer support interventions, technology-based interventions, and resource facilitation. Headings were developed inductively through examination of the included interventions, with little overlap between groups. The results of the data extraction and quality appraisal, also found in the Appendix, are presented as both overall and percentage scores. Quality assessment scores ranged from 44% to 100% with two RCT studies (Matusевичiene, Eriksson, & DeBoussard, 2016; Trexler, Parrott, & Malec, 2016) scoring 100%. The most common problems identified were related to recruitment and participation rates for eligible persons ($n = 22$), with many quantitative nonrandomized studies also lacking comparison or control groups ($n = 12$).

Group Skills Training

Fifteen studies focused on improving social skills, and fourteen of these occurred in a group format. The majority of these were aimed at individuals with ASD ($n = 12$), with only three studies including ABI populations. While approaches varied, a subset of four studies used the same Program for Evaluation and Enrichment of Relational Skills (PEERS) (Gantman, Kapp, Orenski, & Laugeson, 2012; Gardner, Gerdes, & Weinberger, 2019; Laugeson, Frankel, Gantman, Dillon, & Mogil, 2012; Laugeson, Frankel, Mogil, & Dillon, 2009).

The 14-week PEERS intervention focuses on identifying key social situations and teaching rules of etiquette through instruction of concrete steps coupled with role playing and behavioral rehearsal exercises (Laugeson et al., 2012). To aid with generalization, parents are also provided with instructions for supervision and reinforcement of all learned skills. Laugeson, Frankel, Mogil, and Dillon (2009), who designed the intervention, employed a 12-week version with 33 participants, 13 to 17 years of age, with ASD, and examined changes in social skills knowledge and application, frequency of get-togethers with peers, and quality of best friendships. Seventeen intervention participants were compared to sixteen delayed treatment controls, with significant improvements seen in social skills knowledge, frequency of hosted get-togethers, and quality of best friendships. Teacher ratings, alongside the frequency of invited get-togethers and conflicts during get-togethers, were not significant, with authors suggesting that the lack of reciprocation of get-togethers may have been because of a lack of time postintervention.

Subsequent work by Laugeson, Frankel, Gantman, Dillon, and Mogil (2012) extended the PEERS intervention to include a 14-week follow-up assessment for a group of 28 adolescents with ASD 12 to 17 years of age. Comparisons with controls again revealed improvements in frequency of hosted but not invited get-togethers and social skills knowledge, with parents now also reporting significant improvement in social responsiveness, social skills, and frequency of hosted get-togethers. A 14-week follow-up with the intervention group revealed maintenance of treatment gains in all outcomes except one social cognition subscale. Gantman et al. (2012) also found significant improvements in social responsiveness, social skills, and ratings for both invited and hosted get-togethers among their sample of young adults with ASD (18 to 23 years of age). The results are limited, however, by a sample size of only nine treatment and eight control participants. Gardner and Gerdes' study (2015) was the only one to use PEERS with adolescents, 11 to 16 years of age, with

ADHD. Significant improvements were only seen in frequency of hosted get-togethers and social skills knowledge, though 78.9% of parents and 68.4% of adolescents reported initiation of a new mutual friendship postintervention. Despite the small sample and lack of control group, the authors emphasized that at least one new mutual friendship can function as a protective factor against the effects of negative peer interactions.

The PEERS program was the most replicated intervention identified, with notable social participation improvements observed among the participants. However, other interventions, such as the Superheroes Social Skills program, also showed promise in improving social participation among children and adolescents. Radley et al. (2014) used the Superheroes Social Skills program with three individuals with ASD aged 10, 11, and 14 years. Parent-identified skills were presented to participants in the form of animated superheroes who provided rationale and steps for demonstrating and engaging in the skill. Participation skills were defined as: demonstrating close proximity to partner, maintaining eye contact, waiting one's turn, and using appropriate methods to join in activities. All three participants showed immediate increases in both use and generalization of skills, with maintenance observed following withdrawal of instruction. MacKay, Knott, and Dunlop (2007) focused on improving social and emotional perspective taking, conversation skills, and friendship skills among 46 participants with ASD 6 to 16 years of age. Improvements were noted in all skill areas, though age-expected social interaction levels could not be achieved. Effort was made, however, to generalize skill acquisition by encouraging practice at home and through outings to the community. The study by Choque Olsson, Rautio, Asztalos, Stoetzer, and Bölte (2016) was the only one to focus solely on qualitative outcomes for 11 children with ASD (9 to 17 years of age) following social skills training. They highlighted that despite quantitative measures categorizing participants into high and low treatment gains, both groups expressed similar positive improvements in verbal and nonverbal communication that positively impacted their ability to interact with peers.

While most social skills training interventions were conducted in a more traditional teaching style, studies by Guli, Semrud-Clikeman, Lerner, and Britton (2013), Goldingay et al. (2015), and Agnihotri et al. (2014) employed creative drama-based interventions to improve social skills. Interventions ranged from cooperative games and improvisation (Guli, Semrud-Clikeman, Lerner, & Britton, 2013) to story board development (Goldingay et al., 2015) and theater skills (Agnihotri et al., 2014). While no significant social participation changes were reported among the ASD and ADHD samples (aged < 15) (Goldingay et al., 2015; Guli et al., 2013), improvements in friendships, participation and leisure goals, and participation in group activities was reported among the four adolescents with ABI (13 to 15 years of age) (Agnihotri et al., 2014).

Only two other studies (Dahlberg et al., 2007; McDonald et al., 2008) examined the use of social skills groups among individuals with ABI. McDonald et al. (2008) used a RCT design to evaluate the impact of a 12-week social skills training on 39 adults (23 to 46 years of age), while Dahlberg et al. (2007) examined a 12-week social communication skills group using 52 participants 22 to 64 years of age. However, neither intervention led to significant group differences in social participation.

The remaining three studies that aimed at improving social skills differed significantly in design relative to the previous interventions. Two studies conducted by Hillier, Fish, Cloppert, and Beversdorf (2007) and Hillier, Fish, Siegel, and Beversdorf (2011) used the Aspirations program with participants with ASD (18 to 30 years of age). While other interventions were largely instructor led, the Aspirations program was participant driven, with individuals sharing stories and experiences, offering advice, and using group problem-solving strategies. Subjective evaluations of the quality of peer groups alongside self-evaluations of social traits and behaviors, such as making friends, were

collected, though no significant improvement was seen postintervention. Finally, Parent, Birtwell, Lambright, and DuBard (2016) addressed social skills deficits using a combined cognitive behavioral therapy and behavior-analytic approach with two males with ASD 12 and 16 years of age. Reduced conflicts in the home environment and successful participation in community activities were noted for both participants. Outcomes were measured primarily through observation and interview format; therefore, the results may be biased. And given the small sample, it is difficult to generalize these findings.

Peer Support Interventions

Of the 10 peer mentor interventions, five (Bambara, Cole, Kunsch, Tsai, & Ayad, 2016; Glang, Todis, Cooley, Wells, & Voss, 1997; Haring & Breen, 1992; Hughes et al., 2013; Watkins & Wentzel, 2008) focused on peer support in a school context, while five (Hanks, Rapport, Wertheimer, and Koviak, 2012; Hibbard et al., 2002; Kolakowsky-Hayner, Wright, Shem, Medel, and Duong, 2012; Nieto et al., 2015; Struchen et al., 2011) involved age and gender-matched peers in the community.

Studies using peer support interventions in school settings primarily focused on the frequency of interaction between participants and peer mentors as opposed to the wider school community. Hughes et al. (2013) matched three students with ASD, 16 to 17 years of age, to three peer partners, who set goals for interacting with the student and monitored achievement of those goals. Haring and Breen (1992) had groups of four and five peers meet weekly to discuss social interaction goals with two participants, 13 years of age, one with intellectual difficulties and one with ASD. In addition to improved interactions, friendships with recruited peers extended outside of the school environment for both participants.

Bambara, Cole, Kunsch, Tsai, and Ayad (2016) used groups of between two and four peers who would meet one of three students with ASD, between 14 and 15 years of age, for daily lunch. Participants were provided with cue cards that included prompts for eliciting conversation while peer mentors were trained on strategies to encourage engagement in conversational acts. While the number of conversational acts increased, no significant change in satisfaction with lunch conversations was reported. Glang, Todis, Cooley, Wells, and Voss (1997) recruited special educators as facilitators, who formed a friendship team for three students with TBI (8, 11, and 13 years of age), comprised of a parent, facilitator, and at least one peer, who would meet every 2 to 3 weeks. Social interaction goals were developed and ratings were taken of the degree to which the student was a part of regular school life. Despite an increased number of social contacts for each participant, satisfaction levels decreased with the authors suggesting that the intervention may have drawn attention to the student's own difficulties. Watkins and Wentzel (2008) focused on fostering collaborative social participation in 24 males with ADHD (9 to 13 years of age) engaged in a route navigation planning task. Female peers were trained in group facilitation and fostering peer interactions before joining the planning activity. Observation of passive, solitary, and joint behavior by researchers in both the pretest and posttest trial revealed significant increases in joint participation and decreases in solitary behavior.

Nieto et al. (2015) examined the perceived effect of a volunteer supported one-to-one leisure intervention on opportunities for individuals with ASD (3 to 43 years of age) to relate to others. Outcomes of physical capital (level of satisfaction with support), economic capital (financial benefits of participation), human capital (acquisition of skills), and social capital (opportunities for social interaction) were assessed. Lower mean scores were observed on items relating to social capital relative to others suggesting that families viewed the intervention as more beneficial for children's physical activity levels than their opportunities for socialization. Struchen et al. (2011) piloted a

social peer mentoring intervention with 12 adult participants and 18 controls with TBI (21 to 68 years of age). Eleven mentors, matched by geographical proximity, age, gender, and interests, arranged at least two outings per month aimed at increasing social contact and social networking in the community. No significant improvements were reported in social integration and network size, with the authors noting that impacting change in these areas may require a longer, more intensive intervention.

Hibbard et al. (2002) examined the impact of the TBI Mentoring Partnership Program on 11 individuals, 19 to 46 or more years of age, with TBI and nine family members. Mentors provided a mix of emotional, knowledge, and informational support. Little improvement in social support from friends and family was reported, with the primary intervention benefit reported as having someone with which to share experiences. In a similar intervention by Hanks, Rapport, Wertheimer, and Koviak (2012), mentors provided social and emotional support, directed participants to community resources, and discussed topics related to TBI and caregiving. However, community integration did not significantly improve for participants with TBI (20 to 58 years of age). Kolakowsky-Hayner, Wright, Shem, Medel, and Duong (2012) were the only peer support study to report significant improvements in community integration among their 57 successfully matched participants with TBI (mean age 20.3 years). Their Back on Track to Success Mentoring Program matched participants to community-based mentors, based on age, gender, disability type, location, and interests, who provided advice and guidance on the services available to help achieve their goals of returning to either work or school. Goal achievement was high with improvements also noted in levels of community participation.

Mentor Training and Support

All peer support studies offered some form of training to their included mentors, with the exception of Glang et al. (1997), who trained only the special educators as friendship group facilitators. Training varied from 20-min mentee specific training (Hughes et al., 2013) to a series of eight full-day mentor training workshops aimed at improving listening, communication, and advocacy skills in mentors, alongside knowledge of TBI and community resources (Hibbard et al., 2002). While some training was designed around the needs of individual mentees (Bambara et al., 2016; Haring & Breen, 1992; Hughes et al., 2013), the majority provided knowledge training around TBI, alongside strategies for communication, listening, and relationship building (Glang et al., 1997; Hanks et al., 2012; Hibbard et al., 2002; Struchen et al., 2011). Role-playing and modeling were also used to reinforce training (Glang et al., 1997; Hanks et al., 2012), allowing mentors to practice their learned skills in a supportive environment. The need for continued mentor support was repeatedly emphasized, particularly among community-based mentor studies for participants with TBI. Such support ranged from booster training sessions (Struchen et al., 2011) to resource recommendations (Hibbard et al., 2002) to psychosocial support (Kolakowsky-Hayner et al., 2012). Both Hibbard et al. (2002) and Hanks et al. (2012) also highlighted that interventions should recognize the intensity of ongoing mentor support that is needed.

Technology-Based Interventions

Two studies used technology as a medium through which to deliver the intervention (Diener et al., 2016; Kandalaf, Didehbani, Krawczyk, Allen, & Chapman, 2013), while for two, the technology itself acted as the intervention (de Kloet, Berger, Verhoeven, van Stein Callenfels, & Vlieland, 2012; Raghavendra, Newman, Grace, & Wood, 2013). Kandalaf, Didehbani, Krawczyk, Allen, and Chapman (2013) piloted the delivery of 10 social cognition training sessions through virtual reality. Eight participants with ASD, 18 to 26 years of age, controlled an avatar who navigated a virtual world alongside a clinician who provided coaching through specific social

scenarios. Significant improvements were seen in social perception and Theory of Mind assessment scores, though improvements were not generalizable outside of the game. Diener et al. (2016) qualitatively examined the use of a 7-day creative design program coupled with six weekly after school workshops on social engagement in students with ASD. Dialogue and behavior recordings were taken of seven boys 8 to 17 years of age who were mentored on how to use the design software. The results indicated that social participation emerged through both the development of authentic peer relationships and scaffolded learning, whereby peers acted as co-teachers to one another.

Raghavendra, Newman, Grace, and Wood (2013) examined the effectiveness of one-on-one support for five young people (10 to 18 years of age) with ABI in accessing the Internet for social networking. Barriers ranged from technical issues to social needs, with intensive and repeated support often required. While increased self-esteem and confidence were reported, alongside the development of new connections on-line, the authors noted that the demanding nature of this intervention may limit its feasibility. Finally, de Kloet, Berger, Verhoeven, van Stein Callenfels, and Vlieland (2012) examined the use of Nintendo Wii games on the physical, cognitive, and social functioning of 45 participants 8 to 30 years of age with ABI. The 12-week intervention involved matching treatment goals to appropriate Nintendo Wii games, which would then be played for between 20 min and 2 hr each week. While significant changes were seen in the diversity of recreational activities and the intensity of physical activities, no significant social participation improvements were observed.

Resource Facilitation

Three studies (Matuseviciene, Eriksson, & DeBoussard, 2016; McDougall et al., 2006; Trexler, Parrott, & Malec, 2016) examined the effects of early access to rehabilitation services on the participation outcomes for youth and adults with TBI. Neither Matuseviciene, Eriksson, and DeBoussard's (2016) early access to specialist rehabilitation nor McDougall et al.'s (2006) multidisciplinary discharge planning and transition team led to significant social participation improvements among their ABI and TBI samples. Trexler, Parrott, and Malec (2016), however, examined the effect of 15-months of access to a resource facilitation team (comprised of a resource facilitator, local support network leader, and clinical management team) on vocational, academic, home, and community outcomes for 22 participants and controls (n = 44) with ABI (23 to 52 years of age). While both groups demonstrated improved vocational and school outcomes, the treatment group reported significantly higher vocational independence. Both groups also improved on measures of home and community participation, though differences were not statistically significant.

Discussion

The aim of this review was to examine and compare interventions for improving social participation in young people with ABI, ASD, and ADHD. The two dominant types of interventions were peer mentoring and social skills training. Although 32 intervention studies were identified, few of them employed designs and approaches that could reliably assess the effectiveness of the intervention on social participation, with almost a third of the studies (n = 10) also containing fewer than 10 participants. Only eight RCT's were found, six of which were aimed at individuals with ABI (Dahlberg et al., 2007; Hanks et al., 2012; Matuseviciene et al., 2016; McDonald et al., 2008; Struchen et al., 2011; Trexler et al., 2016), with the remaining two examining the PEERS program (Gantman et al., 2012; Laugeson et al., 2009) among adolescents and young adults with ASD.

The most promising intervention, based on replication of significant improvement in social participation outcomes, was the PEERS program (Laugeson et al., 2009). Part of the success of this social skills intervention seemed to stem from its focus on dyadic friendship formation rather than the broader goal of peer group acceptance or demonstration of social skills. As Gardner and Gerdes

(2015) noted, the presence of at least one mutual friendship can be a protective factor against the consequences of negative peer interaction, with the PEERS program participants reporting improvements in frequency of both hosted and invited get-togethers alongside the initiation of new mutual friendships posttreatment. Above other social skill groups, there was a clear impact from the use of parents in reinforcing and supporting learned behavior. Parents took on a role similar to the mentors in the peer support interventions, which appeared to promote generalization of behavior beyond the classroom.

Among the peer support interventions, there was evidence that peer mentoring for individuals with ABI was helpful for improving knowledge around injury (Hanks et al., 2012; Hibbard et al., 2002) and providing emotional support (Hanks et al., 2012; Hibbard et al., 2002; Struchen et al., 2011). Social participation outcomes showed little to no improvement in many of these studies. As Hibbard et al. (2002) noted, the building of social networks may only be applicable to a subset of individuals with ABI, and it may be that factors such as injury severity, type of deficit, or even participants' own social goals and desires may limit the success of such interventions. Kolakowsky-Hayner et al. (2012) and Glang et al. (1997) were among the only interventions of this type to report improved social participation. Both incorporated clear goal-setting with mentors reviewing and supporting progress toward the participants' chosen goals. As shown by Allard et al. (2014), many of the health goals deemed important by individuals with neurodisability are complex in nature. Providing support and assistance in breaking goals into smaller more achievable milestones, as well as encouraging flexibility and adaptability at each review stage, may foster a more intrinsically motivated approach toward the intervention goals from participants. Many of the remaining peer mentoring interventions either lacked this element of structured goal setting and review (Hanks et al., 2012; Hibbard et al., 2002; Struchen et al., 2011) or relied heavily on peer mentors' continued involvement as the source of social participation (Bambara et al., 2016; Haring & Breen, 1992; Hughes et al., 2013), which may have limited the extent to which social participation outcomes could be improved.

Evident from the included studies was the need to consider self-awareness of impairments among participants. Several studies of ABI (Glang et al., 1997; Hanks et al., 2012; Matuseviciene et al., 2016; Struchen et al., 2011) and ASD (Goldingay et al., 2015; Hillier, Fish, Siegel, & Beversdorf, 2011) populations noted negative changes in participant satisfaction and attitudes, increased depressive symptoms, and higher self-reported problems postintervention. Interventions aimed at improving social participation may inadvertently draw attention to deficits participants are not aware of or have not yet fully realized. The issue of poor self-awareness is common to ABI, ASD, and ADHD, and merits consideration when designing interventions. Incorporating education and awareness training early on, or in parallel with goal planning, may help address this by offering methods of compensating for such difficulties.

Tailoring treatment to match individuals' needs and goals also appeared to greatly aid in improving social participation. MacKay et al. (2007) incorporated participant-led goals into their social skills group intervention by asking parents for "three things" that represented difficulties for their children with ASD. Raghavendra et al. (2013) provided support and assistive technology to overcome individually identified barriers to Internet use for participants with ABI. Among both samples, feedback from participants indicated high levels of satisfaction from these person-centered approaches. Fostering a sense of ownership and self-motivated improvement may be a key factor to successful interventions, with individuals more likely to take part in and complete an intervention that is tailored to their needs and in which they have control over the outcomes.

A number of interventions have attempted to improve participation using person-centered goal attainment approaches. These studies were not included in this review because they did not include participants with ABI, ASD, or ADHD or because they were published after the systematic review was completed. Examples include Project TEAM by Kramer and colleagues (Kramer, 2015; Kramer, Ryan, Moore, & Schwartz, 2018; Levin & Kramer, 2015), which involves mentoring young people, the majority of whom have intellectual disabilities, using a “Game Plan” problem-solving process to generate adaptive strategies to reduce environmental barriers to participation. Similar one-on-one goal directed coaching interventions (Pathways and Resources for Engagement and Participation [PREP]) have been conducted by Anaby and colleagues (Anaby, Law, Feldman, Majnemer, & Avery, 2018; Anaby, Law, Majnemer, & Feldman, 2016; Law, Anaby, Imms, Teplicky, & Turner, 2015), whereby environmental barriers and facilitators to participation are identified, alongside strategies to support the achievement of individualized goals (Anaby et al., 2018). Finally, Bedell, Wade, and colleagues (Bedell, Wade, Turkstra, Haarbauer-Krupa, & King, 2017; Narad et al., 2018; Wade et al., 2018) have preliminarily tested an app-based coaching intervention, Social Participation and Navigation (SPAN). SPAN combines aspects of peer mentoring and goal attainment by allowing teenagers with ABI to set social participation goals and implement planned steps to achieve these, with the support of trained college student mentors. Such individualized, peer-mediated interventions have the potential to address many of the environmental barriers to social participation experienced by individuals with ABI, ASD, and ADHD, as well as other neurodisabilities.

Limitations

The heterogeneity of the included studies limited the extent to which they could be compared. Coupled with this, some studies included some participants who were outside of the target range of 13 to 24 years of age. Nonetheless, it was determined that the interventions proposed remained applicable to our age group of interest, despite the mean sample age being higher or lower. Finally, the interchangeable use of the terms participation, social participation, social integration, community participation, and community integration, alongside variation in use of both implicit and explicit measures of social participation resulted in significant discussion around inclusion and exclusion criteria. A review of available social participation measures by Bedell (2012) and Bedell and Coster (2008) acted as a guideline for identifying explicit tools for social participation, as well as those with relevant implicit components. Given the relative infancy of this area of research and variation in definition, it is possible that some articles were missed because of the selected keywords or because of a primary focus on outcomes other than participation. While justification was provided for excluding studies that had only one participant, this could also be viewed as a limitation, as such studies may have pointed to potentially beneficial interventions or highlighted possible future research directions.

Conclusion

There is a clear need for further work in this area. The lack of RCT studies with large samples coupled with the high degree of variation in outcomes between studies suggests that there is a lack of reliable interventions to address social participation challenges for individuals with neurodisability. Several components of the reviewed interventions appear promising, however, such as allowing individuals to identify goals and barriers and supports to social participation; providing practical skills and knowledge training; and using peer mentors to monitor, review, and support goal attainment. Fostering a more person-centered approach to social participation may be the first step in both identifying the needs of this group and developing community-based solutions to address potential barriers and improve access to existing supports and resources.

One of the major challenges of this review related to defining and identifying studies of social participation. The current authors imposed a conceptualization of social participation outcomes in the included studies where conceptualization was not fully clear or present. Also, the broad scope of the term poses a challenge for researchers, as involvement in activities with others (Bedell, 2012) can encompass a wide range of scenarios. Different activities can present with different barriers to participation or require different sets of skills, and they can be measured in numerous explicit or implicit ways. As such, the present breadth of possible interpretations of the concept was simply too wide to allow for meaningful comparison of interventions. This issue extends also to the measures employed, with a wide range of both implicit and explicit measures currently in use. In the future, researchers will need to be clearer in how they conceptualize and operationalize social participation to allow for improved measurement and comparison between studies. Moreover, more work is needed in developing responsive measures that can detect the intended effects of social participation interventions. Until such a time, guidelines highlighted earlier (Bedell, 2012; Bedell & Coster, 2008) can help inform the selection of tools for potential future interventions in this area.

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Appendix

Summary of Included Studies Highlighting Intervention and Change in Social Participation Outcomes

Author (Quality Appraisal)	N (Male:Female)	Design	Age (mean)	Condition	Intervention	Outcome Measures (social participation and others)
Group Social Skills Training (n = 15)						
Laugeson et al., 2009 (6/9, 67%)	33 (28:5)	RCT	13-17 (14.6)	ASD	Parent-Assisted, Friendship-Building (PEERS) program; social skills group	SSRS (+) QPQ (+ in hosted get-togethers) TASSK FQS (+)
Laugeson et al., 2012 (8/9, 89%)	28 (23:5)	Pre/post group	12-17 (14.6)	ASD	Parent-Assisted, Friendship-Building (PEERS) program; social skills group	SSRS (+) SRS (+) QPQ (+ in hosted get-togethers) TASSK-R
Gantman et al., 2012 (7/9, 78%)	17 (12:5)	Pilot RCT	18-23 (20.4)	ASD	Parent-Assisted, Friendship-Building (PEERS) program; social skills group	SRS (+) SSRS (+) SELSA EQ QSQ (+ in hosted/invited get-togethers) SSI TYASSK
Gardner et al., 2015 (8/9, 89%)	20 (14:6)	Pre/post group	11-16 (12.4)	ADHD	Parent-Assisted, Friendship-Building (PEERS) program; social skills group	Initiation of a new mutual friendship (+) FQS (-) TASSK SPPC (-) SPPA (-) QSQ-R (+ in hosted get-togethers)
Radley et al., 2014 (5/9, 56%)	3 (2:1)	Pre/post group	10-14 (11.67)	ASD	Superheroes Social Skills program	Demonstration of target skills in the training setting (+) Generalization of target skills (+) ASSP (-) PSI/SF BIRS

MacKay et al., 2007 (10/16, 67%)	46 (38:8)	Pre/post group	6-11, 6-16 (8, 14)	ASD	Social skills group	SSQ-P SCPQ-P (+) SSQ-PU SCPQ-PU (+) Three parent rated problem areas (+ improvement in social problem areas) Interview (+ in social participation in real-life setting)
Choque Olsson et al., 2016 (8/9, 89%)	11 children 11 adults (8:3)	Qualitative	8-17 (12.9)	ASD	Social skills group	Experience and opinions on intervention (+ communication skills leading to improved interactions with peers)
McDonald et al., 2008 (6/9, 67%)	39 (28:11)	RCT	23-46 (36.3/33.1/35.2)	ABI	Social skills treatment program	BRISS-R TASIT DASS KAS-R1 SPSS LCQ SPRS (-)
Dahlberg et al., 2007 (7/9, 78%)	52 (44:8)	RCT	22.58-64.5 (41.17)	TBI	Social communication skills training	PFIC SCSQ GAS CHART-SF (-) CIQ (-) SWLS (+)
Hillier et al., 2007 (11/16, 68%)	13 (11:2)	Pre/post group	11-23 (19)	ASD	The Aspirations program, social and vocational skills support group	IPR (-) AQ (-) EQ Number and appropriateness of member interactions (+ relevant interactions between members) Feedback on program/behavioral changes (+ interest in social interaction/peer engagement)
Hillier et al., 2011 (5/9, 56%)	49 (42:7)	Pre/post group	18-28 (21)	ASD	The Aspirations program, social and vocational skills support group	BDI-II STAI IPR (-)

Guli et al., 2013 (7/9, 78%)	39 (31:8)	Pilot pre/post group	8-14 (10.97)	ASD ADHD NLD	Social Competence Intervention Program (SCIP)	BASC (-) DANVA2 Observed social interaction (+) Treatment satisfaction interview (+)
Goldingay et al., 2015 (8/9, 89%)	5 (4:1)	Pre/post group	(13.5)	ASD ADHD	Group-based pretend play skills	AFT SSIS (-) AMT
Agnihotri et al., 2014 (7/9, 77%)	5 (4:1)	Multiple Descriptive Case Study	13-16 (14.6)	TBI	Group theatre skills training	COPM (+ for 3 participants at follow-up) GAS (+ in “making friendships” for 3 participants) PPIC CASP (-) SNI (+) Emotion discrimination task
Parent et al., 2016 (5/9, 56%)	2 (2:0)	Multiple-baseline design across participants	12/16	ASD	Combining cognitive-behavioral and behavior-analytic approaches	Incidents of aggressive behavior Use of coping strategy Interviews/classroom observations of participation (+ involvement in community activities)
Peer Support Interventions (n = 10)						
Hughes et al., 2013 (5/9, 56%)	3 (2:1)	Multiple-baseline design across participants	16-17	ASD	One-to-one peer support	Number of initiations of interaction/conversation by participant (+) Duration of interactions (+) Peer goal setting
Haring et al., 1992 (4/9, 44%)	2 (2:0)	Multiple-baseline design across participants	13	ASD ID	Group peer support	Frequency and appropriateness of social interactions between student and peer group (+)
Bambara et al., 2016 (6/9, 67%)	3 (2:1)	Multiple-baseline design across participants	14-15	ASD	Group peer support	Number of: Conversation acts (+) Initiations of conversation (+) Follow-ups (+) SIRF Satisfaction with conversations with peers (-) Teach rated changes in quality of interactions (+)

Glang et al., 1997 (11/16, 69%)	3 (3:0)	Multiple-baseline design across participants	8-13 (10.6)	TBI	Building friendships group mentoring process	Social interactions with peers (+) Social integration in school (+ in satisfaction for parents/facilitators, - for students)
Watkins & Wentzel, 2008 (7/9, 78%)	24 (24:0)	Pre/post group	9.8-13.3 (11.1)	ADHD	Peer facilitation of strategic planning task	Observation of: Passive Solitary (+ reduction in solitary behavior) Joint participation (+) Dominant behavior Levels of planning strategy
Nieto et al., 2015 (5/9, 55%)	159	Cross-sectional survey	3-43 (11.98)	ASD	One-to-one leisure support	VIAT Social Capital (-) APUNTATE Impact Questionnaire for Volunteers/Families of People with ASD Social Capital (-)
Struchen et al., 2011 (7/9, 78%)	30 (24:6)	Pilot RCT	21-68 (31.7)	TBI	Community-based peer-mentoring program	CHART-SF (-) SAI (-) CES-D UCLA Loneliness Scale–Version 3 6-ISEL (+) SWLS (-) WSAS (-) Peer/mentor satisfaction with study/mentoring
Hibbard et al., 2002 (13/16, 81%)	20 (9 family members) (6:14)	Cross-sectional Mixed Method	>19-<46	TBI	TBI mentoring partnership program	Interview covering impact of intervention on: Empowerment Quality of life Mood Knowledge and communication skills (+ 27% major, 27% some impact on knowledge of community resources) Social support (-)

Hanks et al., 2012 (6/9, 67%)	158 (62 caregivers) (120:38)	RCT	17-86 (39.7)	TBI	Community-based peer-mentoring program	CIM (-) CISS FAD SF-12 BSI-18 SMAST The Peer Mentoring Questionnaire (+ in support from friends, feeling of belonging, - in support from community)
Kolakowsky-Hayner et al., 2012 (6/9, 67%)	89 (61:28)	Pre/post group	16-26 (20.5)	TBI SCI	Back on Track to Success mentoring program	DRS M2PI (+) SupRS CHART-SF (-) SWLS (-)
Technology-based Interventions (n = 4)						
Kandalaft et al., 2013 (6/9, 67%)	8 (6:2)	Pre/post group	18-26 (21.25)	ASD	Virtual Reality Social Cognition Training (VR-SCT)	WAIS-IV ACS-SP Theory of Mind tasks (Reading the Mind in the Eyes, Social Perception Task) SSPA VR-SCT follow-up survey (+ establishing relationships, social functioning)
Diener et al., 2016 (7/9, 78%)	7 (7:0)	Qualitative	8-17 (11.6)	ASD	Group-based creative 3D design program	Observations of social engagement (+ authentic peer relationships and scaffolded learning)
Raghavendra et al., 2013 (12/16, 75%)	18 (12:6)	Pre/post group	10-18 (13.7)	ABI CP Other PD	Use of appropriate technological solutions to overcome difficulties in Internet access/use and support and training to use the Internet	COPM (+) GAS (+ skills needed for online social participation) Interview- impact of the intervention on social participation (+)
de Kloet et al., 2012 (8/9, 89%)	50 (31:19)	Pre/post group	8-30 (17.1)	ABI	Use of the Nintendo Wii	CAPE (-) ANT Achievement of treatment goals PedsQL (- social functioning)

Resource Facilitation (n = 3)						
Matuseviciene, 2016 (9/9, 100%)	173 (78:95)	RCT	15-69 (38.7)	mTBI	Visit to a specialist in rehabilitation medicine, 14 to 21 days postinjury	RHFUQ (-) OGQ (-) SF-36 Sick leave
Trexler et al., 2016 (9/9, 100%)	44 (27:17)	RCT	18-60 (36)	ABI	Access to acute and outpatient rehabilitation services	Vocational Independence Scale (+) Time to return to work M2PI (-) BSI-18 GSI The Orientation Log Cognitive Log
McDougal et al., 2006 (7/9, 78%)	96 (27:69)	Non-equivalent comparison group quasi-experimental	<4-18 (9/11)	ABI	Pediatric Acquired Brain Injury Community Outreach Program (PABICOP)	IOF Brief FAM ABIQ EQ CBCL (- community integration/social competence) FSII(R) CSQ UPS MPOC-20

Note. Changes specific to the social participation measures are indicated by + (significant improvement) or – (nonsignificant/negative change). SSRS = Social Skills Ratings System; QPQ = The Quality of Play Questionnaire; TASSK = Test of Adolescent Social Skills Knowledge; FQS = Friendship Qualities Scale; SRS = Social Responsiveness Scale; TASSK-R = Test of Adolescent Social Skills Knowledge-Revised; SELSA = Social and Emotional Loneliness Scale for Adults; EQ = Empathy Quotient; QSQ-R = Quality of Socialization Questionnaire-Revised; SSI = Social Skills Inventory; TYASSK = Test of Young Adult Social Skills Knowledge; SPPC = Self-Perception Profile for Children; SPPA = Self-Perception Profile for Adolescents; SSQ-P = Spence Social Skills Questionnaire-Parents; SCPQ-P = Social Competence with Peers Questionnaire-Parents; SSQ-PU = Social Skills Questionnaire-Pupils; SCPQ-PU = Social Competence with Peers Questionnaire-Pupils; BRISS-R = Behaviorally Referenced Rating System of Intermediary Social Skills Revised; TASIT = The Awareness of Social Inference Test; DASS = Depression, Anxiety and Stress Scale; KAS-R1 = Katz Adjustment Scale R1; SPSS = Social Performance Survey Schedule; LCQ = La Trobe Communication Questionnaire; SPRS = Sydney Psychosocial Reintegration Scale; PFIC = Profile of Functional Impairment in Communication; SCSQ = Social Communication Skills Questionnaire-Adapted; GAS = Goal Attainment Scale; CHART-SF = The Craig Handicap Assessment and Reporting Technique Short Form; CIQ = Community Integration Questionnaire; SWLS = Diener Satisfaction with Life Scale; IPR = Index of Peer Relations; AQ = Autism Spectrum Quotient; BDI-II = Beck Depression Inventory; STAI = State-Trait Anxiety Inventory; NLD = Nonverbal Learning Disorder; BASC = Behavioral Assessment System for Children; DANVA2 = Diagnostic analysis of nonverbal accuracy 2; COPM = Canadian Occupational Performance Measure; ID = Intellectual Disability; SIRF = School Intervention Rating Form; SSPA = Social Skills Performance Assessment; VIAT = Volunteering Impact Assessment Toolkit; SAI = Social Activity Interview; CES-D = Center for Epidemiological Studies Depression Scale; 6-ISEL = The 6-item Interpersonal Support Evaluation List; WSAS = Weekly Social Activity Survey; CIM = Community Integration Measure; CISS = Coping Inventory for Stressful Situations; FAD = Family Assessment Device; SF-12 = Medical Outcomes Study 12-Item Short-Form Health Survey; BSI-18 GSI = The Global Severity Index of the Brief Symptom Inventory-18; SMAST = Short Michigan Alcoholism Screening Test; SCI = Spinal Cord Injury; DRS = The Disability Rating Scale; M2PI = Mayo-Portland Adaptability Inventory-4; SupRS = Supervision Rating Scale; WAIS-IV ACS-SP = Social Perception Subtest of the Wechsler Adult Intelligence Scale-Fourth Edition; CP = Cerebral Palsy; CAPE = Children’s Assessment of Participation and Enjoyment; ANT = Amsterdamse Neuropsychologische Taken; PedsQL = Pediatric Quality of Life Inventory; RHFUQ = The Rivermead Post Concussion Symptoms Questionnaire; OGQ = Occupational Gaps Questionnaire; SF-36 = Short-Form Health Questionnaire; IOF = Impact on Family Scale; Brief Fam = Family Assessment Measure III-Brief Version; ABIQ = The Acquired Brain Injury Knowledge Quiz; CBCL = Child behavior checklist; FSII(R) = Functional status II-short version; CSQ = Client Satisfaction Questionnaire; UPS = Usefulness of PABICOP Services; MPOC-20 = Measures of Processes of Care-20.