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Citation:

Brooks, R and Lambert, C and Coulthard, L and Pennington, L and Kolehmainen, N (2021) Social participation to support good mental health in neurodisability. *Child: Care, Health and Development*, 47 (5). pp. 675-684. ISSN 0305-1862 DOI: <https://doi.org/10.1111/cch.12876>

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Document Version:

Article (Published Version)

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**RESEARCH ARTICLE**

# Social participation to support good mental health in neurodisability

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**Funding information**

British Academy of Childhood Disability Castang Foundation Award

**Abstract**

**Background:** Young people with neurodisability experience lower levels of mental wellbeing and are at increased risk of mental illness compared with their non-disabled peers. Social participation is recognized as a protective factor against mental illness and a potential pathway to support better mental wellbeing in neurodisability.

**Method:** This co-design study involved young people, parents and clinicians. First, possible interventions were identified through a rapid systematic evidence review. Any study designs were considered, which included people with a neurodisability aged 0–18 years, which evaluated a therapy intervention with social participation and mental health outcomes. Titles and abstracts were screened by two reviewers, from the included studies data were extracted and then presented using written summaries. Second, the summaries were discussed and prioritized in stakeholder groups with young people, parents and clinicians. Groups were audio recorded and framework analysis was used to identify and specify intervention elements and their delivery.

**Results:** The evidence review identified 13,870 records, from which 43 were included. These records were published 1994–2017 and reported studies with 4–249 participants aged 16 months–18 years with a range of neurodisabilities. Five intervention approaches (social skills training, arts, sports, technology and play) were identified from the review. Two themes emerged from the stakeholder groups: intervention in the real world, feeling judged and feeling safe. The groups prioritized an intervention in real-world social leisure contexts (i.e. existing clubs and groups) using nine key intervention elements (e.g. feedback and positive verbal reinforcement) delivered by club leaders trained by healthcare professionals using five intervention procedures (e.g. a manual and video training).

**Conclusion:** This study has identified core elements of social participation interventions that may improve mental health outcomes in young people with neurodisability, which should now be tested.

**KEYWORDS**

intervention, mental health, neurodisability, participation, therapy

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## 1 | INTRODUCTION

Good mental health is an important outcome for all young people. It is reported that as many as 13% of young people will experience mental ill health including diagnosed conditions such as anxiety and depression (Polanczyk et al., 2015). Additionally, as many as 25% young people may experience poor mental wellbeing (Lawrence et al., 2015). Good mental wellbeing is characterized as being able to feel and express emotions, build and maintain relationships, cope with the stresses of life, feel engaged with life and realize personal potential (World Health Organization, 2019). Young people with a neurodisability have lower levels of mental wellbeing and higher levels of mental ill health. It has been estimated that up to 57% of young people with cerebral palsy meet criteria for a mental illness, with a further 40% at high risk of poor mental wellbeing (Bjorgaas et al., 2013). Moreover, young people with autism spectrum disorder frequently have a co-occurring mental illness (Leyfer et al., 2006). We are beginning to understand that mental health problems in young people with a neurodisability persist into adulthood (Myers et al., 2015; Weber et al., 2016). Accordingly, there has been a call for a more comprehensive approach to addressing the mental health needs of this population (Morris et al., 2015).

The use of 'talking' therapies such as cognitive behavioural therapy to address the mental health concerns of all young people is growing. There is, however, a lack of evidence of their application in the neurodisability population. Indeed, young people with neurodisability, their parents, clinicians and researchers have identified that the effectiveness of talking therapies is yet to be established (Beresford et al., 2018; Morris et al., 2015).

Social participation, which is defined as being involved in activities with others, and having positive interactions with friends, family and the community (Chen & Cohn, 2003), has been found to be a protective factor against mental ill health (Nguyen et al., 2019; Slaman et al., 2015). Through social participation young people create friendships, learn new skills, develop resilience and improve mental wellbeing (Powrie et al., 2015). Young people with neurodisability have lower levels of social participation (Majnemer et al., 2015; Orsmond et al., 2013). However, similar to other complex behavioural interventions, interventions to promote it are limited (Goldingay et al., 2015; Tanner et al., 2015).

To address the gap in evidence, this study aimed to identify features of social participation interventions that could improve mental health outcomes in young people with neurodisability. The study had two objectives: firstly, to identify existing social participation interventions, with mental health outcomes, through a rapid systematic evidence review; secondly, to explore the review findings in stakeholder groups with young people, parents, and clinicians and for them to prioritize, select and specify features of acceptable social participation interventions including key elements and delivery.

### Key messages

- Young people with neurodisabilities have higher levels of mental ill health than their typically developing peers.
- Social participation has been found to be a protective factor against mental health problems.
- Current evidence-based social participation interventions have limitations in their acceptability and generalizability.
- In this study, young people, parents and clinicians reported that social participation interventions should be in real-life context and incorporate nine identified key elements.

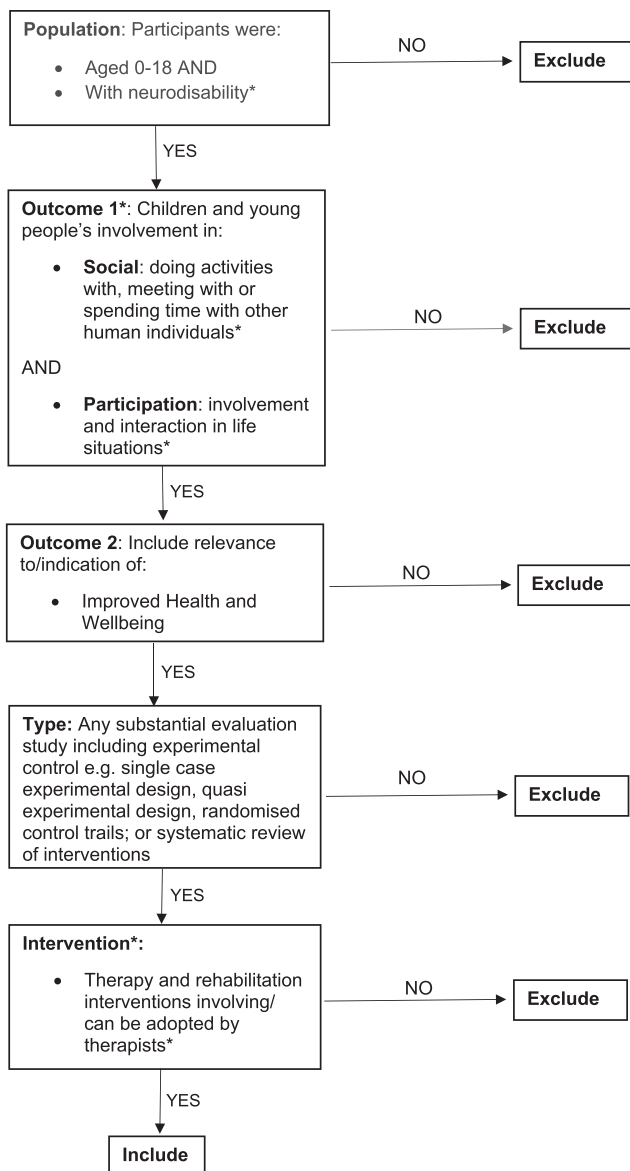
## 2 | METHODS

### 2.1 | Public and patient involvement

This study design replicates previous research and involved parents and young people in the co-design of future research (McAnuff et al., 2016). A member of the research team (LC) was a parent of a child with a neurodisability and was involved in the study design, recruitment, conduct and analysis. The young people who took part in the study created a video to report the findings to other young people with neurodisabilities.

### 2.2 | Stage 1

In the first stage, a rapid evidence review was conducted. Three databases were searched for three facets ('mental health', 'neurodisability' and 'social participation') to cover a broad range of possible citations relevant to social participation interventions: MEDLINE via PubMed, CINAHL Complete, and ERIC via EBSCO. The search strategy used controlled headings, including MeSH, terms within domains were combined using Boolean operator 'OR' and resulting sets combined using 'AND'. Screening of titles and abstracts took place against the Population, Intervention, Comparison, Outcome and Type (PICOT) inclusion exclusion criteria developed for the study (Figure 1). Covidence (n.d.) software was used to manage the review. Two researchers (CL and RB) screened 10% of the titles and achieved a very good level of agreement ( $K = 0.9$ , 95% CI 0.89–0.92) (Altman, 1991). One researcher (CL) screened the remaining titles. RB and CL screened the abstracts of papers that passed the title screen. If a decision could not be reached based on the abstract alone the full text was retrieved. RB and CL independently reviewed all full texts. The wider research team discussed any paper on which RB and CL disagreed until an agreement was reached. From the included studies, data were extracted on the following: title, author/s, year published, aim, number of participants and diagnosis, setting, intervention deliverer, dose, follow-up, results, effectiveness, outcome construct and outcome measure. As the review



**FIGURE 1** Population, Intervention, Outcome and Type (PICOT) inclusion exclusion criteria developed for the study. Additional notes provide rationale and define terms

had a limited timeframe and aimed to give a useful overview of emergent evidence, no formal methodological quality appraisal was undertaken. This reflects rapid review recommendations (Abrami et al., 2010) and previous co-design research (McAnuff et al., 2016). However, each study was classified using the Oxford Centre levels of evidence (Phillips et al., 2009). Included studies were presented to the research team for critical discussion, then interventions were grouped into intervention approaches and the extracted data developed into written summaries for the second stage of the study.

## 2.3 | Stage 2

The intervention approaches and summaries from the rapid evidence review were presented to the three stakeholder groups: young people

with a neurodisability, parents whose child had a neurodisability and healthcare professionals working with young people with a neurodisability. Young people and parents were recruited via known networks, charities, social media and a UK press release. Clinicians were recruited via professional networks and using snowball sampling. Participant information sheets were provided in a developmentally appropriate format to all participants. This study gained research ethics approval from Leeds Beckett University. Written informed consent was provided by parents and clinicians. Verbal or written assent was gained from the young people.

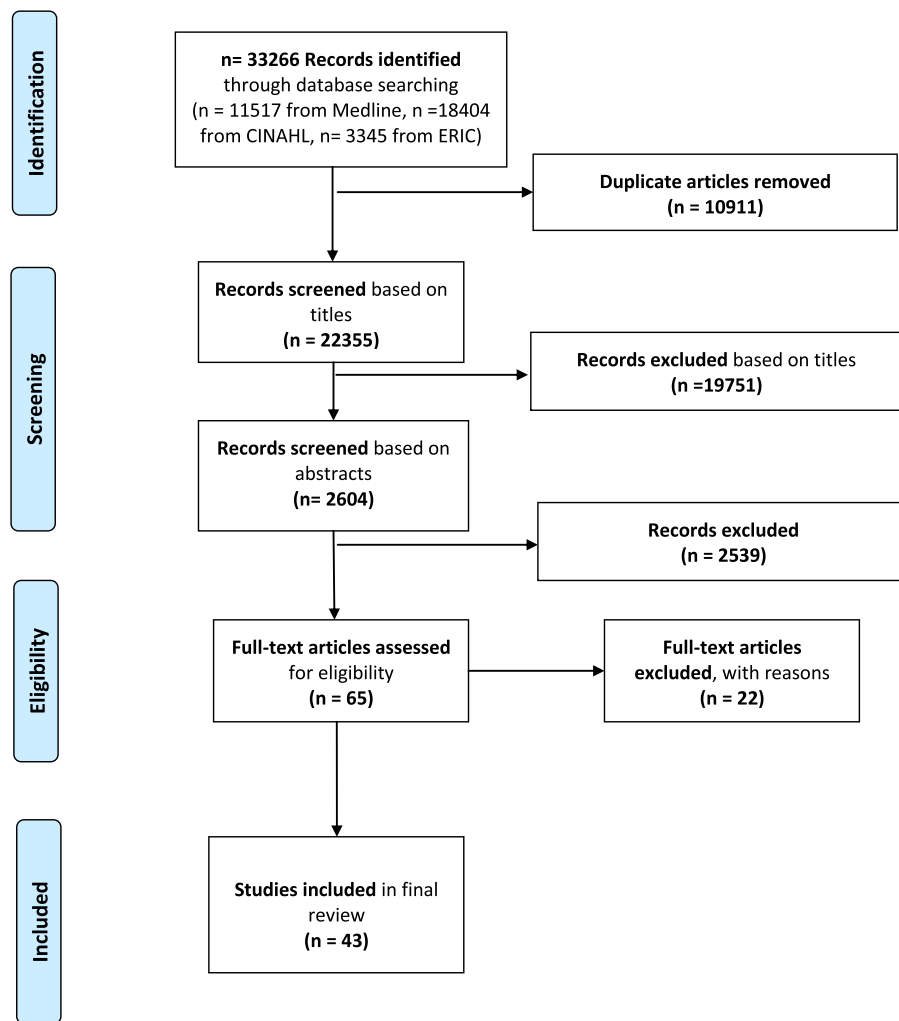
Each stakeholder group met in person on three occasions. The sessions ranged from 60 to 120 min in length and were facilitated by researchers (CL, LC, and RB). Creative methods, including collage, drawing and games, were used to discuss ideas with young people. Written and verbal information, presented on flip charts and easy to read summaries, was used with parents and clinicians. The sessions were iterative, with findings from each session informing the next. The first session focused on members developing rapport and a shared understanding of social participation and mental health through the sharing of stories. The intervention approaches and summaries were introduced to the groups. The second session explored the participants' experiences and views on the acceptability and feasibility of each intervention approach. Each stakeholder group prioritized the intervention approaches in order of what could work best for young people with a neurodisability. In the third session, the focus was on the key elements of an intervention. Key elements were identified from the summaries and from the framework analysis. Elements were discussed and prioritized by each group in order of perceived effectiveness.

The stakeholder sessions were audio recorded, transcribed and analysed sequentially. Visual data were kept or photographed. Data were analysed using framework analysis using the five stages outlined by Spencer and Ritchie (2002): familiarization, identifying a framework, indexing, charting, and mapping and interpretation. The Template for intervention Description and Replication (TIDier) (Hoffmann et al., 2014) domains was identified a priori as a coding framework, but the researchers remained open to other emerging ideas (Spencer & Ritchie, 2002). Two researchers (CL and RB) independently indexed and charted the first transcripts and then met to refine the framework. One researcher (CL) analysed and mapped the remaining data. The research team (RB, CL, LC, LP, and NK) was involved in the final interpretation and theme development.

## 3 | FINDINGS

### 3.1 | Stage 1

The findings from Stage 1 are summarized in a PRISMA flowchart (Figure 2) (Moher et al., 2009). A total of 33,266 titles were identified as potentially relevant. Following the removal of duplicates, 22,355 papers were screened based on titles only. Of these,



**FIGURE 2** Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram [Colour figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]

19,751 were excluded; 2604 abstracts were screened, and 2539 excluded. Sixty-five full-text articles were assessed, of which 43 full-texts were included; a summary of the included studies (Table S1) and the intervention characteristics extracted from the included studies (Table S2) are available as supporting information. Study designs were predominantly quantitative or mixed methods, including randomized controlled trials, controlled studies, case series, pre-test post-test, comparative study and single-case study designs. Study participants had diverse neurodevelopmental diagnoses, including autism spectrum disorder, attention deficit hyperactivity disorder, Down syndrome, cerebral palsy and epilepsy. Participants were aged from 16 months to 18 years. Interventions were delivered in a range of contexts, including schools, leisure centres and home, summer camp and specialist rehabilitation settings by physical, music, speech and language and occupational therapists; teachers; certified instructors; peers; coaches; psychologists; social workers and parents. The number of intervention sessions provided varied widely from 30 min every day to 1 h once a week. The interventions were broadly delivered through five approaches: social skills training, arts, sports, technology and play.

## 3.2 | Stage 2

In Stage 2, the stakeholders were: young people ( $n = 9$ ), parents ( $n = 9$ ) and clinicians ( $n = 5$ ) from the North of England. The characteristics of the young people and parents are presented in Table 1. Four of the parents had children that also took part in the study. Two occupational therapists, a physiotherapist, a community paediatrician, and a speech and language therapist participated, with an average of 16 years (range 8–25 years) experience working in the field of neurodisability. The clinicians worked in different services to the other participants. The findings are presented as two themes supported by data from the charting, mapping and prioritization. The convention P = parent, C = clinician and YP = young person is used for quotes.

### 3.2.1 | Intervention in the real-world

Parents and young people reported that they had received a range of time-limited social skills training programmes in a clinic or school setting. They felt that the skills taught had rarely transferred to different

**TABLE 1** Characteristics of young people and parent participants

Participant	Sex	Age in years	Reported diagnosis of self (young person) or child (parent)
Young person	Female	13	Attention deficit hyperactivity disorder, autism, phobias
Young person	Male	14	Autism, attention deficit hyperactivity disorder
Young person	Male	12	Autism, attention deficit hyperactivity disorder
Young person	Female	10	Autism, trisomy 21
Young person	Female	10	Autism, attention deficit hyperactivity disorder, anxiety
Young person	Female	17	Epilepsy
Young person	Male	13	Autism
Young person	Female	16	Autism
Young person	Male	12	Autism, attention deficit hyperactivity disorder
Parent	Female	49	Learning disability
Parent	Female	46	Attention deficit hyperactivity disorder, anxiety
Parent	Female	39	Global delay, attention deficit hyperactivity disorder
Parent	Female	51	Autism
Parent	Female	41	Autism, attention deficit hyperactivity disorder
Parent	Female	46	Autism
Parent	Female	45	Autism
Parent	Female	46	Epilepsy, learning disability, ataxia
Parent	Female	42	Foetal alcohol syndrome, attachment disorder

situations: 'I can't really see how that kind of intervention would improve social skills and stuff' (P6) and 'I think learning social skills has to happen in the real world' (P5). This finding was echoed by clinicians: 'Often skills are learned in one context and not transferred' (C2). Due to these limitations, groups prioritized social skills training approaches to intervention as least acceptable and effective.

Although parents and young people reported involvement with many social activity groups, they had not experienced interventions that addressed social participation within the context of these real-world activities. Parents valued inclusion in mainstream social groups: 'I want him to actually integrate with regular people' (P4), 'I don't want him just to go for special needs things' (P8) and 'I think my kids could have the potential to then access something mainstream if ... the right support was there' (P3). Accordingly, groups prioritized equally the intervention approaches in real-world settings (arts, sports, technology and play): 'I would go for the sport based and art based just because that's more out there in a natural context kind of thing' (C4). Stakeholders had experienced some of the intervention settings, such as performing arts and afterschool clubs, but added their own, including football, horse riding, gymnastics, rugby, gaming club, youth club, art group, karate and swimming.

The stakeholders identified the importance of being part of a group and therefore that the intervention should be integral to the social activity '... this isn't just about teaching them soccer skills; this is a targeted therapy' (P6) and '... it's got to be a part of that group hasn't it' (C3). Clinicians recognized that they cannot be knowledgeable about every real-world social leisure activity, but that they could work with social club leaders: 'What we might need to do is

something with the instructor which means that they can enable participation' (C4).

### 3.2.2 | Feeling judged and feeling safe

Participants described that it was difficult to find appropriate social activities and when they had done so they experienced judgement and bullying. Being judged was a significant barrier to the choice and setting of any social participation activity: '100% top of my list that we're not being judged' (P1) similarly, 'families want to be in a safe environment where nobody's judging them' (P2). Participants reported difficulties in participation in mainstream social groups: 'He won't join a club because he doesn't think he's good enough' (P3), and 'They tried a gymnastics group and he was just running all over the place, and the stress for mum just meant we're not doing that again' (C1).

Bullying during social activities was experienced by a number of young people: '... I get bullied at the play park, getting hard sweets thrown at me, rocks thrown at me' (YP2) and 'I get bullied a lot' (YP3). Consequently, young people wanted to feel secure when they joined in activities with others, for example 'Sometimes you just want to make sure you feel safe' (YP1).

Despite these challenges all parents and clinicians saw social activities as being important for a child's future: 'It's the fact that they're in a group interacting and learning how to deal with each other and take turns and all those skills you need later down the line' (C2). Parents wanted a safe space where a young person would not be

**TABLE 2** Proposed intervention mapped to the TIDier domains

Item	Item description	Intervention description
Name	Name or phrase that describes the intervention	<p>SPIN (social participation intervention for Neurodisability)</p> <ul style="list-style-type: none"> <li>• A professional-led intervention training programme for social club leaders to enable them to optimise the social participation of young people with neurodisability attending their group.</li> </ul>
Why	Describe the rationale, theory or goal of the elements essential to the intervention	<ul style="list-style-type: none"> <li>• Children and young people with neurodisability have lower levels of social participation and have a higher risk of developing mental illness as compared with their same-aged peers.</li> <li>• Taking part in social and leisure activities can enhance the mental health and wellbeing of all children and young people.</li> <li>• When children and young people with neurodisability do participate socially there is a risk of judgement or bullying</li> <li>• Children and young people with neurodisability often cease participation in social activities before being fully engaged, which limits the transfer of skills to other settings</li> </ul>
What—materials	Physical or informational materials used in intervention	<ul style="list-style-type: none"> <li>• Manual</li> <li>• Goal setting tool</li> <li>• Video training</li> <li>• Fidelity measure</li> </ul>
What—procedures	Procedures, activities and/or processes used in the intervention	<ul style="list-style-type: none"> <li>• Professional and leader engage with parents to understand the individual needs of their child, problem solve and goal set.</li> <li>• Provide a manual which specifies the skills and behaviour components of the intervention. This will include: <ul style="list-style-type: none"> <li>o Peer involvement/social support</li> <li>o Debrief/feedback</li> <li>o Reward</li> <li>o Positive verbal reinforcement</li> <li>o Prompts and cues</li> <li>o Direct instruction</li> <li>o Role modelling/demonstration</li> <li>o Adapting the environment</li> <li>o Natural consequences</li> </ul> </li> <li>• Use of video modelling to demonstrate the application of the intervention components.</li> <li>• Self-modelling—social club leaders demonstrate intervention behaviours and receive feedback as a learning tool.</li> <li>• Professional observes social club leaders application of the intervention using fidelity measure and gives feedback.</li> <li>• Review of goals.</li> </ul>
Who	Expertise, background or support activities of intervention provider	<p>Professional:</p> <ul style="list-style-type: none"> <li>• Professional background working with children and young people with neurodisability (e.g. therapist, teacher and social worker)</li> </ul> <p>Leader:</p>

TABLE 2 (Continued)

Item	Item description	Intervention description
		<ul style="list-style-type: none"> <li>• Experience of working with children and young people</li> <li>• Trained in special needs/neurodisability/mental health</li> <li>• Ability to communicate effectively with the child and their family</li> <li>• Ability to judge when to make changes or adapt intervention</li> <li>• Trained in challenging bullying</li> <li>• Take a flexible approach to running interventions</li> <li>• Further peers understanding of disability</li> </ul>
How	Modes of delivery	<ul style="list-style-type: none"> <li>• Face-to-face</li> <li>• Use of DVD/Videos</li> <li>• Observation</li> </ul>
Where	Describe the types of locations where the intervention will occur	<ul style="list-style-type: none"> <li>• Naturally setting for the activity</li> <li>• Safe space for children and young people</li> </ul>
When and how much	No of times the intervention is delivered and over what period of time	<ul style="list-style-type: none"> <li>• Leaders to apply the intervention components on an ongoing basis.</li> </ul>
Tailoring	The planned personalisation or adaptation of the intervention—what, why, when and how	<ul style="list-style-type: none"> <li>• Make adaptations to the individual</li> <li>• Setting individual goals—setting achievable targets tailored to each individual which can be reviewed as the child progresses</li> </ul>

defined by their disability and was 'allowed' to participate: 'A positive outcome would be for my children to be able to successfully carry out whatever it was and to not feel like they were different' (P1). Young people wanted to be able to make friends through activities 'I only have a few friends who live around near me, but mostly one of them's most close because we do karate together' (YP3).

### 3.2.3 | Intervention elements

The stakeholder groups developed intervention elements to target leisure providers' behaviour—specifically how they include, involve and communicate with young people with neurodisability to ensure inclusion. This was believed to lead to actual social participation and improved related mental health. Groups specified the intervention with nine key elements and five procedures. These are presented in the TIDler (Hoffmann et al., 2014) format in Table 2.

## 4 | DISCUSSION

This study found five potential participation intervention approaches. From this, a co-design group identified and specified an intervention to facilitate everyday social participation for young people with neurodisabilities with  $n = 9$  key elements and  $n = 5$  intervention procedures. The elements were as follows: peer involvement, feedback, reward, positive verbal reinforcement, prompts and cues, direct instruction, role modelling, adapting the environment and

natural consequences. The procedures were as follows: a manual, goal setting tool, video training, self-modelling and a fidelity measure. Collectively, the elements and procedures aim to enable access to mainstream leisure activities and target the skills and behaviours of providers.

The studies identified in the review informed and shaped the stakeholder perspectives. Groups agreed that acontextual social skills training had limited transferability and that training should be embedded within real-world activities. This corresponds with previous randomized-controlled trials (Kasari et al., 2012; Laugeson et al., 2014) and systematic reviews (Banda, 2015; Tanner et al., 2015) that have identified support for the use of peer and sibling-mediated social skills interventions in natural settings. However, some previous trials have been conducted in compulsory social settings, such as school (Carter et al., 2015; Kasari et al., 2016) or constrained to specific diagnostic groups (e.g. autism spectrum disorder) (Koegel et al., 2012; Tanner et al., 2015). The present study suggests how some of these evidence-based principles could be advanced in the UK context, for example, leisure club-based interventions.

The findings of this study resonate with others that have shown that young people with neurodisabilities seek the fun, friendship and mastery that social participation offers (Powrie et al., 2015). Previous studies have also described that a key element of successful leisure participation can be feeling free to exercise choice and being free of demands and restraints that they often experience (Dahan-Oliel et al., 2012). The present study extends this literature by identifying that a central element to enable young people to feel free is to ensure they are safe both psychologically (e.g. not being judged and not being



bullied) and physically. Although physical safety is a common concern in relation to physical health technologies, the psychological safety is considerably less well defined. The intervention identified in the present study provides a structure for how to enable young people with neurodisability to feel safe in social participation.

The main study limitations were that the studies included in the rapid review were not appraised for methodological quality and the co-design participants were recruited from existing networks and therefore may not be fully representative of the population. However, this is in keeping with standard methods, that is, rapid reviews do not often include a quality appraisal, and co-design groups are usually purposively constructed.

## 5 | CONCLUSION

Social participation has the potential to improve the mental wellbeing of children and young people with neurodisability. Current evidence-based interventions have limitations in their acceptability and generalisability. Interventions should be in real-life context and incorporate identified key elements to facilitate psychological and physical safety.

### FUNDING INFORMATION

This study was supported by British Academy of Childhood Disability: Castang Foundation.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

**How to cite this article:** Brooks R, Lambert C, Coulthard L, Pennington L, Kolehmainen N. Social participation to support good mental health in neurodisability. *Child Care Health Dev.* 2021;47:675–684. <https://doi.org/10.1111/cch.12876>