

# Therapy interventions for children with neurodisabilities: a qualitative scoping study

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## Scientific summary

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# Scientific summary

## Background

In a recent James Lind Alliance Childhood Disability Research Priority Setting Partnership (Morris C, Simkiss D, Busk M, Morris M, Allard A, Denness J, *et al.* Setting research priorities to improve the health of children and young people with neurodisability: a British Academy of Childhood Disability-James Lind Alliance Research Priority Setting Partnership. *BMJ Open* 2015;**5**:e006233) for children with neurodisability, ‘therapy interventions’ featured strongly within its top 10 priorities, with four items on the list concerning such interventions. This is not surprising, as existing evidence, particularly that of high quality, on this topic is very limited.

An overarching research question was generated from this process: what therapy interventions are, could and should be offered to children with neurodisability to help improve participation outcomes? This apparently straightforward question belies the fact that this is a highly complex topic. It covers a wide range of issues, including the different ‘schools’ of, or approaches, to therapy; models of service delivery; the ‘dosage’ or intensity of specific interventions; the timing and duration of an overall therapeutic intervention; the skills and qualifications of staff delivering the therapy; and the involvement of others, such as parents and school staff, in the delivery of interventions. Over and above this is the challenge of identifying and measuring the ‘active ingredients’ of therapeutic interventions, and capturing outcomes.

To inform future commissioning of research on this topic, the National Institute for Health Research’s (NIHR) Health Technology Assessment’s Maternal Neonatal and Child Health Panel commissioned a scoping study into current practice and perceived research needs through one of NIHR’s Health Services and Delivery Research programme’s Evidence Synthesis Centres.

## Objectives

The study objectives were to:

1. identify and describe current techniques, practices and approaches to delivering therapy interventions – that is, physiotherapy, occupational therapy and speech and language therapy – for children with non-progressive neurodisability that seek to improve participation as defined by the World Health Organization’s (WHO) International Classification of Functioning, Disability and Health (ICF) framework (WHO. *Towards a Common Language for Functioning, Disability and Health: International Classification 7 Framework*. Geneva: WHO; 2002), that is, the child’s ability to have the opportunity to participate in life situations and activities (e.g. communication, mobility, interpersonal interactions, self-care, learning and applying knowledge)
2. describe the therapeutic approaches that are identified by professionals as promising or innovative but are not currently (routinely) delivered by the NHS
3. identify how and why these interventions may vary according to the nature and severity of the impairment
4. describe the factors that influence decision-making regarding the ‘therapeutic prescription’, including the nature and severity of the impairment
5. understand the dimensions that constitute a therapeutic intervention from the perspectives of NHS health professionals, children and parents, for example the physical environment, the location, the use of/access to equipment, staff skills/qualification, parent involvement/delivery and self-management
6. seek the views of NHS health professionals, parents and children regarding the ‘active ingredients’ of therapy, and how to capture or measure these

7. understand, and compare, the ways in which professionals and families currently conceive therapy outcomes, the meaningfulness of 'participation' as a therapy outcome and how these may vary according to the nature and severity of the impairment
8. map NHS health professionals', parents' and children's views of the evidence gaps related to therapy interventions for children with non-progressive neurodisability, and identify views on the issues that need to be accounted for in the design of any future evaluations.

## Methods

### Design

A descriptive case study design, taking the delivery and practice of therapy interventions as the case, was adopted. Qualitative research methods (interviews and focus groups) were used. A purposive approach to sampling was implemented. Focus groups and individual interviews were used to collect data.

### Inclusion criteria

The scope of the study was set according to the following criteria.

- Intervention: physiotherapy, occupational therapy and speech and language therapy interventions that meet the 'patient group' and 'setting' criteria below and target outcomes within the participation component of the ICF. The domains captured by this concept include participation in learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; major life areas; and community, social and civic life. This criterion includes interventions delivered directly by therapy staff, or by school staff, parents and/or children, in the home or in a school setting, under instruction from therapy staff.
- Patient group: children and young people up to school-leaving age with non-progressive neurodisability predominated by physical/motor impairment, including those without a specific diagnosis. This includes children with cerebral palsy (defined as physical, medical and developmental difficulties caused by injury to the immature brain), brain injury, some metabolic and neurogenetic disorders, and developmental co-ordination disorder, as well as those without a specific diagnosis. Within and across these patient groups, the extent to which physical/motor abilities are affected varies considerably. For many of these children and young people, the presence of neurodisability results in a number of physical/motor and cognitive impairments.
- Setting: outpatient, community, school and/or home.

### Data sources

The study sought to recruit the following stakeholder groups:

1. child/neurodisability/research leads in national professional groups
2. physiotherapy, occupational therapy and speech and language therapy practitioners and assistant practitioners based in community paediatric teams/services, paediatric specialties and tertiary clinics/centres
3. clinical academics/researchers currently active in the field
4. community paediatricians and paediatric neurologists
5. parents
6. children and young people.

More than 70 professionals (therapists, service leads, paediatricians and education staff) and 25 parents took part in the study either through individual interviews or by taking part in a focus group. It did not prove possible to recruit children and young people. Those recruited to the study represented a wide range of settings, geographical locations, neurodisabilities and children's ages.

### Data analysis

All interviews and focus groups were audio-recorded. The recordings were used to create detailed interview summaries organised under the themes covered in the topic guides. Verbatim quotes were also extracted. The research team met regularly throughout the data collection period to reflect on a priori and emerging topics and issues. Once all of the interview/focus group summaries were complete, the team met again on three separate occasions to discuss and develop, through consensus, 'mind maps' of the themes and subthemes covered in the data relevant to the research questions. These maps were then modified to create a structure into which analytical writings, summarising findings on each theme, could be organised. These formed the basis of the project report. Drafts of the findings sections of the project report were shared and reviewed by all members of the research team and final versions were agreed.

### Results

Professionals and parents were clear in their belief about the necessity and importance of therapy interventions with respect to the care, management and support of children with neurodisability.

The three professions are in a state of dynamic change and development. This appears to be taking place in response to, or influenced by, three separate issues:

- debates and conceptual understandings of disability and impairment
- shifts in thinking taking place in other professions and disciplines, and related evidence, regarding goals-focused working, family-centred approaches and supporting self-management
- significant resource constraints.

In terms of the practice of therapy, the key distinctive features are professional autonomy and highly individualised approaches to delivering therapy. This is informed, or underpinned, by clinical experience, 'philosophical positions' regarding the purpose of therapy, and the specific procedures, techniques and/or equipment that the therapist has the skills, or resources, to deliver. Manualised, or protocol-driven, interventions are unusual. There are early signs of a move to care pathways and the application of protocols within this structure. Much of the direct work of delivering therapy to a child is carried out by parents and school staff. Increasingly, therapists assume a consultative role and their skills in this regard are, therefore, critical.

Therapy interventions are complex. Existing frameworks for understanding complex non-pharmacological interventions offer a useful structure by which this complexity can be understood. Many potential 'active ingredients' were identified, some of which would appear to offer challenges in terms of their 'measurement'. Related to this, understandings of mechanisms of change are limited.

Parents and professionals strongly identified participation as one of the overarching objectives of therapy interventions. However, study participants' understanding of this term was extremely varied. In addition, as a concept or intervention objective, it may not be explicitly operationalised in practice. Furthermore, the notion of participation as an appropriate and meaningful outcome indicator for therapy interventions was questioned, particularly with respect to, for example, evaluations of a specific procedure. There was agreement that, when properly implemented into a study design, it may be an appropriate indicator in studies evaluating the impact of wider models of care.

There was broad agreement that any evaluation should capture outcomes across the entire spectrum of the WHO's classification of disability and impairment, including functioning/body structure, engagement in activities and participation (as well as other higher-level outcomes). Some of these outcomes may be better conceived as intermediate outcomes. Quality of life, physical and emotional well-being, resilience and self-management were identified as other potentially relevant higher-level outcomes.

Children with non-progressive neurodisability are a highly heterogeneous population. Many have complex needs and require the support and care of a number of professionals and services. The neurological origins of their impairments mean that children with predominantly physical/motor impairments – specified as the population in question for this scoping study – may well have cognitive impairment. For some types of research, additional or alternative approaches to defining populations, for example in terms of gross motor function or desired goals, may be more meaningful and appropriate.

Typically, there is not a strong culture of research within therapy services; however, within the professions there is growing engagement with and interest in research. There is recognition and acceptance of the need for research, although for some this is tempered by concerns about research's ability to demonstrate the impact they believe therapies to have on children's lives.

A broad-ranging agenda of research priorities was identified. Some were regarded as 'foundational' or prerequisites of other types of studies. A number of methodological and study design issues were identified as barriers to evaluation research.

Evaluations of ways of working (e.g. goals-focused approaches) and service models (e.g. integrated care and multi- or transtherapy teams) were frequently identified as research priorities. Overall, parents' research priorities were located in these types of studies.

Research priorities concerning particular techniques, procedures or items of equipment generated a long list of potential studies. These appeared to be located in personal preferences and clinical experience, and none emerged as receiving strong and consistent support.

There was universal consensus that evaluative research needs to use mixed methods, and that patient experience as well as outcomes should be captured. Health economics and implementation science were consistently identified as needing to be core components of evaluation studies.

## Conclusions

The purpose of this study was to provide a description of current thinking, practices and models of service delivery with respect to physiotherapy, occupational therapy and speech and language therapy. It sought to consult with relevant health professionals, parents and children and young people. In terms of the aspect of the study that sought to explore research priorities, the absence of children and young people in the study represents a significant limitation. However, a broad representation of health professionals and parents was achieved, response rates were very high and study participants were highly engaged.

The context of therapy provision has been described, including shifts and developments in thinking and practice across the professions. These have been influenced by new models of disability and impairment and adopting notions of family-focused and goals-focused care, as well as significant changes in the level of investment in therapy provision.

The study has also described, from professionals' and parents' perspectives, the complexities both of therapy interventions and of their evaluation. It has revealed a wide-ranging research agenda spanning 'basic' neurodisability research, methodological research and work to better understand therapy interventions and their active ingredients, as well as evaluation studies. In terms of evaluative research, there was a strong call for studies that tested and informed developments in practice and ways of working and/or models of service delivery. No particular techniques or procedures emerged as clear research priorities, although sometimes techniques not currently available within NHS provision were identified. For some, research into the effectiveness, or impact, of specific techniques and equipment was seen as secondary to, or irrelevant compared with, research into models of care and ways of working.

Finally, the study also collected views on the 'research environment' within the professions, with a sense emerging of the need to develop research capacity and research culture.

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