

# Therapy interventions for children with neurodisability: a scoping study of current practice and perceived research needs

## Introduction

The recent James Lind Alliance Childhood Disability Research Priority Setting Partnership identified ‘therapy interventions’ for children with neurodisability as its top priority (Morris *et al*, 2015). The following 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 question captures the complexity of this topic including issues such as the different ‘schools’, or approaches, to therapy; ‘dosage’ or intensity; the timing and duration of a therapeutic intervention; and the skills and qualifications of staff delivering the therapy. Over and above this is the challenge of identifying and measuring the ‘active ingredients’ of therapeutic interventions.

Existing evidence on this topic is very limited. For example, recent NICE guidance on the management on spasticity in children was not able to provide guidance on the timing or intensity of any interventions it included. The Guidance Development Group also noted that interventions are themselves poorly defined (NICE, 2012). Evidence reviews in this area note the lack of rigorous research and the very limited nature of the current evidence base (eg. Tinderholt Myrhaug *et al*, 2014; Rameckers, 2014; Novak, 2013; Franki, 2012).

In order to inform future commissioning of research on this topic, NIHR HTA’s Maternal Neonatal and Child Health Panel has suggested two pieces of preliminary work:

1. a scoping study of current practice and perceived research needs;
2. a synthesis of existing evidence.

This paper sets out a proposed approach to the first piece of work.

## Defining the scope

*Intervention:* therapy interventions that meet the ‘patient group’ and ‘setting’ criteria below and target outcomes within the participation component of the International Classification of Functioning, Disability and Health (ICF) framework (World Health Organisation, 2002). 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; community, social and civic life. This includes interventions delivered by directly by therapy staff or by parents and/or children in the home under instruction from therapy staff.

### *Patient group*

Children and adolescents 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 neuro-genetic disorders, developmental coordination disorder and those without a specific diagnosis. Within and across these patient groups, the extent to which physical/motor abilities are affected varies considerably. We will ensure the range of patient groups, including those without a diagnosis, and levels of motor functioning are represented in the study. This will be achieved both via recruitment/sampling strategies and the material covered in data collection.

*Setting:* outpatient, community, school and/or home.

## **Objectives**

The purposes of this scoping study are as follows:

- to identify and describe current techniques, practices and approaches to delivering therapy interventions for children with non-progressive neurodisability which seek to improve participation as defined by the ICF.
- to identify how and why these interventions may vary according to the nature and severity of the impairment.
- to describe therapeutic approaches identified by professionals as promising or innovative but not currently (routinely) delivered by the NHS.
- to describe the factors which influence decision-making regarding the 'therapeutic prescription', including nature and severity of the impairment.
- to understand, and compare, the ways that 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.
- to understand the dimensions which comprise a therapeutic intervention from the perspectives of NHS health professionals, children and parents; for example, the physical environment, location, use of/access to equipment, staff skills/qualification; parent involvement/delivery; self-management.
- to seek views of NHS health professionals, parents and children regarding the 'active ingredients' of therapy, and how to capture/measure them.
- to 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 which need to be accounted for in the design of any future evaluations.

## **The design of the scoping study**

In order to deliver on the objectives of this scoping study, groups and individual interviews and a brief on-line survey will be used to ascertain the views and experiences of a number of different stakeholder groups, namely:

- child/disability leads in national professional groups;
- therapy practitioners and assistant practitioners based in community paediatric teams/services, paediatric specialities, and tertiary clinics/centres;
- placement supervisors within therapy services used by therapy training institutions, both undergraduate and masters' qualification routes;
- clinical academics/researchers currently active in the field
- community paediatricians and paediatric neurologists;
- parents
- children and young people.

Figure 1 provides an overview of the participants, data collection method and sampling or recruitment pool.

**Figure 1: Participants, data collection method and sampling**

<b>Participant group</b>	<b>Method</b>	<b>Sample size</b>	<b>Sampling/recruitment pool</b>
National /professional group representatives	Telephone interview	n= ~ 6	British Association and College of Occupational Therapists, Chartered Society of Physiotherapy, Royal College of Speech and Language Therapists
Therapists and assistant practitioners	Focus groups	8 x ~7/group participants (n=~ 55)	Therapy Service Departments in NHS Trusts
Training Placement Supervisors	Telephone interview	n=9 (3/therapy)	Therapy Service Departments in NHS Trusts used by therapy training institutions for training placements
Clinical academics /researchers currently active in the field	Telephone interview	n=~10	UK universities and Therapy Service Departments
Community paediatricians & paediatric neurologists	On-line survey	n=~ >75	Distributed via organisations such as the British Association of Childhood Disability, European Academy of Disability
Parents	Focus group	4 x ~8 /group (n=~32)	Pre-existing parent groups coordinated by research unit and voluntary sector organisations
Children	Group interviews <sup>1</sup>	4 x ~6/group (n=~25)	Special schools

<sup>1</sup> We deliberately use the term group interview here, rather than focus group. This is because the group work with children will be more actively directed and led by the research team, with high proportion of interaction being between the researcher and each child individually. This is an appropriate approach/expectation given the topic and abilities of this group of children. Focus groups, by contrast, should be dominated by discussions between members of the group which are directed and facilitated by the research team.

## Participants

The rationale for the inclusion of these different stakeholder groups in the study is as follows:

- i. National/professional group representatives offer a 'high level' view of practices/approaches currently being implemented by physiotherapy, occupational therapy and speech and language therapy services in England.
- ii. Therapists will provide the detailed picture of the delivery of therapy and the decision-making about the therapeutic prescriptions.
- iii. Training Placement Supervisors will provide evidence on the approaches/techniques which current students are being taught and trained in, and the rationale for course curricula.
- iv. Clinical academics/researchers currently active in the field will provide evidence on recent/on-going research and the issues/challenges associated with evaluating a therapy intervention.
- v. Community paediatricians and neurologists allow the scoping study to place and understand therapy interventions within the wider context of the care and management of children with neurodisabilities.
- vi. Including parents and children ensures that patients and their families' views and perspectives are represented: this is an essential element of a piece of work of this nature.

### *Sampling and recruitment*

- i. National/professional group representatives: telephone calls to professional organisations will be used to identify appropriate individuals. These individuals will be invited to take part in the scoping study via email/telephone call.
- ii. Therapists and assistant practitioners: six focus groups will be held in locations across England to which therapists based in Therapy Services Departments in nearby hospitals will be invited. The groups will be held sequentially and characteristics of participants monitored. If necessary, invitations to later groups will be targeted to ensure the final sample has good representation of type of therapist, the settings where therapy is delivered, age and diagnoses of patients, and areas of specialism. Two further focus groups will be held in tertiary centres (for example, a residential paediatric acquired brain injury service).
- iii. Training Placement Supervisors: national league tables (provided by the Complete University Guide (<http://www.thecompleteuniversityguide.co.uk>) will be used to identify university departments achieving highly in terms of research and teaching of undergraduate and masters' degrees in physio-, occupational and speech and language therapies. Telephone calls to departments will be used to identify the appropriate individuals within their Training Placement sites to interview. These individuals will be invited to take part in the scoping study via email/telephone call.
- iv. Clinical academics/researchers: will be identified via searches of recent issues of high impact therapy journals and NIHR's research funding database.
- v. Community paediatricians & paediatric neurologists: an invitation to take part in an on-line survey will be distributed via email by organisations such as the British Association of Childhood Disability and the European Academy of Disability.

- vi. Parents: we will work with pre-existing parent groups coordinated by our research unit and voluntary sector organisations with whom we have worked with previously. Using pre-existing groups is time efficient and also has the potential to yield higher quality data as group members know each other can therefore move more quickly onto the particular task or discussion.
- vii. Children: we will work with special schools in our locality to identify one or two groups of children in each school. These groups will represent a range of ages, diagnoses and levels of functioning. All children invited to participate in the study will have current or recent experiences of physiotherapy.

## **Methods**

The method chosen to seek the views of each participant group has been decided on the basis of the type and depth of information required, see Figure 1. The approach to the work with children will be responsive to their communication and cognitive abilities. Visually based tools and non-verbal tasks/activities will be developed to ensure that actively participating in the group interview does not rely on speech or the child having access to a sophisticated communication system. We will meet with each group at least twice in order to allow us to pace the material covered and to develop familiarity and confidence with the researchers. This approach has proved efficient and fruitful in the past (Beresford, 2012).

The topics or issues covered in data collection will be tailored to each participant group, but will include some or all of the issues set out below. Where relevant, we will explore the impact of the nature and severity of the impairment, and age of the child, on views and practices.

- the perceived objectives of therapy interventions;
- the place of therapy interventions within the wider context of the care and management of children with neurodisabilities;
- understanding of the concept of 'participation' and whether it is meaningful as a therapy outcome;
- practices/approaches currently being implemented by physiotherapy, occupational therapy and speech and language therapy services in England which are perceived as seeking to improve participation;
- the factors which play a part in determining decisions about a child's 'therapeutic prescription';
- parent and/or child involvement in therapy;
- the components and 'active ingredients' of an intervention and their measurement;
- the approaches/techniques which current students are being taught and trained in, and the rationale for course curricula;
- emerging or promising interventions/approaches directed at participation outcomes, including those not routinely available in NHS services;
- priorities regarding the development of an evidence base.

### *Data collection*

Individual interviews and groups will be audio-recorded. Detailed fieldnotes will be made during and after each focus group/group discussion. Outputs of activities carried out with a focus group or group interview will be retained and either annotated or a written account made.

### **Data analysis**

Extended summaries (including verbatim quotes) of interviews/groups will be prepared using the audio-recordings, fieldnotes and any outputs from group activities. Quantitative data from the survey will be downloaded into SPSS and 'free text' responses into Excel.

The extended summaries and 'free text' survey responses will be analysed using a topic-based or thematic approach to qualitative data analysis (Miles and Huberman, 1994). The themes, or topics, will be closely informed by the objectives of the scoping study. A spreadsheet for each topic will be created. Columns will be used to divide the topic into smaller 'units' (sub-topics/themes). Each data collection episode will be allocated the same row number on all the spreadsheets. The material in each extended summary will then be extracted into the relevant cells on the spreadsheet.

To start, we will analyse data from the different participant groups separately. The spreadsheets will be used to generate a commentary of the findings. Within this process we will investigate and report evidence of the influence of patient group characteristics, type of therapy, or setting, on participants' views and experiences. The quantitative survey data will be analysed using descriptive and comparative statistical techniques and a commentary of the findings prepared.

Once fully populated, we will use the spreadsheets, survey data and commentaries to investigate differences or similarities between participant groups in the views expressed.

### **Project Advisory Group**

A Project Advisory Group, comprising senior academics/researchers, professionals and parents, will act as advisors to the project. We will use two face-to-face meetings and email to work with the Group.

### **Ethics**

The study will be reviewed by the University of York's Research Ethics Committee (sub-committee: Social Policy and Social Work).

### **Outputs**

A report of the scoping study will be prepared in which the current position regarding the practice and delivery of therapies to children with non-progressive disabilities will be reported. It will describe the factors (condition, setting, patient group) which are regarded as influencing the approach taken to therapy. The report will also discuss professionals', parents' and children's understandings of participation as a therapy outcome and their views on the appropriateness of

this outcome. Views on evidence gaps and the methodological and/or measurement issues facing high quality evaluative research will also be described. Drawing together these findings, the report will conclude with recommendations regarding research priorities and a suggested framework by which these complex interventions should be understood and evaluated. A summary of the findings from the scoping study will also be prepared and distributed as electronic or paper copies to all individuals who participated.

### **Research team**

Professor Bryony Beresford will lead the project. Professor Gillian Parker and Professor Alison Eastwood will provide input to the project as when required and will ensure effective communication/coordination between the scoping study and any subsequent evidence synthesis requested as a second piece of work. A Grade 7 researcher will be appointed to work on the project with administrative support. A second researcher will co-facilitate the focus groups and group interviews.

### **Project timetable**

A proposed timetable for the work is set out below. The start date is 1 May 2015.

- Month 1: Work on developing data collection tools commences  
Identification of sampling/recruitment pools & negotiating support/access commences
- Month 2: Advisory Group meets to review proposed data collection tools  
Application for ethics approval submitted.
- Month 3: Interviews with national /professional group representatives  
Interviews with course directors & teaching/placement leads commence
- Month 4: Group interviews with children commence  
Focus groups with parents commence
- Month 5: Focus groups with therapists and assistant practitioners commences
- Month 6: Survey of community paediatricians & paediatric neurologists goes 'live'
- Month 9: All data collection complete. Meeting of Advisory Group
- Month 10: Project report submitted

### **References**

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