

# Therapy interventions for children with neurodisabilities: a qualitative scoping study (The THINC Project)



## SUMMARY OF FINDINGS

### Why this study was carried out

People agree that more research is needed into physiotherapy, occupational therapy and speech and language therapy interventions. The National Institute for Health Research (NIHR) has been considering what sort of research it should invest in. It commissioned this scoping study as part of an information gathering exercise to inform their decision-making.

### The purpose of the study

The aim of the study was, through interviews and focus groups with families and professionals, to:

- describe the ways physiotherapy, occupational therapy and speech and language therapy are currently provided to children with neurodisabilities in England;
- understand how therapists decide what therapies and treatments to use;
- investigate the purpose or outcomes of therapy interventions, particularly how they may impact on children's participation in everyday life and activities
- to understand how the impacts of therapies can be measured;
- to hear people's views on research needs and priorities.

## Who took part in the study?

Over 70 professionals (therapists, service leads, paediatricians, education staff) and 25 parents took part in the study through individual interview or focus groups. We tried to recruit children and young people to take part too, but this part of the study was unsuccessful.

## Findings

Parents were certain of the value of the therapies, but may experience difficulties with services. For example, some parents felt their child did not get enough therapies, or the advice and information they got was misleading. Sometimes families were using private services as well as the NHS. Parents told us that doing therapies with their child can be time-consuming and disrupted other family activities and routines. Some parents said they felt under great pressure to stick to therapy programmes.

Across the three professions, what therapists do and the way services are organised and delivered are in a state of change. There is a move towards goals-focussed, family-centred approaches. Therapists are doing less direct work with children, instead they are instructing and supervising parents and therapy and teaching assistants to carry out interventions. Therapists told us these changes are due to new ways of thinking about the best way to meet children's therapy needs, and because there are fewer resources.

Study participants believed therapy interventions are highly complex and there are lots of different things about doing therapy that can have an impact on a child. People agreed that therapies should be working towards enabling and supporting a child to have the opportunity to take part in everyday life and activities. However, other outcomes were also seen as important for children and parents, such as quality of life, physical comfort, feeling able to manage the condition, and emotional well-being.

Overall, those who took part in the study agreed that more research into the impacts and effectiveness of therapies for children with neurodisabilities was needed. However, some professionals were concerned that research may not be done in a way

which properly detects changes and improvements. People agreed that researching therapies was challenging. However, they also agreed it was very important.

Parents and professionals suggested lots of different things which they felt should be researched. A few said that, first of all, we need to know and understand more about neurodisabilities. Others said better measures of therapy outcomes were needed before other research could be carried out.

However, most suggestions were for research which would show whether or not therapies worked. Here three areas were identified: overall approaches to therapy; the organisation and delivery of therapy; and the evaluation of specific therapeutic techniques. Parents tended to prioritise evaluations of approaches to therapy (e.g. goals-focussed approaches; supporting family-self management), along with testing and comparing different ways of organising and providing therapy services.

Professionals' views were broadly similar to parents' views, but they also emphasised research into the best way to evaluate therapies and measure their impacts on children's and parents' lives. Some people were keen for research to be carried out into a specific technique or treatments. However, these views were specific to individuals and based on personal interests and experiences.

## Conclusions

Therapy interventions for children with neurodisabilities are poorly understood. There was strong support for investment in research. Research priorities were nominated.

## Further details

A copy of the full project report (to view or download) can be found here:

<https://www.journalslibrary.nihr.ac.uk/hta/hta22030/#/abstract>

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