



Enabling self-care in children with developmental disabilities: pre-protocol research for a cluster randomised trial

Key findings

- An open-access, transparent sampling frame of children's therapy services in the UK, presenting a breadth of services, was developed to enable purposive and representative sampling for national surveys and studies.
- Using trials to evaluate therapy interventions is, in principle, viewed positively by therapists and parents. However, therapists' actual willingness to participate in trials is variable.
- Therapists' willingness to participate may be particularly influenced by their views related to burden associated with trials, intervention allocation, and professional autonomy.
- Current therapy practice to support self-care consistently involves techniques that target knowledge and skills (e.g. instruction on how to perform the behaviour, practice and rehearsal, graded tasks) and techniques that target the child's environment (e.g. restructuring social environment, social support).
- Key costs related to self-care interventions are time, equipment and aids. Key benefits of effective interventions are: child health and development, parent health and sibling wellbeing; savings to health and social care; and productivity benefits for the society.
- A self-care PICO has been specified using an HTA Commissioned call format.

Project aims

The overall aim was to generate pre-protocol evidence for the design of a cluster randomised controlled trial of a multifaceted self-care intervention. The objectives were:

1. To develop a sampling frame, including numbers of eligible services, therapists and children, for the trial.
2. To investigate the willingness of therapists and parents to take part in the research and to be randomised.
3. To specify 'current practice' and agree sampling and recruitment procedures compatible with that.
4. To identify costs and benefits of self-care interventions to inform a future economic evaluation.
5. To develop a trial protocol and a related NIHR Health Technology Assessment programme proposal.

Background

Development of self-care is an important childhood task, a key health outcome for children with neurodisabilities, and a core therapy goal for occupational therapists.

There is little evidence on the effectiveness of self-care interventions for children, no national guidelines, and no costeffectiveness ('value-for-money') evidence for commissioners.

As a result, therapy provision is variable and families receive differing advice. Addressing this evidence gap a key priority for children, families and therapists (McAnuff et al., 2017).

Methodology

The project consisted of three empirical studies and a related stakeholder engagement component. The studies were: **1)** An online scoping and a national survey to develop a sampling frame of children's therapy services in the UK. **2)** A national survey of the acceptability of cluster randomised trial designs in children's therapy. **3)** A qualitative study to specify current self-care practice and to identify costs and benefits. The planned stakeholder engagement was a series of co-creation workshops, which had to be cancelled due to Covid-19. Instead, we used novel remote engagement methods with parents and younger children (6-9yrs) with complex disabilities, and collaborative engagement with a national stakeholder organisation to develop a PICO proposal for NIHR HTA.

Recommendations and Conclusion

The present UKOTRF Research Priority Grant project has advanced research into evaluating interventions for self-care. Based on the work undertaken, we recommend further work to:

- Pilot a full self-care trial protocol, with particular focus on testing strategies to inform the decision-making of younger children with complex disabilities, and their parents, about trial participation. This should include careful consideration of modifications to commonly used trial materials and processes to enable meaningful decision-making by children with intellectual and communication limitations.
- Investigate the effectiveness of strategies to support and incentivise paediatric allied health therapists to become involved in trials – including addressing concerns about perceived control and professional autonomy within trials.

Until a stronger evidence base about self-care interventions and outcomes is established, it is important that therapists carefully consider how self-care outcomes are specified and how techniques for supporting self-care are selected. Existing, evidence-based strategies, such as personalised goal-setting, can be used to aid decisions. In parallel, therapists and managers need to consider how best to facilitate self-care trials, from shaping trial questions and designs to delivering them.

Publications

Armitage, S, McColl, E, Kolehmainen, N, Rapley, T. Describing pre-appointment written materials as an intervention in the context of children's NHS therapy services: A national survey. *Health Expect.* 2021; 24: 386– 398. <https://doi.org/10.1111/hex.13180>

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