Running a research consultation group with parents and carers of children with complex health needs who use children’s rehabilitation therapy services: practical considerations and insights.

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ABSTRACT
Participatory research, user involvement, consultation, co-production, and service user participation are terms and approaches that ensure the beneficiaries of research shape how it is developed and conducted.

While such approaches are accepted practice there is little guidance for researchers on how to conduct such activities with parents/carers of children with complex health needs.

Using insights from a series of consultation activities, the authors explore ways to work effectively with parents/careers when care responsibilities and other constraints may restrict or limit their ability to participate.

We defined children with complex needs children as those who use two or more therapy services (Occupational therapy, Speech and Language Therapy and Physiotherapy) on a regular basis.

METHODS

STAGE 1
Ethics approval
Recruitment of parent/careers via email/networks/flyers

STAGE 2
Face to Face Meetings
Three meetings (May-July 2017)
Generation of research themes
Narrowing down of themes to identify main areas/issues for parent/careers

STAGE 2
Virtual group information from the face to face group circulated and feedback from virtual group then informs face to face meetings.

STAGE 2
Literature review
Review of existing literature to inform developing research themes - feed back to face to face and virtual group

STAGE 3
Summarize themes and integrate with literature before circulating to parent/carer groups.
Development of research proposal in consultation with parent/careers, therapists and virtual group

INSIGHTS

- Multiple routes to recruitment
  - Use national networks to make contact with parents (Kent Parent Carers Forum).
  - Attend events where parents are likely to be present and use the opportunity to network with representatives from a variety of organisations (statutory and non-statutory). Distribute flyers and use email to engage parent/careers.

- Offering parent/career choices in their participation
  - Listen to parent/career views about date/time/location and format of events.
  - Offer options for both face to face and/or virtual involvement.
  - Recognise that parent/careers required flexibility to fit around caring commitments.
  - Offer the choice of a phone call with a researcher at a time convenient to them.

- Provision of child care
  - The majority of parents in the group had school age children and were able to participate during the school day but lack of facilities and/or resources to provide on-site or alternative childcare restricted the face-to-face participation of parents of younger children.

- Allowing enough time for parents to tell their story and express their feelings
  - Allow plenty of time for parent/careers to tell their story and avoid overly structured activities. Acknowledge the need for parents/careers to vent strong feelings of frustration and sometimes anger.

- Finding alternative ways of presenting information
  - Offer alternatives to written documents and consider quicker and less burdensome ways of providing information to participants with very limited, and precious, free time, e.g. audio and video based information.

CONCLUSION

The next stages of this project are to:

- Consult with therapists to gain their perspective before developing a research proposal with parents/careers.
- Provide appropriate support and training for interested parents/careers to be involved in the conduct of the research.
- Undertake internally funded research with the Kent Parent Carer Network to ensure that the input of our consultation group and other local parent/careers can be shared with local service providers.

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