

Interview schedule /focus group topic guide: Professionals

G-PATH STUDY: Gastrostomy feeding and psychosocial support [14/04/40]

[note to researcher please read the national survey results to familiarise yourself prior to interview and ask specific questions relating to the national survey]

Introduction

Evidence reviews have recommended the need to build in structured support in care pathways for children with neurodisability with complex feeding needs, and their families.

We are interested in learning about your experiences of supporting children and parents, and what you think their support needs are and at what stage they need support. We are keen to hear about your views on what you think good care is, what psychosocial support is and what structured support means to you in terms of your service. We are also keen to find out who delivers support, how children/parents access support and any gaps in provision or identify where services could be strengthened.

1. About you and your role and supporting families

First of all can you tell me your role (s) in relation to providing care for children and families?

Can you tell me how your service meets the support needs of children and families?

- Can you tell me who provides support?
- Can you tell me about your role in providing support?
- Could you give an example of the support you typically provide?
- What proportion of time would you say you spend providing support to children and families?
- What support do children and families need?
- Probe mothers, fathers, children, siblings –other family members

2. The service and how it supports children

- Are there specific appointments for support or is this provided as part of general care.
- Are there different offers for children. Mothers . families (ie who is offered the support)
- Is there a designated person who performs this role, if so who is this (i.e. Professional background)

- Can you tell me about the structure of the appointment and how support fits in?
- How is the need for support for children or their families decided? For example is there a formal interview or assessment – please describe)
- Are there any thresholds that children need to meet to access support
- When a parent is in distress about issues relating to feeding what referrals are available to you? Is there a psychologist available, or any other professional? Where do you refer, and what sort of guidelines do you follow?
- What training have staff undertaken to support families? Is training optional or mandatory?
- Are there any gaps in the way the service offers support

3. Variations in support offered

- Can you tell me about variations in the support offered to different children eg are there differences according to diagnosis or referral pathway. Can you give me some examples of who may get support and who doesn't and the reasons
- How are the needs of children families from different ethnic groups met (Cultural differences/language differences). What about children and families who don't speak English as a first language. How are their needs met by the service?
- What about older children and transitions

4. Peer Support

- Can you tell me about the role of other parents or peers in providing support? Do you refer parents to other parents
- How is this organised?
- Do parents take up the offer of support?
- What about children? (ie child to child support).
- Is the arrangement formalised?

Eg. training offered to parents

Eg. Formal evaluation of peer support

Eg. Parents paid to support others

5. specifically re national survey

A questionnaire survey was completed by your service

Ask questions and clarify anything in the national survey or add to specific questions in the interview schedule on hard copy. Do not change interview schedule

6. About referral pathways – visual mapping of the pathway (face to face) this may be asked sooner in relation to question 1 or 2 depending on the flow of the interview

I would like to understand something about the different referral pathways for children and families and the child and family journey .

Ask participants to draw or describe a typical referral pathway

Eg. can you tell me where a typical referral comes from (e.g. child development centre or other). Once the referral is received, who does it go to next (name of organisation/type of professional) then probe “what happens next “, then what happens

Ask about referrals from (name of organisation) to other referral centres. Where are children referred to, what is the reason for the referral?

In what way is support shared or coordinated across the different agencies, if so, how does this happen?

Once they have drawn the pathway, ask them to point out if/ where support is provided in the family journey and where they think the gaps are

Thinking about the variations I asked about before can you tell me about any variations in the pathway in the diagram?

How could support be embedded in a more consistent way across all referral pathways

Can you tell me if support is offered at any part of the external agencies).

7. Structured support

Evidence reviews recommend structured support in care pathways

- Would you say the support is structured, if so can you tell me in what way it is structured.

- [If not] can you help me understand how it could be structured and what the advantages of a structured approach might be
- Any disadvantages ?

8. Conflict & When parents disagree

- What happens when parents/children don't accept the recommendation of having a specific feeding plan or tube including a gastrostomy?
- Can you give me an example of when this happens, what type of issues does it raise?
- Could you please tell me about disagreements that might arise within the team about care plans in relation to feeding
- How are these managed and resolved?
- Do you have a process or framework for managing or resolving conflict?
- Is there clinical supervision or support for staff working with difficult cases?
- How does this work and how does it help? What else might help?

[if safeguarding hasn't been raised ask] –

- What about the role of safeguarding when professionals are concerned about children and families
- Can you tell me more
- Can you give me an example of when it is used.

9. Making changes

- If you wanted to make improvements to the support you/your service offered children and families, what changes would you like to make?
- What would help you to make those changes?
- What barriers if any would you need to overcome to make the changes you would like to make?

Probe: skill mix of teams/ staff training

Finishing off: is there anything else you would like to add. Are there any questions I needed to ask that I didn't ask? Thank participants etc