

A Value-based Co-redesign of an AHP Neonatal and Developmental Follow Up Service: a project based on lived experience of local families

An AHP Career Fellowship Project 2023-24 led by Karen Robertson, Occupational Therapist for Children & Young People on behalf of the D&G AHP Team who provide an in-reach Neonatal service & Developmental Follow Up

Background

National guidelines informing neonatal and follow-up services advise around evaluating infants' needs and promoting family-centeredness is a key recommendation.

Within Dumfries and Galloway, community children, young people and families Speech and Language, Physiotherapy and Occupational Therapy provide an inreach neonatal and a developmental follow up service locally for this healthcare population from existing budgets. Therefore it is a fragile service without ring-fenced capacity.

Aim

Our AHP team wished to better understand what family-centeredness looks like within deliverable practice by exploring lived experience from local families.

"If we only have a limited time with this family, what will make the most positive impact for them now, and for the future?"

We aimed to approach our service redesign to....

- concentrate resource utilisation on where it is of most value and will have the most impact by responding to local lived experience
- reflect the underpinnings of AHP policy in Scotland & existing models of family-centred care for this healthcare population
- outline delivery of a realistic and sustainable local AHP service

Method

An appreciative Inquiry approach with visual supports produced for the project were used to guide lived experience conversations.

13 parents (10 mothers and 3 fathers) participated in their choice of focus groups or individual home visits.

Thematic analysis was used to identify key 6 themes from the data. Our AHP team worked collaboratively to embed the themes into our service delivery.

3 participating families provided feedback on the proposal using a questionnaire method.

Themes from lived experience

Enabling parenting on the neonatal unit

Giving family agency to access AHP support

Supporting parental wellbeing

Communication & resources

The focus of developmental follow-up appointments

Empowering parents to advocate for their child beyond follow-up

Embedding themes into our proposal to co-redesign our service. We aimed to...

- develop a local family-centred Neonatal AHP leaflet
- provide a single point of AHP contact for all local neonatal & follow up families
- provide key AHP messages within time sensitive resource packs

- develop a local family-centred AHP Developmental Follow up leaflet with a visual map of the pathway
- provide a family-integrated approach to follow-up appointments, with parental participation facilitated throughout.

- use a family-centred approach to all AHP contacts, with a focus on family wellbeing
- use of individualised family-friendly feedback sheets to enable families to advocate for their child's needs at home
- provide additional therapeutic assessment, advice and the earliest of intervention where appropriate
- to extend our follow-up care pathway to include an information and support pack at age 4 years

"using parents' and children and young people's stories of their experiences of participation to further up-skill AHPs across Services for children and young people in Scotland and influence future decisions about our ways of working"

Ready to Act (2016)

Key findings

Further family consultation confirmed that the proposal:

- reflected and had responded to their shared lived experience
- would support parents to access AHP's
- enhance families neonatal & follow up experience
- will increase parental confidence in advocating for their child beyond follow up

Findings reflect key recommendations from AHP public health policy (Ready to Act 2016) and models of family-centeredness/integration from the literature

Findings could be relevant and applicable to other areas in Scotland/UK who have similar local baseline service challenges and opportunities

Key outcomes

- A value based co-redesign proposal for an AHP Neonatal and Developmental Follow-Up Service based on lived experience of local families & senior management level agreement to test the proposal.
- A new AHP service identity to enable measurement, management and reporting on risk with any incidence of unmet need
- A journey map of resources for this population including available evidence based resources, and locally co-produced resources with visual supports across AHP team with family consultation.

Next steps

- Implementing the service redesign proposal for a test of change
- Embedding lived experience feedback opportunities as core business
- Creating a dynamic and responsive service which is realistic and sustainable
- Making coproduced resources available for ALL neonatal families

