
Improving early intervention services for parents of infants with complex emerging neurodevelopmental difficulties

Embedding clinical research through participatory design

Phillip Harniess MSc [a, b*], Siew-Lian Crossley BSc MSc [c], Rachelle Joyce [d], Serena Manners [d],
Niyati Patel [d], Deanna Gibbs MOT PhD [e]

[a] UCL Institute of Education

[b] Great Ormond Street Hospital

[c] Monash Children's Hospital, Victoria, Australia

[d] Homerton University Hospital NHS Foundation Trust

[e] Bart's Health NHS Trust

*Corresponding author: phillip.harniess@nhs.net

ABSTRACT

Background:

This paper builds upon previously published findings of early intervention multidisciplinary therapy (occupational, physiotherapy and speech and language therapy) research, surrounding experiences of families of infants with emerging complex neurodevelopmental difficulties (Gibbs, Harniess et al. 2019). The aim of this two-phased project, funded by an APCP research bursary, was to use parental experiences of accessing early therapy services throughout neonatal admission, transition to home, and ongoing community services, and apply findings to implement service co-design through participatory methods. Here we present phase two findings and the outputs (including evaluation) of this research.

Method:

In this second phase we used a participatory workshop with parents (n = 7) of a range of backgrounds, reflecting the diversity of the urban setting in which this research was conducted. Results from phase one were presented to the group, providing a focus towards developing recommendations for service improvement. An appreciative inquiry approach and qualitative descriptive analysis were used.

Results:

Five specific service design recommendations were identified. Specific recommendations directly addressed parental concerns and experiences pertaining to the vulnerability that they feel during this time and the importance of relational continuity. For example, developing and enacting a local integrated pathway from acute neonatal services to community therapy services, alongside the implementation of a new role of a 'link therapist'. Evaluation showed how this output enhanced the existing service structure where the same therapists that provide intervention upon the neonatal unit continue to work with the same family during transition and into the community.

Conclusion:

By combining participatory research and action, this study has enabled implementation of changes in early intervention therapy service provision, such as the development of a new role – a named 'link therapist'. This demonstrates a pragmatic and efficient method to translate research findings into clinical practice.

Introduction

Infants with complex neurodevelopmental difficulties usually present with early neurological signs that impact function, including atypical movement, tone, posture, state regulation, interaction, and early feeding difficulties. Ordinarily, these infants are affected by their condition more severely in the long term. Therefore, they require sustained engagement with early intervention (EI) therapy services, which include physiotherapy, occupational therapy and speech and language therapy and are often initiated within the neonatal unit continuing into community services following discharge. The adverse impact of the neonatal experience upon parents is well established in the high-risk infant literature, causing disruption to parental role development and the parent-infant relationship, as well as heightened risk of anxiety, stress and depression (Aagaard and Hall 2008, Borghini, Habersaat et al. 2014, Gibbs, Boshoff et al. 2015). For parents of infants with emerging complex neurodevelopmental difficulties, using cerebral palsy as an exemplar, stress and anxiety is often

compounded by more complex and time-consuming parenting demands, as well as dealing with grief of an unforeseen diagnosis (Rentinck, Ketelaar et al. 2007).

Previously, having identified a literature gap accounting for the experience of families with infants with emerging complex neurodevelopmental difficulties receiving EI therapy services within the NHS, we undertook a two-phase research study, which received funding through an APCP research bursary. The aim of this project was to first explore the experiences of parents with infants with complex neurodevelopmental needs accessing EI therapy services throughout neonatal admission, transition to home, and ongoing community services. The project then sought to use these findings to implement further service co-design with further participatory methods. The first phase of this study was recently published (Gibbs, Harniess et al. 2019). This paper reports the qualitative interview (n=6) findings in depth, which were summarised in four key themes articulating the parent experiences during their evolving relationship with therapy providers in the neonatal unit and following discharge: (a) a vulnerable start—adjusting to the unexpected; (b) becoming a mother—becoming a family; (c) the therapy journey; and (d) a new reality. The vulnerability that parents feel during this time and the importance of relational continuity for parents with therapists was highlighted, which could be enhanced with early introduction of EI therapists within a neonatal unit admission continuing into the community. Other relational attributes were seen as essential, pertaining to the development of collaborative communication styles, supporting expectations of the parent-provider relationship, and ensuring clarity in the nature, scope, and contribution of EI therapy to their child and overall family development. These findings reinforced the ‘action’ requirement of the project, with a view to build these positive features into the ongoing development of the EI therapy service, for example within the evolving care pathways. The aim of phase two was to co-design recommendations with parents, using phase one findings, and implement specific service improvement strategies for future evaluation.

Method

Design

Phase two design used a participatory workshop with parents. The results of phase one were presented to elicit wider group discussion, leading to a focus upon developing recommendations for service improvement. The workshop lasted three hours and involved facilitated open discussion by an external research occupational therapist (author – DG), which was audio recorded and later transcribed.

The facilitated discussion was conducted in two main steps. Firstly, an outline of the thematic analysis from the individual interviews was presented. This presentation was directly followed by a facilitated discussion to explore parental perceptions of whether the themes reflected their own experiences. Parents identified if any experiences or attributes were missing from the analysis and highlighted the most important aspects of parent experience. Secondly, an appreciative inquiry approach was used to co-construct how the positive elements of the existing structure of service provision could be built on to more comprehensively meet the needs of infants and their families (Whitney 1998). Finally, the discussion facilitated the parents to rationalise these brainstormed ideas and prioritise them into a set of specific recommendations for the service. Whilst having parallels with a participatory action research approach it is important to highlight that this study did not fulfil the strict methodological requirements of this approach, which is used mostly in social activism research (Baum, MacDougall et al. 2006). For example, further parental involvement was not possible within the subsequent cycles of implementation of service development and evaluation, owing to time and financial constraints. Except through consultation in development of the parent leaflet. Evaluation was undertaken of specific outputs (discussed later) through surveying parent users of the service and was conducted by the therapy team.

Analysis followed a descriptive approach as outlined for phase one of the study. Qualitative description adopts a naturalistic approach, by understanding a phenomenon through exploring the meanings that individuals provide for certain events (Bradshaw, Atkinson et al. 2017). Ontologically, qualitative description is placed in relativism, which asserts that reality is subjective and varies from one person to another. Therefore, what is offered in qualitative description research is “a subjective interpretation strengthened and supported by reference to verbatim quotations from participants” (Bradshaw et al., 2017, p. 2). This is described in more detail within the paper reporting phase one findings (Gibbs et al, 2019).

Ethical approval was provided before the commencement of the study (15/LO/1134). All personal and research data was stored safely, kept confidential and anonymised for the purposes of sharing; in alignment with data protection regulations.

Setting

The study was conducted in an urban area of the UK. The local setting has a culturally and linguistically diverse population, with a high level of poverty and inequality. The hospital included in the study was a level 3 neonatal unit, which provides neonatal care to extremely premature and critically ill infants and their families. A therapy team, including physiotherapy, occupational therapy and speech and language therapy, was part of the neonatal unit service. This team provides developmental intervention from birth for infants during their admission and into the local community therapy services through the first two years of life, for infants with complex neurodevelopmental needs. Therapeutic input was offered individually, usually in the family home following discharge. The intervention approach included joint goal setting with families and blocks of therapy sessions focused on supporting families to enable their child to meet their developmental targets. Depending on the family's goals and preferences, therapy sessions could include one or more of the therapy team members. Intervention typically focused on developing parental occupations, sensorimotor, feeding, and early communication skills.

Participants

Parents who met inclusion criteria were identified through the local clinical database by treating therapists. The inclusion and exclusion criteria are summarised in table one. Parents were purposively sampled to be approached for participation. Treating therapists (authors SLC and PH) then approached parents who met the criteria and provided a participant information sheet. Parents who indicated their interest were invited to the workshop. The consenting process was undertaken by the external researcher (author - DG). The final number of participants for the workshop was seven, made up from five families. This number included five parents who were involved in the phase one interviews, in addition to two partners. Table two displays the characteristics of all parents who participated in the workshop.

Inclusion criteria	Exclusion criteria
☐ Child had an admission on the neonatal intensive care unit and/or the special care baby unit. ☐ Child met local criteria for neurodevelopmental assessment and follow-up due to being born prior to 32 weeks of gestation and/or birth weight below 1.5 kg and/or experiencing an acute neonatal neurological event (e.g., neonatal seizures, neonatal stroke, HIE, congenital brain abnormality). ☐ Child between 6 months of corrected age and 24 months of corrected age. ☐ Child received individual therapy input from occupational therapy, physiotherapy, and speech and language therapy during and following discharge from hospital. ☐ Parent(s) had conversational English language skills.	☐ Parents and their children have only had contact with therapists at hospital settings, in developmental clinics, and in group settings. ☐ Parents with learning difficulties. ☐ Parents with a history of mental health problems (see caveat*).

Table 1: Participant inclusion and exclusion criteria

* This exclusion criteria focused on the recognition that parenting a high-risk infant may influence their mental health and well-being either from pre-existing conditions or resulting from their neonatal unit experience, and the nature of the data collection process may result in their recollection of experiences that were emotionally distressing. Potential parent participants were asked to consider their own mental health and well-being within

the recruitment process, and to discuss their involvement with their family and general practitioner before consenting to participate. Therefore, parents were given the opportunity to decide whether they would like to participate and not excluded on the grounds of mental health, unless their decision-making capabilities were impaired.

Parent	Gender	Parent Age	Parent ethnicity	Infant Gestational Age at Birth	Infant Birth weight	Infant Length of stay (days)	Infant Diagnosis
1	F	39	European	23+5	470g	86	Cerebral Palsy; periventricular leukomalacia <u>Chronic lung disease</u>
2	F	40	European	37+4	2240g	20	Congenital neurological condition Intrauterine growth restriction
3	F	43	White British	39+4	2880g	12	Congenital condition
4	F	39	South Asian	38+5	1940g	30	Cerebral palsy; Hypoxic ischaemic encephalopathy Intrauterine growth restriction
5	M	NC	South Asian				
6	F	34	White British	30+4	1835g	35	Cerebral Palsy; periventricular leukomalacia
7	M	NC	European				

NC – Not collected

Table 2: Parent participant demographics

Results

The prioritisation process used within the workshop discussion identified five specific recommendations. These incorporated a mixture of practical and resource-based recommendations, and others that aligned more with foundational values for service outlook and how it engages with families. The following recommendations were co-constructed with the families:

1. Early intervention services work with parents towards operationalising what constitutes family centred care in the local context.
2. Therapists work collaboratively with families, shifting from a culture of infallibility, to one where all parties are open to learning and sharing ideas to best support infant development.
3. Specific pathways to support transitions from hospital to home and within community services are enacted. Attributes suggested for this recommendation were in relation to ensuring a consistency in therapy service provision from hospital to home, and also mechanisms by which to improve the transfer of infants between therapists within the community to ensure continuity of care.
4. There is improved support for families on the neonatal unit. The specific attributes suggested for this recommendation included increasing access to the provision of psychological support, and also a whole-unit approach to the timing of information sharing and disclosure of difficult information
5. Communication pathways between therapists and families are improved. The specific attributes suggested for this recommendation focused on:

- Clearer communication of the role of and collaboration between specific therapy professions during the neonatal admission.
- Co-ordination of specialist and universal services in community following discharge.
- Communication between professionals, including; improving transitions for families between professionals
- The implementation of more accessible forms of sharing information with families, through the enhanced use of information technologies.

Outputs

These recommendations reflected a variety of aspirations with differing levels of complexity. Some were complex at a conceptual-praxis level (e.g. moving away from an infallibility culture) and others involved complexity outside of the control of the EI therapy team (e.g. IT use for information sharing). Nevertheless, from the basis of these broad recommendations, we were able to identify and prioritise a number of local, meaningful recommendations that potentially could have feasible implementation strategies to improve the support and experience for families with infants with complex neurodevelopmental difficulties receiving EI services. Figure 1 provides some transparency of how these outputs came directly from initial phase one findings and subsequent phase two recommendations.

Acute to Community Complex discharge pathway

Research findings supported the creation of the 'acute to community complex discharge pathway' (figure 2). This has been an important clinical development for the new service and incorporated aspects of existing multidisciplinary service structure, such as the neurodevelopmental follow up service of high-risk infants. Its aim is to guide and establish consistency of best therapy service provision for families of infants with complex neurodevelopmental needs.

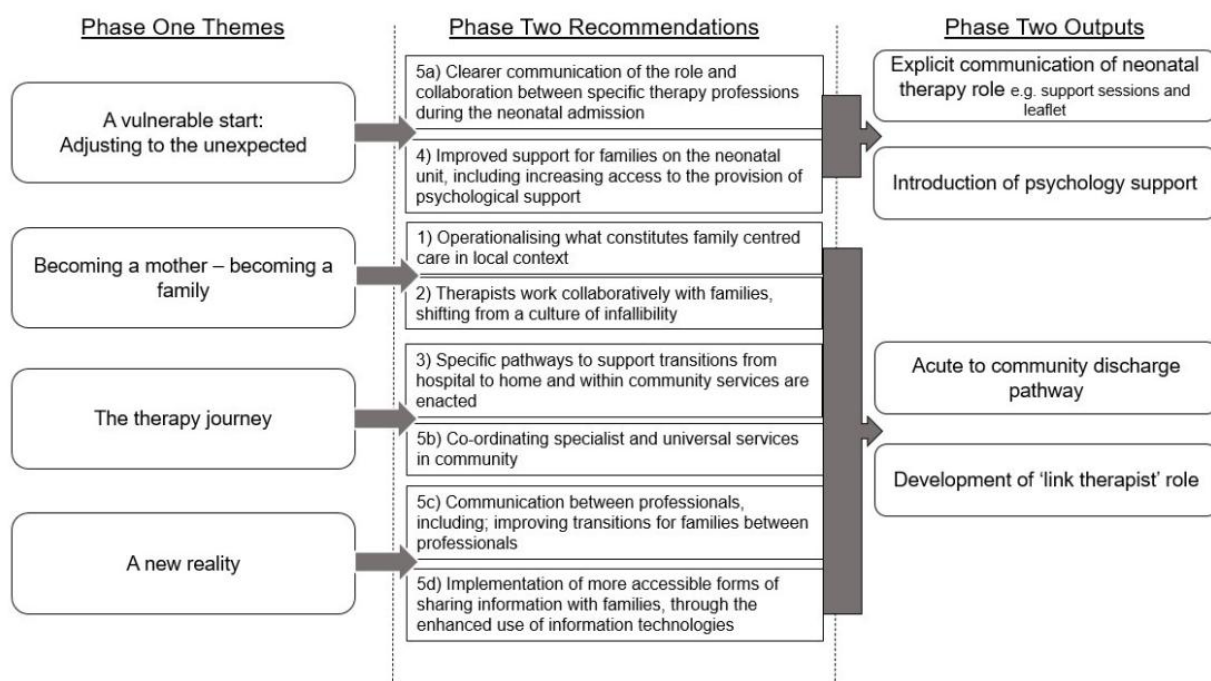


Figure 1: Findings - Recommendations – Output trail

Development of 'link therapist' role

The development of a new 'link therapist' role was a key action from this research and aligns with the 'acute to community complex discharge pathway' (figure 1). This role entails assigning a named member of the neonatal therapy team to any family with an infant with complex neurodevelopmental difficulties identified within the neonatal unit, to provide continuity and focused support. This support is particularly important during transition from the acute neonatal unit to community services. The 'link therapist' role includes a number of responsibilities, such as;

1. Being a first contact for families
2. Leading on collaborative therapeutic treatment plans
3. Guiding families through the early developmental assessment pathway, including communication between the family and other services regarding their diagnostic work up
4. Connecting the family into the existing wider local developmental community services, with regular communication within existing multi agency meetings, including closer integration with the key worker service

Participants and therapists believed that with the continuity and shared knowledge with families offered by the therapy service, this initiative ('link therapist') became an effective way to help parents through this vulnerable and stressful early period, particularly around transition from the neonatal unit to the community.

Another important consideration was the challenge of transferring families between therapists, as required for case management purposes. Therefore, to avoid wholesale changes in families' service user experience, phased transfers have been introduced and hand over is a careful process with forewarning and planning with the family to enable adequate adjustment.

Communication of neonatal therapy role

To address parental uncertainty of the role of therapists in the early stages, particularly on the neonatal unit two resources were created. These included;

1. Parent support sessions set up and led by nurses and therapists for parental education on developmental care and parental peer support
2. A developmental leaflet with information about the therapy role, and including space to write details of the link therapist for families to take away.

Introduction of psychology support

At the same time of introducing changes from the research, the neonatal unit was able to fund 0.4 (whole time equivalent) of psychology support for the neonatal unit. This new service has been integrated with the therapy team to enhance the service delivery on the neonatal unit and into the community.

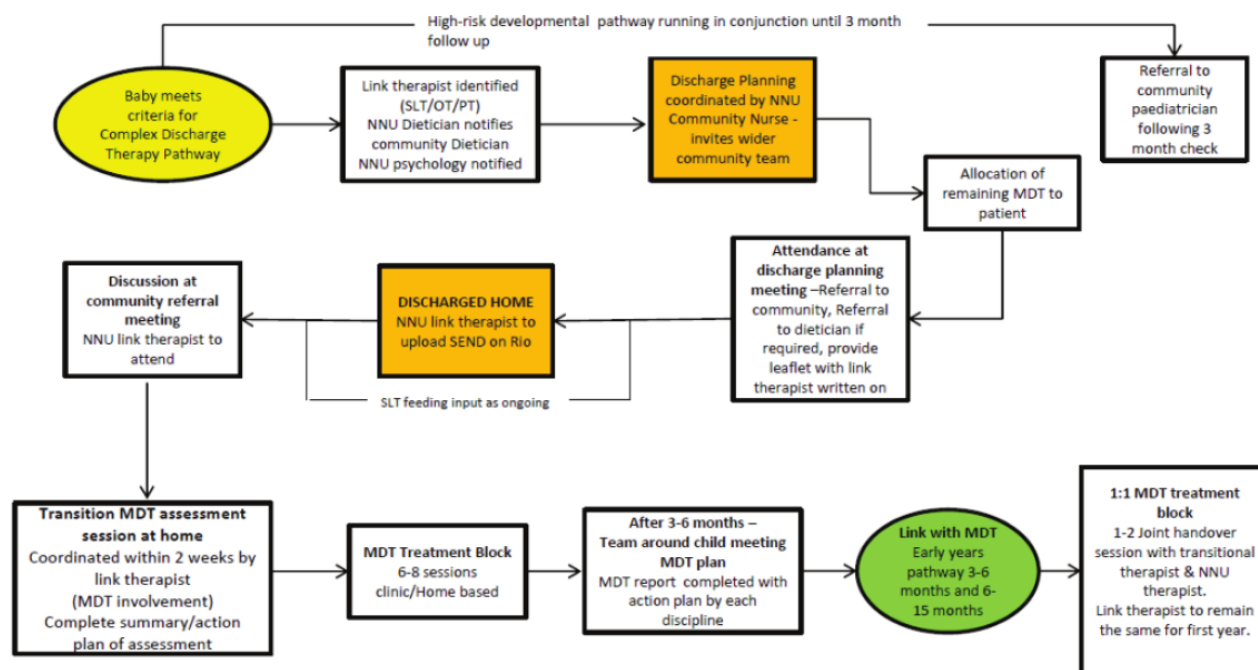


Figure 2: Acute to community complex discharge pathway

Evaluation

To complete the cycle of this participatory research project, after implementing the changes an evaluation was undertaken. Specifically, evaluation of the 'link therapist' role was undertaken by subsequent therapists working within the service (authors RJ, SM and NP). We found that over three years (2016-2019) 20 families had been assigned a link therapist through the acute to community complex pathway. Of these families, seven parents responded to a service evaluation survey, the key findings were:

- i. Eighty-six percent of families agreed continuity of care was done well
- ii. Parents reported that duplicating information sharing happens rarely (57%) or sometimes (43%), as therapist feeds back to other team members
- iii. Each discipline offered clear therapy blocks, and worked together through joined up appointments and treatment plans
- iv. Parents concerns were prioritised
- v. Appointments were flexible in location and time

Further evaluation is planned through auditing therapy adherence to the local acute to community complex discharge pathway.

Discussion

This project aspired to improve the service provision and experience for parents of infants with emerging complex neurodevelopmental difficulties. We have demonstrated how participatory research can be used to create meaningful and tangible outputs. The study has enabled prioritisation and successful implementation of changes, such as the development of a named 'link therapist' that is helping to meet the project's original aims. Whilst these changes are localised, the publication of the phase one findings give broader resonance and transferability. We believe that this process of research with implementing outputs, is transferrable and attainable for other clinical teams in the UK to improve practice. It can provide a pragmatic approach to clinical research by focusing on how findings can be implemented efficiently and effectively, therefore overcoming the commonly reported '17-year lag' of research to practice translation (Morris, Wooding et al. 2011).

The successful translation was achieved by using an overarching participatory design, beginning with open exploration of parental experiences by listening carefully to the parent voice. Through subsequent collaboration in this second phase, we were able to identify how the project findings could be used practically to initiate change. These findings highlighted the vulnerability that these parents feel at the point of receiving EI therapy services. Hence, the model employed by the local team whereby the same therapists that provide intervention upon the neonatal unit continue to work with the same family during transition and into the community, was a helpful foundation for this project and the developments implemented. The link therapist can be the 'constant' that parents need during challenging transitions; as they 'adjust to the unexpected' of becoming a parent to a child with emerging complex neurodevelopmental difficulties, transfer from a NICU environment to home and subsequently navigate services that they had no prior understanding of (Gibbs et al, 2019).

Other research in this area has identified the complexity to providing good quality EI therapy services for families of children with complex neurodevelopmental needs. Good service structure with systems (integrated with other agencies) that enable consistent quality and access for all families, needs to be balanced with other factors that may be deemed more subjective but are equally important, such as continuity of good parent-therapist relationships and collaborative communication (Ziviani, Darlington et al. 2014). It is noteworthy, with the presence of family-centred care principles in practice for over 20 years that therapists are often aware of these factors and can identify when parents are optimally engaged, but there are still circumstances when parental engagement doesn't work as well (D'Arrigo, Copley et al. 2019). Some of the reasons for this may be outside of the control of therapists but there may also be aspects of our practice that impact negatively upon parents without our awareness. Being reflective as therapy practitioners and service providers is integral, and using qualitative research that listens to and articulates the voice of parents can support this. However, we also need to practice humility in our position as experts in practising family-centred care, which may still be in tension with traditional therapy models (Lawlor and Mattingly 1998).

Limitations

Although phase one of the study included a smaller than anticipated sample, the participants in both phases of the research reflected the ethnic diversity of the local population. The overall study was designed to recruit mothers and fathers, but ultimately only mothers participated in the phase one interviews. Therefore, in this second phase of the study, we purposefully planned the focus group discussion to occur during a weekend, which served to enable the participation of both mothers and fathers. While we believe that the approach used in this study is transferrable to other contexts, further research capturing a greater diversity of families whose infants receive services in different EI models of care, is recommended. The participatory approach was used to reduce the power imbalance between researcher and participants, to enable honest reflection and co-construction of recommendations for implementation. Our preference would have been to involve the parents further within the implementation and evaluation as co-researchers to continue the participatory experiential action cycle. However, the feasibility of further involvement was constrained by time (including parents') and financial resources.

Conclusion

This participatory study has demonstrated how therapy services using research data in a direct and practical way can improve service provision, within this example with families of infants with complex emerging neurodevelopmental difficulties. The service has been able to be more effective at meeting the needs of families during this vulnerable time by listening to their experiences and using findings to collaboratively design recommendations and implement changes.

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