

# Integrating Parent Lived Experience into Training Programmes for Healthcare Professionals

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## Introduction

Inviting parents to bring their lived experience to the education of neonatal healthcare professionals has proved to be both a revelation and an inspiration. Since 2017 we have been developing active roles for parents as part of the Family and Infant Neurodevelopmental Education (FINE) foundational education faculty. This began in Hungary and Romania with parents as organisers, co-coordinators and translators, but it soon became apparent that their lived experience and their passionate interest in improving service for children and families in neonatal units could be captured, extending their role to explore family experiences in a unique way. As they became familiar with the programme, they became very willing to take this on with confidence and we recognised the unique contribution their knowledge and experience brought to the validity of the training. In the last year and a half, we have recruited and prepared parents for the UK faculty. Recruitment was through personal contacts and with the help of Bliss, a national charity that supports neonatal units. Our first recruits have brought a wealth of other professional skills to our team as well as their experience as parents.

## Aims

- To bring lived experience into the training space
- To highlight the importance of communication with parents in the newborn intensive care unit (NICU)

## Methods

- Parents who are not currently in the middle of the neonatal experience, who can participate and respond with knowledge and hindsight, are invited to be part of the faculty for foundational education programmes.
- They provide continuous insights during training days, help to shape the curriculum, and with experience and guidance lead some of the topics.
- They provide a space for discussion and reflection, and opportunity to ask questions in more intimate group workshops.
- The programme is semi-scripted so that the boundaries of discussion are contained.

- In recognition of the emotional energy that this work demands and the need to make it sustainable, professional psychological support is provided for parents who participate and, in addition, supervision and support from senior faculty is provided.

## Results/Findings

- Through the participation of parents as faculty several aspects of the foundational education programme have been changed and improved, including the kind of language used and introduction of coaching techniques.
- Faculty report on the impact that parents' contributions have had on their way of teaching, how it has changed their perspective of their practice, and their perceptions of how the course has benefitted from the addition of this shared lived experience.
- Participants report that they highly value the powerful contribution of parents lived experience.
- Parents feel that by sharing their experience and the values of the FINE programme they have an impact on improving the care for preterm babies and therefore their future outcome. Furthermore, to be able to shape and improve the experience of parents on neonatal units gives the parent faculty members an enormous sense of fulfilment.

## Conclusion

This approach highlights the benefits of drawing on lived experience. It enhances the value of foundational education particularly when this experience is also drawn on to shape the way training is delivered. Other ways in which this experience may be extended to help healthcare professionals gain skills in understanding and communicating with parents are being explored.

## Relevance to NIDCAP

This approach could be integrated into the NIDCAP training programme to deepen the understanding of the training participants with regards to the lived experience of the parents and carers.