

Informed Choice: a view through the lens of then and now

Gwen Carr looks back at the principle of Informed Choice and how it works now

The 'Early Support Programme', funded by the Department for Education, ran from 2002 to 2015 and aimed to improve coordination between education, health and social care professionals and improve outcomes for disabled children and their families by promoting integrated, partnership-based, family-centred service delivery. Although the programme itself has ended, its core values and principles remain in evidence in current policy and practice guidelines – although professionals frequently report substantially more challenging resource environments in which to enact them.

Within a policy climate which promoted parental empowerment and the centrality of parents and children in decision-making processes around their own care (DH National Service Framework 2004¹, DH/DfES Together from the Start, 2003²), 'Informed Choice' was one of the fundamental principles of Early Support. It acknowledged the issues of the highly variable quality and nature of information available to families, lack of equity in service access, and a growing questioning of 'expert' models of provision. With Early Support's initial phases focusing on children in the 0-3 age range coinciding with the Department of Health's national roll-out of newborn hearing screening, however, there arose a unique and timely opportunity to examine the issue of Informed Choice specifically in the context of childhood deafness – recognising the significance of Choice and Decision-making as an enduring experience of parenting a deaf child (DesGeorges, 2003³, Young and Grealley, 2003⁴).

Work on the Informed Choice research and development project began in 2004, funded by the Early Support Programme and carried out by NDCS in partnership with the University of Manchester. The commissioned brief was to investigate the complexity of Informed Choice as a concept and to develop a deeper understanding of what it meant both in theory and in practice. The outputs were to be two Early Support publications: a professional handbook with practice guidance for those involved in providing services to young deaf children and families⁵, and support materials for parents making decisions (ultimately entitled 'Helping You Choose'⁶).

The project team⁷, co-led by myself as then NDCS Director of UK Services and Professor Alys Young from Manchester, recognised immediately that the issue of Informed Choice would present some challenges to long held natural biases – not least our own as we brought diverse professional identities as teachers,

social workers, third sector advocates and CODA to the dynamic as well as our focus as researchers. What we hadn't anticipated, however, was the strength of some of the negative reaction from Local Authority support services when the project was first announced, especially those with long histories of commitment to and strong advocacy of particular communication methodologies. Fears were expressed that the work might lead to their being compelled to provide support for approaches to communication development that they didn't espouse, with which they fundamentally disagreed, and for which they felt they were not resourced.

During the two-year project 'journey', however, in which the team worked closely with parents and professionals from a wide range of disciplines at both strategic and operational levels in three distinctly different geographical areas and service contexts, it became clear that for parents, the issue of Informed Choice pervaded their experiences far beyond concerns about communication decisions. For them, choice – or perceived lack of it – affected their experiences, good or otherwise, in all areas of their interfaces with services: with all agencies and in matters ranging from appointments and transport to the way in which they received and accessed information and how professionals worked together and in partnership with families themselves. The process and experience of the project and the way in which the conceptual and practical understanding of Informed Choice, the 'underpinning concepts and enduring challenges', evolved as it progressed, is discussed in depth in Young et al, 2006⁸, and the two Early Support publications formed the basis of a dissemination and training programme that had impact beyond the UK and stimulated positive reaction in an extensive international context.

The work resulted in clear consensus on the meaning of Informed Choice: that "families can make knowledgeable decisions which reflect their own culture, values and views ... based on access to comprehensive, unbiased and evidence-based information about the full range of options"

(Professional Handbook). The implications of embracing an Informed Choice approach to professional practice in which "service providers adopt open and flexible policies that effectively endorse a range of possibilities" and "make no value judgements about one option over another" clearly challenged services. However, developments in practice since – at least in respect of some of the key elements of Informed Choice –

would indicate that, whilst recognising the challenges and acknowledging inherent biases, much has progressed.

In more recent years, there would appear to be less polarisation in the debate about communication methodology, together with a discernible shift towards an evidence-based consideration to support the discussion rather than philosophical belief. Information to parents is arguably much more balanced and comprehensive, and information produced by advocates of specific approaches to developing communication tends now to avoid criticism of alternative methods, acknowledging that a range of choices exists which can also lead to success for deaf children. The importance of parents being able to make informed choices has also been recognised internationally as a key component of best practice which contributes to positive outcomes for children and families (Moeller et al, 2013⁹, GPODHH Position Statement, 2010).

A focus on supporting families through their decision-making processes has also come to the fore with the development of decision aids (some successfully adapted from Health-based models). The Ottawa Personal Decision Guide (O'Connor et al, 2011¹¹) has for example underpinned the development of the Decision Guide to Communication Choices produced by the US Center for Disease Control and Prevention (CDC) and the Dartmouth Institute for Health Policy and Clinical Practice's "Interactive Option Grid Decision Aid: Deafness in infancy and childhood language options"¹² is another evidence-based structured tool. Other organisations such as the Ida Institute have also put considerable emphasis on supporting the psychosocial processes of decision-making, and from an audiological perspective, attention has also been given to the role of decision aids to support parents making choices about the use of amplification or cochlear implantation.

Perhaps the most significant change in the appreciation of what facilitates informed choices however is the enhanced recognition of the key contribution of 'shared lived experience'. The original Informed Choice work highlighted that the crucial relationship was not between 'Information' and 'Choice' but between 'Understanding' and 'Choice', and that to develop the depth of understanding required to make truly informed choices, parents needed to hear the experiences of other parents. Janet DesGeorges, Executive Director of Hands and Voices in the US and herself a parent of a deaf child has written extensively on parent peer support and the need for systematic mechanisms to ensure its existence in the fabric of support services and advocates parent developed decision aids¹³ whilst Henderson et al 2014¹⁴ have explored and developed a conceptual framework for parent to parent support, and initiatives such as the Hands and Voices Guide by Your Side programme in

the US, the online forum Parent Place (NDCS) in the UK and the Aussie Deaf Kids parent forums are excellent examples of such peer support in practice.

In current times when services are under pressure in terms of resources, implementing all elements of practice which facilitate Informed Choice for families is undoubtedly challenging. In terms, however, of the key aspects of high quality evidence-based information, privileging parental knowledge and expertise, and the involvement of parents as partners in decision-making processes, there is clear commitment in today's climate, which was less evident ten years ago. The future challenge will be to sustain, nurture and develop all areas of Informed Choice moving forward. The original work highlighted the fact that Informed Choice is a process not an end, and the process continues. ■

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