

Informed choice – National Deaf Children's Society position statement

(for external audiences)

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1. Background

- 1.1 Making choices and decisions for and on behalf of their children is of course common to all parents, influenced by their own cultures, values and beliefs and informed by what they have experienced and know about raising a child. Most families with a deaf child, however, have little or no experience of childhood deafness and as a result, little prior knowledge to support them with the extra decisions involved around, for example, about amplification and communication.
- 1.2 Where children are identified as deaf through newborn hearing screening or early in life, parents may also feel pressure to make decisions that they feel ill equipped to consider in a very short timeframe. This is in addition to the usual demands of having a new baby in the family. Families whose children are identified at an older age can also find themselves faced with choices and having to make decisions which they had not anticipated and for which they feel unprepared.
- 1.3 Children and young people also have rights in relation to informed choice, and as they grow and develop, they become increasingly able to form their own views and express their own preferences. These should be respected and listened to as informed choices are made which impact their futures.
- 1.4 Given the right support, deaf children can and should develop and achieve at the same rate as hearing children of similar abilities. To ensure that deaf children have the same opportunities as their hearing peers to fulfil their potential, we believe that it is vital that:
 - a) professionals not only provide high-quality services and accessible information about the full range of options, but also give families the support they need to make the choices they feel are best for their own child and family
 - b) UK governments ensure that professionals and services are resourced and able to provide support in ways that enable the different choices and needs of families to be addressed and realised.

2. What does informed choice mean?

- 2.1 Informed choice means that families can make knowledgeable decisions, which reflect their own cultures, values, and views. It is based on access to comprehensive, unbiased, and evidence-based information, about the full range of options – not just those available in each locality.

2.2 Service providers who promote informed choice ensure that they:

- a) support families to reach decisions in ways that are sensitive to their individual strengths, resources, needs and experience
- b) provide support, information and experiences which help families become skilled and confident decision makers
- c) adopt open and flexible policies that effectively endorse a range of possibilities
- d) make no value judgements about one option over another and reflect this stance in their strategic decision-making and resourcing
- e) recognise that informed choice is not a one-off decision but an ongoing process, which responds to the changing needs and views of the child and family at different times and stages of life.

2.3 All choices entail risks, benefits, and consequences. In and of itself, no choice is 'right' or 'wrong'. * A choice which works well for one child and family (whether that may be in relation to communication, amplification, education, or healthcare) may not work well for another, because individual needs and circumstances vary. If a choice is working well, enabling a child to develop positively and to thrive, and it suits the family's context, culture, values, and views, then it is the right choice for that family, at that time. As children grow and develop, choices should be reviewed and either confirmed or modified as necessary, always informed by the individual needs of the child, guided by the family's knowledge and experience, and respecting the family role (and increasingly that of the child or young person themselves) as informed decision makers.

*There may be occasions in which there are ethical considerations involving potential risk or harm, where a family's preferences may be at odds with the child's rights and assessed needs.

3. What does informed choice involve?

3.1 For families to make properly informed choices, they need to understand the implications of any decisions they make and what they may mean for their child and their family, both in the short and in the longer term.

3.2 Therefore, in addition to receiving full and accessible information about all options, presented without value judgements, families need support to deepen their understanding through gaining experience. The importance of meeting a variety of other parents and families who have made a range of different choices, together with individuals who have lived experience of deafness, cannot be overstated, and service providers should facilitate opportunities for families to make and share these connections.

3.3 Families may also need the support of a range of professionals who can discuss with them the implications of potential choices and the evidence base that underpins them. Some families may face extra uncertainty when there may be limited evidence to support some potential options or where evidence may be open to interpretation.

Service providers should be honest and open about uncertainties and support families in evaluating their options. This can promote shared decision making which can empower informed choice.

- 3.4 Shared decision making is a collaborative process in which professionals can support individuals to reach decisions. It combines the expertise and knowledge of the professionals with the preferences, circumstances, values and beliefs of the person who is faced with a decision to make and can help achieve the outcomes which they hope for.
- 3.5 Parents are able to make informed choices when they understand the options and the risks, benefits and uncertainties each may bring, together with the practicalities of implementing their potential choices for their child and family.

4. Implications for UK governments and service providers

- 4.1 To ensure that families can make informed choices, we believe that UK governments should:
 - a) ensure that services are resourced to provide a range of high-quality education, health, and care support to meet the diverse choices and needs of families
 - b) promote the importance of informed choice and be clear in its expectations that all service providers should support families to make informed choices.
- 4.2 We also believe that service providers should commit to the principle of informed choice and ensure this is embedded in their work. This should involve:
 - a) employing professionals who can:
 - i. support families to gain the necessary knowledge, information, and experiences to reach fully informed decisions in ways that show respect and understanding for their cultures and values and are sensitive to their individual strengths, resources, needs and experience
 - ii. present information in a form that is accessible for individual families.
 - iii. convey information in an equitable, unbiased and non-judgemental way, not influenced by strongly held personal views or philosophies or those of service planners.
 - iv. express the implications of all choices in terms of risks, benefits, and impacts in both the immediate and longer term
 - v. undergo ongoing professional development in supporting families within an informed choice approach
 - b) appropriate signposting to other information sources which can provide insights into potential choices, supporting experience of a breadth of approaches and views on different issues
 - c) facilitate opportunities to meet other families with deaf children and people with lived experience of deafness who have made a range of different choices for their children, their families or themselves
 - d) provide information about the National Deaf Children's Society and other national or local voluntary organisations, and commitment to working alongside any voluntary

sector organisation from which the family may be receiving support, in the best interests of the child and family

- e) have open and flexible policies in place that effectively endorse a range of possibilities, making no value judgements about one option over another and reflecting this stance in strategic decision-making and resourcing. This will involve informing families about, and supporting them to explore all options, regardless of whether they are available locally
- f) be honest and open about what they can and cannot provide and the reasons for this in a neutral and balanced fashion, working to remove these restrictions wherever possible and where appropriate. Provision should not adopt a blanket policy which would serve to restrict opportunity for individual families based on their informed understanding of their child's needs
- g) facilitate access to the options which best meet a child and family's needs and preferences. Enabling access may necessitate addressing a range of other social or economic needs experienced by families
- h) recognise that informed choice is not a one-off decision but a fluid ongoing process, which responds to the changing needs of the child and family at different times and stages of life, and support for families as they evaluate, re-evaluate, and confirm or revise their choices.