

Informed choice for families position statement

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1. Background

- 1.1 With the advent of newborn hearing screening the importance of providing full and impartial advice to families at the outset and throughout the child's life cannot be over-stated. Providing this full range of information to families is the essential foundation for ensuring that a deaf child achieves their potential throughout life.
- 1.2 Given the right support, there is no reason for any deaf child to develop at a slower rate than a hearing child with similar abilities. In order to ensure that every deaf child develops at an age appropriate rate and achieves their full potential it is imperative that services working with those children and their families provide a full range of information and support to enable those families to make the choices they feel are most appropriate for their child.
- 1.3 Offering Informed Choice to families of deaf children means that families are better placed to make informed decisions that reflect their own culture, values and views and meet the needs of their child.

Such an approach is based on access to comprehensive, unbiased and evidence-based information, about the full range of possible options.
- 1.4 An approach to service provision that promotes Informed Choice is one in which:
 - a) Service providers adopt open and flexible policies that effectively endorse a range of possibilities and communicate all of these possibilities to families.
 - b) Services and professionals make no value judgements about one option over another and this stance is reflected in their strategic decision making and resource allocation.
 - c) Families are supported to reach decisions in ways that are sensitive to their individual strengths, resources, needs and experience.
 - d) Families' decisions are respected and upheld by those working with them.
 - e) Informed Choice is not seen as a one-off decision but as an ongoing process, which should be capable of responding to changing circumstances.
- 1.5 An Informed Choice approach does not restrict information to options that are available in a given locality, nor does it allow personal views or beliefs to influence the provision of information.

2. Context

- 2.1 A focus on Informed Choice for families with deaf children has emerged out of three related factors:
 - a) The reported experience of families with deaf children who are not always informed about all of the options available.
 - b) An emphasis on the empowerment of parents and the importance of family-centred services, aligned to the rights of the child.
 - c) A wider political and policy climate that encourages Informed Choice.

3. Policy

- 3.1 NDCS has based its vision, values, support and campaigning over many years on the goal of ensuring that every family of every deaf child is supported with the

information and resources they need to make genuinely informed choices in the best interests of their child.

In order to realise this vision the following success measures must be met.

Families

- 3.2 Every family is given access to information, knowledge and is able to understand all of the options available to them.
- 3.3 Families are given access to every option (communication method, health interventions and educational provision).
- 3.4 Information is presented to families in their own terms, taking into account their cultural and social background.

Professionals

- 3.5 Professionals working with families of deaf children receive appropriate training.
- 3.6 Professionals working with families of deaf children reflect a commitment to Informed Choice in their attitudes and values.
- 3.7 Professionals working with families of deaf children are open to working alongside any voluntary sector organisation from which the family may be receiving assistance.

Services

- 3.8 All services are provided using an Informed Choice approach throughout childhood and into the transition to adulthood. This includes the possibility that children and their families may need to change a communication, health or educational approach according to changing needs.
- 3.9 There is appropriate resource allocation of the various options available for deaf children.
- 3.10 Every local authority reflects a commitment to Informed Choice in their resource allocation strategy and philosophy.

These success measures can only be achieved if:

- 3.11 Central government sets a minimum standard of provision that all local authorities must meet for every deaf child. This standard should be the “core offer” provided by the state to every family.
- 3.12 Central government actively monitors and measures this provision and takes action where provision falls below a minimum standard.
- 3.13 Central government takes action to ensure sufficient quality and quantity of professionals working with deaf children and their families are available in every part of the country.