

## Consultation form

We are seeking your views on potential topics relevant to social care for guideline and quality standard development. We would like your views on an initial list of proposed topics and any other areas that you feel need to be included. **The consultation is open from Friday 17 July 2015 to Friday 9 October 2015.** Please return this form to [socialcaretopics@nice.org.uk](mailto:socialcaretopics@nice.org.uk) by 5pm on Friday 9<sup>th</sup> October.

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<b>Please note:</b> comments submitted may be published on the NICE website.	

The personal data submitted on this form will be used by the National Institute for Health and Care Excellence (NICE) for the purpose specified. The information will not be passed to any other third party and will be held in accordance with the Data Protection Act 1998.

# **Draft response by the National Deaf Children's Society to the suggested social care topics for future NICE guidance.**

## **Background**

The National Deaf Children's Society (NDCS) is the leading charity dedicated to creating a world without barriers for deaf children and young people. NDCS helps deaf children thrive by providing impartial practical and emotional support to them and their families, and by challenging governments and society to meet their needs. NDCS believes that every deaf child should be valued and included by society and have the same opportunities as any other child .

National Deaf Children's Society (NDCS) uses the term 'deaf' to mean all types of hearing loss (hearing impairment), including unilateral deafness and temporary deafness such as glue ear. We support all deaf children and young people, regardless of their level of deafness, how they communicate or what technical aids they use.

## **Introductory comments on this consultation**

NDCS is primarily responding to this consultation in terms of the needs of children, young people who are deaf and the proposed topic on **support for adults, children and young people with sensory disabilities**. However, some of the key areas outlined below have direct relevance to the outcomes and experiences of deaf adults.

Within any standard, we believe there should be a specific recognition that services must be readily accessible to deaf people whose first language is British Sign Language, through the provision of sign language interpreting and translation in order to promote equality of access and enable full participation.

## **Should the topic be included?**

Yes, NDCS believes the topic **Support for adults, children and young people with sensory disabilities** should be included. We have no comment to make on the other topics.

## **Why should this topic be included?**

There are a number of factors identified through research which, we believe, demonstrate why this topic should be considered within future NICE guidelines. Additionally, significant changes in social care legislation and policy in recent years also lend weight to the need for quality standards in this area.

## Evidence of increased risk factors for deaf children/adults

Research shows that deaf children are at greater risk of poorer well-being outcomes than other non-disabled groups. These include;

- **Mental health difficulties-** 40% of deaf children experience mental health difficulties in childhood/early adulthood<sup>1</sup>, compared to 10% in the general population.<sup>2</sup>
- **Deaf children are more at risk of abuse:** Deaf children are more than twice as likely to be abused as other children, 20% compared to a prevalence rate of 9% among non-disabled child population.<sup>3</sup>
- **Lower educational attainment** Deaf children consistently lag significantly behind their hearing peers at key national attainment targets. This is despite deafness in itself not being a learning difficulty. In 2014 only 36.3% of deaf children in England left secondary school having hit national GCSE benchmarks compared with 65.3% of other children.<sup>4</sup>
- **Live in lower income households:** Many deaf children live in families on a low income. In 2009 pupils where hearing impairment was the main type of special educational need were 38% more likely to be eligible for free school meals than other children<sup>5</sup>
- **Experience unemployment**<sup>6</sup>
- **Difficulties accessing health services.** Many deaf children and young people reported having to rely on hearing family members to book appointments on their behalf and provide communication support at GP surgeries.<sup>7</sup>
- **Poorer health outcomes** A recent study reported an under-diagnosis and under-treatment of potentially serious health conditions among deaf adults<sup>8</sup>.
- **Additional disabilities:** There is a relatively high incidence of other disabilities in children with a hearing impairment.<sup>9</sup> This can mean that a deaf young person has involvement from a wide range of service providers across health, education and social care.

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<sup>1</sup> Department of Health (2005) *Mental Health and Deafness: Towards equity and access*

<sup>2</sup> Department of Health (2013) *Our Children Deserve Better: Prevention Pays* Annual Report of the Chief Medical Officer 2012,

<sup>3</sup> Sullivan and Knutson (2000) Maltreatment and disabilities: A population-based epidemiological study' in *Child Abuse & Neglect*, 24.

<sup>4</sup> [http://www.ndcs.org.uk/professional\\_support/national\\_data/england\\_education.html](http://www.ndcs.org.uk/professional_support/national_data/england_education.html)

<sup>5</sup> Department for Children, Schools and Families (2009b) *School Census*. (DCSF 2009)

<sup>6</sup> Office for Disability Issues Annual Report 2008: Annex one: Indicators data reported that between 33% and 52% of deaf adults are unemployed (95% confidence intervals) compared to 20% of non-disabled adults. Figures taken from Labour Force Survey. RNID (2006) Opportunity blocked: The employment experiences of deaf and hard or hearing people reported that one in five deaf adults are unemployed compared to one in twenty of the UK labour market.

<sup>7</sup> *My Life My Health Deaf young peoples experience of health services* NDCS (2013)

<sup>8</sup> *Sick of It: A report into health of deaf people in the UK* Sign health (2014)

<sup>9</sup> Moores (2001) estimates the incidence as between 30-40% and Shallop (2008) reported it to range from 39%-54% among children with cochlear implants

## **Deafness is a low incidence disability.**

Deafness is a low incidence sensory disability<sup>10</sup> but can have a significant impact on children's social emotional and intellectual functioning if they are not given the right support. This makes it very difficult for services to respond and recognise the specific and varying needs of deaf children at the delivery or commissioning level.

Significantly 90% of deaf children are born to hearing parents<sup>11</sup> who have not had any prior experience of deafness, many who require advice and support as to what the implications this will bring for their child and their family.

## **Lack of access to children's social care services.**

Research has shown that in many areas children's social care fail to recognise deaf children as *children in need* within established statutory legislation and therefore fail to make arrangements to assess their needs and ensure access to services<sup>12</sup>.

In an NDCS social care mapping survey, carried out in 2014<sup>13</sup>, of English children's social care services, we found:

- nearly half of local authorities' social care teams (49%) said their eligibility criteria did not include any specific reference to deaf children or sensory impairment.
- 45% of local authority social care teams could not identify the numbers of deaf children receiving social care services.
- children's social services frequently assumed that deaf children's need would be met via education colleagues even though there were no clear protocols in place to ensure this.

The increasing marginalisation of deaf children within children's social care has largely come about following the Children Act 2004 which resulted in the separation of adult and children's services. Many specialist generic deaf social work teams were disbanded and individual posts became subsumed with general children with disability teams whose eligibility criteria has not reflected the needs of deaf children.

A serious case review in 2011 concluded that a children's disability social care team had failed to accept that a deaf child with additional needs had clearly met the criteria for a statutory social care assessment and to understand the impact on the child of not meeting their needs relating to their deafness.<sup>14</sup>

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<sup>10</sup> Annually in the UK 840 babies are born deaf, meaning around 1 in 1,000 or 60 children are born with a severe to profound hearing loss. Around half of all deaf children are born deaf, and around the same amount acquire deafness during childhood.. Scottish Council of Deafness.

<sup>11</sup> Mitchell and Karchmer 2002 'Chasing the Mythical Ten Percent: Parental Hearing Status of Deaf and Hard of Hearing Students in the United States' in *Sign Language Studies*.

<sup>12</sup> Young A, Hunt R, Smith C (2010) *The Impact of Integrated Children's Services on the Scope, Delivery and Quality of Social Care*

<sup>13</sup> *Services for Deaf Children and their Families: Phase 2 report*. NDCS Social care mapping survey (2015) [http://www.ndcs.org.uk/professional\\_support/our\\_resources/social\\_care.html](http://www.ndcs.org.uk/professional_support/our_resources/social_care.html)

<sup>14</sup> Smith, C (Independent Chair) (2011) Executive summary available online at <http://www.kirkleessafeguardingchildren.co.uk/>

The rate of language development of deaf children born to hearing parents is often less than the development of language of children born to deaf parents. (Karchmer & Mitchell, 2003). The importance of exposure to a rich language environment as early as possible cannot be underestimated. It is therefore crucial for social care services to understand the potential risks that this may pose and therefore ensure they are supporting families to create communication-friendly homes so that their deaf child can develop language and social skills and develop educationally.

### **Ending of established multi-agency frameworks**

The 2006 Newborn Hearing Screening Hearing Programme (NHSP) aimed to encourage a clear multi-agency pathway to meet the holistic needs of deaf children following diagnosis in England across education health and social care. Due to recent health service restructuring in England, this multi-agency framework is now under review. Before it was disbanded, it had established good working protocols between health and education at initial diagnosis but, for the most, part children's social care failed to adhere to its requirements.

Therefore, in the absence of a similar framework, the development of a quality standard would therefore help ensure that the holistic needs of deaf children across services are properly considered.

### **What are the key areas that should be covered by the topic?**

#### **Early intervention**

Research suggests that the timing and quality of support offered to parents and carers of newly diagnosed deaf children are important to ensuring deaf children are given the right support to help them progress. Research by Yoshiana-Itano (2003) identified that successful early intervention programmes included:

- contact with parents immediately following diagnosis;
- providers are specialist professionals across education, health and social care;
- weekly support to parents providing emotional, information on communication and child development; and
- children's developmental progress assessed twice yearly and used to help parents make or revise decisions on how to support their child's development.

A quality standard should aim to ensure that this key initial trigger for support takes place and will be able to use qualitative feedback from parents commenting on the support they are given.

## **Multi-agency working**

Multi-agency working is key to support the holistic needs of deaf children, young people. This is recognised within the Newborn Hearing Screening Programme (NHSP) as mentioned above and also within Paediatric Audiology Standards in Wales and Scotland and the NHS Scotland Quality Standards for Transition from Paediatric to Adult Audiology Services.

## **Transitions**

Transition is widely recognised as a difficult time for deaf young people as it coincides with a period of rapidly changing physical, psychological, social and educational development and may also be a significant time in terms of identity development. This has implications for a range of services deaf young people will access. A quality standard could ensure that services which work across the age ranges from children to adults are working together to ensure the transition managed in way which is supportive to the young person moving between them.

Part 3 of the Children and Families Act 2014 introduced a new requirement for Education, Health and Care plans for children with special education needs (SEN) from 0-25 yrs. This Act dovetails with the Care Act 2014 for adult social care and emphasises the importance of transition between children's and adult services in order to ensure children young people and adults with SEN are given the support they need to progress in education and training.

One example of where deaf young people may face difficulties in the move to adulthood lies in their experiences in further education (FE). Many deaf learners enter FE with deficits in social skills, emotional maturity and mental health problems compared with their hearing peers. However, Young et al (2014) found a wide variation in responses by FE institutions with some offering tailor made curriculum for deaf learners to develop their social and emotional skills whilst other FE institutions had nothing specific in place, assuming that deaf young people would gain this knowledge informally through general college experiences. Such gaps in deaf learners social and emotional skills should be recognised and planned within Education Health and Care plans. However, as a significant number of deaf students will not have these plans, there is a risk that their specific social and emotional issues related to their deafness will not being addressed in more ad hoc transition arrangements.

Evidence of a supportive pathway in post 16 transitions, including in FE and training, could be included within this quality standard. Whilst this falls partly within the educational boundaries, this would ensure social care needs in terms of social skills training, and access to appropriate communication support in all post 16 destinations, including within FE, will ensure services are promoting the independence and well being of deaf young people as they move into adulthood.

Also deaf young people will also move from paediatric to adult audiology services within health services. At present only NHS Scotland have developed quality standards in this area.<sup>15</sup>

### **Access to health services**

As outlined above, there is evidence to show that deaf young people and adults are at greater risk of not having significant health needs diagnosed or their health needs met. A key barrier to deaf people accessing health services is the ability of community services such as GPs to provide ready access to communication support in order for deaf people to book appointments and for interpreters to be used when necessary. There are clear duties under the Equality Act that GPs must make reasonable adjustments for disabled people to use their services but evidence suggests that there is clearly some way to go. In 2016, the new NHS Accessible Information Standard (England) will aim to strengthen the requirement on health services to find out and meet the communication needs of disabled people including people with a sensory loss. The quality standard could also help ensure this standard is also being met.

## **What are the key sources of evidence for the topic?**

### **Early intervention**

Yoshinaga-Itano C (2003) 'From screening to early identification and intervention: Discovering predictors to successful outcomes for children with significant hearing loss' in *Journal of Deaf Studies and Deaf Education*, 8, pp 11-30.

Yoshinaga-Itano, Sedey A L, Coulter D K, Mehl A L (1998) 'Language of Early- and Later-identified Children With Hearing Loss' in *Paediatrics: Official journal of the American academy of American paediatrics*, 102 (5), 1161-1171.

### **Accessing social care**

Young A, Hunt R, Smith C (2010) *The Impact of Integrated Children's Services on the Scope, Delivery and Quality of Social Care Services for Deaf Children and their Families: Phase 2 report.*

Young A, Hunt R, Smith C (2008) *The Impact of Integrated Children's Services on the Scope, Delivery and Quality of Social Care Services for Deaf Children and their Families: Phase 1 report.*

NDCS Social care mapping survey (2015) at

[http://www.ndcs.org.uk/professional\\_support/our\\_resources/social\\_care.html](http://www.ndcs.org.uk/professional_support/our_resources/social_care.html)

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<sup>15</sup> Quality Standard s for Transition from Paediatric to Adult Audiology Services (2013).

## **Mental health**

Department of Health (2005) *Mental Health and Deafness: Towards equity and access*

Hindley (1993) 'Signs of Feeling: A prevalence study of psychiatric disorder in deaf and partially hearing children'. London RNID quoted in Department of Health (2002) *A Sign of the Times: Modernising mental health services for deaf people*.

## **Transitions**

Fordyce M, Riddell S, O'Neill R and Weedon E, (2013) *Post-school Transitions of People who are Deaf or Hard of Hearing*

## **Further education**

Young A, Oram R, Squires G, Sutherland H (2014) *Identifying effective practice in the provision of education and education support services for 16 – 19 year old deaf young people in Further Education in England*

## **Accessing health care**

*Sick of it: A report into health of deaf people in the UK* (2014) Sign Health, The University of Bristol

*My Life My health*; The National Deaf Children's Society Youth Advisory Board (2014)

## **Employment**

RNID (2006) *Opportunity Blocked: The employment experiences of deaf and hard or hearing people*.

## **Additional disabilities**

Shallop J K (2008) 'Complex children and cochlear implantation', Cochlear Implants 2008 State of the Art Conference.

## **Quality Standards (all include standards around multi-agency working)**

### **Early identification and multi-agency support**

Newborn Hearing Screening Programme 2010 (under review)

<http://hearing.screening.nhs.uk/standardsandprotocols>

### **Social care**

Association of Directors of Social Services, British Deaf Association, Local Government Association, National Children's Bureau, National Deaf Children's Society, Royal National Institute for Deaf People (2001) *Deaf Children: Positive practice standards in social services*.



## **Paediatric standards**

Quality Standards for Paediatric Audiology (Scotland)

<http://www.gov.scot/Publications/2009/04/27115728/0>

Quality Standards for Paediatric Audiology (Wales)

<http://gov.wales/topics/health/publications/health/guidance/qualitystandards/?lang=en>