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## Disabled Children

### Headlines

Disabled children and their families face a distinct and often challenging set of circumstances that demand a unique and sometimes specialised response from both the universal and targeted services that support them. Locally 1 in 8 (12%) of 14 year olds reported that their everyday life was affected by a health problem and/or disability.

As well as their physical and/or learning disability, disabled children are at increased risk of experiencing further ill health, such as:

- Health problems associated with specific genetic and biological causes.
- Communication difficulties and reduced health literacy.
- Personal health risks and behaviours such as poor diet and lack of exercise.
- Problems with access to healthcare provision.

The needs of disabled children, young people and their families are unique to them, often complex, and change over time. The challenge is to understand these needs and develop a system around them that is flexible enough to meet the needs of the person and their families.

A lack of data at both national and local level about the numbers of disabled children, their needs and their use of local services, compounded by the absence of a consistent and universally applied definition of disability makes it difficult to determine the scale and scope of disability and to identify needs. 21 in 1,000 children have moderate learning disability, 3.5 in 1,000 have severe disability and 1 in 1,000 profound and multiple disability. Cerebral palsy is the most common source of long term physical disability in children, 2 in 1,000 live births.

Locally, taking special educational needs (SEN) as a proxy, males aged under 19 are far more likely than females (23% compared to 16%) to have SEN. Children living in the more deprived areas of Kirklees were 2 to 3 times more likely to have SEN.

### Why is this group important?

The Disability Discrimination Act 1995 defines a disabled person as someone who has:

- A physical or mental impairment, which has substantial and long term adverse effects on his or her ability to carry out normal day-to-day activities.
- Physical and mental impairments including sensory impairments such as those affecting sight and hearing. Mental impairment includes learning disabilities and mental health problems.

A Health Needs Assessment for Disabled Children in Kirklees was undertaken in 2009<sup>1</sup>. It highlighted a lack of precise data at both national and local level about the numbers of disabled children and their use of local services. Nationally it is estimated that 21 in 1,000 children have moderate learning difficulties, 3.5 in 1,000 have severe disability and 1 in 1,000 profound and multiple disabilities<sup>2</sup>. Children with moderate learning disability have an educational delay of three years and those with severe disability need help with communicating, mobilising and co-ordination. Some people with learning disability also have physical and/or sensory impairments, mental health problems or other 'neuro-developmental disorders' such as autism.

The numbers of children with SEN is used as a proxy for some form of disability, but it is not an ideal measure. The main reasons for identifying SEN are mild to moderate learning difficulties and specific severe learning difficulties, both of which are increasing in numbers. Estimates for Kirklees in 2010 suggest that 1 in 50 (2%) of the school population have a SEN requiring a statement. 1 in 6 (17%) primary school children and 1 in 5 (21%) secondary school children require some extra assistance for SEN<sup>3</sup>.

Cerebral palsy remains the most common source of long-term physical disability in children, around 2 in 1,000 live births but more boys than girls<sup>4</sup>.

## What significant factors are affecting this group?

Disability may arise because of biological, social or environmental factors or a combination of these. The majority of disabled children have genetic or pre-natal causes, e.g. chromosomal abnormalities or infections during pregnancy. Low birth weight and/or extreme prematurity can also affect the child's development – see infant mortality section. In pre-school years disorders of language development and autism may be identified. Progressive neurological, muscular or metabolic disorders also appear. During early school years other problems such as communication, behavioural, emotional and social problems may arise, e.g. dyslexia and self esteem issues.

The increase in the rates of children identified as SEN arises from a combination of the increase in the proportion of younger English adults who belong to Pakistani ethnic communities, and an increased survival rate among young people with severe and complex disability<sup>5</sup>.

All disabled children are dependent to some degree on the adults who care for them. There is evidence that learning disabled people take less exercise than the general population and that their diet is often unbalanced with an insufficient intake of fruit and vegetables<sup>6</sup>. Learning disabled people can find it hard to understand the consequences of their lifestyle on their health. Many learning disabled children are obese by adulthood and may suffer from conditions that are associated with being overweight.<sup>6</sup> Rates of smoking among young people with a mild learning disability are higher than among their peers<sup>5</sup>.

The frequency of mental ill health in children increases with the severity of intellectual impairment. So up to half of learning disabled children may need special services for emotional/mental health problems at some time during their childhood. Between 5 and 15% of learning disabled people also have challenging behaviour and many experience being bullied<sup>6</sup>.

Families, carers and young carers are central to providing care and support to disabled children. This can be demanding and place a huge amount of stress on families and carers, who should be supported, have their needs met and help shape services<sup>1,7</sup>.

## Which specific groups are affected most?

Locally, the number of children and young people with a SEN or statement in males aged 0-19 is much higher than in females of the same age group. Nearly 1 in 4 (23%) males have a SEN and 4% a statement of SEN, compared to nearly 1 in 6 (16%) and 1.7% females respectively<sup>1</sup>.

White and Pakistani origin children have similar levels of SEN, 1.6% with statements of SEN and 21-24% with SEN. This contrasts with children of Indian ethnicity who have 1.1% with statements of SEN and 14% with SEN<sup>1</sup>.

The infant mortality programme has identified a higher rate of deaths and long term disability in those of Pakistani origin, particularly from congenital abnormalities. About 1 in 3 of such children die before five years of age and most survivors experience chronic disability and are cared for with support from specialist community paediatric services<sup>8</sup>.

## Where is this causing greatest concern?

Huddersfield, Spen and Dewsbury had higher rates of SEN. Children living in the most deprived areas of Kirklees were between two and three times more likely to have a SEN. Nearly half of children (46%) with a SEN and 2 in 5 (43%) with a statement of SEN lived in the most deprived 20% areas in Kirklees<sup>1</sup>.

## Views of local people

Using the 'Aiming High for Disabled Children' framework,<sup>7</sup> parents were sent a questionnaire to express their views of health, education, care and family support services for their disabled child as experienced in the previous 12 months. Kirklees achieved 62 (out of 100) compared to a national average of 61 in 2009/10.

The majority of parents and carers of disabled children feel that they are not routinely involved in shaping services. A lack of support in helping families to make informed decisions about treatment and care was also highlighted. In addition, families felt that they were not able to access appropriate information at every stage of their child's life. Parents and carers would like to find out about services through GPs and schools.

Parents and carers also highlighted the assessment process as a source of frustration, both in terms of length and complexity. There was also a perceived lack of continuity and co-ordination between agencies. Parents and carers stressed the need for stronger links with adult services in order to better support 16-19 year olds through the transition period into adult care<sup>1</sup>.

Over half of disabled children and young people consulted, stated that they would like to undertake sports activities, but parents and carers felt that there is a lack of sports and leisure opportunities. Other activities that children and young people would like to undertake include arts, crafts, computer work, cooking, and going to clubs. Most of these children and young people said that needing someone to help them stops them from doing the things they like<sup>1</sup>.

Parents and carers have also emphasised insufficient emotional and practical support for parents and carers, insufficient out of school activities and a lack of training for parents.

## What could commissioners and service planners consider?

The NHS Operating Framework and the Kirklees Children's Trust Plan have confirmed a commitment to ensuring that disabled children are a priority. It is imperative that disabled children are given the support that they and their families need in order to fulfil their potential. Aiming High for Young Children<sup>10</sup> aims to improve access to services and empowerment for disabled children and families; having in place responsive services with improved service quality and capacity.

To better scale and scope out the needs of disabled children and young people the main agencies need to agree a definition of disability which all agencies work to. The newly formed Learning Disability Observatory hosted by NEPHO has devised standard criteria to define and collate data for learning disabled children<sup>11</sup>. It is recommended that this approach is used within Kirklees. A standard definition and/or mechanism needs to be defined to ensure that those physically disabled children who do not necessarily require a SEN are also identified.

## Commissioners and service planners could also consider<sup>12</sup>:

- Improving sign posting and information about appropriate services for parents, carers and disabled children.
- Ensure GP registers for learning disabled people are managed and that general health checks are included in the annual check up. The opportunity to discuss healthy behaviours should also be taken.
- Commissioning services or designing current provision more in line with the needs of physical and/or learning disabled children including appropriate access. Services may include sports and leisure activities, out of school clubs with a focus on arts, cooking and computers and services to support smoking cessation, alcohol misuse and sexual health.

- Ensuring support for parents and carers is identified and opportunities provided.
- Improve the assessment process, links between agencies and develop a transition process to adult care sensitive to the identified needs of children, young people and their parents/carers.
- Encouraging health and social care staff to be aware of how learning disabled children may communicate in hospital and other health settings, as they may not be able to tell health professionals how they feel, or what they want and need.
- Ensuring that the needs of disabled children and young people are met in relation to the general health and wellbeing challenges of all children and young people within Kirklees.

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