

JSNA: Disabled children and young people

Introduction

This chapter sets out the key issues for families, how we are responding, and the ongoing challenges for the local area in supporting disabled children and ensuring positive health and social care outcomes. It does not address adult disability issues.

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.

Some will have highly complex needs requiring multi-agency support across health, social services, and education – the most extreme example perhaps being those who are technology-dependent. Other children will require substantially less support, although nevertheless have a long-term disability.

Disabled children and young people are at greater risk of underachieving, are often excluded from the opportunities available to their non-disabled peers, and can experience greater poverty. These circumstances can lead to poor physical and mental health outcomes.

The Department for Education (DfE) has stated that:

- Disabled children and young people currently face multiple barriers which make it more difficult for them to achieve their potential, to achieve the outcomes their peers expect and to succeed in education;
- Approximately 29% of disabled children nationally live in poverty;
- Nationally the educational attainment of disabled children is unacceptably lower than that of non-disabled children and fewer than 50% of schools have accessibility plans;

- Disabled young people aged 16-24 are less satisfied with their lives than their peers and there is a tendency for support to fall away at key transition points as young people move from child to adult services;
- Families with disabled children report particularly high levels of unmet needs, isolation and stress;
- Only 4% of disabled children are supported by social services.

Implications for commissioning

Incidence of disability is higher in boys in Bolton, across the range of disability, including complex health care needs; this matches the national picture.

Numbers of children from BME communities with severe and complex disabilities indicate a higher prevalence than the population as a whole.

Young disabled people aged 16-19 years in Bolton face a number of additional challenges as they move into adulthood.

Who's at risk and why?

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. 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 disability¹.

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. 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 overweight².

¹ Emerson, E. and C. Hatton (2008) *People with learning disabilities in England*, Centre for Disability Research.

² Emerson, E. and S. Baines (2010) *Health Inequalities and People with Learning Disabilities in the UK: Durham: Improving Health and Lives*, Learning Disabilities Observatory.

Rates of smoking among young people with a mild learning disability are higher than among their peers³.

Disability can occur in any socioeconomic group. However a Warwick University Study suggests that disability appears to be not simply an accident of birth but a “confluence of intergenerational poverty and modern medical progress”. The extent to which factors such as low income precede or follow disability is difficult to tell, but what we know is that poor diet and stressful living conditions do increase the chances of premature birth and low birth weight which are indicators of future disability⁴.

Analysis by the Family Trust Fund found that the prevalence rates of children and adolescents with mild disabilities were higher for those from semi-skilled manual and unskilled manual family backgrounds. The prevalence of children with mild disabilities from professional family backgrounds was lower in comparison to the other socioeconomic groups. The rate of severe disability was found to be greatest amongst children from semi-skilled manual family backgrounds, whilst the lowest rates were for children from professional and managerial family backgrounds.

Other studies suggest disability is higher in the Black Minority Ethnic (BME) population than the white British population⁵, while analysis of data derived from NOMIS by C4EO suggested that the prevalence of disability is higher in families living in social housing than in the rest of the population.

Research cited by Ofsted suggests that disabled children are more at risk of being abused than non-disabled children. However, they are less likely than other children in need to become the subject of child protection plans⁶.

The level of need in the population

It is widely recognised there are limitations in the sources of information on the numbers of disabled children in Britain, depending on criteria used. National estimates vary from 10% of children⁷, 7% by Office for National Statistics estimates, 3% by OPCS, and 1.2% (estimate of

³ Emerson, E. and C. Hatton (2008) *People with learning disabilities in England*, Centre for Disability Research.

⁴ Blackburn, C. et al (2010) 'Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey' in *BMC Pediatrics* 10:21.

⁵ Emerson, E. et al (1997) 'Listening to adolescents and adults with intellectual disabilities from South Asian communities' in *Journal of Applied Research in Intellectual Disabilities* 10(3):250-263.

⁶ C4EO (Undated) *Children with Disabilities: Overview of National Outcomes: the data*, C4EO.

⁷ Emerson, E. and C. Hatton (2005) *The socioeconomic circumstances of families supporting a child at risk of disability in Britain in 2002*, Lancaster University.

young people with severe disabilities by DCSF. Thomas Coram Research Unit (TCRU) estimates the number of disabled children in England as between 288,000 and 513,000⁸.

There have been many attempts to provide accurate estimates of disability in children and young people. Some of these have provided condition based estimates based on the literature and others have utilised specific survey data. Information on self-reported (by the parent) long-standing illness or disability is provided from the General Household Survey.

The local authority collects data on children with statements of Special Educational Needs, but this does not reflect the spectrum of disability and is only a weak proxy measure for severity. There is ongoing work to define disability in the context of the child's participation in usual activities, using questionnaires to families and children. If this approach were to be adopted nationally (for local implementation) then meaningful comparisons could start to be made.

Overall prevalence

The number of disabled children in England is estimated to be between 288,000 and 513,000 by the Thomas Coram Research Unit (TCRU). The mean percentage of disabled children in English local authorities has been estimated to be between 3.0% and 5.4%, through a survey of all Directors of Children's Services in England undertaken by the TCRU. If applied to the population of Bolton this would equate to between 1,822 and 3,280 children experiencing some form of disability⁹.

Chapter 10 (Disability) of *The health of children and young people, Office for National Statistics (ONS)*, calculated prevalence rates using two sources – the General Household Survey (GHS) and the Family Fund Trust (FFT) register of applicants. Much of the following analysis and observation is taken from this document.

The table below shows estimated numbers for mild disability. Children aged 0 to 4 years display lower prevalence than children in the higher age groups.

Bolton:

- Boys age 0-4 living with longstanding illness or disability estimate: 1,344;
- Boys age 5-9 living with longstanding illness or disability estimate: 2,200;
- Boys age 10-14 living with longstanding illness or disability estimate: 1,840;
- Boys age 15-19 living with longstanding illness or disability estimate: 1,674;
- Boys age 0-19 living with longstanding illness or disability estimate: 7,058;
- Girls age 0-4 living with longstanding illness or disability estimate: 1,196;

⁸ Thomas Coram Research Unit and Institute of Education (2008) *Report to DCSF Disabled Children: Numbers, Characteristics and Local Service Provision*, University of London.

⁹ Thomas Coram Research Unit and Institute of Education (2008) *Report to DCSF Disabled Children: Numbers, Characteristics and Local Service Provision*, University of London.

- Girls age 5-9 living with longstanding illness or disability estimate: 1,476;
- Girls age 10-14 living with longstanding illness or disability estimate: 1,615;
- Girls age 15-19 living with longstanding illness or disability estimate: 1,392;
- Girls age 0-19 living with longstanding illness or disability estimate: 5,679.

Bolton, severely disabled population:

- Boys age 0-19 who are severely disabled estimate: 35;
- Girls age 0-19 who are severely disabled estimate: 17.

Numbers of pupils in Bolton schools receiving support because of their Special Educational Need as at January 2012 were as follows:

Type of School	Number of Pupils School Action	Pupils School Action (%)	Number of Pupils School Action +	Pupils School Action + (%)	Number of Pupils with a Statement of SEN	Pupils with a Statement of SEN (%)
Nursery	14	4.1	25	7.3	1	0.3
Primary	2744	10.5	1193	4.6	296	1.1
Secondary	2707	14.6	670	3.6	364	2.0
Special	0	0.0	6	1.1	488	93.1
Total	5465	12.0	1879	4.1	1149	2.5

Current services in relation to need

As a result of legislation which came into force during 2011, the Council now has a legal duty to provide short breaks for disabled children and young people, and to produce an annual statement explaining to the parents of disabled children how the Council is discharging its duties. Bolton Council's current statement is available at [this link](#).

In 2003, Bolton achieved Pathfinder status for its proposal to establish a Children's Trust for Children and Young People with Disabilities (now dissolved). The Trust supported the development of a number of services for severely disabled children and young people including:

- The redesign of traditional 'respite' services to provide a wider choice of residential, family based and community based short breaks through BRIDGES, an integrated health/social care service. These have proved to be effective and highly valued by parents and by the children and young people who use them;
- A multi-agency Young Adults Team focusing on supporting the key transition between children's and adults services;
- An integrated community equipment store, to include equipment for children and young people, with a pooled budget;
- A Communication Aids Project (CAP) - a multi-agency team undertaking assessment and provision of communication aids using a pooled budget;

- ‘The Record’, Bolton’s Children Act register of disabled children and the ‘On the Record’ newsletter which has become one of the main sources of information for registered families.

Recent Years have also seen:

- The continued embedding and development of integrated working tools including the CAF (Common Assessment Framework) to share information across agencies;
- The establishment of a paediatric Occupational Therapist post based in health and funded by the LA to support the streamlining and coherence of assessments for aids and adaptations;
- The development of Person Centred Reviews for disabled young people at 14 plus;
- The introduction of a multi-agency transitions group to support young people on the transition to adulthood and adult support services;
- Development and launch of the Bolton Information Guide for parents of disabled children;
- The establishment of a joint protocol between health and social care services on the provision of services for children and young people with complex needs;
- Service Reviews to reconfigure borough wide support services provided to schools and SENCOs which, in turn, support children and young people with disabilities.

Projected service use and outcomes

Hutton, Cooke and Pharoah suggest that there is evidence that medical advances mean the survival rates for children who might, in the past, have been stillborn or died soon after birth are improving. However, these children are more likely than their peers to be disabled.

C4EO analysis of Children in Need data points to faster increases in the rates of disabled children becoming classified as Children in Need than in the population as a whole.

ONS projections based on the 2011 Census suggest that the number of children and young people aged 18 and under in Bolton will increase by just over 10 % over the next decade from 68,201 in 2011 to 75,124 in 2021. In 2013 this population group numbers 69,338.

ChiMat projections suggest that between now and 2020, the number of disabled children and young people aged 19 years and under in Bolton will increase by approximately 2.5% overall. The increase in numbers of disabled children and young people will be particularly notable among school age children. However, in light of the more recent ONS projections of the way the Bolton population could change over coming years, ChiMat’s projected increase may seem modest.

Evidence of what works

Research conducted by Barnardos¹⁰ identifies the following issues which should be considered if service provision is to be effective:

- Meet the child and family's need for information about the child's disability;
- Recognise that disability can be expensive and help families access sources of financial support;
- The need for breaks from care;
- The potential need for extra domestic help for the child's family;
- Helping parents and carers develop skills and strategies for supporting their child;
- Providing appropriate social support for the family;
- Coordinating services;
- Consider whether there are any special or extra needs for BME children.

Further key sources for information on effective interventions and evidence-based policy are highlighted on Bolton's Health Matters which can be viewed [by clicking here](#).

Community views and priorities

There is a comprehensive programme of consultation with disabled children and their parents in Bolton. This has raised a number of key learning points.

Parents tell us that they trust the services the Council and the NHS provide. Parents think these services will hire good staff who will understand the needs of their children. Parents tell us how crucial it is that the people who become involved in the care and the support of their children have the right skills to do this. Similarly, parents of disabled children from BME communities stress how important it is that services provided for their children are culturally sensitive.

Parents stress how important it is that services are flexible enough to meet the needs of their children. Disabled children also tell us that they need services to be flexible, and they need services to understand that children change as they get older. Disabled children also tell us that staff providing them with services shouldn't make assumptions about what they can and can't do.

The key available outcome indicator for disabled children is the parental experiences of provided services, last undertaken in 2009/10 for which the overall score for Bolton was 62. The scores were calculated on a 0-100 scale with higher scores denoting greater satisfaction with services. The table below shows the individual scores for Bolton. This data shows that at that time parents were relatively satisfied with their experiences of information provision, assessment processes, and the transparency with which services operated, but were considerably less satisfied with opportunities for participation and the receipt of feedback

¹⁰ Beresford, B. et al (1996) *What works in services for families with a disabled child?*, Barnados.

Equality impact assessments

Assessment of planned changes to services provided by the Council in 2010 emphasised the value that parents placed on the ability of services to respect the varied ethnic, faith, and cultural backgrounds of service users. The EIA also raised concerns that changes to marketing/promotion budgets could potentially make it more difficult to continue to recruit as wide a range of foster/short breaks carers as we would wish.

Recommendations for further needs assessment work

To conduct further assessment of prevalence within BME communities as current evidence is somewhat contradictory.

Further analysis of data to gain clear picture of children being supported across health and social care teams.

Key contacts

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