

## **Mencap submission to Chance for Change**

Mencap is the leading UK charity working with people with a learning disability, their parents and carers. We aim to ensure that people with a learning disability have equal access to choice, opportunity and respect.

Mencap welcomes and supports the process of gathering evidence for the cross-cutting review of services for disabled children. Although many of the service gaps and issues are common to all families with a disabled child, Mencap's evidence will focus on the specific needs of children and young people with a learning disability.

There are an estimated 346,000 children under the age of 18 with a learning disability in England representing 2.8% of all children. Although learning disability is the most common form of childhood disability it has received relatively low levels of attention in terms of planning and service delivery at either a local or national level.

Children with a learning disability are a large group within the wider population of disabled children but there are specific groups of children who are not typically seen as having a learning disability, for example low birth weight babies. These groups of children and their families have very distinct needs. Although there are some common solutions, one size does not fit all and some groups of children need quite different and carefully targeted support.

### **(See recommendations for action in Appendix 1)**

Some of the children who have distinct needs include:

- Children with profound and multiple learning disability
- Low birth weight babies and babies born before 27 weeks
- Children with a moderate/severe learning disability
- Children with foetal alcohol syndrome
- Children from black and minority ethnic communities

### **Children with a profound and multiple learning disability (PMLD)**

There are an estimated 10,000 children with PMLD and with advances in medical technology the numbers of these children surviving beyond the early years is increasing. A substantial number of children with PMLD have additional health needs (CDC/DfES 2005).

Research has shown a 77% increase in the number of children who are oxygen/ventilator dependent (from 135 children in 1997 to 241 in 2000) (Ludvigsen and Morrison 2003). In 2 years there was a 60% increase (to 887 children) in the number of children who are tube-fed (Townsend and Robinson 2000). In 1998/9 there were an estimated 6,000 technology dependent children (Glendinning et al 1999). It is very likely that this group of children has expanded significantly over the past 7 years.

*'I won't be able to do this for much longer. What I'll do then I just don't know'*

In many ways children with PMLD are an invisible group because they typically do not use mainstream services and they experience multiple barriers to being part of

their local community. In the recent DfES Low Incidence Audit, children with PMLD were also invisible as this audit failed to include them despite the fact that they were covered in the terms of reference. Most local authorities and PCTs are not aware of the number or needs of the children with PMLD in their area. For an average local authority it is expected that there will be 66 children with PMLD under 18 years.

For the vast majority of children with PMLD mainstream children's services do not address their needs. They are not included in mainstream early years services (e.g. children's centres) as staff lack the skills to meet their complex needs, in particular their medical needs. Very few of the main carers of children with PMLD are able to work as childcare services are simply not geared to meet their needs. Childcare is not available, not accessible and not affordable for the parents of these children. For the second carer, work options are also constrained by the need for 2 carers either all or some of the time, for example during school holidays.

*'On paper everything looks great but without the money to back it up things still aren't happening for a lot of people'*

A minority of children with PMLD are included in mainstream schools (1780 pupils) which again do not have the staff, skills or facilities (e.g. medical rooms) to meet their needs. Although some out-of-school provision has been developed with the needs of children with PMLD in mind, most leisure facilities do not include children with PMLD.

There are many barriers to the community involvement of children with PMLD. A lack of suitable (tail-lift) transport is a major barrier. Most venues (e.g. cinemas) are not fully accessible. There is a very real lack of Changing Places toilets (toilets with a changing bench, hoist and enough space for 2 carers and a wheelchair). This means that families are unable to enjoy a family day out at shopping centres or family attractions.

*'I can't take her to the places we would like to go simply because there is nowhere that we can go to the toilet'*

For many families with a child with PMLD a lack of short breaks means a very real limitation to the quality of family life. The families with the highest levels of need often have the lowest levels of access to short breaks due to a lack of staff skills, for example in meeting additional health needs. The 2006 Mencap survey found that 7 out of 10 families with a son or daughter with PMLD had reached breaking point or come close (Mencap 2006).

*'I feel I am living in a cage and can't get out. I look at my life and I don't have one'*

Transition planning for children with PMLD does not address the needs of the whole family and typically fails to include housing or income planning. The lack of post-16 services and short breaks leaves many families with no option apart from long term residential provision.

### **The key issues for children with PMLD**

1. They are a low volume and high cost group of children
2. Good quality specialist services are vital for these children and their families
3. The level of community inclusion is low and these are typically invisible children

### **Recommendations**

- A key worker with an individual budget is offered to every family with a child with PMLD
- A minimum entitlement of one break a week for every family with a child on higher rate DLA and a comparable break for other families
- A dedicated transition co-ordinator in every local authority with a PSA of 100% transition plans for all statemented children
- A benefits health check offered to all young people eligible for a transition review and an extension of the Family Fund to 18 years

### **Low birth weight babies (LBW)**

*'At birth society makes a contract with its families'* (Conliffe 2000)

Although some of these low birth weight babies children will have PMLD, for the vast majority their impairments are more subtle and less easy to identify. From 1984-89 to 1990-1994 the survival rate of LBW babies increased from 27% to 42%.

The UK has the highest rate of low birth weight babies in northern Europe and the relationship between LBW and poverty means that these children tend to cluster in the most disadvantaged wards (Emerson 2003). Typically they are discharged from special care baby units after weeks or often months of specialist intervention to be offered nothing more than a standard health visitor follow up. Of the babies born at less than 1500 grams, up to 50% show later cognitive impairment (Hack and Fanaroff). There is also evidence of increased risk of neglect and abuse in the pre-term population (Taylor et al 2001).

*'For most families the birth of their child is a joyous time, however nearly 4% of parents receive distressing news about their child's health'* (Barrett et al 2003).

In New Zealand all babies born under 1500 grams or born before 32 weeks are offered on discharge from hospital a specialist adviser visit once a week for 4 months either at home or at a clinic. By 12 months many of these families were found to need no further specialist intervention but were able to access mainstream services (Champion 2005).

In the UK the EPICure study has followed up a large cohort of children born before 27 weeks. At 6 year follow-up, 8 out of 10 children showed a degree of impairment with 4 out 10 having a moderate or severe disability (Marlow et al 2005).

Children with a mild/moderate learning disability should be a key target group for local Sure Start programmes but the evidence from the initial evaluation (NESS 2005) indicates that they are not accessing these programmes. The value of high

quality early education has been demonstrated in the EPPE (Sylva et al 2004) EYSTEN projects (Sammons et al 2003).

As these children enter the education system their complex mix of mild/moderate impairments challenge the skill base of early years workers and teachers. The combination of cognitive and sensory impairments together with co-ordination difficulties and attention deficits requires skilled early intervention. Approaches such as Webster Stratton (an intensive and specialist parenting support programme) have proven benefits for these children.

The development of parenting programmes for these children has not been matched by similar advances in teaching programmes or skill development for the teaching staff who encounter these children with their complex mix of often subtle impairments that do not fit existing SEN categories.

#### **Key issues and recommendations for low birth-weight babies**

1. A lack of planning for this substantial group of children
2. Low cost interventions can reduce the need for specialist services
3. Families are left to struggle on with no offer of interventions

#### **Recommendations**

- All babies born under 1500 grams and before 27 weeks offered a minimum of one specialist adviser visit per week for the first 6 months post discharge
- A National Centre for Early Intervention to disseminate the key messages from research into early intervention
- All families with a child with a learning disability under 3 years offered a Portage service

#### **Children with a moderate or severe learning disability**

The current pattern of service delivery for these children and their families is extremely patchy in different parts of the country. In some areas the early years provision is reasonably well developed for these children but mainstream schools are not welcoming and are unable to meet their learning needs due to a lack of staff with specialist teaching skills. In other areas schools are proving to be more successful at including pupils with a learning disability but there is a complete absence of inclusive out-of-school activities or leisure facilities.

In most areas, children with a moderate learning disability will not meet the eligibility criteria of local authorities for short breaks. Many children with a severe learning disability are also excluded unless there are additional family needs, for example a carer with mental health problems (Mencap 2006 in press). This lack of short breaks, combined with the lack of access to leisure services, places intolerable burdens on these families. As these children enter the teenage years the demand increases for very expensive out-of-authority residential provision due to a lack of local alternatives.

*'After being on a waiting list for months I couldn't do it any more. I rang social services but I couldn't even compose a sentence. They told me to ring back'*

For many children with a moderate learning disability employment should be a realisable goal but only 1 in 6 adults with a learning disability are in employment

(Emerson 2003). Not only are there few role models but there are real deficiencies in IAG services (information, advice and guidance) with Connexions Personal Advisers typically lacking the expertise to offer help to these young people. Young people with SEN are twice as likely to not be in education, employment or training (NEETs) as other young people (DfES 2004). Young people with a moderate learning disability are heavily over-represented in this NEET group. Access to work schemes are only available in the minority of areas of the UK. This group of young people enters adulthood with an increased likelihood of becoming and remaining a workless household.

For children with a severe learning disability moving into adulthood presents different challenges. Significant numbers of these children are placed during their teenage years in residential out-of-authority schools. The lack of transition planning and the paucity of local services for these young people often result in continued and expensive out-of-authority placements.

#### **Key issues for children with a moderate or severe learning disability**

1. Families experience a post-code lottery of services
2. Many families do not meet current eligibility criteria for support services
3. Too many young people are excluded from employment

#### **Recommendations**

- Extend the universal offer of 15 hours per week free education for all 3 years olds to 30 hours per week for children identified as having a learning disability
- All mainstream schools to have a guarantee of 2 hours per 100 pupils school nurse contact and 5 hours per 100 pupils dedicated SENCO time
- A minimum entitlement of one break a week for every family with a child on higher rate DLA and a comparable break for other families
- A specialist access to work co-ordinator for young people with a learning disability

#### **Children with foetal alcohol syndrome (FAS)**

Foetal alcohol syndrome and its strong association with learning disability has been recognised for many years in the US and Scandinavia. The size of the UK child population affected by FAS is only now coming to be appreciated with increased concern about binge drinking in all age groups.

The incidence of foetal alcohol syndrome disorder (FAS) is estimated to be 1 in 300 infants (Plant 2004). This compares with the incidence of Down Syndrome of 1 in 666 live births (Grainger 2004). The milder form of the condition, foetal alcohol spectrum disorder (FASD) has an estimated incidence of almost 1% of the total child population (Mukherjee et al 2005). Children with the milder FASD still have a mild/moderate learning disability, often with behaviour disorder at a level that challenges mainstream school staff.

These FAS and FASD children have cognitive and memory and attention impairments as well as growth deficiencies. Although the issue of FASD is gaining more attention with concerns about alcohol abuse in young people, FASD is typically undiagnosed in the UK (compared with the US, South Africa and Scandinavia). Rather like the low birth weight children, children with FASD typically

have a subtle mix of impairments each of which in themselves fail to meet the criteria for specialist intervention.

The failure to identify children with FASD means that they challenge the education system with their problems with number processing and mathematical recognition as well as their attention and increasing behavioural difficulties. They are often mis-diagnosed as ADHD and not offered the specialist educational programmes that are needed to address their specific learning needs. It is very likely that children with FAS and FASD are heavily over-represented in the school exclusion statistics.

#### **Key issues and recommendations for children with foetal alcohol syndrome**

1. The learning disabilities of this group of children are not widely recognised
2. Parents and professionals lack information about what works
3. Early education interventions would reduce the risk of exclusion

#### **Recommendations**

- A National Centre for Early Intervention to disseminate the key messages from research into early intervention
- All families with a child with a learning disability under 3 years offered a Portage service
- Extend the universal offer of 15 hours per week free education for all 3 years olds to 30 hours per week for children identified as having a learning disability

#### **Children with a learning disability from black and minority ethnic communities (BME)**

The prevalence of learning disability in South Asians aged 5-32 is three times higher than in other communities (Azmi et al 1996). This higher rate of learning disability in South Asian populations is linked to high levels of material and social deprivation which may combine with other factors such as poor access to maternal health care and higher rates of environmental or genetic risk factors (DH 2001).

Within service provision, stereotypical opinions about South Asian families ('they look after their own don't they') exacerbates the invisibility of South Asian and underpins the neglect they experience from service planners (Ahmad et al 1998).

*'I just never thought the service was for me or my family'*

The South Asian population has the highest birth rate increase in the UK and access to both mainstream and specialist services are typically low. There is a need to ensure that information about local services and welfare benefits is developed and delivered to meet the needs of South Asian families with a child with a learning disability.

Information about local services e.g. childcare, welfare rights, leisure and short breaks do not reach families from minority ethnic communities (Chadwick et al 2002). Chamba et al in 1999 found that in comparison with white families that BME families were less likely to be receiving DLA and where they were they were less likely to be awarded the higher rates.

The poor reach of information to BME communities is only part of the reason for low service take up. For many BME families services are not culturally sensitive, for

example the reluctance of some local authorities to promote kinship care. Families from black and minority families are under-represented as users of short break services (Chadwick et al 2003). The Social Services Inspectorate report 'Excellence not Excuses' in 2002, highlighted the lack of provision for black disabled children. Against this backdrop of a lack of provision is a huge demand for services (Chamba et al 1999) Twice as many (9 out of 10) BME families report that their child's needs are not being met, compared with white families (Chamba et al 1999). This same study found that both groups of parents had the same 7 most pressing needs with more money and more help planning the child's future at the top of the list.

Where local authorities have paid particular attention to the needs of BME families with a disabled child, there is good take up local services and reduced social exclusion. The Hamara project in Waltham Forest is a good example of a multi-service project designed to meet the needs of an ethnically diverse area.

**Key issues and recommendations for children with a learning disability from black and minority ethnic communities**

1. They are very likely to be living in poverty or in disadvantaged areas
2. Information about services does not reach these communities
3. Services are not culturally sensitive

**Recommendations**

- All families with a child with a learning disability under 3 years offered a Portage service
- Regional BME/disability advisers to support local agencies in developing culturally sensitive services and information
- A minimum entitlement of one break a week for every family with a child on higher rate DLA and a comparable break for other families

**(See recommendations for action in Appendix 1)**

## Appendix 1

### Mencap submission to change for children: service gaps and solutions

| <b>Service gap</b>  | <b>Solution</b>  |
|---|--|
| Low birth weight and pre-term babies are discharged from hospital without an agreed package of support                        | All babies born under 1500 grams and before 27 weeks offered a minimum of one specialist adviser visit per week for the first 6 months post discharge  |
| Families with children with profound and multiple learning disabilities have to manage contacts with multiple agencies        | A key worker with an individual budget is offered to every family with a child with PMLD   |
| Professionals and parents lack access to the evidence of what works in early intervention                                     | A National Centre for Early Intervention to disseminate the key messages from research into early intervention   |
| Families lack access to low cost early interventions of proven efficacy and family acceptability                              | All families with a child with a learning disability under 3 years offered a Portage service   |
| Families from minority ethnic communities are not able to access services or benefits   | Regional BME/disability advisers to support local agencies in developing culturally sensitive services and information   |
| Children with a moderate learning disability do not get access to the early education services                                | Extend the universal offer of 15 hours per week free education for all 3 year olds to 30 hours per week for children identified as having a learning disability                                      |
| Parents of children with a learning disability are excluded from the workforce because they cannot find childcare             | Double the childcare element of CTC for families DLA, and fund a disability/childcare adviser in every local authority to meet a PSA for year on increases in childcare places for disabled children |
| Mainstream schools lack the skills to include children with a learning disability, especially those with complex health needs | All mainstream schools to have a guarantee of 2 hours per 100 pupils school nurse contact and 5 hours per 100 pupils dedicated SENCO time  |
| The lack of short breaks means that families break down   | A minimum entitlement of one break a week for every family with a child on higher rate DLA and a comparable break for other families   |
| A lack of expertise in transition planning leaves many families without services post 16                                      | A dedicated transition co-ordinator in every local authority with a PSA of 100% transition plans for all statemented children  |
| A reduction in family income post 16  | A benefits health check offered to all young people eligible for a transition review and an extension of the Family Fund to 18 years   |
| Young people with a learning disability are x2 as likely to be NEETS (not in education, training and employment)              | A specialist access to work co-ordinator for young people with a learning disability   |

