

## Newcastle JSNA: Learning disability in children February 2009

### What is a learning disability?

There is no single accepted definition of learning disability. It does *not* include learning *difficulties* such as dyslexia, although some people use the terms interchangeably. The agencies who are involved in developing and delivering services for people with learning disabilities in Newcastle work with the definition taken from the [Valuing People White Paper](#) (2001):

*“A person is considered to have a learning disability if he or she has a significantly reduced ability to understand new or complex information or to learn new skills, together with a reduced ability to cope independently. These problems will have started before adulthood and have had a lasting effect on the person’s development.”*

### Facts and Figures

Citizen’s First, a three year (2008-11) plan for Newcastle written by the Newcastle Learning Disabilities Partnership Board took their estimates of the number of people with learning disability from [‘A Life Like No Other’ Healthcare Commission 2007](#)

- In Newcastle the most recent figure for children is 456, taken from family doctors practice lists i.e. people confirmed as having a disability. (Source: Community Team Learning Disability, 2007, from Citizens First 2008)
- However Newcastle has a population of 274,000, with some 63,800 children (aged 0-19). If the accepted prevalence of Learning Disability of 2% is applied to this number it would suggest 1276 children of whom 319 would have a severe learning disability. (Citizens First 2008).
- Quality Outcome Framework (QoF) data for 2007-08 suggests a total of 1,206 people with learning disabilities (and will include both adults and children) on GP registers in Newcastle. This gives an unadjusted prevalence rate of 0.4%.
- As part of the School Census information is gathered relating to the primary need of children and young people with additional support needs (School Action Plus) and statements of Special Educational Needs (SEN). The number of children and young people in this group totals 2,916. The table below shows those children and young people with a form of learning difficulty as their primary need.

<b>Primary Need</b>	<b>Numbers of Children and Young People (aged 0-16)</b>
Moderate Learning Difficulty	939
Severe Learning Difficulty	240
Specific Learning Difficulty	349
Total	1528
<b>Source: School Census January 2008</b>	

- There are plans to agree systems for sharing data regarding the learning disabilities and difficulty population to inform service planning.

### **Trends**

- Overall, there will be an increase over the next two decades in both the numbers of people with learning disabilities known to services 11% over the decade 2001-2011, 14% over the two decades 2001-2021 and the estimated 'true' number of people with learning disabilities in England 15% over the decade 2001-2011, 20% over the two decades 2001-2021.
- The number of children with complex health needs are increasing
- More children are being identified with Autistic Spectrum Disorder
- The awareness of Attention Deficit Hyperactivity Disorder is increasing.

### **Targets**

[Valuing People \(2001\)](#) presents detailed targets. See Annex A pp122-131. These are addressed in Citizen's First (2008) for Newcastle and in [Valuing People Now \(2007\)](#) which reviewed progress nationally and set a new agenda for the next three years.

### **Outcome Improvement Targets in Newcastle Plan for Children and Young People**

1. The provision of timely information for parents and carers regarding services available for those with learning disabilities and difficulties.
2. Agree system for sharing data regarding the population with learning disabilities and difficulties to inform service planning
3. Engage localities in the service planning for children and young people with learning disabilities and difficulties.

4. Ensure more young people experience smooth transitions to adult services including improved vocational opportunities.

**Local Targets in the North of Tyne Strategic Plan specifically relating to people with learning disabilities (all ages)**

**Goal 21:** To improve the health outcomes and support the social inclusion of people with learning disabilities by increasing the number of people with a learning disability having a physical healthcare check and health action plan

**Performance**

Direct payments for disabled children were introduced in the Carers and Disabled Children Act (2000). Children’s Services, through an assessment of need in 2003, offered this method of arranging support for disabled children and their families.

- There has been a gradual increase of the use of the Direct Payment Scheme over the past 5 years, with a significant increase over 2007 – 2008 with a current total of 73 families.
- Direct payments are used to commission a range of short break provision involving childminding, nursery, day care, domiciliary support, sitting service, play schemes and overnight stays.
- There has been a significant increased use of Direct Payments by the B.M.E. families who were traditionally “the hard to reach” families to engage in services. Again this allows greater use of family and kin who will provide care that is individual and culturally sensitive to their needs.

<b>Year</b>	<b>Users</b>	<b>Breakdown</b>	<b>Money Spent</b>
2006	41	16A – 5B – 20PA	£249,921.87
2007	58	20A – 4B – 34PA	£222,943.26
2008	73	4IB – 25A – 6B – 38PA	£423,145.21 up to 19.10.08
<b>Codes: A –Agency, B - Both PA &amp; Agency, PA - Personal Assistant, IB - Individual Budget</b>			

- There has also been considerable development in developing self directed support and individualised budgets with an initial small number of families exploring the processes and impact of managing their own indicative budget.
- There has been an Increase in the provision of therapy services into special schools. (Annual Performance Assessment (APA) 2008)

- There has been an increase in the number of places for 16+ year olds with LDD by 40 to improve vocational options. (APA 2008)
- An ASD pathway, designed with parents and carers, has been produced to guide parents through services and is available through the Family Services Directory. (APA 2008)
- The number of children with LDD receiving support into play groups, nurseries, school and play schemes in 2006 was 34 with a further 25 in 2007. By April 2008 7 more children have received support. (APA 2008)
- The Children with Disabilities and Special Needs Management Partnership is ensuring a cross agency strategy for LDD children is being delivered. (APA 2008)

### **Local views**

- The opportunities for those with learning difficulties and/or disabilities to be involved in consultation have been expanded and are increasingly embedded in day to day practice.
- Six organisations focused on children and young people with LDD have achieved investing in Children, including 4 out of 5 special schools and the Pupil Referral Unit.
- All children and young people with LDD give their views and these are considered to inform key decisions about their future during the statutory assessment process.
- Annual reviews ensure that views are listened to and taken into account when making decisions about future targets and provision.
- Person Centered Planning Reviews in special schools are leading to children and young people having a stronger voice and making them central to the review process.

### **National and local strategies**

#### National

The white paper '[Valuing People](#)' (2001) set out the Government's vision for people with a learning disability, across a range of services based on four key principles of rights, independence, choice, and inclusion. The white paper's vision covered a range of issues including health, housing and employment. Other relevant publications since include the '[Our Health, Our Care, Our Say](#)' (2006) and '[Improving Life Chances for Disabled People](#)' (2005) white papers as well as a national review of Valuing People '[The Story So Far](#)' (2005). These have reinforced and developed the vision of Valuing People. The most recent is '[Valuing People Now](#)', published for consultation in December 2007, which sought people's views on the priorities for the learning disability agenda over the next three years. It set out the priorities for 2008 to 2011 as:

- personalisation – so that people have real choice and control over their lives and services;

- what people do during the day (and evenings and weekends) – helping people to be properly included in their communities, with a particular focus on paid work;
- better health – ensuring that the NHS provides full and equal access to good quality healthcare;
- access to housing – housing that people want and need with a particular emphasis on home ownership and tenancies;
- making sure that change happens and the policy is delivered – including making partnership boards more effective.

It also highlights particular areas concerning children and young people. It states:

Valuing People (2001) covered policy about children with learning disabilities as well as adults. Shortly afterwards, the Government produced several other policies about children which became the focus of change for children with learning disabilities. Those policies have continued to develop and so there is less need for this 'renewal' of Valuing People to also cover children.

However, in addition, they highlight:

- Getting the right educational support. The 2001 *'Special Educational Needs and Disability Act'* strengthened parents' rights to have their child educated in a mainstream school if they wish. It gave schools and local authorities a duty to plan to increase schools' accessibility, both in terms of premises and the curriculum.
- In 2004, the Government's special educational needs (SEN) policy *Removing Barriers to Achievement* set out a programme of action on early intervention, removing barriers to learning, raising expectations and achievement, and bringing improvements through partnerships between agencies
- Other government policies such as Every Child Matters and the National Service Framework for Children, Young People and Maternity Services have set objectives for children's health and social care, including a standard for disabled children and young people. A key aim of these policies is better inter-agency working. The Early Support programme focuses on this and recommends that families are assigned 'key workers' to help them negotiate access to services.

[Aiming High for Disabled Children: Better Support for Families](#) launched in May 2007, is the transformation programme for disabled children's services. Supported by substantial new funding and measures designed to make the system work better, the AHDC programme aims to deliver:

- Access and empowerment for disabled children and families
- Responsive services and timely support

- Improved service quality and capacity

## Local

Citizens First organised the objectives of Valuing People into nine themes.

Theme	The main things each theme includes
<b>Learning and Employment</b>	<p>Maximising adult learning opportunities using a person centred approach</p> <p>How learning opportunities can help a person's employability</p> <p>Adult services' Employment strategy – maximising chances of people with learning disabilities finding and keeping a job</p>
<b>Growing up</b>	<p>Making the process for a young person with learning disabilities moving from children to adult services person centred</p> <p>Restructuring the commissioning process and partnerships to widen opportunities for young people when they reach adulthood</p> <p>Finding ways of keeping young people in Newcastle who would have otherwise had to live outside the city because of their special needs</p>
<b>Safety and Quality</b>	<p>Systems and processes to ensure person centred monitoring of quality of care and support provided</p> <p>Prevention of abuse and the coordination of all existing systems</p> <p>Ensuring people feel safe in their communities and at home – community safety</p> <p>Getting and keeping the right staff through a widely owned workforce development plan</p>
<b>Health</b>	<p>Ensuring people get equal access to general health care services – primary and secondary care.</p> <p>Ensuring people get health information in a way they can understand.</p> <p>Providing people with learning disabilities with comprehensive health checks</p> <p>Refocusing specialist services ( like services for People with autistic spectrum disorder ) provided to people with learning disabilities to fulfill the principles of Valuing People</p> <p>Plan to give people who have behaviours that</p>

<b>Theme</b>	<b>The main things each theme includes</b>
	challenge services a better quality of life
<b>Money</b>	Individual budgets and In Control Direct Payments Access to normal personal finance opportunities like savings and bank accounts Benefits and Welfare Rights
<b>Community</b>	Community Life opportunities- daytime, weekends, evenings Community links, connections and development Making the most of Newcastle Partnership opportunities especially the Regeneration agenda Small Sparks Transport Citizenship rights
<b>Families and carers</b>	Support for Carers Carer involvement in the Board and other decision making processes Older Carers work Short Breaks service change
<b>Housing</b>	Widening and ensuring a choice of housing Promoting and ensuring Housing rights Making housing processes easy to understand All means all – targeting groups within learning disabilities who are especially disadvantaged Fairness in accessing housing

**The North of Tyne Strategic Plan** contains the overarching goal to:

- Have more specialist learning disability care closer to home
- Improve health and inclusion for people with learning disabilities

### **Current activity and services**

Information on support for children with special educational needs, including learning disability can be found on the [Special educational needs section](#) of the City Council website.

A scheme testing Key Workers for families with children with disabilities was piloted between June 2007 and April 2008. The pilot included five key workers from different professional backgrounds and agencies delivering a key worker service to ten families with disabled children under four. The report does not include details of the families and it is not clear whether they included children

with learning disabilities. Families and professionals contributed to the evaluation and were positive about the scheme. As a result the steering group recommended that the key working arrangements are rolled out to include other members of current teams involved plus some health visitors and children centres.

To achieve the next stage of roll out the following resources have been highlighted:

- 1 full time coordinator £60,000
- Admin support £20,000
- Training £8,000

In the short term, the funding of a coordinator for 1 day per week and further training would ensure current arrangements continue. £10,000 would cover this cost. (Newcastle Children's Care Services 2008b).

The Newcastle Speech and Language Team provide a seamless multi disciplinary service for young children with severe speech and language difficulties through a joint referral system between education and health. This has resulted in significantly improved outcomes for children and eradicated waiting lists for the Speech and Language Additionally Resourced Centre's (ARC). Many are now able to continue their education in their local school whilst having their speech and language needs met.

A wide range of sports, leisure and cultural activities are available to children and young people with LDD, particularly in special schools and ARCs, e.g. Football coaching and Disability Dance in Newburn Activity Centre.

The "Response" anti bullying team is successfully raising awareness regarding bullying of children with disabilities.

### **Social care**

Children with disabilities social work team provide support via assessment and planning for children with complex disabilities.

- 218 families are currently receiving a service from the team.
- 212 of the above families receive short breaks.
- 21 children with complex disabilities receiving full time care away from their families and 150 children are receiving care packages to support them living with their families.
- The Shared Care Service provides children and young people with disabilities from birth to aged 18 with a range of short breaks. There are

currently (October 2008) nine shared carers looking after twelve young people.

- Cheviot View is a new short break unit offering overnight short breaks to 59 children aged between 6-18 years of age. The unit also provides an outreach service and befriending service.
- Social Care commissions a range of short breaks for children with disabilities including overnight stays and daytime provision.
- Partnership arrangements between Health and LA are in place for joint commissioning of short breaks for children with complex health needs.

Aiming High for Disabled Children is being developed and will change the way services are delivered for disabled children. Over the coming months the following reviews will take place:

- A needs analysis to inform a review of short-break services.
- Access to child care
- Transition from Children to Adult Services
- Access to equipment and wheelchairs
- Strengthen the voice of families with disabled children

The Families Information Service provides good information to Children and Young People and their parents and carers. It includes pathways to services for children with autism

## **Health**

Newcastle PCT total spend on learning disability (adults and children) for 2006/07 was £23 million; 12.6% of the total PCT spend (Robson et al 2008). This represented £7,753,393 per 100,000 population against an average of £5,090,432 in comparable PCTs. Thus Newcastle spent roughly £2 million more per 100,000 population. The absolute overspend on learning disability in 2006/07 was £7,914,979.

The specialist community learning disabilities team aims to improve independence and health outcomes for people with learning disabilities.

NHS North of Tyne are developing a comprehensive action plan to address the recent findings of the Healthcare Commission. Current work includes ensuring access to advocacy for service users in patient settings and reviewing admission, discharge and care planning policies to ensure admissions are focused on assessment and treatment as part of an integrated pathway.

## **Voluntary sector**

The [Newcastle Parent Partnership](#) provides information and support for parents/carers of children and young people with special education needs.

Parent / carer participation worker for CWD

North East Special Needs Network provide support to parent / carers of C&YP with disabilities.

Partnership arrangements are in place with the voluntary sector to provide short breaks for children with complex health needs.

## **What is this telling us?**

### **What are the key inequalities?**

People with learning disabilities are 50 times more likely to die before the age of 50 than the general population. It is known that people with a learning disability are predisposed to the development of a number of health limiting conditions (congenital heart conditions, alzheimers, gastrointestinal problems and cancer). Many of these conditions can either be prevented, or the severity reduced by early screening and good access to primary and secondary care health provision.

There needs to be improved systems to share data about children and young people with learning disabilities to understand the key inequalities that exist in Newcastle.

### **What are the key gaps in knowledge / services?**

Access to, and use of, health services appears to be an issue.

The Quality Outcomes Framework data showing a prevalence of 0.4% based on those people whose GP has recorded their learning disability suggests that general practice records are not comprehensive.

### **What are the risks of not delivering our targets?**

Unnecessary pressure on families and carers, poorer services to children, increasing demand from co-morbidity, increasing costs in providing emergency care where planned care would have been possible.

### **Is what we are doing working?**

- The Direct Payment scheme appears to be reaching some groups such as BME families who traditionally have not accessed services. The increase in payments suggests that families find this a valuable resource and appreciate the flexibility that it gives them.
- The Investing in children accreditation is increasing among services for children and young people with learning disabilities and difficulties.
- There is a good sign up to key working pilot and roll out from all relevant services.

- There are clear governance arrangements established for learning disability and difficulties services.
- A new short break unit has been opened and parents and carers of children and young people were involved in the design.
- An attention deficit hyperactivity disorder pathway has been established.
- Children's information system engaged in process of providing accurate and timely information for parents/carers of LDD.
- Joint commissioning arrangements including pathways for children with life limiting conditions.
- The Children with Disabilities and Special Needs management Partnership is ensuring a cross agency strategy for LDD children is being delivered.

### **What is coming on the horizon?**

The number of people with severe and profound learning disabilities is likely to increase by 1% each year due to increasing life expectancy and the growing number of children with complex needs who survive into adulthood.

*Valuing People Now* includes outline action plans to meet the identified priorities. Addressing all of these in ways that are appropriate to Newcastle and build on existing strengths, services and progress will be a major work stream. It will need to span policy, commissioning, service provision across every agency and stakeholder involved in valuing and supporting this population group.

A review of the health needs of people with learning disabilities will be carried out. There will be new investment in Newcastle and North Tyneside to ensure all people have health action plans. We will also provide support to non specialist, services to improve access to healthcare for people with a learning disability. (Annual Operating Plan 2008/09).

There are active plans for campus closure (patients living in campus-type, accommodation), including the assessment of individuals' needs and the development of person centered plans leading to the identification and implementation of new care arrangements within the community.

### **What should we be doing next?**

1. Maximize opportunities for regional learning Aiming High agenda; liaise with neighboring pathfinders and networks already established.
2. Build on regional networks highlighting good practice examples e.g. Palliative care network and North of Tyne transition group.
3. Roll out of Key Working /Lead Professional will ensure workers are delivering timely and effective service to parents/carers of children and young people with learning disabilities and difficulties.
4. Identify opportunities to share skills between specialist and universal services to achieve more inclusion service provision.

5. Build on individual budget successes
6. build on current practice to involve parents / carers in recruitment of staff.

A copy of the improving outcomes action plan for 2008/09 is provided here.

## References

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