

Changing philosophy and architecture



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Our history

- Up to 1970's –institutional services based in large hospitals
- 1970's-1980's the beginning of the move to community services
- 1990's family based services at their height, but realisation of a need to embed
- 2007-Aiming High for Disabled Children
- 2010, Economic crisis and uncertainty

Our population

A changing picture-Children



- A quest for citizenship
- Rise in ASD
- Rise in children with complex needs
- The impact of Inclusion

The changing population

- Since 1975...
- children 0-16 have formed the fastest growing group of disabled people in the UK (from 476,000 in 1975 to 772,000 in 2002)
- This represents an increase of 62%.

[Improving Life Chances Report, 2005]

A Changing Picture- Parents

- Increasing expectation on parents in relation to care and therapy needs
- Increasing expectation on services
- A stronger voice for parents

But still...

Disabled children and their families being

- Discriminated against
- Services are under funded and patchy
- Full citizenship yet to be achieved
- We still have some “respite”

And significant groups still miss out

- Children with complex health needs/palliative care/ lifting and handling needs
- Children with severe ASD and children with challenging behaviour which is impairment based
- Young people who are 14+
- Siblings

What do families want

- **Parents said their biggest priorities for making them stronger are:**
- They want more opportunities to **enjoy play and leisure** and want a real choice in the activities they can take part in.
- They want to see their **child reach their full potential.**
- They want a **support package** to meet their child's needs and **flexible and regular short breaks.**

What do disabled young people want?

- *'As disabled young people we only want the same things as any other young person, such as friends, relationships, money, a place of our own and the freedom to do the things we enjoy. In short, we want choice, control and independence over our lives. A good transition process is a necessary vehicle towards greater social inclusion and equality for disabled young people.'*
- *Our communities around us should realise we are part of that community too, there has to be more positive roles for people with learning disabilities in our community.'*
- *treat all disabled people as full members of society and put structures in place to enable them to take their place alongside, not tagging on, the rest of the population.'*

The policy response

- 2007-2010 Aiming High for Disabled Children
- 2011-current Support and aspiration

Aiming high: system reform

National indicator

- 'Core Offer'

- Information
- Transparency
- Participation
- Assessment
- Feedback



AHDC core themes

- **Access and empowerment**
(core offer, parents' forums, Individual Budgets)
- **Responsive services and timely support**
(Indicator, data, Transition Support Programme, rollout of Early Support, early intervention)
- **Improving quality and capacity**
(short breaks, childcare, community equipment and wheelchair services, workforce issues)

Key Challenges

- Changing Population
- Starting from a low baseline
- A Political Environment
- Creating Strategic Linkages
- Engagement with Parents
- Joint Delivery with Health
- Commissioning
- Workforce

Challenges to Commissioning

- Lack of data
- Lack of senior engagement
- Under developed marketplace
- Local authority reluctance
- Issues in engagement of third sector
- Understanding of commissioning processes
- Workforce

Transition Support Programme

- 2008 – 2011
- Focussing on five outcome areas:
 - **Participation** of disabled young people and their families
 - Effectiveness of **‘personalised’** approaches
 - **Joint assessments processes** within children’s trusts and adult services
 - Realistic **post 16 opportunities** for living life
 - **Strategic joint partnership** working

Transition Support Programme

- Every Local Area in the country has named advisor
- Self Assessment Questionnaire
- Regional events and activity
- Profile of transition increased
- Disabled young people and families experiencing better support at transition

Short break regulations

- Laid in parliament 18th November 2010
- By October 2011 local authorities must;
- Publish a statement for parents which sets out
- Details the range of short breaks
- Any criteria against which eligibility is assessed
- How the range of services is designed to meet carers needs
- Carers must be involved in the process

Raised expectations: Parental experiences of short breaks

- Choice and control
 - Crucial to parent satisfaction
 - Mixed experiences of emergency provision
 - Direct Payments
- Information and Transparency
 - Lack of consistent information available to parents
 - Continued confusion on eligibility criteria

Raised expectations: Parental experiences of short breaks

- Assessments
 - More consistent
 - Concerns on taking into account too many personal details
 - Continue to focus on what child can't do
- Participation and feedback
 - Parent participation is becoming entrenched leading to high parental satisfaction.
 - Parent carer forums playing a central role
 - Feedback after consultation is crucial
 - Little parental knowledge of local complaints procedures

Support and Aspiration

- Personal budgets

- By 2014, the intention is that all families with the proposed 'Education, Health and Care Plan' will have a right to/have the option of a personal budget
- How will parental decisions on personal budgets work in schools alongside school policies?
- If parents have the money, who has responsibility for the service?
- Who will bear the brunt of the bureaucracy?

Preparing for Adulthood

The Partnership

- National Development Team for inclusion
- Council for Disabled Children &
- Helen Sanderson Associates.

The Preparing for Adulthood programme will:

- Build on the learning from past initiatives
- Support peer to peer learning at a local level to improve outcomes
- Share knowledge of what works, the challenges and solutions with Government, local agencies, families and young people.

Building on

Transition Support Programme

Worked to improve and co-ordinate services for disabled young people in transition to adult life.

[Read more](#)



Showed what needs to happen so young people with learning disability get paid jobs and full lives when they leave school.

[Read more](#)

Valuing Employment Now

Demonstrated what needs to happen to increase the number of people with learning disabilities in employment.

[Read more](#)

aspirations for life

A campaign working on raising aspirations and expectations for people with learning disabilities from birth.

[Read more](#)

Learning for Living and Work

Aims to help individuals achieve their full potential in life through learning and work.

[Read more](#)



Is a supported internship model which helps disabled people secure and keep paid permanent jobs.

[Read more](#)

for disabled
children

Preparing for Adulthood

Three strands of work

1. Pathfinder support
2. Wider support for all local areas
3. Best practice and information sharing

Focus on outcomes

- Paid work
- Independent living (choice and control over life and support and housing)
- Good health
- Friends, relationships and community inclusion

Find out more

- www.preparingforadulthood.org.uk
- www.transitionsupportprogramme.org.uk
- www.transitioninfonetwork.org.uk
- Email: info@prepforadulthood.org.uk
- FB: www.facebook.com/preparingforadulthood
- Twitter: [@PfA_tweets](https://twitter.com/PfA_tweets)
- Phone: 0207 843 6348



Where next ?

- Next steps document due
- Key directions
- Continued move to personalisation
- Local offer/single plan
- Tensions between localism and minimum standards
- Tensions about change against a poor economic picture
- The role of parents further enhanced