

## Aiming High! – Transition on the agenda for young disabled people: a national perspective

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## Every Child (and Family!) Matters – Five key outcomes for *all* children and young people

- Being healthy
- Staying safe
- Enjoying and Achieving
- Making a positive contribution
- Economic well-being

*'Refocusing children's services on long-term outcomes rather than short-term interventions'.*

## But what about disabled children and young people in the UK?

- Around 700,000 disabled children 0-16 in UK (about 7% of child population, using DDA definition).
- Disabled children form the fastest growing group of disabled people – an increase of 62% since 1975.
- Only 4% of disabled children currently receive support from social services.
- 55% of disabled children live in or have lived in poverty as compared to non-disabled children in UK.
- Parents report transition planning as a 'black hole' with many regarding this period as now more stressful than early diagnosis and intervention.

## And some challenges ahead – disabled children face multiple disadvantages

- Only 40% of disabled students aged 16-17 have GCSE grades A-C compared to 56% of non-disabled students.
- Disabled students 16-19 are twice as likely as their non-disabled peers to 'NEETs', ie not in education, training or employment'.
- *'New Survivors'* - an increasingly complex population of children with disabilities or SEN – but high parental expectations of educational and social inclusion.

## Growing up with a disability – Families with disabled children are more likely to be:

- ✓ Single parents (30% compared to 14% in rest of population) – 73% of parents experience '*stress, relationship problems*' because of caring.
- ✓ Working part-time (32% compared to 15%)
- ✓ 50% less likely to afford 'treats' or school outings or holidays
- ✓ 50% more likely to live in temporary, over-crowded or poor accommodation, often in poor areas
- ✓ 50% more likely to be in debt [Source Emerson and Hatton (2008), analysis of General Household Survey data, University of Lancaster and Contact a Family 2009]

## 'Aiming High' – new promises in Treasury/DFES review of services for disabled children and families [2007]

- New resources - £340 million over 2008-11 to '*transform services across the country*'. The money is backed by:
  - ✓ *A new national indicator on disabled children as part of new Public Service Agreement targets to be agreed across Government.*
  - ✓ *A 'core offer' for families with disabled children;*
  - ✓ *Work to improve data collection (and hence commissioning) at local and national level.*

## 'Aiming High' – the big intentions – and new money

- £280 million (plus £90m capital) to improve range of short breaks options
- £35m for childcare for disabled children
- £5m for Parent Forums
- Reform of community equipment and wheelchair service
- £19 m for Transition Support Programme
- £20m for children with life-threatening conditions

## 'Aiming High' cont....

- A **'core offer'** for all young disabled people and families, to include:
  - ✓ Improved information
  - ✓ Transparency (ie clear eligibility criteria)
  - ✓ Participation
  - ✓ Assessment (integrated across agencies)
  - ✓ Feedback

## Transforming health and social care: The 'big ambition'

### After 18, what next? Seven outcomes for adult social care

[Our Health, Our Care, Our Say, 2006]

- Choice and control
- Improved health and emotional well-being
- Improved quality of life
- Making a positive contribution
- Freedom from discrimination
- Economic well-being
- Personal dignity

## Transition in context – a range of multi-agency policy initiatives affecting disabled young people and their families

- The Independent Living Review
- Putting People First
- Valuing People Now
- Aiming High for Disabled Children
- ODI and Equality 2025
- The Right to Control
- The Equalities and Human Rights Agenda
- A National Strategy for Carers
- Health and Social Care Bill

## 'Are we ready for adult life?' - young people's perspectives on growing up with a disability

[DRC Mori Survey of young disabled people 16-24, 2007, updated 2009]

- **69%** sometimes felt lonely and reported low self esteem.
- **89%** thought it would be hard to get a job because of their disability.
- **35%** did not expect to find a partner.
- **68%** had experienced bullying, or hate crime.
- **58%** felt they had insufficient information about their disability or health condition.
- **74%** valued their schools, health professionals etc., but **60%** said they were heavily dependent on parents for 'getting a life'.

## So what do families want at transition?

[EDCM, 2009, National Carers Strategy, 2008]

- Information, advice and 'key workers'/lead professionals.
- An end to multiple assessments!
- Practical help – including short breaks.
- An 'ordinary life' for the whole family.
- **'Choice and control, getting a life - designing services round young people and families. not fitting families to services!'**

## And what do young people want? [Every Disabled Child Matters, 2009]

- *'I want a life, a career – not a placement!'*
- *'I wish they didn't stop me doing sport, PE, school trips, all the fun things. They're always talking about risk.'*
- *'My mum's tired, I really worry what will happen to me if she can't cope. They say every child matters – I don't!'*

## What do young people want cont...?

- *'Friends, a social life, the chance to be me!'*
- *'Honesty about the 'big questions' like am I going to die? Have I got a future? I just don't know!'*
- *'Better careers advice – mine focused on what I couldn't do rather than on a long-term future!'*
- *'An advocate – I am poor at speaking up for myself, I'd like someone to help me be more assertive, more ambitious.'*

## And the 'big policy drivers' for disabled young people over the next decade!

- **Personalisation - Direct payments and individual budgets** – developing the role of families (and disabled young people) as creators of their own personal support and services.
- **'Putting People First'** – new social care concordat for adult social care, with emphasis on choice and personal control – interesting issues about developing the market place for personal care (and relationship of individual budgets to health and education services).

## Changes to the system! Direct payments and personal budgets

- Government committed to switch to Personal Budgets and direct payments.
- Evaluation of pilot social care projects for adults published, Personal Health Budgets coming next!
- Some preliminary work around children and young people. Young people 16-17 can already receive direct payments in their own right.

## Personal budget – conditions for success

- **Greater clarity over assessment of need and allocation of resources.**
- **A debate about 'who cares'** – Sunderland PCT first health provider to agree to pay parents for care of young woman with complex disabilities. Judge claimed this was *'not a direct payment'* but case raises issues about who cares for young adults and roles and rights of parents when children go through transition.

## Personal budgets and risk management

- **Who decides**, if a young person wishes to engage in a 'risky' activity or if he/she chooses to spend a direct payment on a support worker who professionals feel to be unreliable?
- **A role for health champions?** Young disabled people want support in managing (not avoiding) risk and in practical advice on health and well-being.

## 'My school, my family, my life'

[University of Birmingham and DRC, 2007]

Largest study of the views of disabled children and young people, families and schools found major concerns around transition:

- **Health and well-being** were seen as critical issues.
- **'Choice and control'** seen as paramount but often not available.
- **Transition** seen as a negative hurdle in most cases. Parents of severely disabled young people most concerned at lack of options and support.
- **Inclusion** important but parents and young people wanted **'equal citizenship and opportunity'** not **'services!'**.

## 'I don't talk about 'Jane's disability with her. We're an inclusive family!'

### ■ **DRC/Birmingham study found that:**

- *Parents and teachers rarely talked about disability.*
- *Children and young people had very poor (and sometimes very alarming) information about their disability or health condition.*
- *Assessment and long-term planning could be affected by unrealistic expectations or excessive pessimism.*
- *Mainstream schools were least likely to discuss a disability or health condition with child or young person or even to see a young person as 'disabled'.*

## And a key challenge for child health services!

■ *'Nobody ever really talked to me about my disability. I suppose I thought I'd grow out of it one day.'*

- DRC/Birmingham University study (2008) found worrying evidence of lack of awareness in disabled children and young people about the nature and implications of their disability or health condition.

## Why is Transition such a 'big challenge' for disabled young people and families

- A fluid process – spread over a number of years.
- Post-16 options are limited for many young people.
- Support can be patchy and inconsistent.
- Stringent eligibility criteria for social care.
- Different ages for transitions (paediatric to adult health services at 16, children's to adult social care at 18).

## What makes a 'good transition'?

- Person-centred transition reviews.
- High quality information on options.
- Advocacy and self advocacy – encouraging young people to develop confidence and to plan for the future.
- Multi-agency transition protocols – many young disabled people have additional health needs.
- Redefining roles and responsibilities of parents and young people.

## And new opportunities

- **Education and Skills Bill** – will entitle (and require) all young people to engage in appropriate study, training or work placements such as apprenticeships between 16 – and 18. But currently concerns about whether there will be appropriate provision for young disabled people

## 'Speaking for ourselves!' - A Ten Year Youth Strategy and a second 'Aiming High'!

- **Youth Opportunity Fund** - Focus on young people taking part in enjoyable and purposeful activities in their free time which will help develop new skills, raise aspirations and encourage participation in the local community.
- **'Speaking Up!'** – Over £3m from Youth Sector Development Fund to help create positive choices for disabled young people and encourage self-advocacy.

## Working together: the big opportunities – a new national Transition Support Programme

- **The Transition Support Programme:** a national programme (with £19m committed funding) to improve support for disabled young people in their transition to adulthood and to raise the profile of transition across specialist and universal services..
- **A three year programme 2008-2011** run jointly by DH/DCSF, supported by the National Transition Support Team (based at Council for Disabled Children), National Strategies and the Child Health and Maternity Partnerships.
- For further information, e-mail [tsp@ncb.org.uk](mailto:tsp@ncb.org.uk) for updates or go to the website at: [www.transitionssupportprogramme.org.uk](http://www.transitionssupportprogramme.org.uk)

## What works at transition: A postscript from a family carer

[Archives of Disease in Childhood, Vol 90, No 1]

- 'Parents have a life-long investment in their child so – how do you make me an active partner, NOT a 'pushy parent' and NOT negative and over-anxious?
- Am I properly involved in discussions about the future – or the last to know?
- Do I have the information and time I need in order to make an informed choice?
- Do I feel that I have control in what is happening to us?
- Are my emotions and feelings acknowledged?
- How much do you expect ME to do in any plans? Am I safety net or partner?
- Do I have somewhere to go just to 'talk it over'?

## So, 'work in progress' and a challenge for all of us to ensure that 'Aiming High' and The Transition Support Programme make a difference?

- *'Disabled young people and their families are now part of a national policy framework which should improve their life chances – but constant vigilance will be needed to ensure that they are valued as equal citizens and have the lives they dream about. Personalisation is the 'road map' of the future, but we are still a long way from the gold-standard 'ordinary life' of the NSF Standard 8!'* [Parent responding to consultation on National Strategy for Carers, 2007]