

Voluntary
Organisations
Disability Group

V O D G

Shadow Lands

Application and Impact of Eligibility Criteria on
Young People with Disabilities

Produced by the Institute of Public Care,
Oxford Brookes University for the Voluntary
Organisations Disability Group



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The Voluntary Organisations Disability Group (VODG) is the leading national umbrella group of voluntary sector providers of social care support to disabled people. The VODG members provide services on a contractual basis to more than a million disabled people each year.

The VODG:

Addresses with government those issues that affect its members' ability to deliver high quality services to disabled people.

Offers government and other bodies a means by which voluntary providers of support services to disabled people can be consulted in a coherent way.

Leads the sector both in terms of the innovation and quality of the services its members provide and through the strength of their collective voice.

Conducts practical research to inform the work of its members, leading to improved opportunities for disabled people.

The VODG is committed to ensuring that disabled people's needs are met in ways that they themselves define.

www.vodg.org.uk

Foreword

My son, Keith, has Asperger's syndrome. We have no support as Social Services say he does not fit the criteria as he has no learning disabilities. We need someone to help go out with him. We always have to be around to either help my son go out, go for a walk, go to guitar lessons, arrange and be with him for any sort of outing from home, even shopping. Therefore I have had to give up my job as a SEN teacher, which has meant a lot less income. Keith needs help to develop his independence skills to get out and about without us parents. He needs help to meet teenagers his same age and make friends – at the moment he has none.

Parent

The transition from teenage years to adulthood is not an easy time for most young people. Concerns about the future often combine with leaving home for the first time and having to sort out issues around finance, lifestyle and accommodation. The same is true for young people with a disability... or they would like it to be.

This review has confirmed that very little is known about the numbers of young people with disabilities, what happens to them as they enter their adult lives, how many people secure ongoing support and how many people don't. The decision making process is arcane, seemingly arbitrary, with poor planning and insufficiently targeted resources. Most importantly, very little is known about what happens to those who fail to gain support and who disappear into the "shadow lands".

For young disabled people and their families, the key problem is a lack of continuity in the provision of services which stems from the different entitlement criteria and definitions between child and adult services. It is the view of the Voluntary Organisations Disability Group that this situation is completely unacceptable and that immediate steps should be taken to find solutions, centred on each young person that ensures their successful transition to adult life as valued citizens.

The current Commission for Social Care Inspection review of eligibility criteria and its application is welcome. It would be hoped that its conclusions will explore discontinuities between different groups of service users and the consequences of such differences. This paper, in reviewing current evidence, outlines some of the consequences of young people currently not being eligible. The danger is that as increasing pressure falls on local authorities, owing to the demographic increase in the number of older people, then the bar of eligibility gets raised higher for other groups such as young people with a disability.

So what needs to be done?

There is an urgent need to:

1. Review the impact of eligibility criteria on young people with disabilities in transition to adulthood.
2. Identify the size and scope of the problem among young disabled people.
3. To understand the short term and long term consequences of what happens to young people with disabilities who disappear into the "shadow lands".

4. To create and adequately resource a specialist pan disability transition service to ensure effective planning and tracking.
5. To share current best practice.

If the government is serious about its desire to pursue a preventative agenda then there will be a need to identify, not only who is being targeted with what interventions, but also to ensure that a proportion of funding gets allocated for this purpose beyond the confines of substantial and critical eligible needs. Without such a change social care will increasingly become the next 'emergencies only' service.

Bill Mumford
Vice Chair VODG
& Managing Director MacIntyre

Shadow Lands

The Application and Impact of Eligibility Criteria on Young People with Disabilities – A Review

1 INTRODUCTION

This review by the Institute of Public Care was commissioned by the Voluntary Organisations Disability Group (VODG) in order to contribute to the national debate about Fair Access to Care (FACs) and the operation of the current eligibility criteria. The review aims to:

- Estimate the number of young people with disabilities¹ in England aged 18 to 25 who might be eligible for social care and support.
- Understand what is currently known about the application of social care eligibility criteria on young people with disabilities in transition and the impact this might have.
- Examine the issues faced by young people in transitions and models of good practice.

2 THE PROBLEMS IN COUNTING

There is a startling lack of accurate and reliable data about the numbers of young people with disabilities who might be eligible for social care and support services in England. Not only is there a shortage of information about young people at the threshold of care services but there is also little longitudinal data which follows the pathways of young disabled people as they move from childhood to adult life.^{2 3 4 5}

Gordon et al⁶ comments, '*We enter the 21st century with as little quantitative knowledge about disabled children as we had at the beginning of the 20th century... If the present government's rhetoric about the importance of combating poverty and social exclusion is to be realised, then this scandalous lack of basic information will have to be made good*'. Despite the lack of data, government does recognise its importance. '*Good quality, consistent and up-to-date information is essential to the provision of services to all those in need including disabled children*'.⁷

¹ Young people with a disability are a very diverse group, including some who are multiply disabled. In this project, we have used disability to refer to '*aspects of functioning: mobility, hand function, personal care, continence, communication, learning, hearing, vision, behaviour and consciousness*', Department for Education and Skills (2003) Children's Social Services Core Information Requirements. Glossary of Terms. November 2003 Version 3.1
http://www.everychildmatters.gov.uk/_files/41CFDF02BFB2958A95924F2FC84D1040.pdf

² HM Treasury and DFES (2007) *Ibid*, p29

³ Office for National Statistics (ONS) (2004) *The Health of Children and Young People, Chapter 10, Disability*, National Statistics Online, London

⁴ Prime Minister's Strategy Unit (PMSU) (2005) *Improving the Life Chances of Disabled People*, The Stationery Office, London

⁵ C. Blackburn, J. Read and N. Spencer (2007) 'Can we count them? Scoping data sources on disabled children and their households in the UK', *Child: care, health and development*, 33, 3, 291–295

⁶ Gordon D, Parker R, Loughran F, & Heslop P (2000) *Disabled children in Britain, A reanalysis of the OPCS Disability Surveys*, The Stationery Office, London

⁷ HM Treasury and DFES (2007) *Aiming higher for disabled children: better support for families*, p28

Limited availability of key information is not the only problem. Of the data that is available, there are wide variations in the definitions of who is being counted. Such variations are caused by:

- Real changes over time in the numbers of people experiencing disability.
- Differences in the way that 'disability' is defined.
- Methodological differences between surveys.⁸

The way that disability is defined, not only determines the nature of the data being sought and the process of data-collection, but also affects the range of responses by participants. Subjective and objective measures of disability are clearly a cause of variation, whilst one-off surveys may fail to capture the multidimensional and dynamic nature of disability.

In addition to methodological differences between surveys, there are differences in the way data relating to service use is collected, often reflecting the needs and priorities of the service provider. There is also likely to be some overlap between databases which may result in double counting.⁹ There are also tensions between conceptual models of disability which emphasise to a greater or lesser degree individual characteristics or social barriers.

Even without the variations in how numbers are counted and how disability is defined, predicting numbers into the future can vary due to a range of factors, from economic circumstances to health and well being. Advances in medicine have impacted on the numbers of children experiencing disability surviving into young adulthood. For example, mortality in congenital heart disease was once greatest in infancy, but now 70-80% of children reach adulthood and the average age of death is 25.4 years,¹⁰ while ante-natal screening has influenced the numbers of live births of children with both physical and learning disabilities.

3 WHAT DO WE KNOW FROM WHAT HAS BEEN COUNTED

Limiting long term illness

The 2001 Census asked respondents whether or not they had 'any long-term illness, health problem or disability which limits your daily activities or the work you can do?' The results are as set out below in Table 1.

⁸ Bajekal M, Harries T, Breman R, & Woodfield K (2004) *Review of Disability Estimates and Definitions In-House Report No. 128*, Department of Work and Pensions, London

⁹ C. Blackburn, J. Read and N. Spencer (2007) 'Can we count them? Scoping data sources on disabled children and their households in the UK', *Child: care, health and development*, 33, 3, 291–295

¹⁰ Sommerville J (1997) near misses and disasters in the treatment of grown-up congenital heart patients. *J Social Medicine* 90; 124-7

Table 1: Number of young people with a limiting long-term illness in England in 2001

Age	Population with a LLTI	Total Population of Young People	% with LLTI
18-19	57,499	1,062,730	5.4%
20-24	165,697	2,805,950	5.9%
Total	223,196	3,868,680	5.8%

Source: ONS Census 2001

Bajekal et al (2004)¹¹ in a detailed review of the various approaches to estimating numbers of people with disabilities by different surveys produced three potential prevalence rates for disability in young people based on the Labour Force Survey (LFS). By applying the age-specific prevalence rates for disability from the Labour Force Survey to the mid-year population estimates for 2006, we have obtained a range of estimates for the number of young disabled people aged 16-24 in England (see Table 2).

Table 2: Estimate of disabled people aged 16-24 in England

	Age 16-19	Age 20-24	Total
DDA Current Prevalence rate	5.5%	7.9%	
Estimated Number	146,714	265,566	412,280
Work-limiting disability Prevalence rate	6.6%	9.0%	
Estimated Number	176,056	302,544	478,600
Long-term disabled Prevalence rate	8.6%	11.4%	
Estimated Number	229,407	383,222	612,629

Source: Bajekal et al (2004), LFS 2001 & ONS 2006 Mid-year estimates

Note: 'DDA current' covers people with a currently existing condition covered by the Disability Discrimination Act, or a progressive health condition; 'long-term disabled' is defined as those with a work-limiting disability or covered by the DDA, or both.

As can be seen from the table, relatively small changes in prevalence produced by different definitions of disability can produce wide variations in the actual numbers of people. It is also likely that the wider the definition then the greater likelihood that a smaller proportion of any sample would see themselves as needing social care,

¹¹ Bajekal et al (2004) op cit

although people may well need other forms of support if they are to enjoy the same life opportunities as those without a disability.

Emerson and Hatton¹² have also applied known prevalence rates of a specific disabling condition to population estimates. They estimated the prevalence of young adults with learning disabilities in England in 2001 as in Table 3. 'True prevalence' means as distinct from the population with a learning disability estimated to be in receipt of care services.

Table 3: True prevalence of young adults with learning disabilities in England in 2001

Age Range	Male	Female	Total
15-19	50,290	31,295	81,586
20-24	45,545	31,335	76,881
All	95,835	62,630	158,467

The above figures are estimates of disability for whole populations. Information is also available from select populations, ie, those who have already received a particular service either because of their disability or through which their disability has been recognised.

Education

Provisional figures from the Department for Children, Schools and Families for 2008¹³ indicate that there are 18,560 children aged 16-18 in England with statements of special educational needs (SEN), (see Table 4).

Table 4: Secondary and special schools: number and percentage of pupils aged 16 to 18 by primary type of need

Definition	Numbers
Severe learning difficulty	4,350
Moderate learning difficulty	3,130
Autistic spectrum disorder	1,990
Physical disability	1,670
Specific learning difficulty	1,650
Behaviour, emotional and social difficulties	1,650
Profound and multiple difficulties	1,310
Speech, language and communication needs	900
Hearing impairment	720
Other disability	670
Visual impairment	470
Multi sensory impairment	50
Unclassified	10
Total	18,560

Source: DCFS, 2008

¹²Eric Emerson & Chris Hatton (2004) *Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England*, Institute for Health Research, Lancaster University, UK

¹³Statistical first Release (2008) Pupil Characteristics and class sizes in maintained schools in England, (provisional) Department for children, schools and families www.dscf.gov.uk

The Government has made an effort to increase participation in further education for disabled children and young adults through the Education Maintenance Allowance for 16 to 18 year olds and there has been a rise in student population known to be disabled from 2% in 1994/95 to 5% in 2002/03. Figures from the Higher Education Statistics Agency show the number of students undertaking a first degree 'known to have a disability' studying full time in the UK in 2006/2007 as 30,525¹⁴ (of whom 14,790 students are dyslexic). Most of these will be aged 18 to 21.

Training and employment

Young people with a disability or health issue are less likely to be employed, and less likely to be in full time higher education. They are also 3 times more likely than their non-disabled peers not to be in any form of education, employment or training (NEET) than their peers.¹⁵ According to the 2001 Census, there were 62,000 people aged 16-24 in England and Wales who were permanently sick or disabled and, therefore, unavailable for work. Among 18-24 year olds, rates of unemployment and economic inactivity for disabled people are twice as high as those for non-disabled youth.¹⁶

Figures from the Labour Force Survey (2005) indicate that 23,000 16-19 year olds who were 'disabled' and 'work-limiting disabled' were engaged in post compulsory education, training, or participation in job related training.

The number of 18-24 year olds with disabilities joining the New Deal for Young People participating in May 2007 was 13,300 (self assessed and defined as having a physical or mental impairment which has a substantial and long-term effect on their ability to carry out normal day to day activities).

Criminal justice

In August 2006, there were 11,588 15-21 year-olds being held in prisons in England and Wales¹⁷ of whom 9,060 were aged between 18-21 years. The Social Services Inspectorate (1997) found that one-third of young within the criminal justice system had a primary health disorder.^{18 19} The Prison Reform Trust (PRT)²⁰ estimates that around a quarter of children and young people in contact with the youth justice system have learning disabilities.

¹⁴ Higher Education Statistics Agency (2006/7) First Year Higher Education Students UK domiciled 2006/2007. www.hesa.ac.uk

¹⁵ Youth Cohort Study; the Activities and Experiences of 19 year olds; England and Wales (2005) Department of Education and skills First Release Nov 2005

¹⁶ Burchardt T (2005) *The education and employment of disabled young people*, Joseph Rowntree Foundation, York

¹⁷ Op Cit C. Blackburn, J. Read and N. Spencer (2007) 'Can we count them?

¹⁸ Social Services Inspectorate (1997/8) Facing the future. The 7th annual report.

¹⁹ Gunn J, Maden A, Swindon M (1991) Treatment needs of prisoners with psychiatric disorders. *BMJ* 303;338

²⁰ National Offender Management Service (2006). Population in custody: monthly tables: England and Wales. See: <http://www.homeoffice.gov.uk/>

Benefits

Young disabled people can claim Disability Living Allowance in their own right from age 16. There are a number of different components depending on the area of need:

- Care needs allowance which applies to assistance needed with basic needs such as eating, dressing, washing etc. This is categorised into three rates depending on the severity.
- Mobility needs which includes people who are deaf or blind.
- A special section for progressive terminal illness for those who have a terminal diagnosis expected to last for 6 months.
- A tiered dependency assessment which uses time of input to measure severity.

Incapacity Benefit can apply to those aged 16-25 who are too disabled or ill to work, usually when national insurance has been contributed, but the Incapacity Benefit in Youth (IB in Youth) can be paid if the applicant is:

- Aged 16 years or above.
- Under 20 years, occasionally 20-25 years.
- Has been incapable for work for 196 days previously.

Young people receiving the highest rate of Disability Allowance may not qualify for Incapacity Benefit.

Table 5 indicates the number of young people claiming the available disability benefits in November 2007. It should be noted that if someone is eligible for Job Seekers Allowance and Disability Living Allowance then the former takes precedence over the latter.

Table 5: The number of young people claiming the available disability benefits in Great Britain, November 2007

Aged 18-24 years old	Number
Incapacity Benefit	162,740
Disability Allowance only	38,950

Source: DWP Tabulation Tool

Social Care

It is not possible to calculate the number of young disabled people aged 18-24 who receive social care and support in England as community care statistics are presented for the whole of adult service users, ie, aged 18-65.

The closest approximation available is from the Children in Need survey²¹ which presented data on the number of children receiving local authority social services (Table 6).

²¹ DFES, *Children in Need in England: Results of a survey of activity and expenditure as reported by Local Authority Social Services' Children and Families Teams for a survey week in February 2005: Local Authority tables and further national analysis* (Internet only) Issue No vweb-02 – 2006, DFES <http://www.dfes.gov.uk/rsgateway/DB/VOL/v000647/vweb02-2006.pdf>

Table 6: The age distribution of disabled children receiving local authority social services in England, February 2005

Age	Children looked after	Children supported in families or independently	Total children in need
Between 16 and 17	1,300	1,300	2,600
Between 17 and 18	1,100	1,100	2,200
18 and over	200	1,000	1,200
Total	2,600	3,400	6,000

Source: DFES

4 THE POLICY CONTEXT

Services for young adults with disabilities going through the transition process from children's services to adult services have been highlighted as an area of concern in a range of recent policy documents and associated guidance:

- **Valuing People** (2001), the first White Paper concerning people with learning disabilities, set an objective for young people with learning disabilities moving into adulthood '*to ensure continuity of care and support for the young person and their family*'.²²
- **Removing Barriers to Achievement - The Government's Strategy for SEN** (2004) asserted that the Department for Education and Schools would '*work across Government to improve the quality of transition planning*'.²³
- Standard 4 of **The National Service Framework for Children, Young People and Maternity Services** (2004) includes the expectation that '*transition to adult services for young people is planned and co-ordinated around the needs of each young person to maximise health outcomes, their life chance opportunities and their ability to live independently – this is particularly important for disabled young people or those with long-term or complex conditions*'.²⁴
- **Improving the Life Chances of Disabled People** (2005) identified four key areas for practical attention, of which '*facilitating a smooth transition into adulthood* (emphasis in original) *by putting in place improved mechanisms for effective planning for the transition to adulthood and the support that goes with this; removing "cliff edges" in service provision; and giving disabled young people access to a more transparent and more appropriate menu of opportunities and choices*' was one.²⁵
- **Aiming High for Disabled Children: Better Support for Families** (2007) noting the additional challenges faced by disabled young people in the critical transition to adulthood, allocated £19 million over the Comprehensive Spending Review period for a Transition Support Programme to help disabled young

²² Department of Health (2001) *Valuing People: a new strategy for learning disability for the 21st century*, Department of Health

²³ Department for Education and Schools (2004) *Removing Barriers to Achievement - The Government's Strategy for SEN*, DfES

²⁴ Department of Health (2004) *The National Service Framework for Children, Young People and Maternity Services*, Department of Health

²⁵ Prime Minister's Strategy Unit (2005) *Improving the Life Chances of Disabled People*, PMSU

people and their families benefit from intensive, coordinated support and person centred planning.²⁶

- **Valuing People Now** (2007) is part of the consultation to update the 2001 White Paper.²⁷

Most recently, the cross-government strategy on independent living for disabled people²⁸ sets the objective of ensuring 'a seamless transition into adulthood for young disabled people, including those with complex needs, in all aspects of their life, including between children's and adult services, as well as housing, transport, employment, education and training'.

The government has set a goal that all young people with a disability and their families will experience continuity and co-ordination in the services that they receive, as both children and adults by 2015. This will be achieved through mechanisms such as: person-centred planning and individualised budgets, improved communication, and sharing of information, responsibility and joined up budgets across agencies and between child and adult services.²⁹

In addition to the transition policy agenda, the government has a strong commitment to personalisation, and the provision of more person-centred and responsive services is clearly stated in *Transforming Social Care*³⁰ and *Putting People First*.³¹ Individual budgets giving disabled people a choice, about how and what care they receive, are being promoted as a way of increasing choice and control for disabled people.

5 MAKING THE TRANSITION TO ADULTHOOD

The transition process

Despite the consensus on the importance of good transition planning, research shows that young people are not getting the help they need.³² The National Service Framework for Children, Young People and Maternity Services³³ recognises that young people with disabilities and their families experience particular difficulties in the transition from full time education into the adult world. Young people's lives change rapidly during this period. Leaving compulsory schooling is accompanied by decisions about future education and employment and there are also changes in family life and social networks.³⁴ The choices for individuals are often a range of segregated services, rather than help to achieve the same things as other young people.³⁵

For young disabled people and their families, the key problem is a lack of continuity in the provision of services which stems from the different entitlement criteria and

²⁶ HM Treasury/DFES (2007) *Aiming High for Disabled Children: Better Support for Families*

²⁷ Department of Health, (2007) *Valuing People Now*, Department of Health

²⁸ Office for Disability Issues (2008) *Independent Living, a cross-government strategy on independent living for disabled people*, HMG, p.18

²⁹ Prime Minister's Strategy Unit (2005) *Improving Life Chances of Disabled People. Final Report*, p.53 & 131

³⁰ Department of Health (2008) *LAC (DH) (2008)1: Transforming social care*, DH.

³¹ Department of Health (2007) *Putting People First: A shared vision and commitment to the transformation of Adult Social Care*, DH.

³² Beresford, B (2004) 'On the road to nowhere? Young disabled people in transition', *Child: Care, Health and Development*, 30, 6, 581-587

³³ Department of Health, Department for Education and Skills (2004) *The National Service Framework for Children, Young People and Maternity Services*

³⁴ Everitt, G. (2007) *Transition? How to find your way through. An overview of recent transitions research for parents and practitioners*. Dimensions (UK) Ltd. p9

³⁵ DH (2007) *Valuing People Now. From Progress to Transformation*, London, DH Publications

definitions between child and adult services.³⁶ For example, while social care services determine the age of transition as 18, the health service uses 16 as the threshold age. This can result in confusion and bargaining between health and social care services, in particular, over inter-organisational relationships and responsibilities.³⁷ A study conducted by the Commission for Social Care Inspection (CSCI) reported that at least half of the councils questioned, stated that the level of young people's services changed at transition, and that young people could not maintain activities provided before transition because the local authority did not provide the same level of support.³⁸ The difficulty in referring some young people to the relevant adult services suggests that eligibility criteria should be agreed between agencies applying a life span approach, rather than being set independently by individual teams and driven by resource limitations.³⁹

Transition Outcomes

At age 16, young people with disabilities have aspirational levels similar to their non-disabled peers, yet these diverge significantly in early adulthood.⁴⁰ As the material below suggests, research evidence on young people with a variety of disabilities shows that their aspirations are seldom met.

A report for the Joseph Rowntree Foundation highlighted that few young people with a disability are employed, many use day centres, college is often the expected route of progression from school regardless of desire, and little emphasis is placed on leisure, friendship and emotional support.⁴¹ In addition, young disabled people often find that the only option for leaving their parents' home is not a move into a home of their own, but instead into a 'housing scheme' or group home.⁴² The decision about where to live is more often determined by what vacancies are available, than by a young person's choice about where and who they want to live with.

A survey of 2,898 people with learning difficulties,⁴³ nearly half (45%) of whom were under 30 years old, found that:

- Half of all adults with learning difficulties were still living with their parent(s).
- Only one in fifteen were living either on their own or with a partner.
- Two out of three people in supported accommodation had no choice over either who they lived with or where they lived.
- Only one in six people with learning difficulties who were of 'working age' had a paid job.
- Nearly one in three said they did not have any contact with friends.

³⁶ Council for Disabled Children (2005) *Individual Budgets for disabled children and their Families*, p.8

³⁷ Hudson, B. (2006) 'Making and missing connections: learning disability services and the transition from adolescence to adulthood', *Disability & Society*, Vol 21(1) p.47- 60

³⁸ Commission for Social Care Inspection (CSCI) (2007) *Growing Up Matters. Better transition planning for young people with complex needs*, p.Vii

³⁹ Ko, B and McEnery, G. (2004) 'The needs of physically disabled young people during transition to adult services', *Child: Care, Health & Development*, Vol 30(4) p.317-323

⁴⁰ Burchardt T (2005) *The education and employment of disabled young people: Frustrated ambition*. York: Joseph Rowntree Foundation, Policy Press

⁴¹ Morris, J. (1999) *Hurling into a Void: Transition to adulthood for young disabled people with complex health and support needs*, Joseph Rowntree Foundation.

⁴² Everitt, G. (2007) *Transition? How to find your way through. An overview of recent transitions research for parents and practitioners*, Dimensions (UK) Ltd.p61

⁴³ Emerson, E., Malam, S., Davies, I., and Spencer, K. (2005) *Adults with Learning Difficulties in England 2003/4*, The Information Centre for Health and Social Care.

- One in three said they did not feel safe either in their homes, their local area or using public transport.
- One in six said their general health was not good.

The survey also showed that people with learning difficulties were much more likely to be poor, socially excluded and have an unmet need, than young people in general.

Such poor outcomes were further evidenced by the Prime Ministers Strategy Unit⁴⁴ which reported that:

- 20% of young people with a disability were discouraged from taking GCSEs because of their impairments.
- 60% who did not enter further education said they don't believe they would have got enough support.
- 86% felt it was harder for disabled people to find work.
- 32% said they had limited access to social activities because of additional needs.

The evidence implies that young disabled people do not, on the whole, achieve good outcomes. What is less clear is the degree to which this is a result of the application of eligibility criteria to determine access to social care and other services.

6 ELIGIBILITY AND FAIR ACCESS TO CARE (FACS)

Originating in the 1998 White Paper, *Modernising Social Services*,⁴⁵ and described in detail in the 2003 guidance,^{46 47} FACS provides the national *eligibility* framework for social care in England. It recommended that councils “*should have clear rules about who can get help*” so that “*everyone in the area gets treated fairly*”. The guidance provides councils with a framework for setting their eligibility criteria based upon individuals’ needs and associated risks to independence, and identifies four eligibility bands – critical, substantial, moderate and low (see Appendix 1).

Because of the different resource positions of councils, the guidance does not require them to reach similar decisions on eligibility, or to provide similar services to people in similar needs. However, within a council area, individuals in similar circumstances should receive services capable of achieving broadly similar outcomes. The FACS framework is intended to apply equitably to all adults needing social care.

FACS makes a distinction between ‘presenting needs’ (the needs described by adults seeking social care support) and ‘eligible needs’ (those needs that are assessed as falling within a council’s eligibility criteria, and which should be met). Little information on unmet need is gathered.⁴⁸ Indeed the concept of unmet need is usually interpreted as unmet eligible needs and takes no account of unmet presenting needs.⁴⁹

⁴⁴ Prime Minister’s Strategy Unit (2005) *Improving the Life Chances of Disabled People*. p127

⁴⁵ Department of Health (1998) *Modernising Social Services*.

⁴⁶ Department of Health (2003) *Fair access to care services - guidance on eligibility criteria for adult social care*.

⁴⁷ Department of Health (2003) *Fair Access to Care Services: Implementation Questions and Answers*

⁴⁸ Clough, R. and Manthorpe, J. (2006) *The Support Older People Want and the Services they Need*. Joseph Rowntree Foundation.

⁴⁹ Henwood M. and Hudson B, (2008) *Lost to the System? The Impact of Fair Access to Care: A report commissioned by the Commission for Social Care Inspection for the production of The state of social care in England 2006-07* p.21

Early in 2008, the Commission for Social Care Inspection (CSCI) identified the trend for all councils to raise the threshold for access to social care services, with nearly two thirds setting the FACS entry point at 'substantial' in 2006-07 and almost three quarters expecting to be operating at such thresholds in 2007-08.⁵⁰ These findings resulted in the current consultation on eligibility criteria.

Eligibility tests have been used as a form of rationing limited resources by governments for many years. However, rising levels of need for support combined with constrained financial resources have concentrated attention on service rationing in recent years. The increasing pressure upon adult social care budgets comes from a variety of sources including the high cost of meeting the needs of a growing number of younger people with complex needs⁵¹ and the rising numbers of older people. According to the CSCI report by Henwood and Hudson,⁵² it has resulted in a tendency for FACS to be used as '*a means of reducing budgetary demands upon the council, limiting professional discretion, and legitimating the diversion of demand away from council funded services*'.

Henwood and Hudson describe three types of rationing in operation, to a greater or lesser degree, in all localities:

- (1) Rationing by directive: the various formal attempts by agencies to locally implement national policy on eligibility criteria (FACS).
Henwood and Hudson found that the bands were often used in a crude way to restrict demand, resulting in poor outcomes for some vulnerable people. In practice, one of the most disadvantaged groups were young people, particularly 16 and 17 year olds in transition between children's and adult services who were particularly at risk of falling outside eligibility criteria.
- (2) Rationing by discretion: the exercise of professional judgement in the operationalisation of the rationing process.
The extent to which rationing by discretion occurs differs from locality to locality. Henwood and Hudson noted 'a pervasive view among social services staff that people do not 'need' support with simple tasks and are often trying to trick the council into giving them help they are not entitled to'. The authors commented on the risk that these young people simply disappear from the system, quoting one service manager: "We never hear about them, or we don't hear about them until they're 25 and their Mum has got ill (...) they may have been sitting at home for 10 years".⁵³
- (3) Rationing by diversion: the attempt to limit demand upon one part of the system by either diverting it to other parts, or by simply returning responsibility to the applicant.⁵⁴
Some people who are not eligible for council support are directed towards other services or sources of help. It is difficult to ascertain the degree to which such rationing by diversion is adequately meeting the needs of individuals, rather than just reducing the demands on a council's social care budget.

The above three categories, of course, relate to those who apply for support. Beyond those numbers lie those who never get that far for a variety of reasons. This may be

⁵⁰ CSCI (2008) *State Of Social Care in England 2006-07*, CSCI

⁵¹ Prime Minister's Strategy Unit (2005) *Improving Life Chances of Disabled People. Final Report*, p.9

⁵² Henwood M. and Hudson B, (2008) op.cit. p.70

⁵³ Henwood M. & Hudson B, (2008) op.cit.

⁵⁴ Henwood M. and Hudson B, (2008) op.cit. p.29

owing to simply not knowing what is available, being discouraged from applying knowing that resources are in short supply, or possibly owing to a feeling of optimism that adulthood will be alright although after a couple of years this may not prove to be the case.

7 OUTCOMES FOR YOUNG DISABLED PEOPLE

This section examines the available evidence on the impact of the application of the FACS criteria on the outcomes for young disabled people.

The RITE research project focused exclusively on disabled people aged 17 to 42 with the academic ability to study for mainstream qualifications in further and higher education, who require high levels of support and use assistive technology to support their mobility, communication or access to computers. The study found that the move to adult health and social care services usually triggered the withdrawal of the specialist services that were essential to participants' quality of life.⁵⁵

As young people grow up, leisure time is increasingly used to explore their own interests and to make new relationships, relying less on their families. We know that disabled young people may need additional support in order to share this experience, but this tends not to be deemed as a critical or substantial need, and hence such support is often not available.⁵⁶

“Not going to college... makes me feel angry. I can get bored at home. I want to be able to go out and do things with people my age.”

Service user, Individual Budgets in Coventry

A recent study for Leonard Cheshire Disability found that disabled people who were not eligible for direct council support were being forced to go without a service which was resulting in limits to their independence. Over half (52%) said the shortfall in social care services had led to more accidents, serious illness, suicide attempts and/or more visits to the doctor and hospital. Fourteen per cent were very concerned that it had also led to illness, accidents and stress in their carers.⁵⁷

Tim has Asperger's Syndrome although we didn't know that until recently. He always had his odd ways and could be very obsessive about things being just so. He was badly bullied at school and it didn't matter how many times we spoke to the teachers they never seemed to do anything about it. He won't go to college because he thinks he will get bullied there too. We couldn't find him any supported employment which meant he sat at home all day getting more depressed and very obsessive about all sorts of things.

A couple of weeks ago he had an argument with his father and then ran out of the house. He was eventually picked up by the police who found him threatening to jump off of a bridge. He is in hospital now but I am worried about what will happen next. The hospital said that if he continues to make progress they will discharge him next week but then we will just be back to square one. We think he needs to live with other people his own age who are like him. The GP helped us make a referral to social services but we received a letter to say that they don't provide services for people with Asperger's Syndrome.

Tim's Parent.

⁵⁵ Rustin, C. et al (2006) *The RITE transition: the only way forward. Summary and Recommendations*. DARE foundation. P6

⁵⁶ Wheatley et al (2007) *A Transition Guide for all Services. Key information for professionals about the transition process for disabled young people*. Nottingham: DCFS Publications. p60

⁵⁷ Foster, J. et al (2008) *Your Money or Your Life. Disabled people's experiences of the loss of social care services in England*. Leonard Cheshire Disability. p7

Many of the young people judged ineligible for social services support are typically signposted to other services. This often leaves people to take the initiative in following up other leads for themselves, and for some people the signposts lead to a dead end where they remain with no further assistance.⁵⁸ Many are left managing with extreme difficulty or using arrangements that are far from ideal and at risk of breakdown.

We (Mum, Dad and I) all used to live at home. Then Dad got ill and had to live at the hospital. Mum goes to see Dad for a couple of days most weeks but says I am not allowed to go. I can't be trusted in the house on my own so I sleep outdoors those nights.

James – a 22 year old man with mild learning disabilities

James has always been different. There were always problems at school and he has never had a job. My husband is waiting for a transplant so when I visit him in London I have to leave James on his own. I can't trust him in the house since the fire so I have to lock him out. I did go to the social once but they said James was not disabled enough so they couldn't help. They suggested he goes to stay with family when I am away, but there isn't anyone else, only us.

James's Parent

The exclusion of lower bands of eligibility means that people have particular difficulty in getting support with practical tasks such as housework, managing money, gardening and shopping.⁵⁹ This often means that the ability to live on one's own becomes impossible without either a great deal of informal support or unacceptable personal risk. Over half of the participants in the RITE research project lived in the family home. Meeting the support requirements of their children places a great strain on parents, many of whom struggle to manage the demands on their time and finances.⁶⁰

I have tried to get onto college courses to enhance my chances of getting back to work.... but no one seems to know how to help me... I don't know which way to turn next!

Service user, Individual Budgets in Coventry

Young disabled people report that the interconnectedness of the barriers they face only serves to exacerbate issues. Low expectations generally of disabled people's abilities, poor physical access, inadequate support, inadequate transport and ill-informed or discriminatory attitudes affect every stage of their lives.⁶¹ The provision of personal and social support by social services is generally felt to be inadequate, inflexible and disempowering. The anecdotal evidence cited above, indicates the negative impact of the application of FACS on the quality of life of young disabled people.

⁵⁸ CSCI (2008) *State of Social Care 2006-07*. p28

⁵⁹ CSCI (2008) *State of Social Care 2006-07*. p29

⁶⁰ Rustin, C. et al (2006) *The RITE transition: the only way forward. Summary and recommendations*. DARE Foundation. p6

⁶¹ Rustin, C. et al (2006) *The RITE transition: the only way forward. Summary and recommendations*. DARE Foundation. p6

Even for those who are eligible for support, there are questions about whether the current arrangements for the planning and commissioning of services results in the type of service provision that young disabled people want.

I work for a parent-led charitable organisation that provides support to parents of disabled children. We provide services across two neighbouring localities. One of the Councils is still meeting substantial, critical and moderate needs whilst the other has raised the threshold to substantial and critical only. We hold forums where the parents get to chat to each other and share their stories. Some parents living in opposite localities have adult children with very similar needs. Due to the difference in thresholds one family gets a service and the other doesn't – it just doesn't seem fair.

Volunteer

8 MODELS OF GOOD PRACTICE

Much of the research on transition has been concerned with identifying current problems in service provision, and people's experiences of this. The evidence about 'what works' and service evaluations is much smaller⁶² The following section aims to describe how services for disabled people, aged 18 to 25 years, can be planned and commissioned to support young disabled people to achieve their desired outcomes.

The relevance of effective commissioning and planning of services

Commissioning and market development are necessary, not just in relation to 'traditional' services, but also to meet the needs and preferences of young disabled people in control of their own budget. Young disabled people who are in control of their own budget often report that the types of innovative services they require are not available (although this may depend on the severity and type of disability). Equally, for those who do not qualify for direct council support, a good range of voluntary and private sector services are important, to enable them to gain or maintain a good quality of life.

A key responsibility of all local authorities is to work in partnership with providers to develop appropriate services. The size of the partnership remit required to deliver successful transitions is considerable,⁶³ encompassing health and social care, youth services, leisure, careers guidance, housing, education, benefits and employment services.

Valuing People Now (2007) suggests that at the heart of good transition planning are person centred transition plans:

*'that will inform the commissioning and provision of future services and supports, be reviewed each year, and be at the core of a smooth transition to adult services.'*⁶⁴

Nevertheless, simply having plans is not enough. The plans need to be translated into action⁶⁵ and this implies that the necessary systems need to be in place. Such systems should be linked to the three elements of effective transition planning:

⁶² Beresford, B (2004) 'On the road to nowhere? Young disabled people and transition', *Child: Care, Health & Development* Vol 30(6) p.581-587.

⁶³ Hudson, B. (2003) 'From Adolescence to Young Adulthood: the partnership challenge for learning disability services in England', *Disability & Society* Vol 18(3) p.259-276

⁶⁴ DH (2007) *Valuing People Now. From Progress to Transformation*, London, DH Publications.

⁶⁵ Mansell, J. (2007) *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs. (Revised Edition)* London, DH Publications

- Strategic Transition Plan.
- Transition Pathway.
- Individual Transition Review/Plan.

Models of good practice in relation to each of these three elements are outlined below.

Strategic Transition Planning

To effectively commission and plan services it is imperative that appropriate information is collected to inform decision making. The Learning Disability Task Force⁶⁶ discovered huge weaknesses in the collation of accurate demographic and financial information surrounding the learning disability population. Much of the information was said to be in a format that defied analysis or comparison, or was not readily available.⁶⁷ Experience suggests that the data for young people with other disabilities is just as patchy. CSCI states that:

'effective planning and commissioning of adult social care services, education, employment, health and housing can only be achieved with informed analysis and systematic monitoring of transition needs and good financial planning'.⁶⁸

Information from person centred plans must be collated and fed into the strategic planning and commissioning of services. This requires systems to be in place to ensure that the information collected through developing person centred plans is captured and analysed at a strategic level, as well as an individual level, to provide a basis for developing strategic objectives.

Stakeholders need to have the opportunity at this stage to influence – both to add quality to the decisions, and to encourage commitment to the final plan. At present, this seems to happen rarely:

'overall the involvement of young people and their families in strategic groups and wider consultations on transition is very poor. Few senior managers were involving people at every stage of transition planning' (CSCI).⁶⁹

In addition, the Strategic Transition Planning Group needs to be linked into the children and young people strategic partnership board, and the learning disability partnership board in adult services.

⁶⁶ Learning Disability Task Force (2004) *Transforming the quality of people's lives – how it can be done: financing improved services to people with learning difficulties*, London, Department of Health.

⁶⁷ Hudson, B. (2006) *Making and missing connections: learning disability services and the transition from adolescence to adulthood*. *Disability & Society* Vol 21(1) p.47-60

⁶⁸ CSCI (2007) *Growing Up Matters: Better transition planning for young people with complex needs*. p47

⁶⁹ CSCI (2007) op.cit. p38

Case Study 1

For some years the Transition Strategy Group, chaired by a team manager from Children's services, has been a sub-group of the Learning Disability Partnership Board. The group includes SENCOs, frontline staff from adult and children services and community paediatricians. The meetings involve a discussion about all the year 8/9 cohort of young people who have statements of special educational need. This has ensured that Adult services know who will be in need of services and what services they are likely to require.

A shared database containing information on all groups of young people is also crucial if the commissioning of services is to be based on real rather than perceived demand.

Case Study 2

One local authority is about to pilot a new way of doing reviews. Previously the local authority attempted to collate all the information about children from all the client groups into one database. They began by looking at the information that was already held and mapping it into one single database. It was assumed that all the relevant information was being collected at transition reviews. However, an audit of transition reviews found that this was not the case. Reviews tended to focus on the educational needs of young people, and in some cases, the transition plan was written by the school without an actual review. Their new review process will ensure that all the relevant topics are covered. It has been agreed that Connexions will attend these and then feed the information into the shared database.

Transition Pathway

Once a strategic plan is agreed, it needs to be translated into something that everyone concerned with the transition process can understand and act upon. Many localities have developed a transition pathway to do this. A pathway gives operational detail to the strategic protocol, identifying how services and individuals can work together effectively to support young disabled people and their families.

Pathways are important as they identify at what points - and what type of data - should be collected and fed into the strategic commissioning and planning of adult services.

Case Study 3 (part 1)

A West Midlands transition team is part of an integrated team located in Adult services. The transition team has a network meeting once a month which is attended by representatives from Children's services and Adult services. The full range of services are represented including looked after children and physical disabilities. The aim of these meetings is for Children's services to make Adult services aware of young people who are going to require Adult services in the future. The meetings are well attended and work well in terms of picking up people who used to slip through the net, such as those placed out of area. Information from this meeting is collated by the transition team and used to forecast the need for services.

'We know that by 2010 we will have double the number of school leavers, a large proportion of whom will have severe and complex needs. We are now able to plan for this'.

Having local agreements on sharing assessment information means that less time will be spent on assessment and all agencies have access to all the relevant information.

Case Study 3 (part 2)

The nature of the integrated team is such that all assessments undertaken by the team are completed jointly by community nurses and social workers. This is seen to be crucial due to the complex nature of the young people who are coming into the system. This effective joint working results in all young people having health action plans and person centred plans by the time they leave school.

Transition Reviews and Plans

A review that leads to a transition plan outlining the wishes and aspirations of individual disabled young people as well as the support that they need, is a highly effective tool. It enables young people, their families and professionals to keep track of the complex process, review the support, and plan what support will be needed in the future.⁷⁰

Many young people who would benefit from a review do not fall into the definition of 'SEN' or 'disabled' that would trigger the statementing process. It may, therefore, be helpful to adopt the principle of assessment and annual review with those requiring extra support as a matter of course to ensure their needs are identified and met consistently.⁷¹ This will require working closely with health colleagues, for example, Child and Adolescent Mental Health Services. Ensuring that young people do not fall through the gap will require a strategic multi-agency approach to identify all those in need of support.

Case Study 4

'Many young people were falling through the gap. Not all families had social workers so kids were not always getting flagged up. We are a multi-disciplinary team and we have set up a system of having one point of contact for all referrals re: transition. Each referral is then discussed at a multi-disciplinary team meeting twice a year where it is decided which adult team will pick the case up. The system is still not fail safe but it is much improved'.

The organisation of and preparation for review meetings should be centred on disabled young people's needs and how they will be supported to fully participate in the review process.⁷² A small number of authorities have developed a range of communication frameworks for disabled young people, including using multimedia equipment to record their views and wishes, which can be shown at their transition review meeting if they do not want to attend. Other authorities have worked on developing advocacy services, including non-instructed advocacy.

⁷⁰ Wheatley et al (2007) *A Transition Guide for all Services. Key information for professionals about the transition process for disabled young people*, Nottingham, DCFS Publications p.9

⁷¹ Wheatley et al (2007) op.cit. p.9

⁷² Carnaby et al (2003) 'Participation in transition review meetings: a case study of young people with learning disabilities leaving a special school', *British Journal of Special Education* Vol 30(4) p.187-193.

Case Study 5

One local authority recognised that the voice of the young person was not always being heard in their review, particularly those with severe communication difficulties. The decision to involve the local advocacy service has empowered those who are able, with the appropriate support, to voice their opinion. The rights of those who are unable to say what they want, or instruct an advocate, are upheld through the use of non-instructed advocacy. This is a form of advocacy which sets out to ensure that:

- All options are considered
- The person's preferences and personal tastes are taken into account
- Their rights are respected
- No particular agenda is being followed

It is through the person centred planning process that authorities can build up accurate profiles of individual and local need.⁷³ The information from the 'person centred transition' plans what support and services young people want and need should be fed back into the strategic commissioning and planning of Adult services.

9 CONCLUSION

The transition from teenage years to adulthood is not an easy time for most young people. Concerns about lifestyle and futures often combine with leaving home for the first time and having to sort out issues around finance, lifestyle and accommodation. The same is true for young people with a disability, or they would like it to be. These young people often find their aspirations about having a job, education, relationships and being able to participate in society are hampered by poor support and a lack of recognition that help received, when in education, needs to continue. As a consequence, for this group of people even reaching adulthood, as we generally conceive it, is very difficult.

Some young people are able to access the help and support they need, whilst for others their prospects are diminished by either, not being seen as eligible for services, even though they were received when they were younger, or for a plethora of reasons, they even fail to apply for care and support. There is a need to review the impact of eligibility criteria on young people with disabilities in transition to adulthood and for policy makers and commissioners to better understand the economic and social consequences for individuals and communities of those deemed to fall below the threshold.

Elements and examples of good practice for effective transition planning do exist. They incorporate:

- A strategic approach to transition planning.
- The development of a transition pathway that details how services and individuals can work together effectively to support young disabled people and their families.
- Individual transition review/plans.

⁷³ Hudson, B. (2003) *From Adolescence to Young Adulthood: the partnership challenge for learning disability services in England*. *Disability & Society* Vol 18(3) p.259-276

- Dedicated health and social care teams, as distinct from those providing services to older people, are needed to work with young disabled people when they move to Adult services. Such teams could draw on a wide range of people and experiences in order to effectively understand and deliver what is needed.

Implementing a planned approach to transitions, with clarity about what is and what is not available, with a proactive approach to ensuring that those most needing support can access it, would be much more compatible with the original concept of fair access to care.

Although we have a reasonable idea of the numbers of young disabled people reaching adulthood each year, there is little detail on their characteristics and the level and type of needs for care and support which they have. Therefore, whilst there are many anecdotal examples of young people who fall through the transitional crack between teenage and adulthood, there is little sharp evidence of exactly how many and what are the quantifiable consequences of this problem. Better data on young disabled people is urgently needed, particularly those with high support needs, both to inform commissioning and help providers offer appropriate services both locally and nationally.

APPENDIX 1

Fair Access to Care Eligibility Bands

Critical when:

- Life is/or will be threatened; and/or
- Significant health problems have developed or will develop; and/ or
- There is, or will be, little or no choice and control over vital aspects of the immediate environment; and/or
- Serious abuse or neglect has occurred or will occur; and/or
- There is, or will be, an inability to carry out vital personal care or domestic routines; and/or
- Vital involvement in work, education, or learning cannot or will not be sustained; and/or
- Vital family and other social roles and responsibilities cannot or will not be undertaken.

Substantial when:

- There is, or will be, only partial choice and control over the immediate environment; and/or
- Abuse or neglect has occurred or will occur; and/or
- There is, or will be, an inability to carry out the majority of personal care or domestic routines; and/or
- Involvement in many aspects of work, education and learning or will not be sustained; and/or
- The majority of family and other social roles and responsibilities cannot or will not be undertaken.

Moderate when:

- There is, or will be, an inability to carry out several personal care or domestic routines; and/or
- Involvement in several aspects of work, education or learning or will be sustained; and/or
- Several social support systems and relationships cannot or will not be sustained; and/or
- Several family and other social roles and responsibilities cannot or will not be undertaken.

Low when:

- There is, or will be, an inability to carry out one or two personal care domestic routines; and/or
- Involvement in one or two aspects of work, education or learning cannot or will not be sustained; and/or
- One or two social support systems and relationships cannot or will not be sustained; and or
- One or two family and other social roles or responsibilities cannot or will not be undertaken.

APPENDIX 2

VODG Members

Adepta	www.adepta.org.uk
Aspire	www.aspire.org.uk
Camphill Village Trust	www.camphill.org.uk
Canterbury Oast Trust	www.c-o-t.org.uk
CARE	www.care-ltd.co.uk
Crossroads	www.crossroads.org.uk
Guide Dogs	www.guidedogs.org.uk
HFT	www.hft.org.uk
Jewish Care	www.jewishcare.org.uk
KeyRing	www.keyring.org
Leonard Cheshire Disability	www.lcdisability.org.uk
Livability	www.livability.org.uk
MacIntyre	www.macintyrecharity.org/
MCCH	www.mcch.org.uk
Mencap	www.mencap.org.uk
Multiple Sclerosis Society	www.mssociety.org.uk
National Centre for Young People with Epilepsy (NCYPE)	www.ncype.org.uk
Norwood	www.norwood.org.uk
Papworth Trust	www.papworth.org.uk
Queen Elizabeth's Foundation for Disabled People	www.qef.org.uk
RNIB	www.rnib.org.uk
RNID	www.rnid.org.uk
Scope	www.scope.org.uk
SeeAbility	www.seeability.org.uk
Sense	www.sense.org.uk
Sign Health	www.signhealth.org.uk
St. Elizabeth's Centre	www.stelizabeths.org.uk
Sue Ryder Care	www.sueryder.org.uk
TACT	www.tactltd.org/
The Brandon Trust	www.brandontrust.org/
The Disabilities Trust	www.disabilities-trust.org.uk
The National Society for Epilepsy	www.epilepsynse.org.uk
Thomas Pocklington Trust	www.pocklington-trust.org.uk
United Response	www.unitedresponse.org.uk
Vitalise	www.vitalise.org.uk

