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**Transition Pathways for Disabled Young People with Complex Needs:
Exploring the Economic Consequences**

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ABSTRACT

Background Disabled young people with complex needs face particular challenges when they reach adulthood and seek to move from school to employment or further education. There are potentially substantial personal and social costs arising from these challenges.

Methods We sought evidence from recent UK research, policy and related literatures; undertook exploratory statistical analyses of birth cohort data; and analysed information provided by thirty disabled young people requiring high levels of practical and communication support.

Results The personal, family and social costs that result from unsuccessful transition are substantial and wide-ranging. Health service and local authority expenditure are important elements, but do not allow young people to achieve the educational or employment goals to which they aspire, resulting in considerable costs for the state, whether through missed opportunities to contribute to the economy or through dependence on welfare benefits.

Conclusions The considerable sums currently spent on disabled children and young people are clearly not enough, or not deployed appropriately, to enable those who reach adulthood to fulfill their ambitions, or to meet government policy intentions for young people to achieve economic well-being.

INTRODUCTION

Disabled young people with complex needs face particular challenges when they reach adulthood and seek to move from school to employment or further education. They must accommodate many changes in the support services that enable them to study, work and maintain key relationships. But even more importantly, many start with the disadvantage of lower educational qualifications than their abilities suggest are appropriate, resulting in missed opportunities for the remainder of their lives.

The costs to young disabled people and their families can therefore be high. Our aim was to quantify these costs and to identify the societal economic impacts arising from these challenges. After setting the policy, funding and experiential contexts, we then consider participation in further/higher education and employment, followed by a review of services and family-borne costs. Our conclusions reflect on the overall economic consequences and their implications.

METHODOLOGY

The approach adopted was to seek evidence from multiple sources. No single source could be found which provided directly relevant evidence pertinent to the research question.

We searched recent UK research, policy and related literatures including – in so far as we could find it – unpublished ‘grey’ literature. We also went through national survey reports, for example national or large surveys of health and disability, to seek relevant statistics. One of the limitations of most such surveys is that they are cross-sectional and do not provide much information on the dynamics or development of transition. This led us to employ a further approach, which was to use data from the 1970 Birth Cohort Survey (BCS) to try to identify links between disability and complex needs in adolescence and employment experiences in early adulthood. Together with colleagues in the DARE Foundation we examined the instrumentation used to collect data from the BCS sample at age 16. Questions were identified that gave information on disability and needs, and any young person in the BCS sample who scored positive on at least one of these questions, but who did not have intellectual disability was described (for the purposes of this analysis) as a disabled young person with complex needs; comparisons were then made with all other sample members (see below for details). We used multiple regression methods to compare the employment and income experiences at age 30 for these two groups of young people, after adjusting statistically for other characteristics at age 16.

A number of disabled young people requiring high levels of practical and communication support with complex physical and communication needs provided personal insights and data as part of a wider research project into transition (DARE Foundation, 2006). Participants in the RITE (Realising Independence Through Education) study were recruited through project workshops, conferences, organisations of disabled people, and advertisements on relevant websites and newsletters. Consent forms were signed prior to the topic-based semi-structured interviews (n=45). A background questionnaire was also used (n=40). Twenty-four participants kept a diary on service contacts and other activities. Participants included both disabled people and their parents. The participatory approach meant that disabled

people were involved in all stages of the research. All the disabled participants identified themselves as requiring high levels of practical or communication support, or both. They felt 'in control of their own lives and living the life they wanted to live and not the life others thought they should be living' but many felt attempts to achieve greater levels of independence were hindered by physical and attitudinal barriers (DARE Foundation, 2006, p.22). Roughly half the sample were currently experiencing transition (average age: 20) and half were 'post-transition' (average age: 30).

BACKGROUND

Prevalence

Data from the Health Survey for England (DH, 2003) show that around 5% of men and women aged 16-34 report having one or more of the five types of disability (locomotor, seeing, hearing, communicating, personal care); 1% have a serious disability. Of people in this age group with any disability, 74% had one disability and 26% had two. Estimates of disability prevalence for children aged 10-15 are compromised by small numbers: 4% of boys and 3% of girls aged 10-15 were reported as having at least one disability, with 1% having serious disabilities.

Current policy

Recent policy statements indicate a clear concern to enable disabled children and young people to live full and independent lives, with growing attention to the period of transition. The five key outcomes for children's services, given legal force in the Children Act 2004, are those desirable for any child: they should be able to be healthy, stay safe, enjoy and achieve, make a positive contribution, and achieve economic well-being (HM Government, 2004).

The National Service Framework for Children and Maternity Services emphasises that children and young people with complex health needs should receive high quality services based on assessed needs, aiming to enable them to lead 'ordinary lives' and to promote social inclusion (DH 2004). The Prime Minister's Strategy Unit (2005) similarly promotes independent living and support for families, with particular attention to the process of transition. The Government's strategy for special educational needs stresses the importance of breaking down barriers between mainstream and special schools (DfES, 2002). All these policy documents stress the need for greater cooperation between agencies to meet children's needs.

Financial support

Sizeable resources are devoted to activities that will help disabled children and young people to achieve independent lives.

Social services expenditure on children in need was equivalent to £3.5 billion in 2005 (DfES 2006). Of those children receiving a service in the week of the *Children in Need* survey, 15% (34,100) were described as 'disabled', accounting for 17% of gross expenditure. Many of these will require support from adult social care services

yet few councils can easily provide information on numbers of young people approaching transition (CSCI 2007, p.29).

Direct payments are viewed as a means of promoting independence by providing individuals assessed as needing support with the resources to purchase their own services. Provided by the Independent Living Fund since 1988, direct payments are now also available through local authorities. Disabled people are the largest user group, although only a minority of all disabled people use them. The Carers and Disabled Children Act 2000 extended access to disabled young people aged 16-17, and parents of disabled children. At 31 March 2005, 2265 direct payments were being made to parents/carers of disabled children and 495 directly to disabled young people aged 16 and 17 (CSCI 2006).

Total current and capital expenditure on education and training in England for 2004/05 was £63.7 billion, of which local authority current expenditure was £41.9 billion. Within this total, special schools received £1.7 billion and secondary schools £13 billion. Other support services, including education welfare and psychological services, were estimated at £1.1 billion (DfES 2005).

Service provision

Despite policy intentions there is a wealth of evidence to suggest that resources are insufficient and that services are far from ideal (DARE Foundation, 2006). Most statutory health and social services bodies have little accurate information on the numbers of young people with complex health and social care needs (Morris 1999). The Audit Commission (2003) found a lottery of provision, varying by residence and the extent of parental pressure. Earlier reports found that those responsible for equipment services had little idea of underlying demand, resulting in widespread unmet need (Audit Commission 2000, 2002). Organisational, structural, budgetary and procedural problems all cause delays to service implementation (Grewal 2004).

RISING ASPIRATIONS

Young people have rising educational and career aspirations. A study of young people in the 1958 birth cohort found that the proportion of disabled young people aspiring to semi-skilled or unskilled jobs was six times higher than the proportion for non-disabled youngsters (Walker, 1982). Burchardt (2005) compared this finding with data from the 1970 Birth and Youth Cohorts Surveys. She found that among all young people aged 16, 62% of disabled (and 60% of non-disabled) young people aspired to stay on at school after 16 and 33% of disabled (24% of non-disabled) young people aspired to a professional career. The differences were not statistically significant. In the last 30 years or so, the gap between the work-related aspirations of disabled and non-disabled young people appears to have reduced.

EMPLOYMENT OF YOUNG DISABLED PEOPLE

Are disabled people able to secure employment and meet their aspirations? The HSE data show that among those aged 16-34, 74% of non-disabled men were employed,

compared with 47% of disabled men; for women the figures were 61% and 39% respectively. Burchardt (2005) found that at age 26, those disabled at both 16 and 26 were four times as likely not to be in employment compared to those who were not disabled and that 39% had fallen below their initial aspiration level, compared with 28% of non-disabled people. Earnings were also found to be lower for disabled young adults; by age 26, they were earning 11% less than non-disabled people with the same educational qualifications.

We looked at the 1970 Birth Cohort dataset and identified just over 100 children at age 10 with complex physical and/or communication disabilities (but not with intellectual disabilities). We did this by first identifying those young people who were deemed in an interview of one of their parents to have a disability which interfered with normal everyday life, or which might be a problem at school. From this subset of children we then excluded those who, based on question A12 on the Medical Examination Form, were receiving special education as a result of being 'moderately or severely mentally handicapped' (intellectually disabled). We compared this group at age 30 with others from the same cohort who were not disabled by looking at earnings, occupational status, whether or not economically active, and whether the household had low income. After standardising for a wide range of personal and family factors at age 10, disabled young people with complex needs at age 10 were found to have significantly higher probability of being in a low-income household at age 30 (defined as below 60% of median equivalised household income) than other young people, adjusting for other factors.

EXPLANATIONS FOR UNDEREMPLOYMENT: EDUCATION

Why are disabled people employed less fully than they would like? A key explanation lies in lower educational attainment. Compared with stopping education at age 16 without qualifications, Blundell et al. (2004) found increasing 'economic returns' for O-levels (18% wage gain at age 33 compared to having no O-levels), A-Levels (24%) and higher education (48%).

A number of surveys and research studies demonstrate that disabled young people achieve fewer educational qualifications than their non-disabled peers. Data from the HSE show that, controlling for age and social position, disabled people were significantly more likely to have no formal educational qualifications. Moreover, within each age group the proportion without qualifications was significantly higher for disabled than non-disabled people. An 18-year old with a disability or health problems is only 40% as likely to enter higher education as an 18-year old without these characteristics (SKILL, 2002). Despite the similar educational aspirations of disabled and non-disabled young people, Burchardt (2005) found considerable disparity in their *achievements*. By age 18-19, nearly half (48%) of the disabled group had a level 1 qualification (GCSE grades D-G, NVQ level 1, GNVQ foundation level) or no qualification as their highest qualification, compared to only 28% of non-disabled young people.

[CHARTS 1 AND 2 ABOUT HERE]

Participants in the RITE study had varying experiences of education. As Charts 1 and 2 show, many had attended special schools for at least part of their secondary education, particularly among the older group. Most had statements of their special educational needs. All those interviewed continued into further/higher education, and attended mainstream or special needs colleges or used them in combination. In all, eleven of those interviewed had completed an undergraduate university degree or were studying for one. Only six of the 18 who had completed their education were in work.

EXPLANATIONS FOR UNDER-EMPLOYMENT: SUPPORT SERVICES

Another explanation for the difficulties of young people in finding employment is the lack of support services. One study of severely disabled people found that 89% reported at least one unmet need, commonly relating to practical matters, such as adaptations, equipment and physiotherapy (Kersten et al. 2000). Problems with access to wheelchairs and other aids are also common (Beresford 2003).

Table 1 summarises the service use and satisfaction levels from the DARE study participants. Almost all (28/30) of the young people interviewed for the DARE project were wheelchair users. The majority had adaptations made to their homes, most of whom were satisfied with these; those who had no such adaptations were generally less satisfied. In eight cases, there had been full or part assistance from social services or from the Disabled Facilities Grant. In five cases, the adaptations had been fully or partly self-funded. Many studies document the difficulties in obtaining grants and other housing help (Beresford and Oldman 2002).

[TABLE 1 ABOUT HERE]

Young people often lose contact with specialist health and social care services at the point of transition from paediatric to adult services (Morris 1999), resulting in gaps in services and a sense of being abandoned (Fiorentino 1998; Ko and McEnery 2004). The RITE study participants had been generally satisfied with paediatric services, as well as with services received at the time of the interview, but only nine were satisfied with their transition arrangements. For some young people, support services had been provided through their special needs schools but stopped once they left school. The most common unmet needs were for physiotherapy or related services.

Most of those interviewed had received some help from social services when they were children, with a majority dissatisfied with this help. Although only a minority were satisfied with the transition from child to adult services, most of those currently receiving social care services were satisfied with that provision. All but four young people needed some personal assistance (including 11 needing 24-hour help) and many received help from family members. A high number (20) used direct payments and all were satisfied with this system, as it made them more independent and had improved the quality of their personal care.

Of those continuing into further or higher education, half were satisfied (fairly or completely) with their transition from school, with a tendency for greater satisfaction

among those who attended mainstream colleges. Satisfaction with arrangements for learning support and with teaching quality was fairly high, particularly among the younger group. Nonetheless, a few reported they had not obtained all the learning support they needed. Most of those who went to university were satisfied with their transition arrangements and with the support they received. The majority of those interviewed were satisfied with the qualifications they attained, with no apparent difference between the younger and older groups, the type of facility attended, or the level of qualification attained. Most of the younger group thought that their qualifications would enable them to do what they wanted, but the opposite was the case for the older group. Only slightly over half this group thought that their educational attainment corresponded with their ability.

IMPLICATIONS FOR FAMILIES

The difficulties faced by disabled young people may also rebound onto their families. Despite personal satisfactions gained, caring can lead to psychological stress and poor health (Hirst 2005). Many note the lack of help from professionals, including inadequate information about services available and their eligibility (Beresford 1995; Kersten 2001). The Carers (Services and Recognition) Act 1995 provided carers with a statutory right to a needs assessment. Carers were later given the right to NHS and social services assistance and more resources were made available for respite care (Department of Health 1999).

There are, however, substantial out-of-pocket expenses incurred by families (Morris 2002). The *additional* family expenditure over and above current incomes where there was a disabled or very sick child has been recently estimated at £5,445 annually (Woolley 2004). Caring responsibilities also limit the ability of a parent or other carer to work (Carmichael and Charles 1998; Harrison and Woolley 2004). Moreover, those carers with paid employment tend to earn less per hour and often take jobs below those suitable to their qualifications (Kagan et al 1998). The longer that caring responsibilities continue, the more difficult it is for a carer to enter the employment market (Arksey 2003). Many families do not receive their full social security entitlements, but even where they do, benefit levels would need to be substantially increased to meet the essential costs (Smith et al. 2004).

Another cost falls to young disabled people because the various barriers they face in education and employment reduce their opportunities to earn a salary. The HSE data show the distribution of equivalised household incomes was very different between those identified as disabled and non-disabled: 34% of disabled people aged 16-64 were in the lowest income quintile and only 8% in the highest quintile, compared to 13% and 26% of those without a disability. This translates to an absolute difference in mean equivalised household income of over £10,000 per annum. For men aged 16-44, the mean equivalised income was £27,875 for those without disability, compared with £15,832 for those with a disability. The figures for women were £25,616 and £15,727 respectively.

NATIONAL ECONOMY COSTS FROM MISSED OPPORTUNITIES

As well as the economic impact on the public sector and on disabled people and their families, there are substantial costs to the UK economy. Based partly on the approach of Godfrey et al (2002) and bringing in data from the HSE, we calculated the differences in earnings between disabled and non-disabled people, using this as a measure of losses in potential productivity. Losses in direct and indirect tax revenue and national insurance contributions were calculated by comparing actual and potential earnings data, where 'potential' means what is earned by non-disabled people with equivalent qualifications. We have not found any data to quantify the extent of lower or higher productivity by disabled people compared to their non-disabled peers. Indeed, any such evidence would need to be treated with considerable caution unless it derived from observation of circumstances where disabled people have been given appropriate support in the workplace and elsewhere.

Table 2 shows the extent of the losses to the British economy for employed and unemployed disabled people. For example, for unemployed disabled males, and on the assumption that they would be able to contribute to the national economy at the same rate as their non-disabled peers, productivity losses amount to £237 per week per person, £46 in national insurance contributions, and £82 in taxes. In addition, the RITE data show that participants received an average of £93 per week in income-related social security benefits, at current prices. Housing benefit, covering rent and council tax, may also be paid. (Benefits in respect of people's disabilities are not relevant here. They would be incurred by the Exchequer whatever the employment circumstances.)

[TABLE 2 ABOUT HERE]

The employment directive and the Disability Discrimination Act aim to safeguard the interests and rights of disabled people in terms of employment. There are costs associated with enforcement, sanctions, monitoring, review and legal recourse. While most of the associated costs may be marginal, the cost for disability employment tribunal cases has been estimated at around £0.4 million, and to facilitate and promote disabled people in employment, business will incur £4.3 million one-off costs, and £2.4 million recurring costs (www.disability.gov.uk).

CONCLUSIONS

There are clearly many costs associated with disability and complex needs. Health or local authority expenditure is fairly easily identified, but other costs are less readily observed, such as those falling on families. There are also enormous opportunity costs to disabled young people and to the economy because of the difficulties experienced in securing appropriate education and gaining paid employment.

A study of the costs of living with disability using budget standards developed by disabled people estimated that a single disabled person living on benefits alone, irrespective of level of need, required an extra £200 per week to achieve an equitable and acceptable quality of life (Smith et al. 2004). For those with high-to-medium mobility and personal support needs, an extra £533 would be needed and for those with high to medium personal assistance needs a further £980, a total of £1513.

At the moment the state meets many of these costs by providing services, direct payments or individual budgets, and by paying social security benefits. Considerable sums are being spent on disabled children and young people. Yet these spending levels are clearly not enough to enable those who reach adulthood to fulfill their ambitions – or to meet government intentions for young people to achieve economic well being. Service provision often falls short.

Providing better support to disabled children and young people with complex needs to enable them to participate fully in school, further and higher education, and subsequently providing the kinds of assistance that would allow them to work in salaried occupations would surely represent a more attractive and cost-effective arrangement for all concerned.

KEY MESSAGES

- The costs associated with disability and complex needs experienced by young people are considerable and are felt across many parts of society.
- The costs are especially high for these young people themselves, most of whom are unable to achieve levels of educational attainment or employment consistent with their abilities.
- The knock-on economic costs of unsuccessful transition from childhood to adulthood are particularly high relative to current levels of public expenditure on disabled children and young people with complex needs.
- Better support is needed enable to disabled children and young people with complex needs to participate fully in school, further and higher education.
- Better support is also needed to allow young disabled people with complex needs to work in salaried occupations.

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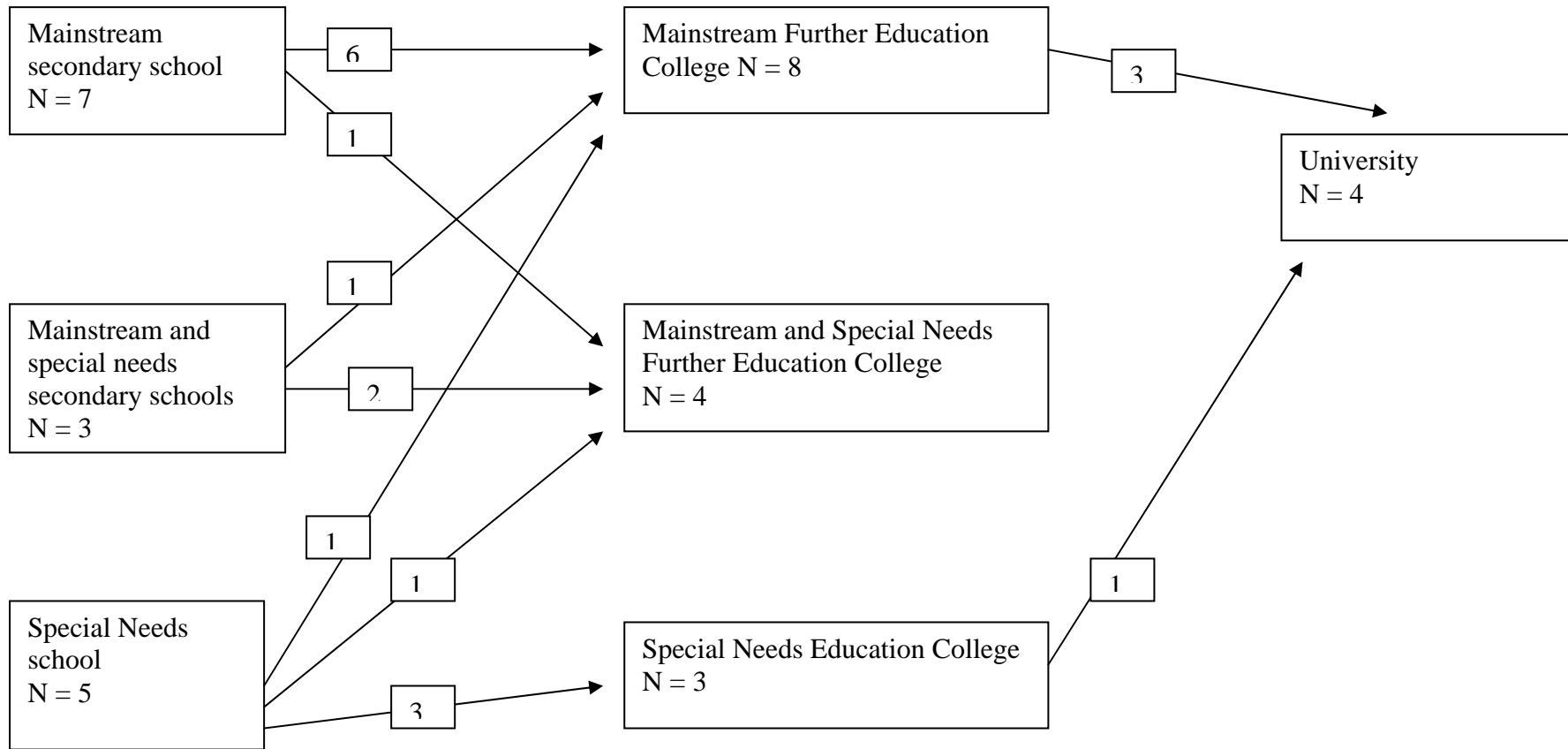
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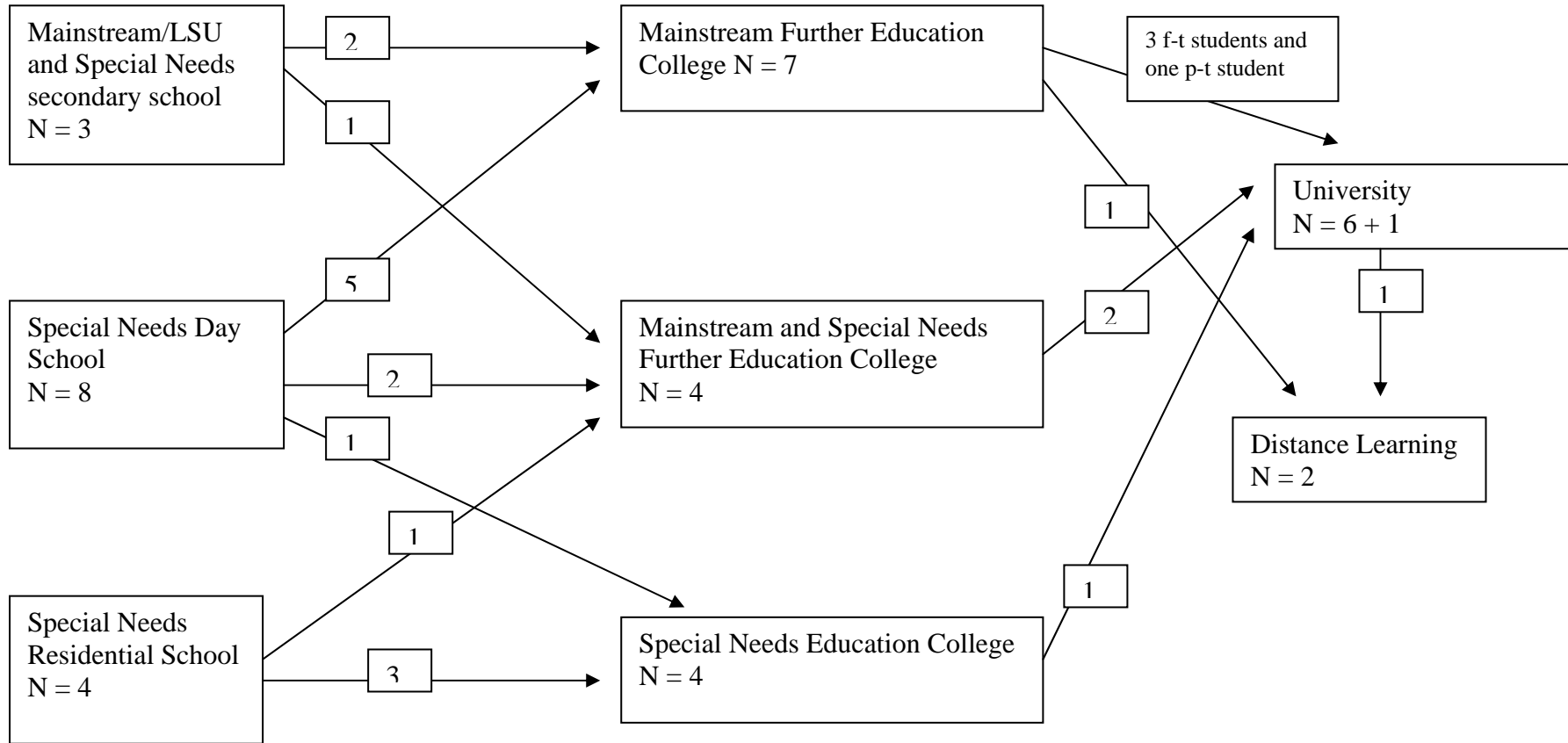
Chart 1: Movement through the education system for the RITE study transition group (n=15)



Employment

One of the four who had finished education was in paid part-time work and one worked as a part-time volunteer. Three people still in education worked part-time: a communications and disability consultant; an IT technician and policy co-ordinator, and a sessional play worker working full-time during the summer holidays.

Chart 2: Movement through the education system for the RITE study post-transition group (n=15)



Employment
 Five people were employed full-time. The two who were paid earned £20,000-30,000 and £50,000-75,000 pa.
 Six people worked part-time, three were paid and earned less than £5,000 pa.

Table 1 Circumstances and support for the RITE study participants (n=30)

Area of support	
Where they are living	Typically single living in adapted domestic accommodation. 2/30 live with partners, 17/30 live with parents and siblings, 8/30 living alone or with personal assistant. Social services or Disabled Facilities Grant and Family Resources Fund housing adaptations.
Education support	Little education-specific equipment is noted. <i>14/30 were fairly or completely satisfied with their transition from school to college.</i>
Highest qualifications	Commonly completed full-time education in mid/late-20s although 3 are still studying for further certificates. Eight have a 1 st degree and four have a postgraduate degree/diploma. Six have A-levels. For others, National Vocational Qualification is the most likely highest qualification (n=10) or RSA secretarial qualifications (n=2).
Social care in previous 3 months	Social worker 8/30. Connexions 4/30. Respite care 2/30. Other social care 2/30. Voluntary organisations 3/30. <i>10/30 were fairly or completed satisfied with transition from children's to adult services</i>
Health care in previous 3 months	GP 18/30. Practice nurse 5/30 Physiotherapist 14/30. Occupational therapist 6/30. Specialist doctor 11/30. Clinical engineer 4/30. Other services used by only one or two people. <i>8/30 were fairly or completed satisfied with transition from paediatric to adult services</i>
Current equipment	Voice output communication aids 7/30. Manual wheelchair 16/30. Powered wheel chair 19/30. Electronic control system 10/30. <i>7/30 can drive. 15/30 use a car/motorised vehicle.</i>
Personal care	26/30 require personal assistance; 11/30 for 24/7. Seven receive between 14 and 128 hours per week. Direct Payments 12/30. Independent Living Fund 8/30. Family members provide support for 18/30.
Social security benefits	SDA under 40s rate (n=9), Disability Living Allowance (DLA) Care highest rate (17), middle (6), and low (2). DLA Mobility higher (23) and lower (1) rate. Income Support or Jobseeker's Allowance (11) with Disability (4) or Severe Disability (7) premiums. Disabled tax credit (1)

Table 2: Costs to the national economy, per person per week 2005-06 prices

Cost item	Unemployed disabled person		Employed disabled person	
	Male	Female	Male	Female
Earnings/productivity	£237	£185	£124	£97
Lost National Insurance	£46	£33	£14	£11
Lost direct taxation	£40	£28	£43	£34
Lost indirect taxation	£42	£34	£19	£15
Benefit payments	£93	£93	0	0