









## Becoming adult: young disabled people speak

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This study of 72 young adults who have grown up with disability compares the experiences of a group who achieved independent households and jobs with groups of people who achieved one of these or neither. The study aimed to draw out the factors that enable and support disabled young people to move to independent adulthood. The study found that:

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-  Respondents found getting work, running an independent household, achieving a social life and citizenship very difficult.
-  Combining different aspects of adult status was especially difficult. Few had a job as well as an independent household, especially if they needed personal assistance.
-  Respondents with both jobs and independent households most often named parents as the key to their achievements. Few had found support beyond the family.
-  Social housing could be a route to owner-occupation but for most finding work that could cover housing costs was very difficult.
-  Respondents saw paid work as the best route into other aspects of adulthood, but even those in better-paid jobs often described the work environment as difficult. Support for getting work was very erratic: essential equipment might be provided by the employment service, but could take a long time to come through.
-  Disability Living Allowance was the only benefit consistently to underpin employment with independent living.
-  Personal assistance can support employment, but in general people's need for personal assistance was a major impediment to taking up paid work. The increasing trend of charging for personal assistance made it very difficult for some respondents to take up employment; few could achieve incomes that compensated for the fall in benefits.
-  Respondents found choosing work was a very tough and expensive option but those who achieved it found it very rewarding.

## Background

Both government and the disability movement advocate independent living for disabled adults. However, research has shown that young people growing up with disability face problems leaving the family home, and accessing housing, education, employment and income to meet their needs.

This study interviewed groups of young disabled people who had achieved varying levels of independence: those with jobs and independent households (described as 'most independent') and those with one of these or neither ('less independent' and 'least independent' respectively). The study examines what difficulties they faced in transition to adulthood and what helped them achieve this.

## What constitutes 'adulthood'?

Respondents described their aspirations for adulthood in terms of paid work, independent householding, social relationships and citizenship.

- Employment – despite its difficulties – was most often seen as the best route to independence, citizenship, membership of a consumer society and the best route away from poverty and social exclusion.
- Becoming an independent householder represented a great – and sometimes seemingly impassable – step in the lives of respondents – but they felt it was crucial to their control over day-to-day life.
- Social relationships were usually limited – especially for respondents without jobs. Marriage and parenthood were rare.
- Respondents had long experience of benefits and other social services, and highly developed notions of citizenship rights and obligations. Many felt a duty to contribute as citizens, whether through paid or unpaid work.

However, the aspirations of the least independent could be much more limited:

"Independence would not necessarily mean leaving home ... it would mean that I could live my days ... without having to ask my parents to help me ... whether that be getting around or using the phone ... things like that." (Jenny)

## Forms of support available

Young disabled people require a broad range of support to meet needs with personal care, nursing, housing, income and jobs if they are to live independently as adults.

The most independent respondents most often saw support from parents as key to this. They valued parents who offered stringent nurture, with high expectations of their educational achievements, of their ability to care and fight for themselves and who assumed that they would grow up – like other adults – to live independently:

"She's never been one for sort of mollycoddling and mothering ... it's bordering on the hard really, it must've been hard for her to watch me struggle and seeing me sort of fail ... but it's the best thing she ever did." (Rachel)

These parents also tended to have the material and cultural resources to support their children with loans and with networks and in contests with local authorities over education.

However, not all respondents were able to draw on such family resources. The least independent respondents could feel trapped in the parental home: it could be very difficult to grow away from the very close relationships that had developed:

"My Mum would miss me if I left home because she would have nobody to look after." (Alice)

Lack of support beyond the family also presented some respondents with an impossible barrier to independent adulthood.

## Education

Educational achievements among the most independent respondents were high. The majority of respondents in all groups had been to segregated schools, 44 compared with 28 to mainstream. Some respondents were strong advocates for their specialist segregated schools, which they felt brought favourable resources, specialised skills, an accessible curriculum and peer group support. However, accounts of segregated schools were very divided; respondents from other groups often felt schools had limited their expectations and achievements. Access to appropriate support in mainstream education also varied widely.

## Housing

Half the most independent group of respondents were owner-occupiers with some choice and control over their housing. But this status was hard won, in the context of the higher costs and rarity of accessible housing and low pay.

The lack of suitable housing could hinder job mobility. Kate had moved to a new job, but was paying personal assistants to take her wheelchair in and out:

"Because my house is inaccessible ... the bathroom isn't accessible and it's not only a problem for me personally – it's a problem because I happen to know lots of people who also need their access needs to be met ... my sister can't come to stay here, quite a lot of my friends can't go to the toilet."

The housing needs of respondents living independently – especially those without jobs – were mainly met by housing associations. Housing association accommodation often brought accessibility, good service, support for needs, and sometimes co-ordinated personal assistance. But some respondents felt segregated. This could also create a benefit trap that made employment near impossible: few respondents earned enough to pay the rents and have money for the rest of life. A few respondents had been able to use housing associations as a route to greater independence through schemes of joint ownership or other assistance with owner-occupation such as mortgage deposits.

### Personal assistance

Accessing, funding and managing personal assistance were issues respondents faced if they were to leave the parental home. Some respondents spoke of social services enabling and managing support that met their needs and reduced the organisational effort on their own part, but the most independent respondents tended to prefer managing their own assistants. They spoke of choice and flexibility and of building personal relationships and trust with people with whom they might have to share personal and family space. Steve found it "like being married to two people, simultaneously, and you've got to keep ... them both happy".

For respondents living independently the means-tests and charges around funding for personal assistance were a major barrier to work. They had no reasonable expectation of support from employers and no expectation of earning enough to pay for personal assistance. Siresh had low expectations of employment because of his poor educational qualifications and personal assistance needs:

"As far as income support or any of those benefits goes I'm happy to give up those benefits for some kind of employment ... but if a person is entitled to personal care benefits then they should be entitled to it regardless of whether they work or don't work." (Siresh)

Respondents living with parents usually had their needs met by their parents. Some parents provided skilled and sensitive nursing care which respondents valued above any alternative form of provision. But

others described their relationships as damaging to their parents or abusive to themselves, making it harder for them to live as independent adults.

"They find me difficult to live with ... all I do is cause work for them ... I feel very unloved." (Tracey)

### Employment

Government policy is to encourage those who can to work, focusing on addressing the attitudes and limitations of potential employees. But very few respondents had jobs that paid enough to cover disability costs. A few respondents had accessed low paid work through public sector schemes, and some graduates valued voluntary sector training schemes. A few had used the employment services to access essential assistance or equipment. But most spoke of delays and obstacles in getting these – especially if they worked in the private sector.

"I have been trying to sort some speech equipment out ... It has been going on for three years so far. Getting quotes for equipment and finding out if the Council or PACT are funding it have proved very difficult. Without this equipment people who I need to talk to need a personal computer handy instead of me having something on my wheelchair and just talking where we are." (Tom)

"The equipment that I need has still not arrived so I am spending my time doing the photocopying. I feel so isolated." (Chloe)

Most respondents worked for personal satisfaction rather than for the money, though a few felt that they were paid more – and could therefore lead a fuller life – than they thought likely on benefits.

There were no obvious differences in attitudes between those who were in employment and those who were not. There were three key deterrents to employment: lack of educational qualifications, failed applications and – looming largest – benefit problems, especially in relation to personal assistance.

### Benefits

Benefits – whether for increased costs, income replacement, or personal assistance – formed a significant proportion of respondents' incomes. They were therefore a key influence on respondents' ability to get work, housing and personal assistance.

- Disability Living Allowance was highly valued. Covering extra costs without means tests, in work or out, it was a crucial secure support to respondents with jobs. But it was not enough to cover personal assistance or to cover the risks of

taking up work for the many respondents on benefit, especially those who were less qualified or supported by parents.

- The Independent Living Fund and local authority direct payments may cover personal assistance in work or out. However, the increasing trend for charging for personal assistance made it very difficult for some respondents to take up employment, as few could achieve incomes that compensated for the fall in benefits.
- Access needs made young adults eligible for housing association accommodation, but the high rents subjected them to means-tested housing benefit. Again, this could make paid employment difficult or impossible.

Respondents felt the benefit system was often at the heart of their difficulties in combining different aspects of adult status. It was particularly difficult to be a householder and to have a job, especially for those needing personal assistance.

"Claiming benefit ... is not necessarily directed towards sensible use of resources, independent living, going on to work ... it's geared if anything completely against that at all levels." (Kathy)

## Conclusion

Most people in the study wanted to achieve adulthood through employment, to gain resources for independent living in their own choice of housing, wider social networks, escape from poverty, and a sense of contributing to society. However, their experience suggests that young people growing up with disability need more support in moving from parental care in parental homes to independent adulthood.

Benefit policy has just begun to recognise the disadvantages faced by young people growing up with disability. Income support, housing benefit and means-tested housing adaptations, personal assistance charges combine to form a means-tested environment which inhibits the movement from parental care to personal autonomy, through specialised housing into owner-occupation and from unemployment into work. The researchers conclude that the difficulties of transition to adult life – and the differences from people with disability acquired later in life – need much wider recognition throughout the policy environment.

## About the project

The study was undertaken by Nicola Hendey and Gillian Pascall at the School of Sociology and Social Policy at the University of Nottingham.

The study is based on in-depth semi-structured interviews with 29 respondents with jobs and independent households (the 'most independent' group) and 43 others in comparative groups who had one or other of these or neither ('less' and 'least independent' groups). Most respondents were entitled to Disability Living Allowance at the middle or higher rates and this was used as a criterion for selecting a sample with high assistance needs. To allow for the extended transition to adulthood of this group, the age of the sample ranged from 21 to 35.

## How to get further information

The full report, *Disability and transition to adulthood: Achieving independent living* by Nicola Hendey and Gillian Pascall, is published for the Foundation by Pavilion Publishing (ISBN 1 84196 051 9, price £12.95).