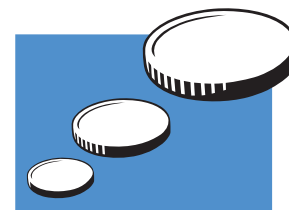


Rights of passage



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Supporting disabled young people through the transition to adulthood

A guide for funders and charities



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Summary

The transition from adolescence to adulthood can be far from smooth. New situations and complicated choices confront us. What will we do when we leave school? What qualifications do we need to get a job? Where will we live?

If you are a young person with disabilities, your hopes and aspirations may be the same as anyone else, but your options are much more limited. Things that most people take for granted—meeting up with friends, going to college, moving out of the family home—may be beyond your reach if you do not have the right level of support.

Yet receiving adequate support is by no means guaranteed. Many disabled young people get lost in the no man's land between children's and adults' services, suddenly cut off from the support and services they received only a few weeks before. Some young people receive help with their special educational needs at school, then find at the age of 18 that they are no longer eligible to receive this help from the state.

Some disabled young people build their independence at a special residential school, only to find themselves reliant on their parents once again at the age of 18. They can lose touch with friends and their self-esteem can suffer. Parents may have to give up work to become full-time carers, and siblings may feel that they no longer receive attention.

All too often, disabled young people feel shut out of decisions made about their own lives, because of communication difficulties, a lack of confidence in arguing for what they want, or a failure by government agencies to consult with them or their families.

The result is that many young people who could have gone on to higher education, interesting jobs and independent lives are held back before their adult lives have even begun. The benefits of investing in disabled children are not carried through unless these children receive support as they move into adulthood.

How are charities helping?

Charities play a vital role in helping disabled young people to make the leap from teenager to adult. They plug gaps in government services, give young people a voice in decision-making, and ensure that the needs of people with rare or 'hidden' disabilities are not overlooked.

Many charities **ease the disorientating process of moving from children's to adults' services** by working with statutory agencies to coordinate young people's support. A number also run **specialist transition services** to help young people develop independent living skills, such as shopping for themselves or taking the bus.

Others **tackle stigma** associated with disability and fight to make sure that the voices of disabled young people are heard by government. Charities' independence means that they are well placed to campaign for change, challenging misplaced preconceptions about disability and influencing policy.

A number of charities **champion the needs of people with 'hidden' or rare disabilities**, such as autism. Many provide services that are tailored to specific conditions and ensure that the needs of people with these disabilities are not overlooked. Conditions such as blindness, for example, affect less than 1% of the population, and could be ignored by those who commission government services, were it not for prompting from charities.

What are the challenges for charities?

Charities helping disabled young people though the transition to adult life face a number of challenges, including evaluating the impact of what they do and ensuring that their services are sustainable in the long term.

Firstly, there is a **lack of data** about the numbers of people with specific types of disability, and a lack of information about their needs. This makes it difficult for local government commissioners to work out what services they should commission to meet the requirements of disabled young people. While collection of this information is primarily the responsibility

of government, charities can also help to create a more detailed picture of the needs of disabled young people by sharing their users' experiences and feeding into policy.

Secondly, charities working on transition often find that **evaluating outcomes** is a challenge. It is difficult to track what happens to young people after they leave transition services, and it is difficult to measure improvements in 'soft outcomes', such as confidence, self-esteem or general well-being. One way charities can overcome this problem is to ask for funding to cover evaluation costs when applying for grants.

Finally, charities helping disabled young people with their transition to adulthood face the challenge of **sustaining support**, ensuring that all their hard work is not lost when the young person moves on to new services. Charities need to liaise with adult services so that their investment is sustained over the long term.

What can funders do?

When supporting charities working in transition, private funding can be particularly valuable in a number of areas. These include:

- **supporting specialist transition services** that equip disabled young people with the skills they need to live more independently;
- **championing low-incidence or acquired disabilities**, which often have a low profile and can be overlooked when statutory agencies allocate funding;
- **supporting overlooked, 'hidden' disabilities**, such as high-functioning autism, where people may not reach the support threshold of adult social care, or where conditions may not be identified;
- **building the confidence and skills** of disabled young people and their families so they can fight for their rights and secure the support they need; and
- **challenging stigma**, by campaigning to improve the accessibility of public facilities, such as cinemas and colleges, or by changing public attitudes towards disability.



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Introduction

Growing up is never a straightforward process. But for disabled young people, it can be particularly challenging. Rites of passage that most young people take for granted, such as leaving school, living independently and finding work, can be fraught with obstacles for young people with disabilities. Even everyday activities, such as taking the bus to college, going out with friends or visiting the park, can be a struggle. But with the right support, these obstacles can be overcome.

The following case studies illustrate some of the challenges that disabled people face as they grow up, and highlight how great an impact the support they receive has on their lives.*

Emma's story

Emma is 23. She has moderate learning disabilities and needs help from a carer to do certain everyday tasks, such as shopping in the town centre or cooking.

While she was at her local mainstream school, Emma lived at home with her parents. She received extra support from the school's special educational needs teacher, who helped her to grow in confidence and gain a couple of GCSEs.

From the age of 14, Emma and her parents had annual meetings with Emma's school teachers and social worker to plan for her future. They explored different options and it became clear that Emma wanted to go to college, and she dreamed of living in a flat with friends, like other young adults do.

One of the main barriers to attending college was transport. Emma had relied on her mother or friends' parents to drive her to and from school, but the college was almost an hour away. Both her parents worked, so driving that distance every day would be difficult, and taxis would be too expensive.

Emma was scared of taking public transport, so her social worker arranged for her to take part in a local travel training programme. With the support of a travel trainer, who accompanied her on the bus until she was happy on her own, Emma learnt her route to and from college, how to pay for a ticket, and where to get on and off. She soon learnt other routes as well. This gave

her more freedom to travel into town and see friends, and helped her to feel more confident and independent.

While Emma was at college, the local transition support team started to plan her next steps, securing a place for her in supported housing. So when Emma left college, she moved into a flat share with four other young people who had similar learning disabilities. Emma loves living there. The housemates eat meals together in the evenings and often go to their local pub.

Emma is also now happily employed. When she left college, she found work experience with the help of a charity. She now works for three days a week at the office of a local newspaper, answering the phone and arranging appointments. She enjoys her job and has become a popular member of the team. Her good work has not gone unnoticed, and her boss has recently offered her a full-time paid position.

John's story

John is 22 and has cerebral palsy, a physical impairment that affects movement. He can walk short distances, but needs a wheelchair for longer distances. He also has complex learning and communication difficulties, and needs one-to-one support to communicate with others and carry out everyday tasks, such as washing himself and getting dressed.

After doing a lot of research, John's parents decided to send him to a residential specialist school for disabled children. Although this was a couple of hours' drive away from the family home, it was able to provide more individualised care than the local mainstream school. The specialist school also had a good track record of getting students into a specialist further education college nearby, once they reached the age of 16.

John really enjoyed his time at school and college. His teachers provided the day-to-day support he needed, and helped him to develop the sort of skills that many of us take for granted, such as cooking. He made friends with other pupils and, as he grew older, his college provided support and education on sex and relationships. In his last year there, John started dating another student.

Rites of passage that most young people take for granted, such as leaving school, living independently and finding work, can be fraught with obstacles for young people with disabilities.

* Throughout this report, names and details have been changed to preserve anonymity.

Almost 600,000 young people in the UK have a disability.

Before he was 18, John's parents, with the help of his teachers and social worker, started thinking about what was going to happen when he left college. His complex learning difficulties meant that university was not a feasible option, so his parents looked into residential care and supported community housing arrangements provided by their local authority. Although John's social worker contacted many different providers, only one offered him a placement. This placement was at a care home in the countryside, a long way from any town, where the majority of residents were much older than John.

As a result, John ended up living with his family again. This was difficult for him. His school friends returned to their homes in other parts of the country and his girlfriend was a two-hour train journey away. John was unable to use public transport on his own, so he relied on his mother to drive him where he needed to go. This limited his independence, making it hard to see his friends from school, as well as limiting his ability to get into town and make new friends.

John's return home had a big impact on his family too. He had been living away from home for most of the last ten years, and his parents and brother were not used to him spending so much time in the house. His mother was suddenly responsible for his full-time care, so she had to give up her job. She often felt stressed and argued more with John's father. John had little to occupy his time, often spending hours in front of the television. A year after returning home, he started showing signs of depression. He has since been referred to a psychiatrist for treatment.

What is the purpose of this report?

Disabled young people like John and Emma need support as they make the transition to adult life. Emma's experience shows what a difference receiving the right support can make to a young person's well-being and chances in life. Sadly, however, her experience is not the norm—John's story is far more typical.

New Philanthropy Capital (NPC) believes that charities play an important role in supporting disabled young people, helping to improve the lives of young people and their families.

This report is a guide for funders and charities. It discusses the challenges associated with disabled young people's transition to adult life, outlines the roles of government and charities, and explores how funders and charities can have the greatest impact.

Introducing the issues

What do we mean by disability?

A disabled person is someone who has 'a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.'^{* 2} Impairments include chronic, degenerative and life-limiting conditions. They also include learning disabilities, specific learning difficulties (such as dyslexia, dyspraxia and attention deficit disorder), and developmental disorders (such as autistic spectrum disorders) that affect a young person's ability to communicate, learn or interact with others.[†]

In many cases, individuals have a mixture of impairments and so are described as having 'complex needs'. For example, people with certain types of autism may have learning difficulties combined with physical and psychological problems.[‡] It is estimated that 55% of people with autism have learning difficulties and 61% have mental health problems. Many also experience severe sensory problems, such as lack of sensitivity to extreme cold or pain.⁵ By adulthood, a third of people with autism have developed epilepsy,⁶ and there is a suspected link with gastrointestinal problems.⁷

However, disability should not simply be seen in terms of physical or mental impairments. Unaccommodating social attitudes can also be disabling. Stigma, lack of understanding and failure to provide disabled access to transport, schools, offices and other public places, may be as significant a barrier to everyday activities as any impairment.

How many people are affected?

In the UK, it is estimated that one in seventeen young people has a disability.⁸ This equates to almost 600,000 young people, and does not include young people who are classified at school as having special educational needs.

* This is the government's definition of disability, taken from the Disability Discrimination Act (2005).

† The Learning and Skills Act (2000) defines an individual as having a learning disability if he or she has 'a significantly greater difficulty in learning than the majority of persons of his [or her] age', or has 'a disability that hinders or prevents him [or her] from making use of facilities of a kind generally provided by institutions providing post-16 education or training'.³

There are many different types of learning disability, most of which develop before a baby is born, during birth, or because of a serious illness in early childhood. They tend to be lifelong. People with a learning disability find it harder than others to learn, understand and communicate. People with profound and multiple learning disabilities need full-time help with every aspect of their lives—including eating, drinking, washing and dressing.

A person with a specific learning difficulty, in contrast, may be as able as other people, except in one or two areas of his or her learning. For example, he or she may struggle to recognise letters and have difficulties with reading and spelling.⁴

‡ Autism should be seen in terms of a spectrum of difficulties, rather than a tightly-defined set of symptoms. Difficulties vary from mild through to profound and multiple difficulties. Not all people with autism would classify themselves as disabled.

Schools in England and Wales estimate that 20% of children—1.9 million—have difficulty learning, to the extent that they need some form of help in class.⁹

And these numbers appear to be growing. Advances in medical science and technology mean that many more children who are born with complex needs are surviving into adulthood.¹⁰ More children are also being identified with autistic spectrum disorders.^{11,12}

Further information about specific types of disability, and their prevalence, can be found in Appendix 1.

What do we mean by transition?

'Transition' describes the period between the ages of 14 and 25, when young people make choices about their future and experience significant changes in the way they live.*

While many of these choices and experiences are common to all young people, those with disabilities may face particular challenges. The main points of transition include:

- **From school to further or higher education:** The transfer from school to further or higher education generally takes place between the ages of 16 and 19. Many disabled young people do go on to a further education college or university, though their choice of course and institution may be limited by accessibility and the support available.
- **From living at home or at school to living elsewhere:** Young people who have been living in a residential school or college may have to live with their parents after they leave. Alternatively, they may move into their own flat and live there with regular support, or move into supported housing run by a charity or local authority.
- **From education to employment:** After leaving school, college or university, many disabled young people look for paid or voluntary work. For some, paid employment will never be a viable option. For others, it will, but only if they are given the right support.
- **From children's services to adults' services:** Between the ages of 16 and 19, responsibility for supporting disabled young people passes from children's services to adults' services. For instance, a disabled young person may be transferred from paediatric to adult health services at the age of 16, and then from child to adult social care at the age of 18. The criteria for who is eligible for support also vary. In some cases, individuals who have received extra support at school find that they are not eligible for assistance from social services when they turn 18.^{11,13} So, at the very time when they

are making the daunting transition to adult life, they are left with less support than ever before.

Young people's options are also affected by practical issues, such as access to transport and public places, and the availability of appropriate advice and financial support.

Transition is not always a linear, one-way process: young people may move into independent accommodation, for example, only to move back to their family home for a time when circumstances change. Equally, they may start a work placement and then move back into education. Support for transition needs to be flexible in order to accommodate this.

What happens if transition is not well managed?

If transition is managed badly, it can have a lasting negative impact on young people's well-being and chances in life, and it can increase the costs of their care, as John's story illustrated. In the absence of adequate support, the benefits of early work with disabled children will not be carried through to adult life. Sadly, it is all too easy for disabled young people to become socially and economically excluded. Indeed it is striking that even by the age of 17, 17% of disabled young people are not in education, employment or training, compared to only 7% of non-disabled people.¹⁴

Lack of appropriate care may also contribute to the development of psychological and physical problems. For instance, The National Autistic Society estimates that at least one in three adults with autism experiences mental health difficulties due to a lack of support. Of the parents the charity surveyed, 60% felt that a lack of help led to greater support needs later on in their child's life.^{15,16} This causes distress and disruption to families and may increase reliance on health and social services, with significant financial repercussions (see Box 1).

The role of government

The government, through local education, health and social care services, tries to ensure that transition occurs as smoothly as possible. In order to achieve this, the different individuals involved in a young person's care—parents, friends, teachers, social workers, advisors, doctors and nurses—need to work together to plan a young person's future, taking into account their needs and preferences.

However, the government recognises that planning often happens too late or not at all. Where it does happen, it is often not well coordinated. This leaves young people without support at a crucial time in their lives. Provision of services can be patchy, and there is a danger

Young people's options are affected by practical issues, such as access to transport and public places, and the availability of appropriate advice and financial support.

“Our concern is that if she goes to an inappropriate placement, she could cause harm to herself and others.”

Parent

* Although many types of transition do not occur until the age of 16 or older, the government requires that transition planning starts when a young person is 14.

NPC believes that transition is a pressing but under-publicised issue.

that young people fall victim to a ‘postcode lottery’. Their experience may be determined by the availability of services in their area and by the willingness or ability of their family to fight (and, in some cases, pay) for the right level of support.

For example, in 2008, only a third of local areas provided young people with access to a key worker or lead professional to coordinate their transition process.¹⁷ As the parent of one young person with autism commented:

‘We’ve not had much support during this transition process. We’ve had to look at nine alternative properties for our daughter, but the social worker assigned to us only came with us to one of these. Our concern is that if she goes to an inappropriate placement, she could cause harm to herself or others. She’ll run away. She can scale a six-foot fence no problem. We’ve been fighting full time for nine months. There’s no alternative. Fighting is the only thing left for us to do. You sort of devote your life to it.’¹⁸

In recognition of this problem, the government launched the Transition Support Programme in 2008. This programme works with local authorities, primary care trusts and charities across England to improve the planning and coordination of transition support (see Chapter 6).

The role of charities

Charities can improve disabled young people’s experience of transition by:

- providing direct services for young people, such as education, training and employment, leisure activities and social opportunities;

- providing advice and guidance for disabled young people, their families, and the professionals whose job it is to support them;
- developing young disabled people’s confidence and self-esteem, and preparing them for independent life and employment;
- championing the needs of people with particular disabilities;
- researching what works and disseminating best practice;
- lobbying government to improve practice and policy relating to transition;
- addressing structural issues in the sector, for example, improving transition planning; and
- helping to coordinate the work of statutory services working on transition.

Transition touches every aspect of disabled young people’s lives—where they live, how they spend their days, and who they socialise with. Although there are few charities that focus exclusively on transition, many have a variety of services that support transition in some form or other, dealing with everything from education and training to housing and employment.

About this report

NPC believes that transition is a pressing but under-publicised issue. This became clear in previous research that we undertook on disabled children, special educational needs, people with autism and children’s palliative care.^{5,20–22} We found that charities providing education were concerned about what would happen next to their students. Charities helping adults to cope with their condition and lead fulfilling lives often wished that the transition from school had been better planned. And charities providing healthcare complained that children’s and adults’ services were not joined up and provided different levels of care.

This report investigates these issues in more detail and explores how they can be addressed. It should not be taken as a comprehensive guide to charities working on transition; rather, it is designed to highlight interesting and important examples of work. In particular, the report could not cover all the local charities doing vital work across the country to support disabled young people in their communities.

Readers who are interested in charities discussed in this report can find additional details and links in Appendix 3. Further information about local initiatives to support transition can also be accessed via the Transition Information Network’s website: www.transitioninfonetwork.org.uk.

Box 1: Diverging paths¹⁹

The Down’s Syndrome Association tells the stories of two men who went to the same residential school, and ended up with very different lives.

Paul has severe learning disabilities. While his transition was being planned, his specific needs were recognised, and he is now happy with his living arrangements.

Malcolm has moderate learning disabilities, yet his support needs were underestimated. While Paul lived in housing with support available 24 hours a day, Malcolm lived independently, with only 23 hours of support a week. While Paul had an individualised programme of learning, work experience and social activities, Malcolm had no work and little structured activity during the day. He had difficulties managing money, shopping for food, and travelling and socialising on his own. He often became distressed and, when his housemate went on holiday, he turned up at a group home and refused to go back to his flat.

As a result, Malcolm was taken into residential care and lost confidence in his own ability to live independently. Not only did this take its toll on him personally, but it also resulted in high support costs—£1,800 per week, compared to £680 per week for Paul, even though his learning disabilities are more severe.

The charities discussed in this report have not been analysed in detail by NPC for this project. However, a handful of these charities have been analysed by NPC as part of previous research. These include ACT (Association for Children's Palliative Care), Contact a Family, the Council for Disabled Children, the Disability Law Service, First Step Trust, Prior's Court, Skill: National Bureau for Students with Disabilities, and Treehouse. Information about these organisations can be found on NPC's website: www.philanthropycapital.org.

Scope

This report covers the transition of disabled young people between the ages of 14 and 25. It focuses on England, although many of its findings also apply to Wales, Scotland and Northern Ireland.

The report is relevant to a wide range of disabilities, but does not discuss any in great detail. We focus on common issues relating to transition, giving specific examples along the way. Readers should bear in mind that disabled young people may face challenges specific to their condition, which are not discussed here. In these cases, NPC would direct readers to charities that specialise in those conditions.

Readers should also note that we use the term 'funders' generically to refer to a broad group that includes individual donors, professional funders, grant-making trusts, and corporate and family foundations. We specify when we are addressing a particular type of funder.

The report aims to provide contextual information about the government policies that affect the transition of disabled young people. Many different government strategies are relevant to transition, and some are referred to in this report, but the purpose of our research was not to provide detailed policy analysis.

Structure

Chapters 1 to 5 of this report consider five of the main issues affecting the transition of disabled young people:

- education;
- employment;
- somewhere to live;
- transport and access; and
- friends and relationships.

These chapters explore problems with the way the system of support works. They highlight the work that charities are doing to address these

issues, and discuss how funding may best be used to improve disabled young people's experience of transition.

Chapter 6 looks at what government and charities are doing to tackle the problems with transition and improve the systems that affect young people's experiences.

Chapter 7 concludes the report, looking at the priorities identified for funders and charities, and the challenges they face.

Research process

NPC started this research in January 2009. We carried out desk research, spoke to policy-makers, funders and charities, and received feedback on a draft of the report from 12 consultative readers. A full list of the people consulted can be found in the Acknowledgements at the back of this report.

In order to illustrate the costs associated with transition and the savings that can be made by providing adequate support, we carried out a cost-benefit analysis as part of our research. This specifically focuses on supporting young people with learning disabilities into employment. This topic was chosen partly because we believe that charities can make a particularly valuable contribution in supporting people with 'hidden' disabilities, such as learning disabilities, and partly due to the availability of data.

About NPC

New Philanthropy Capital (NPC) is a consultancy and think tank dedicated to helping funders and charities to achieve a greater impact.

We provide independent research, tools and advice for donors and charities, and shape the debate about what makes charities effective. We have an ambitious vision: to create a world in which charities and their funders are as effective as possible in changing people's lives and in tackling social problems. For charities, this means measuring the results of their work and using evidence to learn and improve, as well as to attract support. For funders, it means using evidence of charities' results to make funding decisions and to measure their own impact.

To date, we have published over 50 reports on a wide range of social welfare and voluntary sector issues, from education and mental health to social campaigning and funding practice.

For further information about NPC, and to download our reports and analysis, go to www.philanthropycapital.org.



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Education

Education gives young people the chance to gain qualifications that may help them to secure jobs. But it also helps young people to work out where their interests and strengths lie, develop aspirations, make friends, and learn 'softer' skills, such as communication and social skills. Without these opportunities, disabled young people are at a major disadvantage.

Most disabled young people have the opportunity to go to school. But finding a place in further and higher education can be more of a struggle: disabled people are only half as likely to move on to post-16 education as non-disabled people. Charities are helping to tackle this problem.

The issue

Leaving school

For young people with disabilities, finding a suitable place at a further or higher education institution can be a struggle. Disabled young people are only half as likely as non-disabled young people to move on to post-16 education or training,²³ half as likely to be qualified to degree level, and twice as likely to have no qualification at all.²⁴ However, it will soon be compulsory for all young people to remain in education or training until the age of 18, making it even more important for transition to further education to be managed well.²³

In order for disabled young people to find a place at college where they will receive the right level of support, a thorough assessment of their needs is required. Yet there are concerns that not all local authorities are adequately assessing the needs of disabled young people in their area at this time of transition.* In addition, because colleges and universities usually only allocate places a year in advance, it can be difficult to plan ahead and get complicated support arrangements in place in good time.

On top of this, disabled young people tend to have more limited options when it comes to choosing their college, university and course. For instance, charities are worried that there is a lack of appropriate further education programmes for people with learning disabilities, who are unlikely to progress to university and often end up just repeating courses.²⁷

The choices young people make depend on the facilities and support each institution can provide. Choices are also affected by the benefits that individuals are eligible for—and it cannot be assumed that every person knows what benefits he or she is entitled to, and how to access these. As a result, many disabled young people end up choosing an academic institution on the basis of the support it can provide, rather than on the basis of which offers the most appropriate course.

Understanding the options

Disabled young people need high-quality information, advice and guidance to help them navigate the system. This will become even more important as the curriculum for 14 to 19 year olds is reformed, and as education becomes compulsory up to the age of 18. These changes may provide the opportunity to open up new options for disabled young people.²⁸

Personal advisers from government-funded Connexions youth advisory services should be able to guide young people through the transition process. However, many advisers lack specialist knowledge of disabled people's needs.[†]

For example, research by the Down's Syndrome Association found that experience of Connexions was mixed and quality of support was patchy. Although some people commented that Connexions had been helpful, others had less positive experiences. One person felt that he '*continually [has] to chase up for advice/help*'; another remarked that she had '*no faith in the Connexions service*'; and a couple found that '*as parents, we were informing Connexions of what was available for FE [further education] placement*'.³¹ Another charity that NPC spoke to described the service as '*dire*' and agreed that, although there are isolated pockets of good practice, the majority of Connexions services lack specialist expertise about supporting disabled people.

Getting the right support

If disabled young people are to complete their further or higher education course, it is not simply a case of getting them into college or university—they also need the right level of support while they are there.

Disabled young people are only half as likely as non-disabled people to be qualified to degree level, and twice as likely to have no qualification at all.

* For further details about the assessment process and its problems, readers can refer to materials produced by the charity Skill: National Bureau for Students.^{25,26}

† Connexions services were set up to provide information and advice to all young people about anything from education and employment to sexual health and relationships.^{28,29} It is difficult to assess the success of Connexions in supporting the transition of disabled young people, as Connexions services work with disabled young people up to the age of 25, but are only required to monitor the progress of young people up to the age of 19.³⁰

If disabled young people are to complete their further or higher education course, it is not simply a case of getting them into college or university—they also need the right level of support while they are there.

For this reason, some young people and families seek places at specialist further education colleges (known as Independent Specialist Colleges, or ISCs), where support is tailored to the needs of people with disabilities. Unfortunately, ISCs are unable to meet demand, and they are increasingly trying to spread their specialist knowledge more widely. Some are becoming regional centres of expertise, offering outreach services to local communities and working with other specialist and mainstream providers to build their capacity to support young people with complex needs. However, changes in statutory funding mean that independent specialist provision is diminishing: over the last three years, the number of ISCs in England has fallen from 72 to 57. This has serious implications for the sustainability of provision for disabled young people in further education.³²

More broadly, it is crucial that young people are aware of the financial assistance they are entitled to, and that further and higher education institutions know how to help them access the right support package.

This issue is illustrated by a 2007 report by the National Audit Office, which found that students receiving a Disabled Students' Allowance (DSA) were much more likely to continue their university course than other students self-declaring a disability. They were also more likely to continue their course than students who were not disabled.*

However, although the numbers receiving the DSA have increased, there is wide variation between institutions—at some, it is claimed by less than 10% of self-declared disabled students, while at others, it is claimed by 70%.³³ Research suggests that some students who have a disability may not claim the DSA because they want to avoid the negative stigma attached to the 'disabled' label.³⁴

For young people on non-residential courses, transport is another issue that can limit their opportunities to take part in education and social activities. This problem is discussed in more detail in Chapter 4.

For young people with certain conditions, the process of change itself can be very difficult, and they may need additional support in order to cope. For example, people with autistic spectrum disorders often find it hard to adjust to new people and changes in surroundings and routines (see Box 10 in Chapter 6).¹⁵ They may need help to develop their social skills, and practical support with everyday tasks such as managing their finances or preparing their

meals. Indeed, parents of autistic young people cite the lack of social skills programmes as the greatest single gap in support in further and higher education.¹⁸

How charities can help

Charities are working in a number of ways to ease the transition from school to college and university. As the following sections show, some charities run specialist schools and colleges themselves, which can support young people through transition; some work directly with young people to provide information, guidance and practical support; and some raise awareness and research the issues, trying to influence government and education institutions to improve services for young people making this transition.

Specialist schools and colleges

Disabled young people may be educated in mainstream or specialist schools and colleges. Specialist schools and colleges are usually charitable organisations, and tend to play a significant role in supporting transition.

Some specialist schools and colleges have dedicated transition programmes. For example:

- **Treloar Trust** runs a specialist school and college in Hampshire for young people with physical disabilities and complex needs. Treloar College provides flexible support that aims to promote a culture of independence in its students, raising their aspirations and preparing them for adult life. Treloar's has also been developing a programme called Moving On, which is designed to help pupils reintegrate into their home communities after they leave Treloar's (see Box 2).
- **MacIntyre** runs two residential specialist schools in England and Wales, supporting young people with complex learning disabilities. Like Treloar's, it has developed a special transition programme called My Way, discussed in Box 3. The programme helps young people in their final two years of school to plan for their future, working with local authorities and health and social services to ensure that suitable funding and placements are secured for pupils before they leave school.

Specialist schools and colleges also try to improve young people's chances of making a good transition by helping them to develop the confidence and skills that will enable them to live more independently as adults.

* DSA provides financial assistance for purchasing equipment, non-medical support, travel and other incidental services that students with a disability often need. They are not intended to cover the type of disability-related costs that the young people would incur if they were not attending a higher education course, or any course costs not related to their disability.³³

Box 2: Moving On

Treloar Trust's pilot programme, Moving On, is an interesting example of how a charity is using its practical experience to research and develop new ways of supporting disabled people through the changes they face throughout adult life.

Treloar's carried out research with young people who had physical disabilities and had left their school or college in the last ten years, to find out what they were now doing with their lives.³⁵ It found that 47% of those surveyed were still living at home. Many complained of social isolation, lack of success in job-seeking, and frustration at not being able to contribute to society. As a result, Treloar's designed a pilot programme to run between 2004 and 2007, to address these issues and help people make a more successful transition.

The pilot had several components:

- Two 'agents' (or support workers) were appointed to work in separate areas: Lewisham and Woking. Each agent worked with between 75 and 100 disabled people per year, for an average of 12 weeks, to help them to work towards measurable goals in finding employment, improving their social life, or attaining greater independence.
- A self-help guide was produced for people with physical disabilities who wish to make a significant change in their lives, such as getting a job, taking up a new hobby, or moving into independent living arrangements.³⁶
- The pilot made use of a development programme that was initially designed for former Treloar's students, to help them build their confidence and self-esteem. Each course trained 18 young people in presentation skills, attitude and general workplace awareness, with a view to helping them find work as a trainer in equality awareness and diversity.

Treloar's carried out the pilot not only to help its former students, but also to develop a feasible model that could be replicated elsewhere. An evaluation framework was built into the programme, and a 'blueprint' manual was produced to help other organisations develop similar services.

At the end of the three-year pilot, a qualitative evaluation of the programme was carried out by the Centre for Charity Effectiveness at the CASS Business School. The resulting report focused on the operational aspects of the programme. It concluded that the Moving On model has real benefits for disabled people.³⁷ Strengths of the programme include:

- the offer of ongoing one-to-one support, rather than a one-off appointment, allowing plenty of time to explore potential options and turn these into reality;
- provision of a holistic service, with a breadth of knowledge across various areas relevant to transition, from housing to social opportunities; and
- close work with key services, such as further and higher education institutions and social care services—collaboration that is vital to achieving the individual's goals.

The evaluation did not examine the outcomes for individual participants. NPC finds that this is a common issue with retrospective evaluations where no baseline data is available against which to measure progress. NPC believes that, ideally, monitoring and evaluation should be built in from the start of any programme, as this enables charities to understand and demonstrate their impact more effectively. Funders can support this process by ensuring that grants cover the full costs of monitoring and evaluation.

Grants from other sources, such as private individuals and foundations, have played an invaluable role in making the project happen. However, Treloar's reports that, despite a promising pilot, there is little interest from local government in funding this programme. Funders interested in transition might consider contacting Treloar's to discuss how they could support the continuation of the programme and roll-out in other areas.

Prior's Court is a specialist school for young people with autism who have particularly complex needs. The school focuses on developing skills that will prepare young people for adult life. For instance, it provides classes on cooking and cleaning, and vocational training based on what the individual pupil enjoys (such as horticulture or animal husbandry). It also offers on-site work placements, so that students can explore employment options.

Scope is a charity that focuses on creating equal opportunities for disabled people, particularly those with complex needs. Scope runs a specialist further education college, Beaumont College, for 18 to 25 year olds

with a broad range of physical and learning disabilities. It supports 75 students from across the UK who attend the college for three years. The college uses creative arts in particular as a vehicle for developing students' confidence, as well as building literacy, numeracy, social and communication skills. Where appropriate, students also attend courses at local colleges or access work experience in the community. The college supports some students in aiming for higher education, employment or volunteering schemes. For others, being able to make informed choices about their future, manage everyday tasks and communicate with new people can be huge achievements.³²

Box 3: Doing it My Way

MacIntyre's My Way programme provides a good illustration of how charities can work with local government to improve transition.

MacIntyre runs two specialist residential schools for young people with complex learning disabilities from around the UK. After seeing the challenges that students graduating from its schools often face in the move to adult services, the charity set up the My Way project to improve support for these young people and their families.

In this project, a facilitator works with young people from two years before they are due to leave school, using a person-centred approach to help them to plan their future.* The facilitator works directly with young people, helping them think about where they want to live, who they want to live with, how they want to spend their time, and who they want to support them. The facilitator also helps to coordinate regular transition review meetings between the professionals who have supported the young person at school, and the professionals who will work with them after they leave. This may include 20 or more people, from teachers, social workers, doctors and nurses, to parents, siblings and friends.

The My Way facilitator also works with local authorities to secure an appropriate individual budget for the young people (for an explanation of individual budgets see Chapter 6). Alternatively, if the local authority does not offer individual budgets, the facilitator will try to ensure that the young people's preferences are taken into account when the local authority decides the level and type of support they should receive.

The programme was awarded a Community Care Excellence Award in 2008 and has since been extended to Derbyshire and Leicestershire. However, MacIntyre's attempts to attract statutory funding have had little success, so My Way is primarily supported by voluntary funds. NPC believes that projects such as this may provide interesting options for private funders.

* Person-centred planning describes an approach that involves ongoing consultation with the person involved, so that planning identifies and takes into account what is important to the individual now and in the future. The process also makes the assumption that the individual's family and friends have his or her best interests at heart, and actively involves them in planning.¹¹

Understanding the options is of limited use if disabled young people are unable to articulate their needs and preferences.

Similarly, **Mencap** has set up the Mencap National College, which is designed to teach 16 to 25 year olds with learning disabilities the skills that they will need to make a successful transition to adult life. Based on three sites, the college runs residential and day courses that are designed to develop skills for independent living and to enable them to use local community facilities, take part in courses at local colleges, and gain work experience in a variety of different settings such as shops, cafés and farms. Students have personal tutors and individual learning plans to help them monitor their own progress, and there are opportunities to work towards National Vocational Qualifications (NVQs).

Disabled young people often attend specialist schools that are a long way from home. Once students from these schools graduate, they may have to adjust to being part of their home community again. **Treehouse**, a national charity for autism education that runs a school for autistic young people, encourages its students to engage as much as possible with the community around the school. Students are given the opportunity to use local shops and services. This helps to improve their social and independent living skills, while also improving the local community's understanding of the behaviour and needs of people with autism.

Treehouse is another good example of a charity that uses its experience to inform research and development more broadly. It uses its practice-based knowledge of autism education to support other specialist and mainstream schools; it produces resources (such as a guide for parents on campaigning for better services); and it lobbies government to ensure that the needs of children with autism are identified and prioritised.

Information, guidance and support

A number of charities provide specialist information and advice to guide disabled young people through the transition to college or university. This may be particularly useful for those in mainstream schools, who can find it harder to access specialist guidance.

For example, **Skill: National Bureau for Students with Disabilities** provides information and advice for disabled students through a helpline and self-help guides on its website. These guides aim to help disabled young people who are applying for further or higher education to find the right course and the appropriate financial and practical support. Skill also provides case studies of disabled young people in further and higher education, which are designed to showcase positive experiences and raise the aspirations of others (see Box 4 for an example).

As part of the London North Aimhigher Disability Programme, **The National Autistic Society (NAS)** provides information and guidance on routes into higher education and the support available, helping young people with disabilities, parents and relevant professionals. The programme has pioneered the use of 'transition schools' — courses that are designed to equip young autistic learners with the skills they need to succeed at university. Between 2005 and 2007, 11 three-day transition schools were run with a variety of schools across the Borough of Barnet.

Disabled students often need specialist equipment or extra support. The charity Skill, in collaboration with the **Disability Alliance**, provides one-day introductory courses on the benefits, loans and grants available to disabled students. The courses are aimed at informing support staff in higher education of how they can help disabled students secure their disability allowance, and how best to protect their other benefits. In addition, the two organisations have collaborated to produce web-based information on education-specific funding, and its effects on disability benefits.³⁸

Skill also offers consultancy to further and higher education institutions on how best to meet the needs of disabled people in education. This includes training for staff, both academic and administrative, to ensure that disabled learners receive support if and when they need it. And it includes training for disabled young people on what to expect in further and higher education.

Charities also provide guidance and information for disabled students while they are at college or university. Many such charities are dedicated to specific conditions or types of disability, providing specialist services to support young people with those conditions while at college or university. This may vary from working with young people to build their confidence and communication skills, to providing specialist teaching and support services in further education colleges.

For instance, the NAS's Prospects employment service advises young people with autism and Asperger syndrome on the transition to university life, and helps them with issues such as time management, organisational, communication and social skills. The service also provides training for academic staff working with young people with autism.

Another example is the **National Deaf Children's Society (NDCS)**, which has recognised that understanding the options is of limited use if disabled young people are unable to articulate their needs and preferences. It has therefore developed a course called Moving On, which is designed to equip deaf

Box 4: A university experience³⁹

'My name is Susan Hedge. I'm 22 years old and studying a BA Hons in Popular Music Studies at Liverpool Hope University. I've always been interested in music and when leaving St Vincent's School for the Blind, I studied at Liverpool Community College where I obtained an HND in Music. I applied to three universities to study music and found the forms straightforward to fill in. Obviously, being blind, I needed someone to help me do this. I was accepted for all three and chose Liverpool Hope University, as the course content covered subjects I enjoy most.

'I applied for Disabled Students' Allowances which paid for the specialist equipment I needed, such as a laptop with voice-recognition software. It also pays for a note taker who also assists me in specialist areas, such as Music Technology, to help me operate the studio recording equipment.

'I live in a student flat on campus with four other students and have a great social life going to clubs, swimming, choir, etc. The few problems that have occurred have not been because the University staff have been unhelpful, but because they do not always understand my disability needs and do not know how to support me correctly. It is therefore important that you make clear to lecturers what you need, such as equipment or extra time for exams. This is your right, don't be afraid to ask for it or to make further requests during the course if you need extra help or assistance. I was lucky that in attending Liverpool Community College first, I knew what I needed to help me with my studies and was able to present this to my local authority, Hope University and my tutors.

'Attending higher education can be a very exciting and enjoyable experience. I still have many friends from my college days and we keep in touch regularly and meet up for social occasions. Just remember, higher education is your right as much as any other student. Be positive in your approach both academically and socially, and it could be the best time of your life.'

young people in their final years of school with skills and knowledge to make choices about their future. The course materials are free for teachers to download from the NDCS website, and designed so that the course can be fitted around existing school commitments. Different units focus on various aspects of transition, including personal finance, relationships and sex, independent living, and college and employment choices. The initial pilot had 158 participants, and nearly 1,000 worksheets have been downloaded since the launch of the teaching materials.

The **Royal National Institute of Blind People (RNIB)** and **Action for Blind People (AfBP)** run a College Partnerships programme, which is setting up specialist teaching and support services for blind and partially-sighted young people, based in partnership colleges throughout the UK.* The programme plans to set up a network of 'hub' colleges for each region, providing on-site support to learners and tutors from both mainstream and specialist colleges, and some outreach support to other colleges in the region. There are currently hubs in Bristol, Weston, Leeds, Newcastle, Middlesbrough, Surrey and Hertford, with plans to expand the network further.

* Note that since April 2009, AfBP has had direct responsibility for the delivery of the partnerships.

The support that the programme provides to visually-impaired learners will include allocation of specialist equipment, classroom support (such as note taking), careers guidance and support into employment, travel training, and independence training. The type of provision will vary depending on existing local services, and in some areas it may include residential accommodation. In addition, the programme will provide specialist training for staff working with blind and partially-sighted learners, by providing one-to-one mentoring support for college staff and tutors.

Research and awareness

Charities play an important role in raising awareness of the issues that disabled young people can face when leaving school or college. Many produce research in the area and try to influence government and educational institutions, in order to improve services for young people making this transition.

Researching and raising awareness is particularly important when it comes to particular conditions, and a number of specialist charities are active on this front. For instance, the **Down's Syndrome Association**, a membership organisation for people with Down's syndrome and their families, has carried out research into the experiences of young people in their transition from school to further education. The research analysed the responses of 262 young people aged between 16 and 19, and their parents. The resulting report, *Access to Education*, uses these responses to highlight the varying experiences of mainstream and specialist education, the quality of transition planning in different local authorities, and the challenges in gaining a further education placement.³¹ The report highlights best practice in these areas and makes recommendations on how to change service provision to best help young people with Down's syndrome.



Photograph supplied by Leonard Cheshire Disability

Employment

More than half of Britain's disabled people of working age are unemployed, yet many of these people are eager to work. Although employment might not be a viable option for every disabled person, many qualified and able individuals are missing out on the opportunity to enjoy the financial and social benefits that a job can bring.

Many young people with disabilities, who may have recently left school, college or university, need support to find and keep a job. Without this support, they may be kept in education, repeating courses year after year, or find themselves with nothing to do at all. But with the right support, people with disabilities can make the most of an active and fulfilling working life.

The issue

Less than half of all disabled people of working age in Britain are employed, compared to three quarters of the general population, according to 2007 statistics.⁴⁰ Yet many disabled people would like to work. The Disability Rights Commission has found that, of people who are inactive, 31% of those with a long-term disability would like to work, compared to 25% of those without a disability. In total, 1.3 million unemployed disabled people in Britain want to work.⁴¹

The employment rate is significantly lower for certain groups, including people with complex physical disabilities, audio or visual impairments, learning disabilities, and autistic spectrum disorders.

For instance, only 17% of people with learning disabilities are in paid employment.⁴² And The National Autistic Society (NAS) has estimated that only 6% of adults with autism are in full-time paid employment, with 4% in part-time employment and 24% doing nothing or 'helping out around the house'.⁴³ Yet the majority of people on the autism spectrum are of average or above average intelligence. As a recent article in the *Independent on Sunday* suggested, people with Asperger syndrome or mild autism are well suited to certain types of work, and placed in the right environment, they may outperform their non-disabled peers.*⁴⁴ But this is not widely recognised by employers.

A variety of perceived and actual barriers contribute to this situation. For example:

- **Schools, further education colleges and universities** may not promote the skills and knowledge that would best equip disabled young people for the workplace.
- **Employers** may be concerned about the costs involved in providing the right facilities and support for disabled people. For instance, a government survey of 2,000 employers in 2004 found that 92% thought it would be 'difficult' or 'impossible' to employ a blind or partially-sighted person.⁴⁵
- **Intermediaries** involved in the process of transition, such as Jobcentre Plus or Connexions services, may lack specialist knowledge about the type of jobs and workplaces that are appropriate for people with particular disabilities.
- **Young people with disabilities** may have low aspirations or lack the confidence to apply for jobs in the first place. They may also lack information about the benefits and practical support available to help them into employment.

These factors reduce the equality of opportunity for young people and lead to situations where they are kept in education, repeating courses year after year, or moved into day-care services. These may seem easier options in the short term but, in the long term, they may cost individuals and the state substantially more. This is not simply in terms of the financial returns on employment: research suggests that employment can help to improve mental health and social skills, and decrease reliance on health and social care services.⁴⁷⁻⁵⁰

Recent government policies are sharpening the focus on access to employment for disabled people. For instance, in June 2009 the government launched its Valuing Employment Now initiative, which outlines an ambitious strategy for dramatically increasing the number of people with learning disabilities in 'real jobs' by 2025.⁵¹ This is linking into the three-year, cross-government Getting a Life programme, which aims to improve opportunities for people with learning disabilities, helping them to find jobs and live full lives as they make the transition to adulthood.^{† 52}

There are 1.3 million unemployed disabled people in Britain who want to work.

* The article discussed a company in Denmark that specialises in finding employment for people with autism or Asperger's as software and systems testers.

† The Getting a Life programme is working with ten local areas and finishes in 2011.

Box 5: Supporting graduates with autism into employment¹⁸

James, aged 23, has a BA Honours degree in journalism. Through The National Autistic Society's graduate training programme, Transitions, he has received training in interview skills, assertiveness and confidence building. James has had work placements at the *Barking and Dagenham Post* and *The Independent*, where he learnt more about the newspaper industry and developed an understanding of the pressures involved.

James now has a more confident outlook on the rest of his life and attributes this to the help he has received from Transitions. He has been deputising for the sports editor at *The Independent*, and is about to start working for the newspaper full time, covering European and Premiership football.

However, there is a long way to go. Charities are playing a valuable role in working towards these goals.

How charities can help

Charities help disabled young people to find employment in a variety of ways, from developing leadership and entrepreneurial skills, to teaching people about what to expect in the workplace. They also coordinate voluntary and paid employment opportunities, and help employers to recognise the needs and aspirations of disabled young people.[†] Box 6 looks in detail at the costs and benefits of supported employment.

Supporting people into work

RADAR (Royal Association for Disability and Rehabilitation), a membership organisation of over 900 disability charities, ran a leadership project for disabled young people. The project was designed to improve their leadership skills, build their confidence and link them to potential employers. The programme consisted of a series of four leadership events followed by one-to-one coaching by a professional disabled leadership consultant. Around 80 young people have been through the programme, and another 50 through a similar programme aimed at disabled young people in the black and minority ethnic community.

Leonard Cheshire Disability (LCD) has a variety of programmes focused on helping disabled people, including young adults, into employment. For example:

- Enable4Enterprise is aimed at equipping business advisors across London with the knowledge and skills necessary for them to better meet the needs of disabled clients.
- The Suitability programme provides an online matchmaking service for disabled jobseekers and potential employers.

LCD also has two programmes that have developed innovative ways of getting disabled people into work:

- Workability provides disabled people of working age with a free computer, software and access to online training resources so that they can work towards qualifications. An online interactive employment support zone is also being introduced for individuals, plus support for employers who are offering work experience and placements, and a corporate buddies volunteer programme. Since the programme started in 1998, it has helped over 8,000 disabled people, a significant proportion of whom have gone on to full-time employment and further education.
- The new Ability Media Centre in Southwark, London, is designed for young people aged 16 to 25 who are disabled, from a black or ethnic minority community, or not in education, training or employment. Young people at the centre have the opportunity to produce and broadcast programmes and gain qualifications in broadcasting, alongside developing confidence and self-esteem. The centre aims to help 600 young people to gain broadcasting qualifications in the first three years of its operation.

For people with learning disabilities and certain types of autistic spectrum disorders, the workplace can be a confusing and intimidating environment, full of unwritten rules about etiquette. Charities help to prepare people for this. For instance, **Mencap** provides a range of training and supported employment programmes for people with learning disabilities. Mencap Advance helps to build young people's confidence through training, with a focus on personal presentation, decision-making and managing responsibility. Mencap Pathway offers further support by training people about searching for jobs, writing CVs and going for job interviews. It also provides work experience placements and on-the-job training.

In 1995, **The National Autistic Society (NAS)** set up Prospects, the first employment scheme designed to help people with autism with normal and high IQs to get into paid employment. A follow-up study into the impact of the programme found that, between 1995 and 2003, two thirds of clients got a job.⁵³ Of those who had a job after the initial pilot stage in 1996, 68% were still in permanent jobs in 2003.

Prospects has a Transitions service (see Box 5) designed to help young people with autism who are about to graduate or have recently graduated from higher education, and are now

“Everyone should have the opportunity to work. Employment is about having independence, earning your own money and not having to rely on benefits.”

Ismail Kaji
Mencap spokesperson[†]

Box 6: Quantifying the costs and benefits of supported employment

One young person in forty is estimated to have a learning disability, and most young people with a learning disability say they would like to have a job one day.^{42,54} Yet from the evidence provided by employment figures, many will be thwarted in this ambition. Only 17% of adults with learning disabilities are estimated to be in paid work.⁴²

One of the main problems is that the transition to employment is not well supported. One potential solution is provided by so-called supported employment schemes, which, as the name suggests, provide the support people need to find and keep a job. The idea underpinning these schemes is that, with the right support, people can learn skills on the job. Some of the more specialised supported employment schemes are often delivered by charities.

Investing in a supported employment scheme pays off in just over a year, according to NPC's calculations made on the sole basis of wages earned. Approximately one fifth of this benefit accrues to the state through reduced welfare payments and increased tax take, and the rest is money in the pocket of the disabled person.

This calculation relies on various assumptions—the leading one being that people remain in employment. But the continued support that these schemes provide increases the chance of people with learning disabilities keeping their job. And these schemes help people with learning disabilities to find the right job in the first place, which also makes it more likely that they will hold on to it.

The calculation does not include any of the less direct and less tangible benefits that employment can bring. Having a job is associated with a whole host of positive outcomes, such as having better physical and mental health. People who are employed are also less likely to offend, misuse drugs and alcohol, and become homeless.⁵⁵ So helping people into employment leads to additional savings for the public purse—for example, in the healthcare and criminal justice systems—not accounted for here.

Research suggests that employment has particular benefits for people with disabilities. Having a job confers status as well as money, and can provide the opportunity to meet new people and become more integrated in society. Employment has been shown to increase social inclusion to a greater extent than attendance at day centres. It has also been shown to contribute to the chances of young people with learning disabilities becoming more confident and independent.⁵⁶

These benefits are just as important as the benefit of earning a wage—perhaps even more so. But unfortunately, as they are less immediately linked to having a job, and are harder to express in financial terms, most evaluations of supported employment schemes do not include them in a cost-benefit analysis.

Including less tangible benefits would reflect more fully the value of helping young people with learning disabilities into employment. NPC would be pleased to see evaluations of these schemes that assess their wider benefits. This would help to prove that, although costly, adequate support in the transition into employment is worthwhile, bringing financial and other benefits to people with learning disabilities.

For full details of NPC's cost-benefit analysis, see Appendix 2.

looking for work. Clients of the programme are given training in communication skills, interview skills and effective CV writing, and given help in understanding workplace etiquette.

Employment schemes such as Prospects are not cheap, but they ensure that the most is made of the large amount of money required to educate a child with autism. NPC estimates that special education and educational support for a child with high-functioning autism costs £185,000 from the ages of four to seventeen. For less than two percent of this cost, or £5,000, an employment scheme gives that child the chance to transfer skills learned in school to the workplace.

At a local level, charities can help disabled people find work by running supported employment programmes. For instance, **First Step Trust** has 16 projects in England, in and around London, Manchester, Liverpool and Sheffield, which offer people with learning disabilities, mental health problems and substance abuse problems the opportunity to gain work experience in a supportive environment. Projects are run as small businesses and range from garage services to catering projects. Some individuals use them as a direct stepping stone to paid employment, while for others it is primarily a chance to build confidence and improve skills.

Further or higher education institutions may also run programmes directly. For instance, the ROSE (Realistic Opportunities for Supported Employment) programme at Havering College helps students with learning disabilities to find paid work placements. Each student is allocated a 'job coach' who provides one-to-one support at the start of a new job, and this support is gradually reduced until the student is able to sustain the job independently.

Raising awareness and influencing policy

The **Transition Information Network (TIN)** promotes positive case studies of disabled young people in employment through its

magazine, newsletter, website and seminars. The aim is to challenge misconceptions, among both disabled people and employers, provide guidance and raise aspirations.

Skill: National Bureau for Students with Disabilities works with the government on issues relating to disabled students and their transition to employment. Skill has made various submissions to government consultations—for example, concerning guidelines for local authorities on meeting the needs of young learners with learning disabilities; and concerning the Department for Work and Pension's initiatives to improve specialist employment services.



Photograph supplied by Mencap 2009

Somewhere to live

Many disabled young people would like to live independently of their parents or carers when they reach adulthood. This does not necessarily mean living alone. The independent living movement—created by disabled people in response to services that they felt were too medically oriented and institutional—defines ‘independence’ as *‘the ability to decide and to choose what one wants, where and how to live, what to do and how to set about doing it’*.⁵⁷

But all too often, disabled young people have little or no choice over where they live. They may be placed in inappropriate care homes far from city centres, or may be forced to move home, with consequences for their family as well as their own independence. Charities can help to provide greater support and choice for disabled young people working out where to live.

The issue

Young people with disabilities may be educated in mainstream schools and live at home with family or carers, or they may be educated in specialist residential schools. This depends on their level of need, their preference and their family’s preference, and the type of provision available in their area.

Wherever they go to school, young people still face the question of where to live as adults. Disabled young people who have been living at a residential school or college may prefer to live in independent accommodation or residential care rather than move back to their family home. Similarly, disabled young people who have been living with their parents while going to school may decide that they would like to live away from home when they leave school. This may mean that they need to find suitable accommodation at college or university, buy their own home, or find a place in a care home or shared accommodation through ‘supported living’ schemes.*

Finding suitable housing is complicated at the best of times, but when you have to ensure that the accommodation meets the needs associated with specific disabilities, it becomes far more challenging. Many disabled young people need help navigating the system—working out what their housing options are,

what benefits they are eligible for, how to set up direct debits for bills, and how to pay a mortgage.

They also need to find a place to live where there are opportunities to socialise with other young people. Research suggests that there is a lack of accessible accommodation for disabled young people in central locations close to amenities. As a result, many end up in inappropriate residential care, where they can find themselves living in a place where most of the other inhabitants are much older, and where there is a lack of suitable daytime activities.²⁴ Of the 24,000 young adults with physical disabilities who live in care homes, it is estimated that around 9,000 (or 38%) are inappropriately housed.²⁴

In some cases, disabled young people continue living in the family home, either through preference or because suitable accommodation cannot be found. Their families may need advice and support to help them manage this logistically, financially and emotionally. For example, parents who end up caring full time for a severely-disabled young person may have to give up their job. They can benefit from occasional respite breaks (which are referred to in the sector as ‘short breaks’), but these are more difficult to arrange for young adults than for children.

How charities can help

Charities can help disabled young people to find suitable living arrangements by:

- providing residential services that create environments where young people can learn independent living skills;
- helping young people to find suitable accommodation as and when they are ready to live independently (including providing guidance on issues such as benefits and mortgages); and
- influencing government policy.

Enabling independent living

Leonard Cheshire Disability (LCD) runs three residential care services, with ten places at each. These are designed to help disabled young people, most of whom are leavers from specialist colleges, to develop the life

Of the 24,000 young adults with physical disabilities living in care homes, it is estimated that around 9,000 are inappropriately housed.

* ‘Supported living’ refers to programmes that help vulnerable people to live as independently as possible in suitable housing. Such programmes are often provided by charities and housing associations. Support may be provided as part of the overall service (for example, shared accommodation), or it may be part of a scheme that enables people to live in their own homes.

When I came to Lavender Fields, I lacked confidence, so I found it hard to do simple tasks on my own; I found it hard to make decisions.

Hannah

skills and confidence they need to move on to independent living arrangements. Hannah, a young person who uses one of the LCD residential care services—No. 1 Lavender Fields—talks of her experience:

*'When I came to Lavender Fields, I lacked confidence, so I found it hard to do simple tasks on my own; I found it hard to make decisions. The last two years living here have helped me build my confidence, although I still find some things hard. Lavender Fields has helped me become more self-reliant, and I am now at a mainstream college doing a course in Information Technology. Before I came here I didn't believe I could manage a mainstream course.'*⁵⁸

Most young people spend two years at Lavender Fields. However, LCD realises that some take longer to develop the skills they need, so there is a separate 'fall-back' service for those that need more time. When they are ready to move on, the charity helps its residents to secure shared ownership of accommodation by working closely with local Registered Social Landlords.

Scope has developed a new type of transition service. One example of this is Belvoir Lodge in Nottingham, which supports five young people who have complex care, support and learning needs. They are given the opportunity to live independently with their disabled peers in specially-adapted bungalows that are based in the community.

Belvoir Lodge provides one-to-one support to help these young people develop the skills

they need for independent life, and to make sure that they can exercise choice in accessing local opportunities, such as college courses, leisure activities and work experience. Young people can live at Belvoir Lodge for as long as they choose. Box 7 describes the experience of some of the young people there. Scope is currently fundraising so that it can roll out similar transition services elsewhere in the country.

Mencap also runs a transition housing project, Mencap Now. This gives young people with learning disabilities the chance to live in shared housing, with shared support workers. Young people spend up to three years there developing independent living skills, such as shopping for themselves in a supermarket and cooking.

Providing information, guidance and support

Charities can help to improve information and guidance to help disabled young people and their families find the right living arrangements.

For example, **Housing Options** runs a housing advisory service for people with learning disabilities, their families and their friends. Its website links to a variety of resources about different aspects of housing, such as mortgages, shared ownership arrangements, making a house accessible for people with disabilities, and organising care support for independent living. Housing Options also runs a free helpline to provide one-to-one advice, as well as providing training and consultancy for those who support people with learning disabilities.

The charity **Dimensions** commissioned Housing Options to produce a guide called *My home and money* for those supporting adults with learning difficulties. The guide includes information on the different income streams available for disabled people who wish to live independently, information on the practicalities and costs of different housing options, and advice on supporting disabled people to manage their money, for example, setting up bank accounts and budgeting.⁵⁹

In addition, Dimensions has produced a report, *Lost in Transition: A Home of My Own*, which is a good practice guide for parents and carers supporting young people with learning disabilities in their move to independent living.⁶⁰ It draws on Dimensions' experience, offering comprehensive advice on all aspects of transition including choosing the right support staff, thinking about leisure time, arranging financial support, and finding suitable housing.

MacIntyre runs networking and social events for disabled young people, giving them the chance to make friends in their local area and

Box 7: Home away from home

Michael is 20 and has cerebral palsy, a physical impairment that affects movement. Michael has complex communication difficulties and needs a high level of medical support. After attending Scope's Rutland House School in Nottingham, he moved into the charity's Belvoir Lodge transition service. According to Michael's mother:

'At Belvoir Lodge, Michael has the best of both worlds—a first home and the opportunity to come back to see the family when he wants. Michael's transition from school to Belvoir Lodge was very well planned, meeting the needs of Michael and us as a family. The emotional well-being of everyone involved in the process was taken into consideration and this ensured Michael had as smooth a transition as possible into the next stage of his life.'

'Belvoir Lodge has now taken Michael's development to the next level—building his confidence away from his family and living away from home with support from his carers. This has opened up lots of new opportunities for Michael, such as socialising with other young people at the college he now attends, going out shopping and attending the local activity centre. For us as a family, Belvoir Lodge has shifted our perception of Michael. Instead of us seeing Michael as a dependent child with complex needs, we now see a young adult who, with the support of Belvoir Lodge staff, is becoming an equal in society.'

to identify potential housemates. This way, disabled young people can move into shared accommodation with people they know they get along with.

Influencing policy

Charities including **Scope** and **RADAR** are part of the Our Lives Our Choices coalition, which was set up to represent disabled people, older people and carers who are affected by problems with the adult social care system, and promote their rights to independent living. The coalition is campaigning to get the Disabled Persons (Independent Living) Bill adopted as law. The bill would introduce a national framework for minimum independent living entitlements.

The **Voluntary Organisations Disability Group (VODG)** is campaigning around the issue of ordinary residence. Disputes about what defines a disabled young person's 'place of ordinary residence' can often affect transition. For example, for young disabled people living in residential specialist schools, funding comes

from their home local authority, even if their school is in another county. If they wish to move into independent accommodation near their school, their place of 'ordinary residence' is deemed to have changed, transferring the responsibility of funding to the new local authority. This funding is not always easy to access, and support can be hampered by bureaucratic delays, as local authorities argue over who should cover the costs. The VODG has produced a report, *No Place Like Home*, highlighting these issues. It lobbies for revised guidance for local authorities in settling ordinary residence disputes, and aims to ensure that funding follows the individual.

The **Transition Information Network** also provides information and runs seminars to raise awareness and provide guidance on issues around independent living.



Photograph supplied by The National Autistic Society



Photograph supplied by Treloar Trust

Transport and access

Going to college, getting a job and living independently may be beyond the reach of some disabled young people for the simple reason that they struggle to travel around on their own. Public transport can be difficult for disabled people to use, and they may become reliant on expensive private transport or depend on parents or carers to drive them around.

This can prevent young people from moving on. Transport problems can be a barrier to moving out of the family home or residential care, and can severely limit young people's opportunities to take part in education, employment and social activities. A lack of adequate transport is a major barrier to making a good transition to adult life, and one of the biggest contributors to social isolation.

And getting to where you need to go is only half the battle. Once there, disabled young people often experience difficulties accessing services. This may be due to simple physical barriers, such as a cash machine being too high for someone in a wheelchair to reach. Or it may be due to social barriers—people's attitudes to and preconceptions about disability.

The issue

Limited transport options

Lack of accessible public transport is a particular problem for people with physical disabilities. For instance, only 62% of Britain's buses are wheelchair accessible,⁶¹ and less than 60% of licensed cabs in England and Wales are wheelchair accessible.⁶² One of the charities NPC spoke to highlighted the fact that local buses can often only take one wheelchair at a time—two friends in wheelchairs cannot travel on the same bus, as there is simply no space to do so safely.

However, access is not only limited by physical barriers. For young people with learning disabilities, a simple journey on public transport can be a complicated and disorientating experience. As a result, many rely on their parents or carers to get them to where they need to go, which has knock-on effects on the lives of those parents and carers.

Some disabled young people do travel independently to and from school or college by taxi. This may seem like an acceptable solution, but young people can become reliant on taxis as a means of transport. It is also an expensive alternative: for registered disabled people, public transport is often subsidised or free, whereas the local authority will not always foot the bill for non-essential taxi trips or those outside the local authority area.³⁰

A lack of accessible and affordable transport can hinder the development of young people's independence, and limit their opportunities to access education, training and employment, and to take part in leisure and social activities. Government recognises this—indeed, the Disability Discrimination Act requires all new trains, buses and coaches to be accessible to disabled people. Improving access to transport has also been identified as a priority in recent government strategies, such as the Department of Health's Valuing People strategy for people with learning disabilities.⁶³

As we will see, charities are helping to drive improvements to transport. For example, they are carrying out research into problems and solutions, campaigning for change, and developing independent travel training programmes to enable young people to make the most of public transport.

Lack of access to public facilities

When they get there, it is important that public places and leisure facilities are accessible to disabled young people. This is a right recognised by the Disability Discrimination Act.

Accessibility is not simply about wheelchair ramps and disabled toilets. It is also affected by the attitudes of staff and members of the public. This is particularly pertinent when it comes to young people with 'hidden' disabilities, such as learning disabilities, autistic spectrum disorders and deafness. Lack of understanding of these conditions may mean that disabled people receive hostile reactions from others, which makes some places less hospitable. For a young person with a hearing impairment, for instance, not being able to understand what a shopkeeper or bus driver says is as much of a barrier to access as the lack of a ramp is for a young person in a wheelchair.

Only 62% of Britain's buses are wheelchair accessible.

Box 8: Going it alone⁶⁶

Sarah is 16 and has learning difficulties. Her mother explains how she came to have travel training:

'I was asked at one of Sarah's reviews if I would mind her taking part in travel training. I was a bit wary as I've always taken Sarah wherever she had to be or where she wanted to go. I was worried about Sarah being taught to read a timetable, whether she would be able to go to the right stop and get off at the right place, and that she would end up somewhere she shouldn't be. I couldn't visualise her being able to catch a bus on her own without someone being with her.'

Despite these concerns, Sarah's mother agreed to meet with Halton Borough Council's Independent Travel Trainer, and decided to give it a try. The Travel Trainer worked with Sarah during her last term at school, spending time training her in skills such as following directions and buying tickets, and teaching her about personal and road safety.

Sarah's mum says the training made a big difference to Sarah's life: *'Over a few months, Sarah seemed to mature and gain confidence she never had before. She was then able to go on to study for A-levels at Riverside College.'*

Travel training has meant that Sarah can travel independently to and from college, and it has helped her social life too.

'Sarah's biggest highlight was a few weeks ago when her friend came over from Runcorn. They went to the fair in Runcorn then over to her friend's house. Sarah had to come home herself on two buses. She was so pleased that she didn't need me.'

'She has matured and has independence she didn't have before she started travel training ... This time last year I had a child. Now I have a young lady.'

How charities can help

Supporting independent travel

NPC's research came across some charities that teach disabled young people how to travel independently on public transport.

For instance, **Ealing Mencap** runs a 'travel training' programme that enables young people with learning disabilities to travel to school or college independently. Although the training initially focuses on one route, many young people are able to build on that experience and travel independently on other routes. Mencap has found that this has other positive outcomes for participants. While before, they may have been reliant on a parent or carer to take them into town to meet friends, now they can find their own way there. This gives them greater freedom, which builds their confidence and self-esteem.

Local authorities are also developing travel training programmes, either on their own or in partnership with charities and other organisations. Halton Borough Council, for example, was one of the first to introduce a travel training programme for young people

with disabilities and learning difficulties (see Box 8).⁶⁴ Travel training schemes vary in duration and intensity, and in whether they use a classroom-based approach or are more practical. Evaluation of their impact also varies between different areas, and the results are rarely made public, making it difficult to assess which techniques work best.⁶⁵ Private funding could help charities such as Mencap Ealing to evaluate the best ways of providing travel training to disabled young people, and develop a standardised framework that could be shared with local authorities.

Influencing policy and campaigning for change

Charities are not directly responsible for opening up access to public transport and facilities. However, they can liaise with policy makers, transport providers and organisations that run public and leisure facilities to campaign for improvements to access.

For example, the charity **Out & About** helps leisure providers in the east of England to meet the needs of disabled children and young people and improve access to leisure facilities. The charity does this in a variety of ways. For instance, it offers training and advice, and provides volunteers who can support disabled children until they are included in their chosen leisure activity.

Leonard Cheshire Disability (LCD) is an active campaigner on access issues, carrying out research to raise awareness of the challenges that disabled people face, and lobbying for change. For instance, LCD has researched the barriers that people with physical disabilities face in accessing public transport, consulting disabled people about their experiences and looking into the accessibility of different transport options. The resulting reports—*Into the Unknown* and *Mind the Gap*—provide recommendations for policy makers and companies that run train, bus, taxi and underground services on how to make their transport more accessible.^{67,68}

LCD has also investigated disabled people's access to cash. A survey found that 54% of the disabled respondents sometimes found new Chip and PIN keypads difficult to use, and that 35% of respondents would prefer to revert back to a signature-based system. The main problems cited were variation in keypad design; a lack of awareness of alternative Chip and Signature cards amongst disabled people; and a feeling of vulnerability amongst disabled cardholders when entering their PIN.

The research also found that 42% of respondents were unable to use a cash machine without assistance. This assistance

included putting the card in the machine, entering the PIN, and taking money out—all of which increase the vulnerability of the disabled person in question. Of the cash machines surveyed, 59% were not fully accessible for disabled customers. For example, many had obstructions, such as steps or railings, which prevent people in wheelchairs from getting close enough to access the machine.⁶⁹ Off the back of this research, LCD called for specific

improvements to the accessibility of Chip and PIN and cash machines, and produced suggestions for banks and retail outlets on how to make their services more accessible.

LCD is also launching a new campaign called Action for Access, which will canvass disabled people's views about the major barriers to access in their local communities, then use this information to lobby for better access to local businesses and services.



Photograph supplied by Leonard Cheshire Disability



Photograph supplied by Mencap 2009

Friends and relationships

Making friends and developing an active social life is part and parcel of growing up. Yet disabled young people often find themselves socially isolated, lacking opportunities to see friends or meet new people.

When it comes to close relationships, disabled people have the same desires as non-disabled people.⁷⁰ But a lack of opportunities, combined with social stigma, can stand in the way of meeting potential partners.

The issue

Meeting up with friends and meeting new people can be hard for people with disabilities. Many struggle to live and travel independently, and some public places are inaccessible for people with certain disabilities. Relationships can be a particular issue for disabled young people who attend specialist schools outside their home area—when they leave and return home, it can be difficult to meet up with friends who live in other parts of the country.

When it comes to relationships, stigma is a very real obstacle. A survey by Leonard Cheshire Disability (LCD) found that almost a third of non-disabled people would not consider a relationship with a disabled person. Research suggests that this is related to ignorance about what disability involves: it was the non-disabled people who had had little contact with disabled people who were most likely to have negative perceptions about disability and relationships.⁷⁰

In particular, sex is often treated as a taboo subject in relation to people with disabilities. Disabled young people often feel that there is a perception that they are 'asexual'—that they do not have sexual feelings or are unable to act on them. This problem is magnified by the fact that there is limited relevant sexual health support, advice and education available for young disabled people.

Disabled young people may also lack confidence or suffer from low aspirations and low self-esteem. Many are not included in the decisions made about their lives. This can affect the quality of their relationships. The LCD survey found that disabled respondents had lower expectations of relationships than non-disabled people.⁷⁰

How charities can help

Charities are helping to break down the barriers that prevent disabled young people from building friendships and forming relationships. They provide opportunities for young people to make friends and meet potential partners, produce guidelines relating to sex and relationships, and campaign to change attitudes.

Opening up opportunities

A range of charities provide opportunities for young people with similar disabilities, or disabled young people who are living in the same area, to make new friends and access leisure activities.

For instance, the **National Deaf Children's Society (NDCS)** runs a series of regional events for around 900 young people a year between the ages of 9 and 18. These aim to bring young deaf people together, and encourage friendships between young people in a local area. NDCS also involves young deaf people in running events, providing them with experience of management, developing their confidence, and helping to prepare them for employment.

Similarly, the **Royal National Institute of Blind People (RNIB)**, in cooperation with **Action for Blind People**, runs week-long residential holidays for visually-impaired young people who are in mainstream education. These are designed to give young people the opportunity to meet peers and talk to RNIB staff, who can direct them to appropriate support services, if necessary.

Through its Moving On programme (see Box 2 in Chapter 1), **Treloar Trust** helps disabled people to explore the social opportunities in their area. This can include anything from identifying an accessible local sports club to helping young people to plan trips to the local pub. Claire's story highlights this work:

'Claire was referred to the Moving On project by her occupational therapist. She lives with multiple sclerosis, is visually impaired and uses a wheelchair. Claire was interested in getting back into sport. She had previously enjoyed sailing and was eager to resume her hobby.'

Disabled young people often lack opportunities to meet up with friends or form new relationships.

'The Moving On project found a local sailing centre. Then the outreach worker helped Claire make an initial visit and apply to participate regularly. Once Claire had been accepted, the outreach worker supported her at the centre for four weeks to smooth out any difficulties.

*'Claire continues to go sailing and enjoys tremendously the socialising side of the activity. Her confidence has grown hugely through her participation in the Moving On project.'*⁷¹

The Children's Society has a Student Befriending Scheme, which helps around 40 disabled young people a year in York to access social and leisure activities, by running activities and short breaks with the help of student volunteers. The project was externally evaluated and, as a result of initial success, was rolled out to Brighton and Hove. The Children's Society now offers training and consultancy to other local authorities so that similar programmes can be run elsewhere in the country.

The **Transition Information Network** advertises social events for young disabled people on its website.⁷² One event that it advertises is Clive, a club night for young people with learning disabilities, aged 14 to 25, and their friends and families. The event is run every few months by **Arts Depot**, a cultural arts centre in North London. Similarly, a voluntary social group, **Youth Plus Essex**, which is affiliated to Mencap, runs regular community-based activities and weekly meetings at the local youth centre, and provides volunteering opportunities for 14 to 25 year olds with learning disabilities.

Other charities facilitate social events where disabled people can make new friends and meet potential partners. For instance, **Outsiders** is a charity that runs a social and peer support network for disabled people. Its work includes an initiative called Outsiders Club, which offers members the chance to meet, build their confidence, make new friends and perhaps find a partner. The club has members from all over Britain and around the world. It holds monthly lunches in London, Ipswich and the Midlands, as well as parties, outings and women's events. Members receive a magazine and a 'Practical Suggestions' book with ideas for how previous members have overcome difficulties forming new relationships.

Outsiders also runs specific groups (such as a group for lesbian, gay, bisexual and transgendered disabled people), runs a sex and disability helpline, and leads the Sexual Health and Disability Alliance, which consists of 100 professionals who want to promote the sexual good health of disabled people.

Charities that provide specialist education can also help by providing a supportive environment for young people over the age of 16 to express their sexual needs and form relationships. Treloar College, for instance, aims to ensure that appropriate information on sexuality and relationships is freely available to students. It believes that those students who wish to form consensual sexual relationships should have the opportunity to do so, with appropriate safeguards to ensure that they are not coerced or pressured and are acting within the law.



Photograph supplied by Leonard Cheshire Disability

Treloar's SaFE (Sexuality and Further Education) policy provides guidelines for staff at the college, including information on:

- the acceptable boundaries of staff and student relationships;
- the students' right to expect the confidentiality of personal information, unless this puts themselves or someone else at risk;
- the students' right to privacy; and
- identifying potential abuse or lack of consent within a relationship.

Providing information, guidance and support

Disabled young people often miss out on the sexual health advice and support that most young people take for granted. **Leonard Cheshire Disability** has been addressing this issue through its three-year InTouch programme. Launched in 2007, the programme is researching what sexual health information is already available to disabled young people and investigating what support young people would like to have. The aim is to evaluate the best ways of supporting the development of young disabled people's sexuality, with a view to producing guidance for young people to use, and sharing the findings with health providers to influence the development of provision.

Generally speaking, the information available for disabled young people about sex and relationships seems to be improving. For instance, **Contact a Family** provides information and advice for disabled children and young people and their families through publications on its website and a free helpline. The charity has also produced a series of free booklets—*Growing up, sex and relationships*—each of which is pitched at a different audience: teachers, young disabled people and parents. The booklets highlight how disability may affect different aspects of sexual development, discuss what parents and teachers can do to help, and direct parents, young people and professional workers to useful resources.

A number of organisations have produced resources that are targeted at particular groups. For instance, **SpeakingUp**, a charity that champions the rights of people with learning disabilities, has produced booklets on issues including sex and sexuality to help provide young people with the information that they need. The **Family Planning Association** has also published resources for young people with learning disabilities, and for their parents and carers.

Box 9: Challenging perceptions of disability and sexuality⁷³

Leonard Cheshire Disability's Creature Discomforts commercials use animated characters similar to those featured in *Creature Comforts*, the Aardman TV series, to challenge common misconceptions about disability. In these commercials, the audience hears real people talking about living with their disability, represented visually by animated animals.

In the excerpt below, the first character the audience sees and hears is a mouse, who represents a woman with cerebral palsy. The next character is a rabbit in a wheelchair, and the audience can see the father rabbit and their children (small bunnies) playing in the background.

Shelley (mouse): *'Some people think because you have a disability maybe you should be with someone with a disability. And it doesn't work like that. You can't help who you fall in love with.'*

Isobel (rabbit): *'They think that if you're disabled, you can't have a love life. That's not true, though. I can have sex.'*

Similarly, **The Signalong Group**, a charity dedicated to helping people with impaired communication, has produced a sexual awareness resource pack. This is designed as a resource tool for parents, carers, teachers and other people supporting young people with communication and language difficulties.

ACT (Association for Children's Palliative Care) recognises that young people with complex health issues or life-limiting conditions face additional obstacles in developing and expressing their sexuality, given that they are often in full-time care. ACT has produced a booklet that advises parents and professionals involved in the care of young people on how to be supportive when it comes to sexuality, and directs young people towards useful resources.⁷⁴

Combating stigma

A charity that has recently challenged negative preconceptions about disability and relationships is **Leonard Cheshire Disability**. Its Creature Discomforts series of television and radio adverts was designed to make people question their attitudes towards disability. The adverts use recordings of disabled people talking about their experiences and highlight, among other things, misconceptions that disabled people cannot have sexual relationships (see Box 9).* The Creature Discomforts campaign is discussed further in Chapter 6.

Disabled young people often miss out on the sexual health advice and support that most young people take for granted.

* The full Creature Discomforts commercials and scripts are available at www.creaturediscomforts.org.



Photograph supplied by Mencap 2009

Improving the system

Young people often face a sudden reduction in support as they move from children's to adults' services. A lack of planning, inadequate guidance, patchy service provision and negative attitudes to disability are serious problems. There is still a long way to go, but the government and charities are taking some steps to tackle these problems and improve the systems that affect young people's experience of transition.

Problems with the system

The cliff edge

The government recognises that many disabled young people experience a 'cliff edge' in support as they move from children's to adults' services. This is partly due to differences in the ethos and structure of the services, and disabled young people may need support to adjust to this change. But it is also because, in many cases, adult services offer a different level and type of support. As a result, the parents or carers of disabled young people may have to give up work to look after their children.⁷⁵

Health services

Health services for children and adults are structured differently. Each child is the responsibility of a particular paediatric team, which will have an overview of his or her health needs. The team will usually get to know the individual child and his or her family over many years, and will have a good understanding of family circumstances and how they affect the child.

In contrast, in adult services, there is not usually a cohesive team of clinicians with responsibility for a young person. Instead, young people may be seen by a variety of different specialists based in different hospitals and clinics. For example, a young person with multiple learning disabilities and complex health needs might need support from a variety of healthcare professionals: a neurologist for epilepsy; a speech and language therapist for communication problems; a physiotherapist and occupational therapist for physical needs; and a psychologist for emotional and behavioural support.

For conditions that are generally associated with childhood, it may be a struggle to find a clinician with specialist knowledge of how to manage that condition in adulthood. This problem particularly applies to life-limiting conditions for which the life expectancy is higher now than in the past. In 1986, for instance, death due to congenital heart disease was most common in infancy, with over 60% of deaths occurring in babies aged less than 12 months. However, by the early 1990s, death from this disease was most common in adults aged 20 years and over, and it is predicted that 78% of babies diagnosed now with congenital heart disease will survive into adulthood.⁷⁶

Social services

At the age of 18, disabled young people are transferred from children's social care to adult social care. However, the eligibility criteria for the two services are different, and some disabled young people find that they no longer receive support, or that statutory funders disagree over who should fund their support.

For example, young people with mild to moderate learning disabilities, who receive support for special educational needs (SEN) while at school, often find that they are not eligible for adult social care.* Recent research from the Local Government Association showed that, in 2008, almost three quarters of councils only provided care to people with 'substantial' or 'critical' needs.^{77,78}

Young people reach this 'cliff edge' in support just as they leave the familiar environment of school—a time when they may feel particularly vulnerable.

Without the right support, some young people may be at risk of becoming involved in youth crime. Research suggests that a high proportion of young people with SEN end up in the youth justice system. For instance, the Youth Justice Board reported that 33% of children and young people of school age who enter the youth justice system need help with reading and writing, and 15% have statements of SEN.^{† 79}

Almost three quarters of councils only provide care to people with 'substantial' or 'critical' needs.

Only half of local areas in England have a transition protocol, and less than half have a transition pathway.

* Young people with a statement of SEN receive support up to the age of 18 if they stay in the same school for sixth form. However, if they move to further education, including sixth-form colleges, their statement ends at 16. Information on their individual needs may be lost during this transition.¹⁸

† The charity Dimensions runs a group to support people with moderate learning disabilities who are on the fringes of the criminal justice system.

For those young people who do reach the threshold to be eligible for adult services, the type of support they receive may change. For instance, young people who are used to spending time with people their own age in a specialist college may find that they are transferred to day services where they are surrounded by adults who are considerably older than them. In contrast to the full programme of activities that they are used to from school, they may be left with lots of unstructured time and limited activities to suit their age and interests. As the Commission for Social Care Inspection has acknowledged, some people say that this aspect of transition can be ‘a nightmare’.¹³

Cultural differences between children’s and adults’ services

The shift in the type of care a person receives is partly influenced by the different objectives that services have.

Children’s services work within the framework of the government’s Every Child Matters strategy. This stipulates that children’s services should focus on achieving the following five outcomes:

1. be healthy;
2. stay safe;
3. enjoy and achieve;
4. make a positive contribution; and
5. achieve economic well-being.⁸⁰

The third and fourth outcomes are particularly significant—they suggest that government services are responsible for promoting happiness, achievement, and fulfilment.

Adult services tend to interpret policy frameworks differently. They are often more focused on achieving outcomes relating to specific aspects of an individual’s need, impairment, or employment status, which they try to achieve in the most immediate, cost-efficient way. There may be less of a focus on outcomes such as enjoying and achieving or making a positive contribution.

So, for example, a young man with a degenerative condition might be given a manual wheelchair, which allows him to be mobile. However, the assessment he received may not consider the fact that his degenerative condition makes it difficult for him to move his wheelchair for longer than half an hour. This limits his opportunities to get out and about in the community, meet friends, work, and access leisure and social activities.

The lack of a common language between services for children and adults, and the differences in the way they tend to interpret policy frameworks, cause tensions that can have a very real impact on young people’s transition to adult life. They may also lead to situations where young people with complex needs are put into inappropriate residential care, rather than being supported into further education, community living or employment, which would be more likely to improve their emotional well-being and skills over the long term.

Transition services can help by bridging the gap between services, and building the confidence and skills that enable disabled young people to live more independently and articulate their needs and preferences.³²

Poor planning

As we have seen, the government’s responsibility for disabled young people spans education, health, social care, housing and employment. Coordinating the work of all the different departments and professionals working on these issues, and spanning the gap between services for children and adults, is a real challenge.

Government recommends that local authorities and primary care trusts (PCTs) should assemble multi-agency teams to work on transition. Representatives from all the relevant services—education, healthcare, social care, Connexions or other youth advisory services—should be involved, with one person taking the role of ‘lead professional’. Ideally, the team should include representatives from both children’s and adults’ services, and planning for transition should start when disabled young people reach the age of 14.¹¹

In theory, these multi-agency teams should follow a transition protocol and a transition pathway:

- **The transition protocol** is a multi-agency agreement that should be developed with all the organisations and individuals involved in transition, including disabled young people and their families. It should be reviewed regularly to ensure that it is meeting the needs of local disabled people.
- **The transition pathway** is the operational plan that maps out how local services will work together to support disabled young people and ensure that the transition protocol is reflected in the way services are delivered.⁸¹

However, practice varies widely between areas. A survey of 147 local areas in England for the government's Transition Support Programme (discussed later) found that:

- only 50% had an existing transition protocol;
- only 44% had a transition pathway; and
- only 33% said that all young people in their area had access to a key worker or lead professional to coordinate the transition process.¹⁷

Box 10 illustrates planning problems, with specific reference to the experience of people with autism.

Lack of data on local need and existing provision

Services for young people with disabilities are commissioned by local authorities, PCTs, and other local government agencies. However, there is often limited data on the needs of the local population and the different services available to support specific groups. For example, 67% of local authorities and 77% of PCTs do not keep a record of how many adults with autism there are in their area.¹⁶ There are no mechanisms for gathering data about young people in transition as a separate category, as individuals are classified as users of either children's services or adults' services.

This makes it difficult for both funders and charities to make informed decisions about the services that are needed in their area. Charities and funders may fall back on prevalence estimates for specific disabilities, rather than using local data.

It is not charities' responsibility to map need and provision—this should be done by government—but they may be able to spur the process on by lobbying the local authority or PCT about the value of such data. Charities that specialise in supporting disabled people in a particular area may also be in a good position to represent disabled people's needs to commissioners.

Lack of specialist knowledge

Commissioners in local government and professionals in mainstream services, such as teachers and GPs, are unlikely to have specialist knowledge about specific disabilities. This is particularly the case with disabilities that have a relatively low incidence, such as cerebral palsy, which has an annual incidence of approximately two per 1,000 live births in the UK.⁸²

Specialist charities can help by championing a specific disability or condition, such as cerebral palsy, Down's syndrome, deafness or visual impairment. For example, charities carry out research, campaign to raise awareness of the needs of people with that condition, and

Box 10: Transition for young people with autism

Recent reports by The National Autistic Society (NAS) and the All-Party Parliamentary Group on Autism have highlighted a number of problems with transition for young people with autism. For example:

- Only 53% of young people with autism who have statements of SEN were issued with transition plans during the course of their education. The proportion was even lower in mainstream schools, at 34%.¹⁵
- Of those who had experienced transition planning, 45% were dissatisfied with the process.¹⁸
- Only 43% of parents of more able young people with autism believed that their child had been supported to express their views during the transition planning process. The figure was less than 20% for parents of less able young people.¹⁸
- In only 17% of cases were adult social services, which should play a vital role in supporting autistic people, involved in transition planning.¹⁵

Inadequate support for transition leads to poor outcomes for autistic people, who find change very stressful. As one expert commented:

*'Life events or sudden changes (for example, due to a lack of planning) can lead to catastrophic reactions which can be very difficult to reverse, especially if the behaviour becomes entrenched over a period of time. Therefore the amount of work and cost involved in pre-empting the problems and addressing potential future difficulties early on is greatly reduced, compared to trying to react to a negative situation once it has already happened.'*¹⁸

The NAS estimates that at least one in three adults with autism experiences mental health difficulties due to a lack of support. Poorly planned transition also affects young people's chances of securing places in further or higher education or employment, and receiving the support they need to thrive in these settings. Almost two thirds of parents felt that lack of support led to greater support needs later on in their child's life.^{15,16}

This situation is illustrated by the case of Newham Asperger's Service, which estimates that, of its users:

- 60% have experienced additional mental health problems;
- 30% self-harm;
- 30% have attempted suicide;
- 28% have been hospitalised for mental health problems;
- 15% have been in the prison system; and
- a further 15% have been cautioned by the police.¹⁵

Further information about the role of charities in supporting people with autism can be found in NPC's 2007 report, *A life less ordinary*.⁵

provide specialist training for commissioners and practitioners. This will be discussed in more detail later in this chapter.

Limited consultation with young people and families

It is very important that young people and their families are consulted about their needs and preferences when it comes to transition. If their views are not taken into account, it is less likely that they will be satisfied with the type of support they receive. They may feel disempowered and confused about the options that are open to them.

Box 11: The Transition Support Programme

The government's Aiming High for Disabled Children strategy (2007) set out a programme for transforming services for disabled children. One of the issues that it identified was a need to improve and coordinate services to help disabled young people with the transition to adult life. The Transition Support Programme was set up to address this issue.

The programme is a joint initiative of the Department of Health and the Department for Children, Schools and Families. It is running from 2008 to 2011 and being managed by the Council for Disabled Children (CDC), which has for a number of years hosted the Transition Information Network (TIN), an alliance of organisations and individuals supporting the transition of disabled young people.*

The National Transition Support Team coordinates the work of the Transition Support Programme and supports its delivery at a national, regional and local level. Financial and practical support is provided to improve local services through direct grants to local statutory agencies and consultancy from regional advisers.

All local areas in England were asked to complete a self-assessment questionnaire. The findings from these questionnaires are determining the support that areas receive from the programme. There are three levels of support:

- 24 areas that have been identified as having high standards are receiving a direct grant of £37,500 and support from the National Transition Support Team to develop best practice and drive change in other areas.
- Areas with average standards of transition provision are receiving support from regional advisers to build and benefit from networks and pursue best practice.
- Areas that are struggling to provide adequate transition support are receiving assistance from regional advisers to move practice on from minimum standards.¹⁷

Every local area is receiving £10,000 in the first and second years of the programme, plus access to information, networking and development opportunities.

* Other charities acting as partners for the programme include ACT (Association for Children's Palliative Care), the Association for Real Change, The Children's Society, Scope, the National Children's Bureau, SpeakingUp, Treehouse, and The National Autistic Society.⁸³

Although the government recommends that young people and their families are included in annual transition planning meetings from the age of 14, this does not always happen. The 2008 survey for the government's Transition Support Programme showed that in one in five local areas, only 'some' disabled young people in their area are given the support they need to contribute to their transition process.¹⁷ This was reflected in a report from The National Autistic Society, *Moving on up*, which included case studies of individuals' experience of transition. As one parent recalled:

*'At my son's first transition meeting with the annual review, the very first meeting, he wasn't even invited to the meeting ... Under the box for Trystan's comments with the follow-on report, there were no comments obtained from Trystan ... He has communication difficulties but he is able to express opinions on things and I think that should have been taken into account.'*¹⁸

This problem is compounded when young people lack the confidence or ability to articulate their needs and preferences. This can be a particular problem for young people with learning disabilities and communication problems.

What is government doing to improve transition?

Government recognises the need to improve transition for disabled young people. It set up the Transition Support Programme in 2008 (see Box 11), which ties into a raft of other policies aimed at supporting specific groups, such as people with learning disabilities, or addressing themes such as education or employment.

The first stage of the programme was to survey all local areas in England by asking them to fill in a self-assessment questionnaire evaluating their current provision for transition. This showed significant problems with a lack of planning, protocols and pathways in many areas. The programme is now trying to ensure that all local areas have the right procedures in place and is sharing examples of best practice, particularly with struggling areas.

The government is drawing on charities' expertise for this programme through the **Council for Disabled Children (CDC)** and partner charities. Charities have also been highlighted as examples of best practice—for example, **MacIntyre's** My Way programme (see Box 3 in Chapter 1).⁸⁴

Funders who are interested in supporting a particular area or region might find it helpful to work with the **Transition Information Network (TIN)**, which is based at CDC, alongside the government Transition Support Programme. For instance, funders might consider giving money to a charity that is working to improve services in one of the areas that has been identified as having poor-quality provision. This is likely to involve an element of risk, but it could complement the government's work and potentially have a bigger impact than in an area where provision is more sophisticated.

Detailed information about levels of provision is not published online, although examples of good practice can be accessed through the associated website: www.transitionsupportprogramme.org.uk.

Once the Transition Support Programme comes to a close in March 2011, TIN will continue to share the good practice and tools developed through the programme. NPC therefore recommends that funders interested in this approach should contact TIN directly, at the CDC.

What are charities doing to improve the system?

As previous chapters have shown, charities are doing specific work on a whole range of different issues that affect disabled young people's transition to adulthood. The remainder of this chapter looks at the role that charities play in improving the system more broadly (or improving people's experience of the system), in four ways:

- smoothing transition;
- providing specialist support for young people and families;
- providing specialist support for professionals; and
- challenging the status quo.

Smoothing transition

Supporting transition planning

Charities working closely with disabled young people have a good understanding of their needs and are well placed to help coordinate their transition, ensuring that statutory agencies take young people's views into account. For instance, specialist schools and colleges try to ensure that suitable arrangements are made for supporting their students after they leave.

NPC expects any charity that is providing direct services for disabled young people to be in contact with the statutory agencies that support those people, and have some involvement in the transition planning process. In some cases, statutory agencies may even outsource the role of coordinating transition to charities (for example, see Box 3 in Chapter 1, on MacIntyre's My Way programme).

Dimensions, one of the largest providers of support services for people with learning difficulties and autism, is one charity that has a particular focus on supporting the transition-planning process. As well as working with young people and their families, Dimensions works directly with local authorities, helping them to think about their strategic goals in supporting transition, and brokering the relationships between them and disabled young people.

Providing flexible support and continuity

Local charities working with disabled young people can also help to smooth the process of transition by providing continuity in their support while young people are moving from children's to adults' services. The story of Michael in Chapter 3 (see Box 7) shows how **Scope** supports disabled young people through the transition from school to adult life.

Although not focused entirely on transition, Scope also runs inclusion teams that can help disabled young people to overcome barriers that may affect their experience of transition. These teams are designed to provide support for disabled children and young adults in the home and the community, including support to enable them to access leisure, education and employment. The teams consist of highly-trained professionals who provide advice and hands-on support to young people with complex physical impairments, learning disabilities and autistic spectrum disorders. Scope has teams in five regions: the East Midlands, the North West, the South West, Suffolk/Norfolk and West London. Some of these teams have access to additional expertise from Scope's nursing, therapy and education professionals.

Charities also act as a safety net for young people who are particularly vulnerable to getting lost in the system. These may include young people with mild to moderate learning disabilities who find that they are not eligible for adult social care, but would still benefit from support and guidance.

Providing specialist support for young people and families

Navigating your way around health, education, and social care systems, and finding out what benefits you are entitled to, can be a bewildering experience. Charities help disabled young people and their families by providing them with information, advice and guidance to make sure that they secure the level of support that they need.

Providing information and guidance

Previous chapters have discussed specialist information and guidance on specific issues relating to transition. A number of disability charities also produce general information for disabled young people and their families on a broad range of transition-related issues. For example:

- The **Transition Information Network (TIN)** provides information including *My future choices*, a magazine for young people that features stories by and about young people, published three times a year. A quarterly policy and good practice round-up e-newsletter is sent out to all members, and TIN's website provides information for parents of disabled young people and professionals, back issues of its publications, links to national and local organisations, and other resources. TIN is developing a separate website for disabled young people, which will feature videos of young people talking about transition, stories of peoples' experiences growing up, and links to relevant and accessible resources.

Box 12: Taking the local authority to task

Lucy is 21 years old and has complex needs associated with autism. She displays challenging behaviour and experiences high levels of anxiety, which can result in physical symptoms, such as insomnia and vomiting.

After leaving her residential college placement, Lucy's anxiety levels increased, resulting in panic attacks and depression. Social services failed to secure a suitable long-term placement for her despite receiving sufficient warning. Instead, her family found an appropriate placement. However, social services refused to confirm funding on the basis that it was too expensive and that she did not require a specialist placement.

After a long and fruitless battle with social services, Lucy's family contacted the Disability Law Service (DLS). DLS assessed the case and sent a letter to social services threatening legal action. The local authority quickly agreed to fund the specialist placement for Lucy.

Developing confidence and communication skills in disabled young people is vital if they are to articulate their choices and fight for their rights.

- The charity **Contact a Family** is dedicated to supporting the families of young people with disabilities. It provides advice through its helpline, website and publications, including some information that is specifically relevant to transition. For instance, its manual, *Preparing for adult life and transition*, offers guidance for parents of disabled young people on the transition planning process and directs them to other sources of specialist information.⁸⁵
- **Scope** runs a range of information, advice and support services throughout England and Wales. These include Scope Response, which provides telephone, online and face-to-face support services that are accessed by over 2,000 people every month. In 2008, Scope extended this aspect of its work by merging with DIAL UK, the national umbrella body for local disability advice groups. The groups are run by disabled people who are trained to provide specialist information, advocacy support and, in some cases, legal advice. Scope receives over 500,000 visits to its website from people in search of information, advice and support, which gives a sense of the scale of the demand for these services.³²

Some charities provide specific information and advice to help people understand complicated financial and legal systems. They help to ensure that disabled young people are receiving the level of support they are entitled to as they make the transition to adult life.

- The **Disability Alliance** provides information on social security benefits and tax credits for disabled people. It tries to break down the complexities of the benefits system to help disabled young people to understand what support they are eligible for.
- **Contact a Family** has produced a guide for parents of young disabled people called *Money when your child reaches 16 years of age*. Once a child reaches 16, it may be

possible for them to claim certain benefits in their own right, but this might adversely affect the tax credits and benefits the family already receives. The guide discusses the pros and cons of claiming benefits as part of the family and of young people claiming benefits for themselves. It looks at what benefits are available in different scenarios, and directs readers to other useful sources of advice.⁸⁶

- The **Disability Law Service (DLS)** provides free legal services for disabled people throughout the UK. It helps to ensure that disabled people receive the benefits and services they are entitled to. Its work in supporting transition is highlighted by Lucy's story in Box 12.

A range of charities also provide information and guidance that is tailored to specific conditions. For instance:

- **The National Autistic Society** provides information about transition through Signpost, an online database designed to give the parents or carers of autistic children access to information about local autism services.⁸⁷
- **Mencap** has produced a transition guide for parents and carers of young people with learning disabilities to help them understand and prepare for the transition process. It includes subjects including funding, benefits, housing, transport and how to make a complaint.⁸⁸
- The **Foundation for People with Learning Disabilities** has published information booklets for families, friends and carers, illustrating best practice examples of transition for young people with Down's Syndrome, autism, mental health problems and learning disabilities.
- **Sense**, a national charity that supports deafblind people, has produced a guide, (*Getting a Result!*) and DVD, which are aimed at helping young people with multiple sensory impairments to think about transition.
- The **National Deaf Children's Society (NDCS)** is running a project in Scotland—Who am I?—which aims to improve young deaf people's confidence and self-esteem so that they feel more comfortable about being independent. It also encourages parents to become confident about supporting their child's transition to independence. These objectives are being achieved through creative workshops, social activities and forums where parents can meet and share their experiences. Resources include a book for young deaf people by young deaf people, a DVD and booklets for parents.

Training, events and informal support

Some charities offer training courses, seminars and informal support for disabled young people and their families.

TIN runs regular seminars and workshops to bring together disabled young people and their families, and give them the opportunity to discuss transition with local authority commissioners, children's services officers and other professionals. For instance, a 2009 TIN seminar is giving professionals and families the chance to learn about the government's new employment strategy for people with learning disabilities, Valuing Employment Now, as well as other initiatives being developed in local areas to increase employment opportunities for disabled young people.

Specialist charities focusing on specific disabilities also run training and events for young people and their families. Some of these are designed to build young people's confidence and give them the knowledge they need to make choices about their future, as with the NDCS's Moving On course, discussed in Chapter 1.

Many families also value more informal support to help them deal with the pressures of caring for a disabled young person. For the last 15 years, Scope has been running a one-to-one peer befriending service called Face 2 Face Network, for parents of disabled children. This currently has 85 local schemes across England and Wales and works with over 1,000 families every week.

Speaking out

As we have seen, developing confidence and communication skills in disabled young people is vital if they are to articulate their choices and fight for their rights.

Charities such as **Mencap** are developing tools to help disabled young people understand their choices and communicate their preferences. For instance, Mencap's Trans-Active programme enables teachers and non-disabled students to help pupils with learning disabilities, encouraging them to learn about the options open to them when they leave school and to speak up for themselves. Disabled and non-disabled students work together to explore issues, using videos, cameras and computers to record their feelings and points of view. This should help to boost their confidence and prepare them for more formal meetings and discussions about their futures.

The charity **SpeakingUp** runs an initiative called Young People Speaking Up in five areas in England, which helps 11 to 25 year olds with disabilities, learning difficulties and mental health problems to communicate their views.

This initiative includes providing advocates to represent young people, and running self-advocacy groups in schools to build young people's confidence and social skills so that they can articulate their own decisions.

Specialist schools and colleges also aim to develop students' confidence and ability to communicate. For example, **Treloar Trust**, which works with young people who have physical disabilities, has an Independent Living Skills curriculum that covers independence training, personal development, advocacy, citizenship and careers education.

More broadly than the transition age group, **Leonard Cheshire Disability** supports Campaigns Action Groups, which are run by disabled people to tackle issues that affect them in their local communities. They are independent groups that prioritise the issues that matter to their members. Issues include improving access to shops and transport, and campaigning for dropped kerbs for wheelchairs.

Providing specialist support for professionals

Charities can also help to improve disabled young people's experience of mainstream services by providing specialist information, advice and training on transition for professionals.

Information and guidance

Charities produce information to share and showcase best practice. For instance, the **Foundation for People with Learning Disabilities (FPLD)**, with the Norah Fry Research Centre, commissioned research into transition planning and collaboration between Connexions advisory services and social services. The research focused on Somerset, an area that has been identified as having particularly good transition support. FPLD used the lessons learnt from the research to produce a guide for Connexions workers and other staff involved in transition, which discussed the particular challenges for young people with learning disabilities.⁸⁹

Some information and guidance focuses on specific types of disability. **ACT (Association for Children's Palliative Care)** has used its expertise in supporting young people with life-limiting conditions to produce a framework for health professionals involved in transition. ACT's Transition Care Pathway breaks the young person's transition down into various stages, from the initial diagnosis to the end of life, and outlines the roles of the different agencies responsible for care. It also highlights examples of best practice at each stage, and points towards other useful sources of information.⁹⁰

Charities use their expertise to provide training and consultancy, keeping professionals up to date and improving practice.

The **National Deaf Children's Society** has produced a guide for professionals in supporting deaf young people in their transition from paediatric to adult audiology services. The guide highlights good practice in terms of the timing of transition, the best ways of communicating between departments, and the importance of securing the right support in further and higher education.

Training and consultancy

Charities use their expertise to provide training and consultancy to keep professionals up to date and improve practice.

For instance, the **Transition Information Network** works with partner charities to run good practice and legal update events for professionals working on transition. Some of these events bring professionals together with disabled young people and their families.

Skill: National Bureau for Students with Disabilities also regularly undertakes training and consultancy work, from researching specific policy areas for government departments to running training for professionals who work with disabled young people.

Again, specialist charities often provide training and consultancy that is tailored to specific issues or specific types of disability. FPLD, for example, is providing consultancy to local authorities to help them develop systems to manage new self-directed funding arrangements for people with learning disabilities. This covers the introduction of individual budgets, which allow people receiving care to decide how to spend the money allocated to them by government, rather than relying on local authorities to administer it. Individual budgets and other forms of self-directed funding should give disabled people more control and flexibility over the support they receive. However, the introduction of new systems inevitably involves some logistical challenges, which the foundation is helping to address.

Some charities are also developing specialist qualifications. For instance, the **Royal National Institute of Blind People (RNIB)**, in conjunction with the University of Birmingham, offers a postgraduate qualification in Visual Impairment in Further Education. This was because, although there is a mandatory qualification for teachers of school-aged children with visual impairment (the QTVI), no equivalent existed for further education, resulting in a lack of support at a crucial time in transition.

Challenging the status quo

Charities are also helping to change the systems that affect disabled young people through:

- producing research to improve the public's understanding of the needs of disabled young people and how best to support them;

- campaigning to change public attitudes and tackle stigma; and
- influencing the development of government policy (for example, by lobbying MPs or contributing to policy consultations).

A number of disability charities and alliances—including Scope, LCD, Mencap and the Learning Disability Coalition—do all three types of activity. Some of their work focuses on transition, as we will see below, but it is an exclusive focus for very few. The role of the **Transition Information Network (TIN)** is therefore important, as it sharpens the focus on transition and gives its members a single voice and a means by which they can influence policy and practice. TIN has also carried out research. For example, in 2008 it produced a report called *TransMap*, funded by the Department for Children, Schools and Families. This highlighted examples of effective transition planning and practice and identified some of the problems that needed to be addressed.⁹¹

The fact that TIN is hosted by the **Council for Disabled Children (CDC)** gives it good links with government and allows it to feed into the Making Ourselves Heard network, also hosted at CDC. This network aims to ensure that disabled children and young people actively participate in all decisions directly affecting them, in the development of their communities, in the strategic planning of services, and in all aspects of the work of CDC.

Research

Research helps to improve understanding of the needs of disabled young people and explore how effectively these needs are being met. Research can therefore be used to raise public awareness and influence policy and the allocation of resources.

The charity **Livability**, which runs residential care homes, supported living, colleges and accessible holiday accommodation for disabled people, has produced research specific to transition: *Young, disabled and forgotten* and *Freedom to Live*.^{24,92} These reports highlight the scale of need and the issues associated with transition.

Other charities have produced research into specific aspects of transition, such as education, employment, transport or housing, as we have seen earlier in this report. Some have also carried out research into broader issues relevant to transition. For instance, the **Voluntary Organisations Disability Group (VODG)** commissioned research into the different eligibility criteria for social care in children's and adults' social services, and the impact on disabled young people during their transition to adulthood. The report, *Shadow Lands*, draws attention to the lack of

robust data on the care and support needs of disabled young people. It highlights good practice in transition planning, and makes recommendations for how provision could be improved.⁹³

The public, policy-makers, professionals in mainstream services (such as teachers, social workers and GPs) and commissioners in local authorities and PCTs tend to have limited knowledge of specific disabilities, particularly those that affect a small number of people. Specialist disability charities therefore have a vital role to play in driving research into transition for specific types of disability.

For example, the **Royal National Institute of Blind People (RNIB)** partnered with the Association of National Specialist Colleges (NATSPEC) to conduct a study looking at a group of students with visual impairments for three years after leaving their NATSPEC college. The report will be published in Autumn 2009, and will include recommendations on how to improve transition support for young people with visual impairments.⁹⁴

Research is also used to inform the development of more effective services for disabled young people going through transition. Charities have the independence and flexibility to take risks in trying new approaches. Innovative solutions can be piloted; what works and what does not work can be identified through evaluation; and the lessons learnt can be shared with the wider community (although, sadly, funding does not necessarily follow results to enable the replication of promising services).

With easy access to a large number of disabled young people, charities that run specialist schools and colleges have an ideal environment for carrying out research and trialling new ways of supporting transition. For example, **Treloar Trust** used research into the transitions of some of its students to develop its Moving On programme (see Box 2 in Chapter 1). It hopes that this programme may now be rolled-out to other parts of the country.

Challenging public perceptions of disability

Stigma can be a barrier that stands in the way of people obtaining the support they need. For instance, as discussed earlier, university students with mild and moderate disabilities sometimes avoid claiming the Disabled Student Allowance as they do not want the stigma of being labelled 'disabled'.⁹⁴

Leading disability charities are challenging popular misconceptions about disability. For example, as discussed in Chapter 5, **Leonard Cheshire Disability (LCD)** ran a Creature Discomforts campaign, which reached millions of people. The campaign generated significant comment, with over 470 pieces of editorial

coverage after its launch and an estimated 53% of the UK adult population having seen the campaign or editorial coverage relating to it. Further research found that more than 60% of those who saw the campaign were able to recall its message—to change the way they see disability.⁹⁵ Not everyone agreed with the approach the campaign took to combating stigma, but it certainly caught people's attention and provoked debate.⁹⁶

Influencing policy

Disability charities have an active history of lobbying the government for changes to policy.

TIN is the only charity with an exclusive focus on influencing policy relating to transition. It does this by taking issues that affect young people, families and professionals to government on their behalf, and by contributing to government consultations on issues such as adult social care, mental health problems and learning disabilities in the criminal justice system.

Other disability charities focus on cross-disability issues. For instance, **RADAR**, a national network of disability organisations and disabled people that represents their views and concerns to policy-makers, has run campaigns on issues such as independent living and access to work.

Social care is another focus for lobbying, as disability charities are concerned about the potential effects of increasingly stringent eligibility criteria, which rule out support for all but those with the most substantial needs. LCD aims to highlight the role of social care in helping disabled people to live independent lives, and the effect that the eligibility criteria have on those who need social care but cannot afford it themselves.

The **Learning Disability Coalition** has attempted to lobby for improvements to the social and care systems in England. For instance, it contributed to the consultation before the release of the government green paper on the future of adult social care in July 2009.⁹⁷ The coalition was openly critical of the government's proposed support structure, as it estimates that there is a £200m annual shortfall in social care funding for people with learning disabilities.^{98,99}

Scope is running a campaign called Time to Get Equal, focusing on four key areas that are relevant to transition on a broader basis: beating 'disabilism'; encouraging freedom of expression; promoting independent living; and 'making rights a reality'. It supports disabled people to campaign on the issues that matter to them, and runs an annual 'Time to get Equal Week', which brings people together to promote equal opportunities for disabled people and raise awareness of the issues they face.

Charities use their expertise to provide training and consultancy to keep professionals up to date and to improve practice.

Charities specialising in specific types of disability often have a much greater understanding than the government of the needs of people with those disabilities. As such, they are well placed to feed into policy development and, where appropriate, to put pressure on government to change relevant policies. Voicing concerns about specialist needs is particularly important for low incidence conditions or 'hidden' disabilities, which might otherwise risk being overlooked when resources are being allocated.

For example, autism charities have recently been campaigning specifically on transition. A number sit on the advisory group for the All-Party Parliamentary Group on Autism (APPGA), including The National Autistic Society (NAS), Treehouse, Autism Speaks and the Autism Research Centre.* The APPGA commissioned an inquiry into transition, which involved consultation with a variety of specialists, including charities, clinicians and local government agencies.¹⁵ The resulting report highlighted problems with current provision, drawing on recent research by charities, such as NAS's *Moving on up?* report (see Box 10). It also made recommendations to central and local government on how to improve transition support for autistic young people.



Photograph supplied by Skill: National Bureau for Students with Disabilities

Priorities and challenges

Charities have a vital contribution to make in giving disabled young people the support they need to grow up to become healthy, happy and well-adjusted adults. Charities help to fill the gaps in government services and smooth the transition from children's to adults' services. But their value goes beyond this. Charities are better placed than government agencies to take on particular roles. For instance, specialist organisations can champion the needs of young people with particular disabilities, ensuring that their voices are heard and their needs are addressed. Charities can also campaign to raise awareness of transition, provide accessible information and advice, and develop services to help disabled young people live independent, fulfilling lives.

Government is a significant funder of disability charities. But NPC believes that private funding also has an important part to play in this sector. Private funding can give charities flexibility and the opportunity to take risks—for example, by acting as a critical friend to government or by piloting new schemes.

This chapter summarises the different types of charities that funders might support, outlining the challenges they face and how these challenges might be overcome. This discussion is designed both for the interest of charities and to inform funders about the issues that they should consider when deciding how to target and structure their funding.

We then help funders to think through how to prioritise their giving and identify the most effective ways of supporting transition. The chapter has been written with funders of all shapes and sizes in mind, although certain comments are targeted specifically at private funders. Some funders may not yet have a clear view on the type of charities they wish to support. Others may already have a clear view, but may value guidance on identifying effective charities or structuring their funding. Readers should pick and choose the sections that are most relevant to their interests and needs.

The range of options

As we have seen, there is a wide variety of charities working on transition that funders might choose to support, although transition is an exclusive focus for few of them. The structure of the sector is summarised in Table 1.

Challenges for charities

In order to understand how best to support charities working on transition, funders should bear in mind the challenges that they face.

Lack of profile

Transition is not a high-profile issue, and funders who are not familiar with the disability sector may assume that it is adequately covered by statutory services. This means that fundraising can be hard work and expensive for charities.

There is also a tendency at times for funders to prefer supporting children to supporting young adults. This may be because they assume that young adults are better able to support themselves—although some young adults with learning disabilities need the same level of support as children. Funders may also feel less comfortable about supporting young people who display difficult or aggressive behaviour, although that might be related to a specific disability or a lack of care.

NPC urges funders not to shy away from the less obvious or more difficult issues.

Limitations of adult services

Charities working on transition can help to set disabled young people on the right track, but their impact will be limited if there is inadequate support for those people when they become adults. For instance, a specialist school may do its best to plan ahead for when pupils leave, but if their local authorities do not have enough places in supported housing, for example, then they may have no choice but to move back to the family home.

Collaboration is therefore crucial. Transition programmes need to work closely with other charities and statutory agencies to identify gaps in provision and lobby for improved support.

Challenges of evaluation

Charities working on transition often find it difficult to evaluate their outcomes. It can be a logistical challenge to track the paths of disabled young people after they leave a transition programme, particularly if they move to another area. The staff supporting them in adult services may lack the time or inclination to report back on their progress.

Private funding can give charities flexibility and the opportunity to take risks.

Charities working on transition can help to set disabled young people on the right track, but their impact will be limited if there is inadequate support for those people when they become adults.

Table 1: Charities working on transition

Type of Charity	Examples	Services provided
<p>National charities and coalitions representing specific conditions or disabilities</p> <p>These charities focus on a wide range of different conditions.</p>	<p>Learning disabilities: Mencap, Foundation for People with Learning Disabilities, SpeakingUp, Learning Disability Coalition.</p> <p>Autism: The National Autistic Society, Treehouse, Prior's Court.</p> <p>Down's syndrome: Down's Syndrome Association.</p> <p>Deafness: National Deaf Children's Society.</p> <p>Visual impairment: Royal National Institute of Blind People (RNIB).</p> <p>Life-limiting conditions: ACT (Association for Children's Palliative Care).</p> <p>Dyslexia: Dyslexia Action.</p>	<ul style="list-style-type: none"> • Research. • Awareness-raising and campaigning. • Lobbying for policy change. • Information, advice and guidance. • Specialist training and consultancy. • Events and specific programmes, for example, courses to develop young people's confidence and social skills and to prepare them for adult life. • Direct services (such as education, employment and housing programmes)
<p>National charities covering broader disability issues</p> <p>These charities have a wider remit and aim to support the rights of the broader disabled population and address structural issues with the sector. Some also provide direct services.</p>	<p>The Children's Society, Contact a Family, Transition Information Network, Council for Disabled Children, Skill, RADAR, Voluntary Organisations Disability Group, Disability Alliance, Leonard Cheshire Disability, Scope.</p>	<ul style="list-style-type: none"> • Information, advice and guidance (including helplines). • Training and consultancy. • Events. • Research. • Lobbying. • Direct services (such as education, employment and housing programmes).
<p>Small local charities and local branches of national charities providing direct services</p> <p>These charities run local services that support young people through transition, from coordinating transition planning to running social activities and travel training programmes.</p>	<p>Local charities across the country, such as Ealing Mencap and MacIntyre's My Way programme.</p>	<ul style="list-style-type: none"> • Independent travel training. • Supported living programmes. • Access to employment programmes. • Transition planning support. • Employment placements and advice. • Social and leisure activities.
<p>Specialist schools and colleges</p> <p>These charities may provide education for young people with a wide range of complex needs, or may focus on specific conditions, such as autism.</p>	<p>Treloar Trust and MacIntyre (for young people with a wide range of needs). Prior's Court, and Treehouse (for young people with specific conditions).</p>	<ul style="list-style-type: none"> • Individualised care. • Education and programmes to develop confidence and skills. • Social activities. • Transition planning support. • Work experience opportunities.

In addition, some outcomes, such as improvements to confidence, self-esteem and general well-being, are difficult to measure. As we saw with the cost-benefit analysis of supported employment programmes (in Chapter 2), these outcomes might be measured in terms of decreased reliance on health and social care services. So, unless health and social services measure outcomes and share data with each other and with supported

employment programmes, it is not possible to capture the full extent of their impact. And without good cost-benefit analyses of different forms of support, it is difficult for funders and charities to assess how best to allocate their resources.

All this makes it harder for charities to demonstrate their impact to funders. NPC believes that funders should support charities to improve evaluation wherever possible.

Stability of local government funding

Charities are having to adjust to changes in local government funding. The way that statutory funding is administered is being reformed to give young people and their families greater control over the services they receive. For instance, many local authorities are introducing direct payments for disabled children. This means that rather than receiving support services directly from local authorities, the parents or carers of disabled children receive the equivalent amount of money from social services so that they can commission the support their child receives themselves. Parents might choose to use the money to employ someone to support their child at a youth club, buy equipment or finance a short break. Or they may choose to commission some services themselves and allow others to be provided by social services.¹⁰⁰

Some local authorities are also introducing individual budgets for disabled children.* Individual budgets bring together all the funding that a person is entitled to from different statutory agencies.¹⁰¹ This is different from direct payments, which just cover social care funding. The individual directs how the money is spent, and the money may be managed by the family, by children's services or by another nominated service provider (such as a charity).^{† 11}

The introduction of individual budgets is still in its early stages, and disabled young people going through transition have access to them in only a quarter of local areas.¹⁷ Some of the good practice areas identified in the Transition Support Programme are focusing on the use of individual budgets with young people in transition, supporting their personal development plans for more independent living.^{‡ 103}

In both cases, when disabled young people reach adulthood, a decision needs to be made as to whether they are capable of managing direct payments or individual budgets themselves, or whether they need nominated family or carers to administer them on their behalf.[§]

The shift towards self-directed funding means that some charities supporting disabled people may now have to manage relationships with a large number of families and individuals, rather than with a single team in a local authority or primary care trust. Another implication is that charities often need to provide information and advice for disabled young people and their families on how to navigate the intricacies of the direct payments and individual budgets systems. For example, SpeakingUp has

developed an innovative board game called 'My Life My Budget', which is designed to provide a fun way for disabled young people (and other young people receiving social care services) to learn about how personal budgets work.

Funders should be aware that both charities and their beneficiaries may need support to adjust to these new funding arrangements. However, they may also provide opportunities for charities to be creative and develop new services, for example, by brokering self-directed funding.

Prioritising what to fund

Despite these challenges, charities are doing valuable work on every aspect of transition. This is not a high-profile sector, so funders can make a real difference by choosing to fund transition.

Prioritising what to fund is an important first step. The purpose of this report is not to instruct funders on how precisely to direct their money, or to recommend charities for them to support; rather, it is to discuss the options and suggest potential priorities.

Funders should think carefully about where their money can have the most impact. In particular, private funders need to think about what private, as opposed to statutory, funding can achieve in this sector. What are the advantages of private funding in terms of flexibility and scale? What services can private funders support that statutory funders cannot or will not?

NPC recommends that funders who are interested in making a significant strategic investment in transition should talk to the National Transition Support Team at the Transition Information Network, to discuss how their funding might complement the government's Transition Support Programme. Similarly, funders who are interested in focusing on a specific local area could contact the National Transition Support Team to find out about the issues identified in that area through the Self-Assessment Questionnaire (see Box 11 in Chapter 6), and discuss how particular charities fit in with local improvement plans.

Detailed plans for each local area have not been published by the Transition Support Programme, and readers should note that NPC's suggestions for funders are based on our own analysis of options for private funders. We believe that the priorities we outline in this report should support or supplement the work of the Transition Support Programme, which is primarily focused on improving the infrastructure for supporting disabled young people through transition, rather than funding direct services.

Specialist charities can champion the needs of young people with specific disabilities and groups that might otherwise be overlooked.

* 'Individual budgets' now tend to be known as 'personal budgets'.

† Some disability charities, such as MacIntyre, manage individual budgets at the request of the person needing support.¹⁰²

‡ The pilots are running from April 2009 to March 2011, with a possible extension to March 2012.

§ Direct payments can be paid to the parents or carers up until the age of 18, but at the age of 16 or 17, disabled young people can decide to hold them in their own right.^{11,104}

Despite considerable social difficulties at school ... my daughter was refused a statement [of special educational needs]. Because of this, she had no access to trained support (or any support).

The role of private funding

Private funders have more freedom to take risks than statutory funders. They may therefore like to provide 'seed-funding' so that charities can pilot new approaches to supporting disabled young people. If pilot projects are carefully evaluated, they can help to establish what works and what does not. This knowledge may then be used to develop models of good practice that can be replicated elsewhere. Once results are proven, statutory agencies may take over the funding, depending on the type of project—although this is by no means guaranteed, particularly in the current climate of spending cuts. It is therefore important that funders and charities work together to plan how projects can become sustainable after the original seed-funding comes to an end.

NPC also emphasises that private funding should not just be focused on innovation. Charities often find it most difficult to fundraise for core costs and continuation funding. It is extremely valuable to provide unrestricted funding that improves a charity's stability and enables it to develop its capacity. Funders might look at a charity's central office needs. For example, would the charity benefit from buying or developing a database that would allow it to measure its results more systematically? Or would the recruitment of another manager take the pressure off the chief executive and free him or her up to focus on strategy, fundraising and networking?

Again, private funders may have more flexibility to cover these sorts of capacity-building costs than most statutory funders.

Priorities for funders

NPC's research has identified five areas where private funding may be particularly valuable.

Supporting specialist transition services

Services that bridge the transition from school or college to adult life can equip disabled young people with the skills they need to live more independently. These services include residential transition programmes that focus on preparing young people for adult life, programmes helping disabled people to live independently and become part of their local community, and programmes that support them to find suitable work and training opportunities.

Championing low-incidence and acquired disabilities

Low-incidence and acquired disabilities often suffer from a low profile. These disabilities may not show up in significant numbers in local populations, meaning that individuals' needs may be overlooked when statutory agencies allocate funding. Specialist charities can ensure that these disabilities are recognised and people's needs are understood and addressed.

More broadly, non-specialist commissioners and mainstream services may lack knowledge about specific disabilities. Charities specialising in particular types of disability can raise awareness and develop tailored services.

Supporting the overlooked

Charities have an important role to play in supporting young people who fall through the gaps between services. For instance, people with 'hidden' disabilities (such as high-functioning autism, mild to moderate learning disabilities and deafness) are at risk of being overlooked if their disability is not identified or if they do not reach the threshold for support from adult social care.

A recent report also discussed concerns that 'higher-functioning' young people with autism, such as those with Asperger syndrome, may be at a greater disadvantage because they are less likely to have received sufficient support from an early age. For example, they may not have had a statement of special educational needs, which makes them eligible for extra support at school. One parent commented:

*'Despite considerable social difficulties at school (which resulted in school phobia), my daughter was refused a statement. Because of this, she had no access to trained support (or any support). She was, and still is, not eligible for a raft of services which those with a statement or learning difficulty have access to as their right, like independent living skills training, anger management, money management and budgeting, supported housing, specialist housing options, supported employment, Direct Payments, social care, befriending schemes, specialist social activities and more.'*¹¹⁵

Fundraising for 'hidden' disabilities is also difficult as some funders are inclined to support issues where the need is more apparent, as it is with some physical disabilities.

Building the skills of disabled young people and their families

Disabled young people and their families often lack the knowledge and confidence to fight for their rights and secure the support they need. Charities can help by developing their self-esteem and communication skills, and providing them with the guidance they need to navigate the system themselves and make their case to funders and service providers.

Changing attitudes and challenging stigma

Social attitudes and an unaccommodating physical environment can be as disabling as physical and mental impairments. Charities do valuable work in campaigning to change attitudes and improve the accessibility of public facilities, such as GPs surgeries, colleges and cinemas, so that disabled young people have a better chance of taking part in everyday activities.

Identifying effective charities

This report has outlined a range of charities doing important work to support disabled young people through the transition to adulthood. However, it is not designed to recommend effective charities to funders: NPC has not carried out detailed charity analysis for this project.

Funders who are interested in supporting transition can commission NPC to carry out detailed charity analyses of specific charities. This can benefit funders, by informing their investments, and also benefit charities, by helping them to identify strengths, weaknesses and areas for development. Alternatively, funders might like to assess the effectiveness of specific charities themselves before funding them.

Details of NPC's charity analysis methodology can be found on our website.* In a nutshell, NPC believes that effective charities: focus on activities that achieve a real difference; use evidence of results to improve performance; optimise the use of resources; are ambitious to solve problems rather than simply perpetuating their own existence; and have good leadership.

When it comes to assessing particular types of charities, funders might find it helpful to look for specific features. A few suggestions are outlined in Table 2, although many charities discussed in this report cut across the three categories of charity listed in the table.

Structuring your funding

Once funders have identified charities that they want to support, they need to think through the terms of the grants or contracts they are making. NPC believes that in effective funding arrangements:

- **The scale of funding is appropriate** for the chosen charity. Funding that is too small can prevent a charity from recovering its full costs. It may mean that management has to spend more time and resources on fundraising or that a charity can only recruit a part-time worker instead of a full-time one. Grants or contracts that are too large can also have a negative impact if they cause a charity to grow in a way that is too rapid to be sustainable.
- **The length of funding is appropriate.** Long-term funding gives charities stability, eases the pressure and costs of fundraising, and allows space for strategic thinking and planning. This is particularly important in helping charities to weather a recession. If funding is too short term, the charity faces greater uncertainty, contributing to low morale and high staff turnover as staff worry about their job security. It can also mean that a charity does not have time to pilot projects properly and prove their effectiveness to ensure further funding. Smaller and shorter grants also increase the administration costs for charities and funders.
- **Funding does not have unnecessary restrictions.** Funders have a choice between giving unrestricted or restricted funding to charities.[§] NPC believes that funders should try to give unrestricted funding as often as they can. It supports charities to build their core capacity and evaluate their results, and gives them flexibility to be responsive and innovative. It also encourages a more open relationship between funders and charities. Where this is not a feasible option, funders should consider making the restrictions as flexible as possible.[†]
- **Reporting is proportionate** to the size of the grant and the size of the charities. Reporting back to funders is an important way of monitoring charities' results. However, since reporting costs money and time that could be spent on beneficiaries, it is important that it is proportionate, that the information is useful and used, and that it does not place too great a burden on the charity. NPC believes that funders should consider allocating an appropriate proportion of their grants to cover the costs of monitoring and reporting.

* A summary of NPC's charity analysis methodology is available at www.philanthropycapital.org/downloads/pdf/ANA_Charity_analysis_methodology.pdf.

[§] Funders may have to give restricted funding if: there is a mismatch between funder and grantee missions; unrestricted funding could distort the charity's accounts; there are particular circumstances that make the funder sensitive to reputational risk; the funder is using restrictions to influence the grantee.

[†] For many statutory agencies, contracts have replaced grants as the main mechanism for funding charities. Contracts tend to be tied to specific outcomes, so are not unrestricted.

Table 2: What to look for in different types of charities that support transition

Charities that provide services directly	Charities representing specific disabilities	Campaigning charities
<p>Evidence of demand, and services that address the needs of local disabled people.</p> <p>Good links with relevant statutory agencies (eg, schools, colleges, hospitals, GPs, social services, commissioners) and appropriate referral systems so that young people can be directed to other services when the charity is unable to support them.</p> <p>An appropriate degree of user participation (eg, involving disabled young people in reviewing and developing services) and evidence that the charity responds to feedback and results.</p> <p>Appropriate procedures for safeguarding young people’s well-being (eg, Criminal Records Bureau checks).</p>	<p>A membership structure or clear mandate for representing people with a particular condition or disability.</p> <p>Effective mechanisms for listening to and representing the interests of the organisations and individuals that they speak for, incorporating these views in the development of services.</p> <p>Strong links with appropriate specialists in education, health and social care.</p> <p>A clear strategy for championing the needs of the organisations and people represented through appropriate activities (eg, research, campaigning, lobbying, training and consultancy).</p> <p>A collaborative approach to working with other organisations involved in supporting people with that condition, both statutory and charitable, mainstream and specialist.*</p>	<p>A convincing theory of change, supported by a plan to deliver results.</p> <p>Clear objectives and milestones against which performance can be measured.</p> <p>Legitimacy, ie, clarity over who the campaign speaks for and with what mandate.</p> <p>A strong evidence base, to ensure that campaigns have the right objectives and to enable them to make a persuasive case to target audiences.</p> <p>Targeted messages, with the audience for particular campaigns being well-defined and messages being tailored accordingly.</p> <p>A collaborative approach, as charities may have more impact if they work in partnership, as well as reducing duplication, increasing legitimacy and providing synergies.†</p>

* For instance, a children’s charity focusing on a specific disability should have a good working relationship with a charity that represents adults with that disability, as well as with general disability and children’s charities.

† The Every Disabled Child Matters campaign is a good example of an effective partnership by four charities: Contact a Family, the Council for Disabled Children, Mencap and the Special Educational Consortium. The campaign successfully lobbied to secure a review on disabled children’s services within the 2007 Comprehensive Spending Review (*Aiming High for Disabled Children*), which led to the allocation of £430m in new funding to improve services.

Some funders may also consider using different funding mechanisms, such as hybrid grant and loan-based funding for new projects. These may encourage new projects to plan from the start to become self-sustaining. However, this approach can be complicated and funders should consider carefully whether it is appropriate for the specific project. NPC’s consulting team can help funders to think this through.

For further information about effective funding and reporting, readers can refer to NPC’s reports, *Granting Success* and *Turning the Tables*.^{105,106}

Final thoughts

The government is investing millions of pounds in improving the well-being of disabled children. But this money will go down the drain if, at the age of 16 or 18, these young people suddenly find themselves without the support they need to find their way in the adult world. By funding charities that champion the needs of disabled young people, bridge the gap between services, and set them on the right track, funders can help disabled people to overcome the challenges that prevent them from living their lives to the full.



Photograph supplied by Scope

Appendices

Appendix 1: Numbers of young people affected by disabilities

One in seventeen young people in the UK, aged between 14 and 25, is estimated to have a disability.⁸ This equates to almost 600,000 young people.

Unfortunately, breaking down this number by type of disability is difficult, for at least three reasons. Firstly, although there are some major categories of disability, which include a large number of young people, there are also thousands of inherited disorders and non-inherited medical conditions that affect a tiny proportion of the population.¹⁰⁷ Secondly, many prevalence rates are unknown, even for some of the main categories of disability. For instance, NPC was not able to find an estimate for physical impairments. Thirdly, there is significant overlap between the different types of disability. For example, it is estimated that more than half of people with autism also have a learning disability.¹⁰⁸

Estimates for some of the major categories of disability can be found in Table 3. This table estimates the number of young people aged between 14 and 25 who have each type of disability, by applying the prevalence rate to the most recent population estimate for the age group.*

Table 3: Prevalence of different types of disability affecting people aged 14 to 25

Type of disability	Estimated prevalence	Definition
Learning disabilities	244,700 young people, or 2.5% of the population. ⁴²	<p>'Learning disability' is an umbrella term for a spectrum of intellectual disabilities, which either develop before birth or are the result of a brain injury or childhood illness. It is common for learning disabilities to accompany other impairments. For example, more than half of children with autistic spectrum disorder also have a learning disability.¹⁰⁸</p> <p>Learning disabilities vary in severity, and can be categorised as mild, moderate or severe. While those on the mild end of the spectrum require little support to lead an independent life, those on the severe end of the spectrum may require one-to-one care on a full-time basis. This estimate tries to take into account those, primarily with mild learning disabilities, who do not use specialist learning disability services.</p> <p>Although IQ is often used to categorise learning disabilities, it does not take into account how well the individual can cope on a day-to-day basis, so it is not necessarily a good indicator of the severity of the learning disability.</p>

* There are 9,788,700 young people aged between 14 and 25 in the UK, according to mid-2008 Office for National Statistics estimates.

Type of disability	Estimated prevalence	Definition
<p>Autistic spectrum disorders</p>	<p>97,900 young people, or 1% of the population.¹⁰⁸</p>	<p>The ‘triad of impairments’ identifies the three areas of behaviour where people with autism have difficulties. They are:</p> <ul style="list-style-type: none"> • communication, such as inability to speak, monotonous intonation and a literal interpretation of words; • social interaction, including an inability to read facial expressions or body language, poor eye contact, and difficulty understanding basic social rules; and • mental flexibility and creativity, such as lack of imagination, inability to understand other people’s emotions and repetitive behaviours. <p>Autism is a spectrum condition, so although everyone with autism is affected at a basic level in all three areas, the severity of impairment varies from person to person. As a result, there are various different conditions that fall under the autistic spectrum disorder umbrella. For example:</p> <ul style="list-style-type: none"> • Asperger syndrome is characterised by problems with social interaction and repetitive interests and activities. There is no general language delay, but there may be difficulties understanding subtleties used in conversation, such as irony and humour. Most individuals with Asperger syndrome have average or above average intelligence. • Rett syndrome is diagnosed primarily in females. After a period of normal development, symptoms become apparent between the age of six and eighteen months. They include a loss of abilities, such as walking and speech, and the development of repetitive behaviour. Rett syndrome affects one out of 10,000 to 15,000 people. <p>Although the accepted prevalence of autism amongst children is 1%,¹⁰⁹ a recent study suggests that its prevalence may be closer to 2.5%.¹¹⁰ A detailed assessment of the prevalence of autism in the UK can be found in NPC’s report <i>A life less ordinary</i>.⁵</p>
<p>Life-limiting and life-threatening conditions</p>	<p>Between 1,200 and 1,600 young people, or 0.012% to 0.016% of the population.⁹⁰</p>	<p>Most young people who will die prematurely as a result of their illness fall into the following groups:</p> <ul style="list-style-type: none"> • Young people with life-threatening conditions, such as cancer or irreversible organ failure. Curative treatments may be available but may fail. • Young people for whom premature death is probable or inevitable, due to conditions such as cystic fibrosis, Duchenne muscular dystrophy and HIV/AIDS. Periods of intensive treatment prolong life. • Young people with progressive conditions that have no curative treatment options, such as Batten disease and mucopolysaccharidosis. Treatment is entirely palliative and commonly extends over many years. • Young people with severe neurological disability, such as cerebral palsy, which may lead to increased susceptibility to health complications. Deterioration may be unpredictable and sudden.^{90,111}

Type of disability	Estimated prevalence	Definition
Cerebral palsy	19,600 young people, or 0.2% of the population. ⁸²	<p>Cerebral palsy (CP) has three main types:¹¹²</p> <ul style="list-style-type: none"> • Spastic CP causes the muscles to become stiff and weak, with a resultant affect in the individual's ability to control movement. • Athetoid CP leads to lack of postural control and causes unwanted movements. • Ataxic CP leads to problems with balance. The individual may also have shaky hands and difficulty speaking fluently. <p>CP develops as a result of improper brain development, either before birth or in early childhood. It varies in its severity, from being relatively mild to completely incapacitating.</p>
Deafness	<p>All types of deafness: 646,000 young people, or 6.6% of the population.¹¹³</p> <p>Moderate, severe or profound deafness: 195,800 young people, or 2.0% of the population.¹¹³</p>	<p>Deafness can be broken down into the following categories:¹¹³</p> <ul style="list-style-type: none"> • Mild deafness—individuals have difficulty following speech in noisy situations. The quietest sounds they can hear in their better ear average between 25 and 39 decibels. • Moderate deafness—individuals have difficulty following speech without a hearing aid. The quietest sounds they can hear in their better ear average between 40 and 69 decibels. • Severe deafness—individuals rely mostly on lip-reading or sign language, even with a hearing aid. The quietest sounds they can hear in their better ear average between 70 and 94 decibels. • Profound deafness—individuals communicate by lip-reading or sign language. The quietest sounds they can hear in their better ear average 95 decibels or more.
Visual impairment	<p>Registered blind: 4,100 young people, or 0.04% of the population.¹¹⁴</p> <p>Registered as partially sighted: 5,300 young people, or 0.05% of the population.¹¹⁴</p>	<p>In order to be registered blind in England, an individual has to receive a Certificate of Vision Impairment from a consultant in Ophthalmology, who assesses a combination of visual acuity and field of vision.</p> <p>Those with good visual acuity have to have lost a large amount of their visual field to be registered as severely sight impaired (blind) or sight impaired (partially blind).</p> <p>Those who have lost all their visual field will need to have very poor visual acuity to be registered as blind or partially blind.¹¹⁵</p>

Appendix 2: Cost-benefit analysis of a supported employment scheme

The steps taken in the cost-benefit analysis given in Chapter 2 (Box 6) are as follows:

1. This is a cost-benefit analysis of supported employment schemes for people with learning disabilities. One of the best evaluations of a supported employment scheme we came across in our research was an evaluation of Prospects, a scheme run by The National Autistic Society. Because the study is an eight-year, rigorous academic evaluation, we use some of its data. Note that Prospects is a scheme for people with autism and Asperger syndrome, which overlap with the category of 'learning disabilities', but are not equivalent.

We calculate that for every 100 clients, a scheme such as Prospects is successful in finding jobs for 32 people. We assume that without the scheme, the probability of employment for someone with learning disabilities is 0.17. This is based on an estimated 17% of all adults with learning disabilities being in paid work.*⁴²

* Some sources, including the government's Valuing People strategy, have used a lower estimate for the employment rate of people with learning disabilities. This is almost certainly because the government's official figures relate to people with learning disabilities who use learning disability services. The survey that NPC has used also sought to include people with learning disabilities who may not be using learning disability services; this probably includes people who are more able and, consequently, more likely to be in employment.⁴² Readers should also note that this is an overall figure. The proportion of people with moderate, severe and profound and multiple learning disabilities in employment is much lower. Research has suggested that 28% of people with mild/moderate learning disabilities have some form of paid employment, compared to 10% of people with severe learning disabilities, and 0% of people with profound and multiple learning disabilities.⁴²

A recent report by the National Audit Office (NAO) relies on data from the Prospects evaluation to develop an economic model.¹¹⁶ It uses a ratio of 1.9:1 for the probability of employment with the scheme compared to the probability of employment without the scheme.

So, if the probability of employment without the scheme is 0.17, the probability of employment with the scheme is 1.9×0.17 , which is 0.32.

2. We estimate that this outcome comes at a cost of £4,760 per successful job placement. This is again based on the parameter given in the NAO report, which inflates the cost per successful job placement used in the Prospects evaluation (£4,281) to 2007/2008 prices. The total cost of £152,320 is calculated by simply multiplying £4,760 by 32—the number of people estimated to have found a job.
3. We argue that our estimate of the ‘counterfactual’—what would have happened anyway without the scheme—is conservative based on anecdotal evidence that for many people participating in supported employment schemes, employment would not be possible without them. However, we use the overall employment rate for people with learning disabilities so as not to overestimate the impact of such schemes, and to quantify in some way the reality that participants will have found jobs for reasons other than taking part in the scheme.
4. The impact of the scheme is calculated by simply subtracting this estimate of what would have happened anyway (17) from the number of people estimated to have found a job (32).
5. We estimate that a person with learning disabilities earns, on average, a yearly wage of £6,998. This is based on data from another study, which evaluates a supported employment scheme in North Lanarkshire. Those people with learning disabilities who find employment through this scheme earn an average weekly wage of £134.59. This is multiplied by 52 to calculate an annual figure.¹¹⁷
6. We calculate that the total benefit is £104,980, taking into consideration only wages earned. This figure is arrived at by multiplying the average annual wage by the number of people in employment who would not otherwise have found a job (15).
7. The cost-benefit ratio of 0.69 is calculated by dividing total benefit (£104,980) by total cost (£152,320).
8. We calculate that approximately one fifth of this benefit accrues to the state and the rest to the individual. This is based on data from the study evaluating the supported employment scheme in North Lanarkshire

	Earnings	Tax and National Insurance	Welfare benefits	Total income
Before employment	£0.00	£0.00	£139.51	£139.51
After employment	£129.60	£9.80	£122.65	£242.45
Difference	£129.60	£9.80	-£16.86	£102.94

The benefit to the state is increased tax (and National Insurance) take and reduced welfare benefits, $£9.80 + £16.86 = £26.66$. This as a proportion of earnings (£129.60) is 0.21, or approximately one fifth. The benefit to the individual is increased total income, £102.94. This as a proportion of earnings (£129.60) is 0.79, or approximately four fifths.

9. The breakeven assumes that the cost of the scheme falls to zero by the second year, which is a strong assumption but one that we make given the lack of data on how much it costs to provide ongoing support after a job has been found. It also assumes all 15 people remain in employment.

We calculate that total benefits are equal to total costs (£152,320) after 1.14 years. This calculation applies real wage growth of 3% and discounts to current prices after the first year. The discount rate used is that recommended by the Treasury Green Book of 3.5%.

Appendix 3: Charity profiles

ACT (Association for Children's Palliative Care) works across the UK to help life-limited or life-threatened children and young people and their families. It helps them to achieve a better quality of life, and promotes excellence and equity in the provision of care. It aims to do this in three ways. First, it campaigns for improved provision of children's palliative care services. Second, it works with professionals to develop and disseminate the evidence base for what works best, and support the delivery of the best care possible. Third, it informs and empowers families to have a voice in the development of the services that affect them. Resources that ACT has developed include the Transition Care Pathway and a guide for families and professionals on supporting the developing sexuality of young people with life-limiting conditions. ACT's website is www.act.org.uk.

The Children's Society is a national charity with a mission to improve childhood for all children in the UK. Its work includes a network of community-based projects to support vulnerable children, mentoring schemes, work in schools and children's centres, and research and campaigning. Disabled children and young people are one of its priority groups. The charity aims to ensure that all disabled children—including those who communicate without speech—have someone to listen to their needs, understand them, speak up on their behalf and ensure they are heard. The Children's Society's website is www.childrenssociety.org.uk.

Contact a Family provides support, advice and information for families with disabled children, no matter what their condition or disability, through its local, regional, and national offices. Its services include a helpline, publications, medical information, one-to-one support (through its family support service, volunteer parent representatives, and local offices), and campaigning to improve the circumstances of families with disabled children and their right to fully participate in society. Contact a Family's report, *Preparing for adult life and transition*, provides advice for parents and professionals in how best to plan for a disabled young person's transition to adulthood. Contact a Family's website is www.cafamily.org.uk.

Council for Disabled Children (CDC) is the umbrella body for the disabled children sector in England, with links to the other UK nations. It aims to influence national policy affecting children who are disabled or have special educational needs, and their families. It also promotes the active participation of disabled children and young people, to make sure their voices are heard. CDC is a semi-independent council of the National Children's Bureau. It supports a number of networks and consortium organisations, including the Transition Information Network and the Special Educational Consortium. The role of CDC in supporting disabled children is highlighted in NPC's *Ordinary lives* report.²⁰ CDC's website is www.ncb.org.uk.

Dimensions is one of the UK's largest providers of support services for people with learning difficulties and/or autism. It provides: support packages for people living in their own homes; support for people living in shared housing; registered residential care; support to help people to find and maintain accommodation; short breaks; and support to help people access employment and leisure opportunities. It also runs a transition support service for 14 to 25 year olds with learning difficulties and autism. The service is currently supporting over 200 young people and their families. Dimensions' website is www.dimensions-uk.org.

Disability Alliance UK aims to break the link between poverty and disability. It has around 400 members, ranging from small self-help groups to large national charities. Disability Alliance UK publishes *The Disability Rights Handbook*, an annual publication with a print-run of 26,000, which includes information on welfare benefits, social and residential care, and other issues relevant to disabled people. It also provides a range of other guides and resources on its website, runs a helpline for member organisations, and lobbies government on the effects of new and existing disability benefits. Disability Alliance UK's website is www.disabilityalliance.org.

Down's Syndrome Association is a national membership organisation for people with Down's syndrome, their families and their carers. It has over 20,000 members and its aims include: to provide information and support for people with Down's syndrome, their families and carers, and the professionals who support them; to improve knowledge of the condition; and to champion the rights of people with Down's syndrome. The Association's website is www.downs-syndrome.org.uk.

Dyslexia Action is a national charity that provides services and support for people with dyslexia and specific learning difficulties through 26 centres and 160 teaching locations around the UK. During 2008/2009, Dyslexia Action supported over 30,000 children, young people and adults through assessments, teaching, training, projects and partnerships. It also undertakes research and is committed to improving policy and practice so that dyslexia is no longer a barrier to learning, employment or personal fulfilment. Dyslexia Action's website is www.dyslexiaaction.org.uk.

First Step Trust provides work, training and employment opportunities for people excluded from ordinary working life because of mental health problems or other disabilities or disadvantages. It runs 16 projects in England, in and around Manchester, Sheffield, Liverpool, and London. These range from a garage services project to projects focused on gardening, painting and decorating, catering and office work. First Step Trust's website is www.firststeptrust.org.uk.

Housing Options is a housing service that provides practical support, advice and information to help people with learning disabilities to find housing arrangements that are appropriate for their needs, including independent supported living and home ownership. It also offers a consultancy service to individuals, parents and any organisation involved in providing a service to people with learning disabilities, and can be a gateway to accessing different types of social housing. Housing Options' website is www.housingoptions.org.uk.

Foundation for People with Learning Disabilities (FPLD) promotes the rights, quality of life and opportunities of people with learning disabilities, their families, and the people who support them. It carries out research, publishes information and advice, campaigns to raise awareness and influence policy, supports service development, and provides consultancy and training for parent groups, local authorities, the NHS and other organisations on how best to support people with learning disabilities. FPLD operates as a directorate within the Mental Health Foundation. FPLD's website is www.learningdisabilities.org.uk.

Learning Disability Coalition (LDC) is a coalition of 15 charities that support people with learning disabilities. It aims to: provide a unified voice to government and other key stakeholders; gather evidence on cuts to local services; raise awareness of the financial pressures on services for people with learning disabilities; campaign for better funding; and achieve an evidence-based assessment of the long-term resource requirements for people with learning disabilities. LDC's website is www.learningdisabilitycoalition.org.uk.

Leonard Cheshire Disability (LCD) aims to change attitudes to disability and to serve disabled people around the world. It is the largest charitable provider of care and support services for disabled people in the UK. Its services include care homes, supported living, domiciliary support, day services, resource centres, rehabilitation, respite care, personal support, and training and assistance for those looking for work. It also carries out research and campaigns to combat stigma and promote the civil and human rights of people with disabilities. LCD's website is www.lcdisability.org.

Livability runs supported living residential care homes, a school and further education colleges, and holiday accommodation for people with physical disabilities and learning difficulties in the UK. Its emphasis is on creating choices for disabled people rather than making choices for them. Livability also provides resources, advice and support to community organisations working with disabled people and has undertaken research on specific issues, including transition. The charity was the product of a merger between John Grooms and the Shaftesbury Society in 2007, when it also entered into a partnership with John Grooms Housing Association. Today they are known as Livability and Livability Housing. Livability's website is www.livability.org.uk.

MacIntyre is a national charity that provides support for people with learning disabilities through over 120 services across the UK. Its services include residential special schools and a further education college, registered care homes, supported living schemes, lifelong learning services, and specialist training for health and social care professionals. MacIntyre's My Way project has a particular focus on transition. MacIntyre's website is www.macintyrecharity.org.

Mencap is a national charity that supports people with learning disabilities, their families and carers. It aims to change laws and services, challenge prejudice, and directly support people to live their lives as they choose. Its services include supporting people into college or employment; helping them to live independently; advising them on issues such as respite care, individual budgets or transport services; running residential and day-care services and leisure groups; and lobbying government. Mencap also has affiliated local groups that provide localised services. The role of Mencap in supporting disabled children is highlighted in NPC's report *Ordinary lives*.²⁰ Mencap's website is www.mencap.org.uk.

The National Autistic Society (NAS) champions the rights and interests of all people with autism, and aims to provide individuals with autism and their families with access to support and services that will make a positive difference to their lives. It has over 18,000 members and 80 branches and its services include information, advice, advocacy, training and support for individuals and their families; information and training for health, education and other professionals; specialist residential, supported living, outreach and day services for adults; specialist schools and education outreach services for children; out-of-school services for children and young people; and employment training and support and social programmes for adults with autism. The NAS also runs a helpline, commissions research, lobbies for policy change and service improvements, and hosts the All-Party Parliamentary Group on Autism. Its work is discussed in more detail in NPC's report on autism: *A life less ordinary*.⁵ NAS's website is www.nas.org.uk.

National Deaf Children's Society (NDCS) is a national charity dedicated to breaking down the barriers to the achievements of deaf children and young people. It represents families, parents and carers, providing emotional and practical support through its helpline, its network of trained support workers, its publications and websites, and a range of other support services. As the leading provider of impartial information and individual advocacy on every aspect of childhood deafness, NDCS advises on issues such as welfare rights and benefit claims, education choices, health, and audiology and technology. It also campaigns for improvements in services for families with deaf children, working with central and local government, health authorities, education professionals, social services, manufacturers and voluntary organisations. NDCS's website is www.ndcs.org.uk.

Out & About is a charity working in the east of England that supports leisure providers to meet the needs of disabled children and become more inclusive. There are a number of ways in which it does this, from providing training and advice to providing volunteers who can support disabled children until they are included in their chosen leisure activity. Out & About's website is www.oaa.co.uk.

Outsiders runs a social and peer support network of disabled people (Outsiders Club), which provides members with opportunities to meet people, gain confidence, make new friends, and perhaps find a partner. In addition, Outsiders has a Sex and Disability Helpline and runs SHADA, its Sexual Health and Disability Alliance, which consists of 100 professionals who are involved in advising disabled people about their sexual well-being. It has also set up several groups, including a group for disabled women with sexual problems, and a network for lesbian, gay, bisexual and transgendered disabled people. Outsiders' website is www.outsiders.org.uk.

Prior's Court Foundation is a charity based in Berkshire that is dedicated to maintaining Prior's Court School, an independent, specialist school for 5 to 19 year olds with autism and severe and complex learning difficulties, as a centre of excellence. Building on the expertise and experience within the school, the Prior's Court Training & Development Centre offers a range of specialist, autism-specific training courses for its staff and parents, as well as conferences and an autism course for professionals that is accredited by Cambridge University. Its work is discussed in more detail in NPC's report on autism: *A life less ordinary*.⁵ The Foundation's website is www.priorscourt.org.uk.

RADAR (Royal Association for Disability and Rehabilitation) is a national network of disability organisations and disabled people, which currently has a membership of over 800. It represents its members' opinions and concerns to policy-makers and legislators, and runs its own campaigns to promote equality for all disabled people. RADAR's website is www.radar.org.uk.

RNIB (Royal National Institute of Blind people) is a national membership charity that represents and supports blind and partially-sighted people. It offers information, advice and support for people affected by sight problems, and campaigns to eliminate avoidable sight loss and support research into the causes and latest treatments of eye conditions. RNIB's website is www.rnib.org.uk.

Scope is a national charity whose vision is of a world in which disabled people have the same opportunities to fulfil their life ambitions as non-disabled people. It provides information, support, and a range of services for disabled people, particularly those with complex needs, across England and Wales. It focuses on four main areas: early years, education, independent living and work. It also provides local support services that respond to the needs identified by disabled people in their communities. In addition, Scope is working with disabled people, their families, policy-makers, researchers and professionals to advance the human and civil rights of disabled people through its Time to Get Equal campaign. Scope's website is www.scope.org.uk.

Sense is a national membership charity that supports and campaigns for children and adults who are deafblind. It provides expert advice and information and specialist services to deafblind people, their families, carers and the professionals who work with them. It also supports people who have sensory impairments with additional disabilities. Sense's website is www.sense.org.uk.

Skill: National Bureau for Students with Disabilities is a national charity promoting opportunities for young people and adults with any kind of impairment in post-16 education, training, volunteering, and employment. It operates an information and advice service, informs and influences policy-makers to improve legal rights and support for disabled people in post-16 education and training, and disseminates good practice through publications, conferences, and consultancy and staff training for colleges, universities, and other organisations. Skill's website is www.skill.org.uk.

SpeakingUp provides advocacy services, self-advocacy projects and resources for people with learning difficulties, mental health issues and physical disabilities. Its focus is on helping organisations to understand the needs and views of disabled people, and enabling disabled people to find their voice and speak up for themselves. Most of its projects started in Cambridgeshire, but it is setting up new projects in the Barnsley, Nottingham and Lincolnshire areas. SpeakingUp's website is www.speakingup.org.

Transition Information Network (TIN) is an alliance of organisations and individuals who are working together to improve the experience of disabled young people's transition to adulthood. TIN is hosted by CDC and its membership includes 24 disability organisations. It provides information and good practice standards for disabled young people, families and professionals through newsletters, a magazine and seminars. TIN's website is www.transitioninfonetwork.org.uk.

Treehouse is a national charity focusing on autism education. It runs a school in north London for children and young people with autism. In addition, it undertakes research, policy and parliamentary work to ensure that autism is a national priority, supports parents to campaign locally, and offers training and consultancy on autism education. Treehouse is discussed in greater detail in NPC's report on autism: *A life less ordinary*.⁵ Treehouse's website is www.treehouse.org.uk.

Treloar Trust provides specialist education, care, therapy, medical help and independence training to young people with physical disabilities from across the UK. It runs a non-maintained special school for 7 to 16 year olds, a specialist college for disabled students aged 16 and over, and Moving On, a project that aims to help disabled people aged 18 to 65 to achieve short-term goals such as finding a local social activity or investigating housing options. It is also developing a new service called Treloar's Direct, which will provide a bespoke service to young people with learning difficulties and physical disabilities via a mobile facility. Treloar's website is www.treloar.org.uk.

Voluntary Organisations Disability Group (VODG) is an umbrella organisation made up of about 40 national charities that provide social care support to disabled people. VODG carries out research, works to influence national policy relating to issues that affect its members' ability to provide high-quality services, and keeps members up-to-date with changes in regulation. VODG's website is www.vodg.org.uk.

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References

- 1 Mencap press release *Valuing Employment Now: New employment strategy for people with a learning disability*. www.mencap.org.uk/page.asp?id=10551.
- 2 Directgov website, www.direct.gov.uk/en/DisabledPeople/RightsAndObligations/DisabilityRights/DG_4001069 [accessed on 27 May 2009].
- 3 Office of Public Sector Information *Learning and Skills Act (2000)*. www.uk-legislation.hmso.gov.uk/acts/acts2000/ukpga_20000021_en_1.
- 4 The Royal College of Psychiatrists website, www.rcpsych.ac.uk/mentalhealthinfoforall/mentalhealthandgrowingup/11learningdifficulties.aspx [accessed on 23 September 2009].
- 5 Fradd, A. and Joy, I. (2007) *A life less ordinary. People with autism: A guide for donors and funders*. New Philanthropy Capital.
- 6 Volkmar, F.R. and Nelson, D.S. (1990) *Seizure disorders in autism*. *Journal of the American Academy of Child and Adolescent Psychiatry*, 29: p. 127–129.
- 7 Horvath, K., Papadimitriou, J.C., Rabsztyl, A., Drachenberg, C. and Tildon, J.T. (1999) *Gastrointestinal abnormalities in children with autistic disorder*. *Journal of Paediatrics*, 135: p. 559–563.
- 8 Department for Work and Pensions (2009) *Family Resources Survey, United Kingdom 2007-08*.
- 9 Audit Commission (2002) *Special Educational Needs: A mainstream issue*.
- 10 IPPR (2007) *Disability 2020: opportunities for the full and equal citizenship of disabled people in Britain in 2020*.
- 11 Department for Children, Schools and Families and Department of Health (2007) *A transition guide for all services: key information for professionals about the transition process for disabled young people*.
- 12 Office of National Statistics (2004) *Living in Britain: results from the 2002 General Household Survey*.
- 13 Commission for Social Care Inspection (2007) *Growing up matters: better transition planning for young people with complex needs*.
- 14 Department for Children, Schools and Families and National Statistics (2009) *Youth Cohort Study & Longitudinal Study of Young People in England: The Activities and Experiences of 17 year olds: England 2008*.
- 15 Allard, A. (2009) *Transition to adulthood: Inquiry into transition to adulthood for young people with autism*. The All-Party Parliamentary Group on Autism.
- 16 Rosenblatt, M. (2008) *I Exist: The message from adults with autism in England*. National Autistic Society.
- 17 National Transition Support Team (2009) *The Self Assessment Questionnaire: update on returns*.
- 18 National Autistic Society (2007) *Moving on up? Negotiating the transition to adulthood for young people with autism*.
- 19 Learning Disability Coalition (2008) *The Case for Real Change: Submission to the consultation on 'The Case for Change: why England needs a new care and support system'*.
- 20 Langerman, C. and Worrall, E. (2005) *Ordinary lives. Disabled children and their families: A guide for donors and funders*. New Philanthropy Capital.
- 21 Joy, I. (2005) *Valuing short lives. Children with terminal conditions and their families: A guide for donors and funders*. New Philanthropy Capital.
- 22 Joy, I., van Poortvliet, M. and Yeowart, C. (2008) *Heads up. Children and young people's mental health: A guide for donors and charities*. New Philanthropy Capital.
- 23 Skill: National Bureau for Students with Disabilities (2009) *Education and Skills Act 2008: What does it mean for transition?* National Transition Support Team.
- 24 Christophides, R. (2006) *Young, disabled and forgotten: Report of the John Grooms Inquiry into the needs of young disabled people (summary findings and recommendations)*. Livability.
- 25 Skill: National Bureau for Students with Disabilities (2009) *Consultation response on Assessments relating to learning difficulties: Guidance to Local Authorities*.
- 26 Skill: National Bureau for Students with Disabilities (2009) *Education and Skills Act 2008: What does it mean for Connexions and IAG?* National Transition Support Team.
- 27 Personal communication with Mencap (7 August 2009).
- 28 McGowan, A., Watts, A.G. and Andrews, D. (2009) *Local Variations: A Follow-Up Study of New Arrangements for Connexions/Careers/IAG Services for Young People in England*. National Institute for Careers Education and Counselling.
- 29 Personal communication with Transition Information Network (7 August 2009).

- 30 Personal communication with Connexions Cheshire & Warrington (6 May 2009).
- 31 Beadman, J. (2006) *Access to Education: Experiences of transition from school to further education—diversity and practice for young people with Down's Syndrome in the UK*. Down's Syndrome Association.
- 32 Personal communication with Scope (6 August 2009).
- 33 National Audit Office (2007) *Staying the course: The retention of students in higher education*.
- 34 Riddell, S., Tinklin, T. and Wilson, A. (2004) *Disabled students and multiple policy innovations in higher education*. Economic and Social Research Council.
- 35 Personal communication with Treloar Trust (09 February 2009).
- 36 Treloar Trust (2008) *Moving On: Opening doors—changing lives*.
- 37 Barnard, H. and Strang France, E. (2007) *Evaluation Report for the Treloar Moving On Project*. Centre for Charity Effectiveness CASS-CCE.
- 38 Disability Alliance website, www.disabilityalliance.org/skill2.htm [accessed on 10 July 2009].
- 39 Skill student case study website, <http://skillcms.ds2620.dedicated.turbodns.co.uk/page.aspx?p=336&c=218> [accessed on 10 July 2009].
- 40 Office for Disability Issues website, www.officefordisability.gov.uk/docs/res/factsheets/Factsheet_Employment.pdf [accessed on 18 September 2009].
- 41 Disability Rights Commission (2007) *Disability Briefing*.
- 42 Emerson, E. and Hatton, C. (2008) *People with Learning Disabilities in England*. Centre for Disability Research.
- 43 Barnard, J., Harvey, V., Potter, D. and Prior, A. (2001) *Ignored or ineligible: The reality for adults with autism spectrum disorders*. National Autistic Society.
- 44 Booth, M., *Better, faster ... and no office politics: the company with autistic specialists*, in *The Independent* on Sunday, 31 May 2009.
- 45 Emma Bowler, *Willing and able*, in *The Guardian* 17 June 2009.
- 46 Jobcentre Plus (2007) *New Deal for Disabled People: Helping find work if you have a disability*. Department for Work and Pensions.
- 47 Cook, J. and Razzano, L. (2000) *Vocational rehabilitation for persons with schizophrenia: Recent research and implications for practice*. *Schizophrenia bulletin*, 26(1): p. 87–103.
- 48 Warner, R. (1994) *Recovery from schizophrenia, psychiatry and political economy*. Routledge.
- 49 Drake, R.E., McHugo, G.J., Bebout, R.R., Becker, D.R., Harris, M., Bond, G.R. and Quimby, E. (1999) *A randomised clinical trial of supported employment for inner-city patients with severe mental disorders*. *Archives of General Psychiatry*, 56(7): p. 627–633.
- 50 Grove, B. (2001) *Making work schemes work*. *Psychiatric Bulletin*, 25: p. 446–448.
- 51 Department of Health (2009) *Valuing Employment Now: real jobs for people with learning disabilities*.
- 52 Getting A Life website, www.gettingalife.org.uk/ [accessed on 15 September 2009].
- 53 Howlin, P., Alcock, J. and Burkin, C. (2005) *An 8 year follow-up of a specialist supported employment service for high-ability adults with autism or Asperger syndrome*. *Autism*, 9(5): p. 533–549.
- 54 Emerson, E., Malam, S., Davies, I. and Spencer, K. (2005) *Adults with Learning Difficulties in England 2003/4*. Department of Health.
- 55 Godfrey, C., Hutton, S., Bradshaw, J., Coles, B., Craig, G. and Johnson, J. (2002) *Estimating the Cost of Being "Not in Education, Employment or Training at Age 16–18"*. Department for Education and Skills.
- 56 Beyer, S., Kaehne, A., Grey, J., Sheppard, K. and Meek, A. (2008) *What Works? – Transition to employment for young people with learning disabilities*. Shaw Trust.
- 57 Elder-Woodward, J. website, www.scope.org.uk/living/i4all.doc [accessed on 07 July 2009].
- 58 Leonard Cheshire Disability: 1 Lavender Fields website, www.lavenderfields.org/ [accessed on 07 July 2009].
- 59 Pannell, J. and Harker, M. (2007) *My home and money: Managing money and living independently*. Housing Options & Dimensions.
- 60 Dimensions (2008) *Lost in Transition: A Home of My Own*.
- 61 Department for Transport (2008) *Transport Statistics Bulletin*.
- 62 Department for Transport (2007) *Transport Statistics Bulletin*.
- 63 Department of Health (2007) *Valuing People Now: From Progress to Transformation*.
- 64 Coolmove travel training website, www.coolmove.org.uk/contacttrainers.htm [accessed on 07 July 2009].
- 65 Personal communication with the Department for Children, Schools and Families (29 April 2009).
- 66 Halton Borough Council (2006) *Independent Travel Training Newsletter*.
- 67 Webster, L. and Shah, S. (2007) *Into the Unknown: Disabled people's experiences of public transport*. Leonard Cheshire Disability.
- 68 McQuigg, R. (2008) *Mind the Gap: The Next Step*. Leonard Cheshire Disability.

- 69 Leonard Cheshire Disability (2007) *Spending Power: Disabled people's experiences of accessing and spending their money*.
- 70 Laxton, C. and Goldsworthy, A. (2008) *Up close and personal: A report into disabled and non-disabled people's attitudes and experiences of relationships in the UK*. Leonard Cheshire Disability.
- 71 Treloar Trust (2008) *Treloar Trust Annual Review*.
- 72 Transition Information Network events website, www.transitioninfonet.org.uk/events/0 [accessed on 10 July 2009].
- 73 Leonard Cheshire Disability website, www.creatediscomforts.org/scripts/#tv2 [accessed on 09 July 2009].
- 74 Koppenol, C., McNamara-Goodger, K., Ward, T. and Wells, P. (2008) *Let's talk about sex: let's talk about you and me: Relationships, sexual health and sexuality guidance for those working with young people with life-threatening conditions and their families*. Association for Children's Palliative Care.
- 75 Prime Minister's Strategy Unit (2005) *Improving the life chances of disabled people. Final report*. Joint with Department for Work and Pensions, Department of Health, Department for Education and Skills, and Office of the Deputy Prime Minister.
- 76 British Heart Foundation Promotion Research Group and Department of Public Health—University of Oxford (2003) *Congenital heart disease statistics*.
- 77 Local Government Association (2009) *A fairer future. Fit for the future: a new vision for adult social care and support*.
- 78 Local Government Association website, www.lga.gov.uk/lga/core/page.do?pagelid=694861 [accessed on 15 July 2009].
- 79 Transition Information Network & Council for Disabled Children (2009) *Response to The Bradley Report: Lord Bradley's review of people with mental health problems or learning disabilities in the criminal justice system*.
- 80 HM Government (2003) *Every Child Matters*.
- 81 National Transition Support Team (2008) *Transition Planning and Development Tool*.
- 82 Surman, G., Bonellie, S., Chalmers, J., Colver, A., Dolk, H., Hemming, K., King, A., Kurinczuk, J.J., Parkes, J. and Platt, M.J. (2006) *UKCP: a collaborative network of cerebral palsy registers in the United Kingdom*. *Journal of Public Health (Oxf)*, 28(4): p. 400.
- 83 National Transition Support Programme website, www.transitionssupportprogramme.org.uk/about_us.aspx [accessed on 10 July 2009].
- 84 Transition Support Programme website, www.transitionssupportprogramme.org.uk/pdf/TSP_TM%20Macintyre%20CS%20Final.pdf [accessed on 7 July 2009].
- 85 Contact a family (2008) *Preparing for adult life and transition: Information for families*.
- 86 Contact a family (2009) *Money when your child reaches 16 years of age: Information for families*.
- 87 National Autistic Society Signpost website, <http://signpost.autism.org.uk/> [accessed on 09 July 09].
- 88 Mencap website, www.mencap.org.uk/guides.asp?id=9989 [accessed on 15 September 2009].
- 89 Foundation for People with Learning Disabilities (2005) *Linking up: Emotional support for young people with learning disabilities*.
- 90 ACT (2007) *The Transition Care Pathway: A Framework for the Development of Integrated Multi-Agency Care Pathways for Young People with Life-threatening and Life-limiting Conditions*.
- 91 Merriman, S. (2009) *TransMap: From theory into practice. The underlying principles in supporting disabled young people in transition to adulthood*. Transition Information Network, Council for Disabled Children, National Children's Bureau.
- 92 Christophides, R. (2008) *Freedom to Live: Transition for disabled young people. Livability's report on disabled young people moving towards adulthood*. Livability.
- 93 Institute of Public Care: Oxford Brookes University (2008) *Shadow Lands: Application and Impact of Eligibility Criteria on Young People with Disabilities*. Voluntary Organisations Disability Group.
- 94 Royal National Institute of Blind people (due for release Autumn 2009) *In Transition*.
- 95 Leonard Cheshire Disability (2008) *Annual report and consolidated accounts for the year ended 31 March 2008*.
- 96 Sunil Peck, *Some charities 'living in the past'*, in *Disability Now* 16 October 2008.
- 97 HM Government (2009) *Shaping the Future of Care Together*.
- 98 Learning Disability Coalition, *Care for people with Learning Disabilities* [letter], in *The Guardian* 24 July 2009.
- 99 Learning Disability Coalition website, www.learningdisabilitycoalition.org.uk/download/Green_Paper_Launch.doc [accessed on 17 September 2009].
- 100 Scope website, www.scope.org.uk/response/faq.shtml#whatiscp [accessed on 7 July 2009].
- 101 MacIntyre website, www.macintyrecharity.org/search/index.php?search=individual+budgets [accessed on 7 July 2009].
- 102 MacIntyre website, www.macintyrecharity.org/Services/My+Way/42/Individual+Service+Fund/76/ [accessed on 25 June 2009].

- ¹⁰³ Department for Children, Schools and Families website, www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/otherareas/ahdcotherareas/ [accessed on 25 June 2009].
- ¹⁰⁴ Carlin, J. (2003, updated 2006) *A parent's guide to direct payments*. Department for Education and Skills, Council for Disabled Children.
- ¹⁰⁵ Brick, P., Kail, A., Jarvinen, J. and Fiennes, T. (2009) *Granting success: Lessons from funders and charities*. New Philanthropy Capital.
- ¹⁰⁶ Heady, L. and Keen, S. (2008) *Turning the tables in England: Putting English charities in control of reporting*. New Philanthropy Capital.
- ¹⁰⁷ Casswell, D., ed., (2004) *The Contact a Family Directory. Specific conditions, rare disorders and UK family support groups*. Contact a Family.
- ¹⁰⁸ Knapp, M., Romeo, R. and Beecham, J. (2007) *The Economic Consequences of Autism in the UK*. Foundation for People with Learning Disabilities.
- ¹⁰⁹ Office for National Statistics website, www.statistics.gov.uk/CCI/nugget.asp?ID=1229&Pos=&ColRank=2&Rank=448 [accessed on 06 July 2009].
- ¹¹⁰ Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T. and Meldrum, D., et al (2006) *Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)*. *The Lancet*, 368: p. 210-15.
- ¹¹¹ ACT & Royal College of Paediatrics and Child Health (1997) *A guide to the development of children's palliative care services*.
- ¹¹² Scope website, www.scope.org.uk/information/cp.shtml [accessed on 12 July 2009].
- ¹¹³ RNID website, www.rnid.org.uk/information_resources/factsheets/deaf_awareness/factsheets_leaflets/facts_and_figures_on_deafness_and_tinnitus.htm [accessed on 10 July 2009].
- ¹¹⁴ The Health and Social Care Information Centre (2008) *Registered Blind and Partially Sighted People in England*.
- ¹¹⁵ RNIB website, www.rnib.org.uk/xpedio/groups/public/documents/publicwebsite/public_cert_vi.hcsp [accessed on 10 July 2009].
- ¹¹⁶ National Audit Office (2009) *Supporting people with autism through adulthood*.
- ¹¹⁷ Beyer, S. (2008) *An evaluation of the outcomes of supported employment in North Lanarkshire (2007)*.

Other NPC publications

Published research

Research reports are focused on specific areas of charitable activity in the UK unless otherwise stated.

Community

- **Breaking the cycle:** *Charities working with people in prison and on release (2009)*
- **Short changed:** *Financial exclusion (2008)*
- **Lost property:** *Tackling homelessness in the UK (2008)*
- **Hard knock life:** *Violence against women (2008)*
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- **A long way to go:** *Young refugees and asylum seekers in the UK (2007)*
- **Home truths:** *Adult refugees and asylum seekers (2006)*
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- **Grey matters:** *Growing older in deprived areas (2004)*
- **Side by side:** *Young people in divided communities (2004)*
- **Local action changing lives:** *Community organisations tackling poverty and social exclusion (2004)*
- **Charity begins at home:** *Domestic violence (2003)*

Education

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- **After the bell:** *Out of school hours activities for children and young people (2007)*
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- **Rhetoric to action:** *HIV/AIDS in South Africa (2003)*

Environment

- **Green philanthropy:** *Funding charity solutions to environment problems (2007)*

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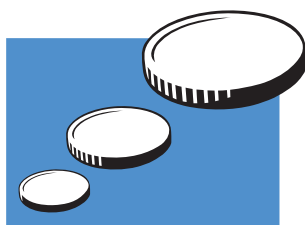
- **Giving in India:** *A guide for funders and charities (2009)*
- **Starting strong:** *Early childhood development in India (2009)*
- **Philanthropists without borders:** *Supporting charities in developing countries (2008)*
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- **Funding success:** *NPC's approach to analysing charities (2005)*
- **Full cost recovery:** *A guide and toolkit on cost allocation (2004, published by NPC and acevo)*
- **Surer Funding:** *Improving government funding of the voluntary sector (2004, published by acevo)*
- **Funding our future II:** *A manual to understand and allocate costs (2002, published by acevo)*



New Philanthropy Capital

New Philanthropy Capital (NPC) is a consultancy and think tank dedicated to helping funders and charities to achieve a greater impact.

We provide independent research, tools and advice for funders and charities, and shape the debate about what makes charities effective.

We have an ambitious vision: to create a world in which charities and their funders are as effective as possible in changing people's lives and in tackling social problems.

- For charities, this means measuring the results of their work and using evidence to learn and improve, as well as to attract support.
- For funders, it means using evidence of charities' results to make funding decisions and to measure their own impact.

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