

# Action for Children briefing



## The transition to adulthood: keeping disabled young people at the centre

### Summary

The process of moving on from childhood to being an independent adult should be an exciting and positive experience for a young person. However, for disabled young people it can be a uncertain, challenging and, in some cases, very distressing. The long-term outcomes for many disabled young people remain poor. Disabled adults are more likely to live in poverty, have poor physical and mental health, be socially isolated and economically inactive.

For most young people, the move to independence is a gradual process, with new challenges and opportunities prepared for and overcome with the support from family and friends. But for too many disabled young people, the process of moving on to adulthood is inhibited by their dependence on education, social and health services that have transition or transfer processes that are not person centred or appropriate to their needs and aspirations.

In its annual report to Parliament on the state of social care, the Commission for Social Care Inspection (CSCI) reported that 'young people making the transition between children's and adult services are particularly disadvantaged by eligibility criteria and that there is a gap in opportunities and outcomes between the

majority of young people and those who use social care services<sup>1</sup>.

This briefing looks at how transition services need to support disabled young people and their families through their transition from childhood to adulthood. It describes the importance of responsive, flexible, high-quality services and contains a number of case studies showing the benefits Action for Children's services are currently delivering for disabled young people and their families.

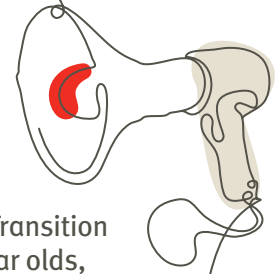
Action for Children believes that:

- ▶ disabled young people must be at the centre of the transition process
- ▶ a keyworker is essential to help navigate and support young people and their families through their transition period
- ▶ during transition, young people should have access to an advocate
- ▶ adult services must meet the needs of the young person as an individual
- ▶ there must be continuity of the level of support if assessed need has not diminished
- ▶ disabled young people should be taught key life skills

<sup>1</sup> *The State of Social Care in England 2006–2007*, Commission for Social Care Inspection, Jan 2008

as long as it takes

# Aiming High for Disabled Children – Transition Support



The Government's Aiming High for Disabled Children (AHDC) programme includes Transition Support as one of its five workstreams. As a part of the AHDC programme, £19m will be used to develop a Transition Support Programme to improve the delivery and consistency of transition support.

The Government acknowledged that 'disabled young people may face additional challenges in the transition to adulthood. Support at transition to adulthood is vital to enable disabled young people to gain independence, choice and control over the assistance they need, and to achieve their aspirations. However, not all disabled young people are getting the co-ordinated, intensive support that they need.'<sup>2</sup>

Action for Children supports the Transition Support Programme for 14–19 year olds, agreeing that access to an adviser or keyworker, advocacy support and person-centred planning from the age of 14 will help young people through this period, as outlined in the Government's Independent Living Strategy.

Cross-departmental initiatives have identified disabled young people at transition as a priority group in recent consultations such as the Independent Living Strategy and Valuing People Now. We believe this cross-departmental work is essential if disabled young people are to be supported with every aspect of their life during and after their transition into adulthood.

**'I think that it is important to plan, as none of us have crystal balls so don't know what could happen. If you don't plan, life goes pear shaped.'**

*Tom, at Action for Children Kingfishers*

## Action for Children

Action for Children is the largest voluntary sector provider of services for disabled children and young people in the UK. Our transition services enable young people to develop appropriate levels of independence, roles and relationships through choice, and provide opportunities for social interaction, community participation and appropriate, meaningful activities.

Action for Children services endeavour to remove the barriers that occur for young people at transition by enabling young people to achieve their potential as confident, included and contributing adults. We provide services that:

- ▶ equip young people with the social and practical life skills for greater independence and self-confidence

- ▶ promote a person-centred, collaborative and co-ordinated approach from services and support around a young person
- ▶ deliver services across the traditional artificial/organisational boundaries established through legislation

In order to ensure the transition into adulthood is a positive experience, Action for Children believes that disabled young people and their families should receive:

- ▶ more holistic advice and support
- ▶ adult services tailored to meet their needs
- ▶ continuity of provision through transition
- ▶ the chance to enjoy the same choices and opportunities as their peers

<sup>2</sup> *Aiming High for Disabled Children: better support for families*, HM Treasury, 2007

**‘For families like mine, transition must be much more than simply a planning process – it is about the hopes, aspirations and safeguarding of our extremely vulnerable children’s future. But while the process itself can be good, we live with constant terror that there’s going to be nothing at the end of it and that’s what keeps us all awake at night. We fear it’s a transition to nowhere.’** *A grandmother, at Action for Children Bury Red Centre*

## **Continuity of provision through transition**

Action for Children is aware of the distress caused when services supporting young people and their families through childhood end and they move on to adult services.

We believe that services should be developed to bridge the gap between the end of children’s services and the beginning of adult services. This will ensure young people do not face the end of all the services they have relied upon and trusted at a time when they need increased support.

Action for Children has developed a number of continuous services that are a constant in young people’s lives when everything around them is changing. These services include short breaks and residential education provisions.

## **Action for Children Redwood House – specialist provision**

Redwood House provides a specialist service for up to six young people under 26 years old with diverse and complex needs who have completed their education at Penhurst School, preparing them for moving on from the school.

Redwood House is not only an extension of the work of Penhurst School but an independent care and training provision for young people with profound and multiple learning needs. As an adult care home, it is inspected by the Commission for Social Care Inspectorate and fulfils all the criteria necessary for developing the young people’s skills for life and living. Young people are helped to develop their life and living skills, and can access therapeutic services and appropriate medical care.

## **Jamila’s story**

Jamila is a young Muslim woman who came to England with her family from Somalia several years ago. In addition to her profound multiple learning difficulties and disability, Jamila suffered a stroke prior to arriving at Penhurst and often found it difficult to communicate her wishes and needs, which sometimes resulted in self-harming behaviour. Through working closely with the local disabilities team, which included clinical psychologists, strategies were developed and implemented to support and enable Jamila to manage her behaviour positively and express herself more clearly.

This has increased Jamila’s ability to participate in social, leisure and learning

opportunities, make a positive contribution and form meaningful relationships. Jamila has regained skills (particularly in communication and mobility), and she can now use a communication system effectively, swim independently and use a walking frame.

All the staff in Redwood House are highly trained and committed to ensuring that Jamila’s transition into her next home is planned, structured and seamless. They work tirelessly to ensure that Jamila has the necessary skills to take the next step in her life.



## Action for Children Yew Trees Residential Short Breaks and Transition Service

There is great emphasis at Yew Trees on empowering and supporting young people as they adjust to adulthood and the many changes that are taking place in their lives.

Action for Children Yew Trees offers residential short breaks and needs-led crisis support for young people aged

between 16 and 21 with a learning and/or physical disability. Much of the care and support provided is based around activity groups, such as youth club-type activities, sensory storytelling, cooking and craft activities, football and independence skills.

## Transition between children's and adult services

We know that some young people, once they leave children's services, have little or no provision due to countless reassessments and the different models of eligibility criteria used in adult services. This can be incredibly distressing and destabilising to the young person and their family. This 'cliff edge' experience, where services suddenly stop, creates a sense of powerlessness.

In many cases, the need for services is greater than the available provision, meaning that some young people are left with no continuity and poor or little service provision. This can be detrimental to the young person's development and self-esteem. Without the support services that have followed them through their lives to date, it can be both daunting and lonely.

Adult services must work hard to ensure disabled young people are allocated provision that is suitable and can cater for their individual needs. A service that cannot fulfil their needs could counteract the positive work and support that children's services had provided over a number of years, putting the young person in a more vulnerable and marginalised position.

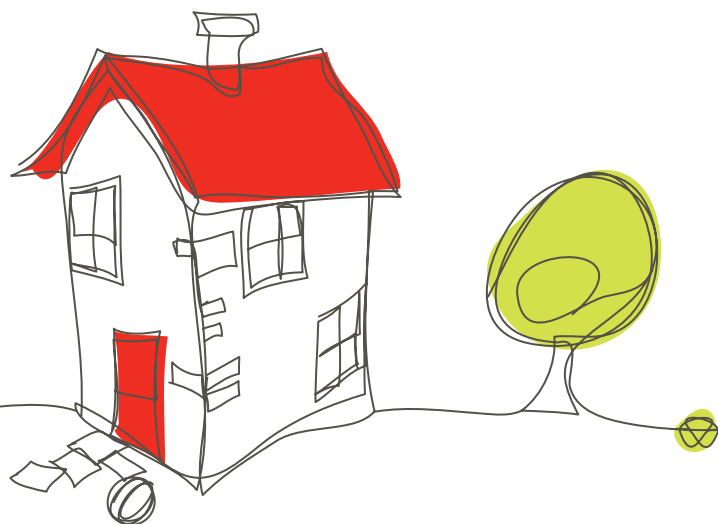
Action for Children uses a variety of methods to work with disabled young people to ensure that their voices and needs are not lost between children's and adult services.

## Person-centred planning

Action for Children believes that person-centred planning can be a positive opportunity for young people to make choices about their future and for their wishes to be heard. Person-centred planning helps young people incorporate every aspect of their aspirations for their future, as well as their practical needs.

It is important that the final plan becomes a live document that the young person can keep with them, amend where appropriate and take though their adult life. By doing this, the young person will have a document that outlines who they are, explains their views, preferences, wishes, aspirations and intentions for the future.

One of Action for Children's short break projects worked with nine young people and their families over a nine-month period to develop person-centred plans and this process has now been evaluated. For copies of this evaluation, please contact the Action for Children public policy team at [publicaffairs@actionforchildren.org.uk](mailto:publicaffairs@actionforchildren.org.uk)



# Action for Children Monksfield Short Breaks Service – evaluation of person-centred planning

## The project aims:

- ▶ to better understand the aspirations of the young people and their families who use our services
- ▶ to develop the skills of the staff team and develop organisational learning
- ▶ to enable young people using the service to better participate in review processes
- ▶ Person-centred planning positively addresses the need for young people to be at the centre of plans for their futures.
- ▶ Staff training resulted in improved practice.
- ▶ Families are concerned about the nature, range and quality of services available to young adults.

## Key outcomes

- ▶ The project achieved all of its aims, with the enthusiasm of all involved clearly contributing to its success.
- ▶ Every young person was involved in producing their person-centred plan, and families felt both the plans and the process were of demonstrable value.
- ▶ Families hold the Monksfield short break service in high esteem and would like to see it extended beyond its current age limit.
- ▶ Action for Children experienced valuable organisational learning in the operational, strategic and service development areas.
- ▶ Action for Children has the potential to deliver person-centred planning well.

## Feedback from families:

Families reported that they found the experience and outcomes of person-centred planning positive. The overwhelming response, however, was a concern about whether the plan would be used in adult services to inform what is provided for their children and how.

When asked if they expect adult services to use the plan as a basis for future provision. Shared concerns included:

- ▶ the apparent lack of appropriate provision for adults in general and young people in particular

- ▶ the expectation that the plan would be used in future, but with no evidence that it will
- ▶ lack of confidence about it being used because adult services have problems with short breaks and problems identifying services for the future
- ▶ concern that transition and adult services' care managers have not been identified

Families were asked '**Has the plan been put into action yet?**' Those who said yes indicated it was very early on in the process but 'it has got people motivated and thinking'.



**'My keyworker listens to me. I am treated as an individual.'**

*Frances, at Action for Children Kingfishers*

## Keyworkers

Action for Children believes that co-ordinated advice, support and reassessment of needs are what make the difference for disabled young people and their families during transition – a keyworker is essential to this process.

Action for Children believes that a keyworker is essential to navigate and support young people and their families through their transition period. Many agencies can be involved with the transition process, with differing models of services, funding criteria and entitlements.

A keyworker should co-ordinate this process, dealing with agency requests for information, ensuring they are proportionate, making sure that the young person and their family have a clear understanding of the options available to them, and keeping the young person at the centre of their transition process.

The need for keyworker support will be increased when more young people begin to use direct payments or individual budgets. Action for Children recognises that these mechanisms will enable young people to build their own care package; however, they must be fully supported in doing so.

## Transition keyworking

Action for Children Pembrokeshire Children's Centre has established transitions keyworker posts, funded by adult social services.

The transitions keyworker co-ordinates the transition planning and provides advice and information for the young person and their family. They continue to be involved with the young person until the young person is 25.

The keyworkers develop relationships with the multiple agencies involved with the young person to ensure that transition is a live and active process.

This is a young person-centred process, where the keyworker ensures all agencies are focused

on delivering services that fit around the young person and their needs, with their views and opinions seen as a starting point, not as an after thought.

Keyworkers use a variety of methods to obtain and record young people's views – for example, they are involved, as appropriate, in family support plans.

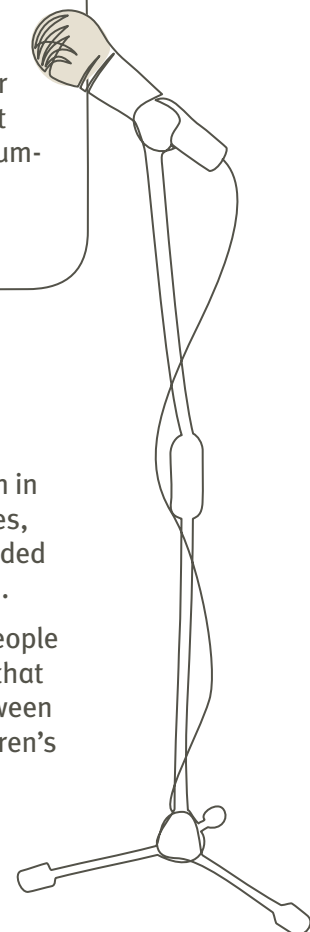
The result for the young person is that, as far as possible, they have driven the plan for their future, envisaged their life as an adult and have acknowledged their short-, medium- and long-term aims.

## Advocates

Based on the views of some service users, we know that transition can be a time of sadness; this is mainly because there is a break in emotional ties with services and individual carers who have provided them with support throughout their childhood. In addition, those people may have officially (but in most cases unofficially) advocated on behalf of the young person, expressing their wishes to family, friends and other services.

Unfortunately for some young people, transition can be the first time they have been asked what they would like to happen in their lives. Up until this period, their families, friends, carers and services may have decided what they feel is right for the young person.

We believe that during transition, young people should have an advocate – it is important that the views of young people are not lost between what adult services can deliver, what children's services recommend and what their family wants or needs.



# Working on independence

## Independent living skills

These are essential for any young person when they leave home – these skills range from knowing how to pay bills to understanding how long it takes to cook meals. The key life skills needed to move into adulthood are no different for disabled young people, which is why it is essential that services are available to support

disabled young people to increase their independence.

When young people are supported to increase their independence, it is essential that future services continue to support these independence skills to ensure that they do not become de-skilled when they move on to new services.

## Action for Children Kingfishers

**‘I can go to town if I want to, catch a train, manage my own money. I have a job and am about to move on to my own place.’**

*Tom, at Action for Children Kingfishers*

Action for Children Kingfishers is a supported housing project in Stroud providing supported accommodation for seven learning disabled young people aged 18–25. The service helps young people develop independence skills for an average of two years before they move on to their own tenancies, with floating support from the project.

The young people who live at Kingfishers have often been protected from taking risks, which has resulted in them not being able to make safe, informed choices for themselves and having limited confidence in their ability to do so.

The Kingfishers’ approach to developing independence skills is led by the young person. If, for example, the young person has a desire to travel to a work placement or visit a nightclub, the approach is to work alongside the young person to fulfil their wishes as safely as possible. Staff will help the young person to consider the risks, enabling them to develop risk-assessing skills. Here the approach is never to prevent an activity, rather to accept the free choice and to enable the young person to participate as safely as possible.

Kingfishers opened in December 2002, and during this time, 21 young people have lived at Kingfishers – all of them wanted to become more independent and the majority wanted to live in their own accommodation by the end of the placement. Ten of these young people have moved on to their own accommodation, receiving a few hours of floating support each week; four have increased their independence

skills and have moved on to supported living; seven are still living at Kingfishers and continue to develop their independence skills.

Action for Children Kingfishers was recently evaluated by researchers at the Norah Fry Research Centre. The evaluation concluded that the following factors have made Kingfishers successful in supporting young people to become confident young adults with independence skills:

- ▶ Kingfishers adopts a holistic approach to progression, taking an interest in the tenants’ employment, future accommodation and social lives, as well as developing practical skills.
- ▶ Kingfishers communicates exceptionally well with other agencies.
- ▶ Kingfishers works hard to maintain good relationships with families.
- ▶ Risk assessments are used positively to overcome barriers.
- ▶ The quality of the staff group is exceptionally high and is maintained through supervision, clear boundaries and good terms and conditions.
- ▶ Peer support is encouraged, which helps to develop the tenants’ confidence and personalities.

For copies of this evaluation, please contact the Action for Children public policy team at [publicaffairs@actionforchildren.org.uk](mailto:publicaffairs@actionforchildren.org.uk)



## Education, employment or training

Action for Children is concerned that disabled 16 year olds are twice as likely to be out of work, education or training as their non-disabled peers. It is our view that more needs to be done to create better opportunities for disabled young people to continue in education, to undertake training and to prepare for employment and living independently.<sup>3</sup>

## Supporting young disabled people to use transport independently

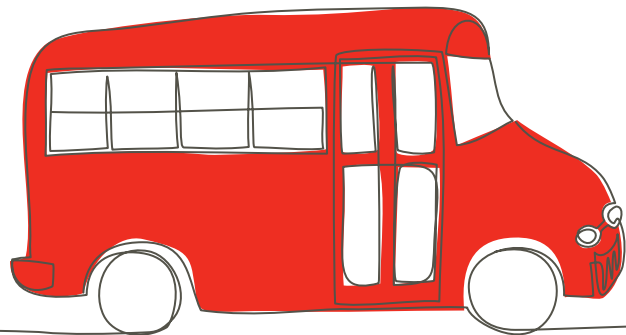
A key aspect to living independently is being able to travel freely to work, the shops, to see friends and family, and generally being able to take yourself anywhere without relying on others. This is just as important for disabled young people as it is for their peers – if not more so. Being able to travel freely can be the key to their independence, and having the skills and confidence to use public transport must be invested in.

More must be done to support disabled young people to become independent users of transport. This means that those working within public transport from planners to operators and conductors must recognise the additional needs that disabled young people may have when travelling. They should be sensitive to their needs in a non-stigmatising way.

## Disabled young people enjoying the same opportunities as their peers

Action for Children believes that while many disabled young people must have access to specialist support and services, they must also be able, where appropriate, to access the same universal youth provision and opportunities offered to their peers.

Many disabled young people experience social isolation. In order to counteract this, disabled young people should be helped to engage with their peers and to play an active role in their communities, via social networks and participation in sport, leisure, play and cultural activities.



<sup>3</sup> *Youth Cohort Study, Parliamentary Briefing, Disability Rights Commission, 2007*

## Volunteering

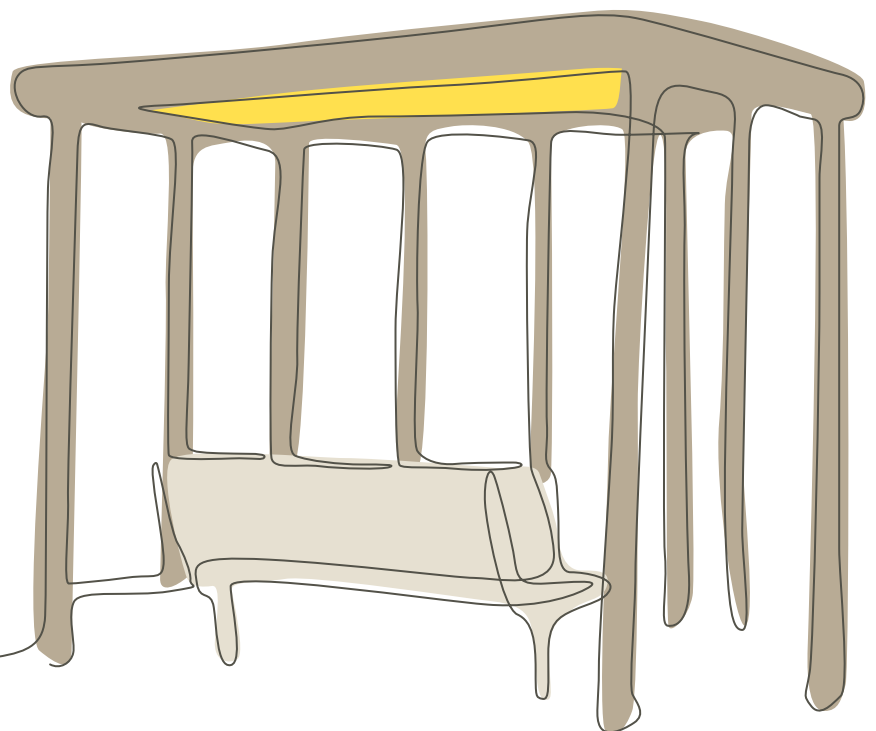
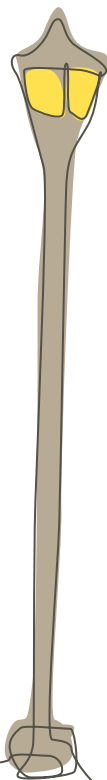
While volunteering is not an alternative to employment, many young people use volunteering as an opportunity to broaden their horizons and test out future career paths and to expand their social opportunities.

Volunteering is a positive and rewarding experience that most young people benefit from through their school life or other extra curricular activities. It is therefore important that disabled young people have the same opportunities to broaden their horizons.

Action for Children promotes volunteering for young people who have used our services. The benefit of this has been to provide the young people with a constructive alternative to further education and paid work, thereby smoothing their transition into the adult world and providing them with an opportunity to give something back to the services they have left.

## Action for Children Yew Trees Residential Short Breaks and Transition Service

To assist with the activities that take place at Yew Trees, the project actively recruits disabled volunteers to help support the young people in the project and to share valuable experiences at this important time of transition. Yew Trees now has three volunteers with learning disabilities, one of whom has his own blog on the Action for Children intranet.



## Participation

Action for Children is committed to participation, ensuring that the wishes of the children and young people we work with (even where expressed non-verbally) are recognised and responded to. We work hard to ensure that disabled young people have a say in their futures.

We also believe that the young people who use services should be fully involved in their design and delivery, and are empowered to have their

voices heard and to facilitate change both locally and nationally. This is no different for disabled young people.

Involvement must not be tokenistic, but one of meaningful engagement, where participants can see and understand its purpose and benefits. Action for Children is, for example, currently supporting two young people on a local authority transitions panel.

## Participation – young people on Lincolnshire’s local authority transitions panel

The Lincolnshire Transition Service Governance Board was established in 2007. This included the membership of two disabled young people who could participate in and contribute to the business with full voting rights.

Their objectives were:

- ▶ to drive the change towards the best outcomes for children and young people with complex needs through the integration and realignment of transitional services
- ▶ to provide the best experience of the transition process for children, young people and their families
- ▶ to use resources in the most cost-effective way

The young people have so far:

- ▶ developed and distributed a transition survey to young adults who have already been through the process
- ▶ attended many meetings with other professionals, both locally and nationally

- ▶ joined the Transition Information Network
- ▶ sat on interview panels for members of the transition team
- ▶ attended consultations and consulted with children and young people

The two young adults currently involved wanted to be part of the transition board because they had not had a very positive experience from the transition process themselves and felt that others should have a better chance in the future.

They have also explained why their involvement on the board was important, saying:

**‘I think it is important that we can speak for those young people who can’t always say what they mean, so they can be heard as well.’**

**‘I think it is important to be involved as I can get my point across, and tell people what myself and other young people think transition should be about.’**

## Peer befriending

Disabled young people are no different to their peers in that they wish to spend time with people their own age who have similar interests.

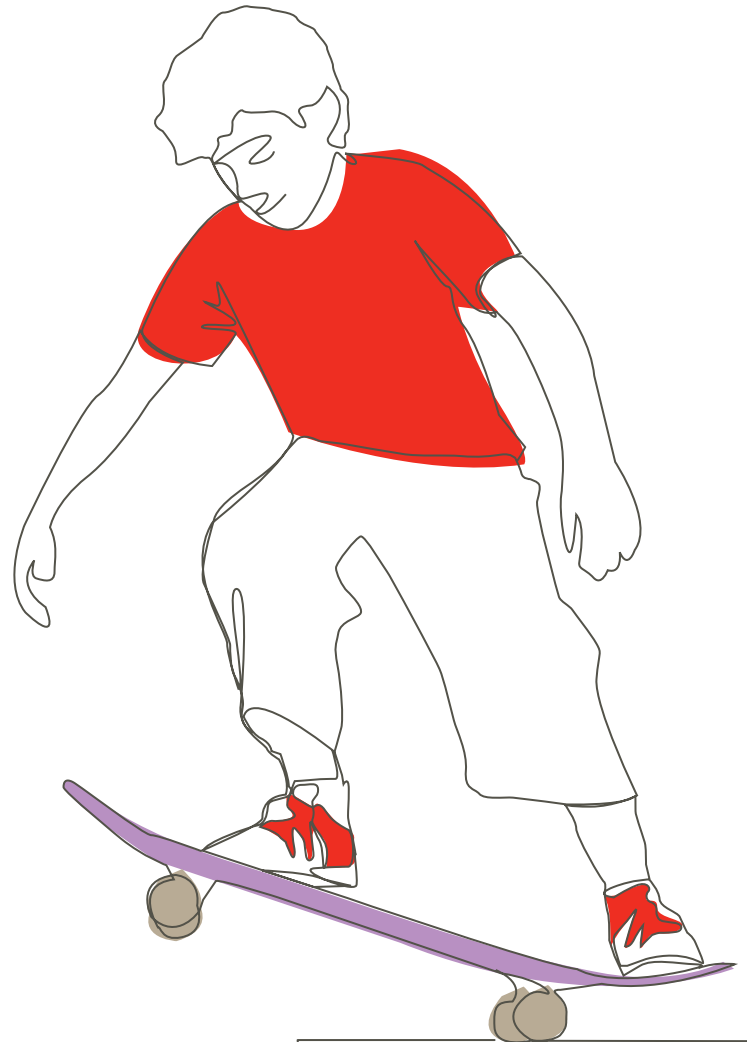
Action for Children believes more must be done to encourage peer befriending to ensure that disabled young people don't miss out on building positive relationships with their peer group.

### Action for Children Umbrellas Project

Our Umbrellas project includes a peer befriending scheme for young people who have a learning disability and whose needs cannot be met through traditional short break services. The young befrienders are all assessed using a model that looks at their values, skills and abilities, and they complete a course of training.

The group is located within a town centre youth provision establishment, in order to minimise transport difficulties and to give the young people greater access to community activities. The young people take part in activities they choose with other young people out in the community. Group numbers are kept small to be similar to a group of friends or any other group of young people who choose to spend time together.

Some individual links have been made between the young people, including two young people now attending a computer group together, and although the arrangements to achieve this were more complex than they would have been for a more typical pair of friends joining a course, it has been achieved in a sensitive manner.<sup>4</sup>



<sup>4</sup> *Aiming high for disabled children*, Short Breaks Implementation Guidance, DCSF 2008

# Conclusion

Many disabled young people and their families are fearful of what the future may hold when they reach adulthood. The period before the young person reaches the age of adulthood is a real opportunity to allay this fear, to plan for the future and to ensure that services are in place to support the young person when they leave children's services.

With the Aiming High for Disabled Children programme and its focus on transition support, we have a real opportunity to ensure that the transition into adulthood is a positive experience and that, as adults, these young people will have more opportunities and have greater life chances.

The key to ensuring this happens is making sure young people are at the centre of their own transition journey.

For more information about our work, please contact the Action for Children Public Affairs team on **020 7704 7132** or at **publicaffairs@actionforchildren.org.uk**

