

NCH submission – Independent Living Strategy

NCH would like to thank the office for Disability Issues and the departments for Work and Pensions, Transport, Health, Children, Schools and Families, Communities and Local Government and Innovation, Universities and Skills for asking our views on this consultation document.

We recognise that the main audience for this consultation is adult service providers however as there is a chapter on the transition to adulthood, NCH as a provider of these services wanted to respond to the consultation. We would be happy to facilitate a visit to one of our projects working with young people in transition or to advise further about our methods of engagement with disabled young people.

Summary

NCH supports the Government's desire to ensure that the Independent Living strategy's implementation is monitored by disabled people at a local and national level.

From our experience, such involvement of young people must not be tokenistic, but one of meaningful engagement, where participants can see and understand its purpose and benefits.

NCH welcomes the commitment in the Independent Living Strategy to seek to ensure a seamless transition into adulthood for young disabled people. From our work, we know that the transition process for disabled young people from childhood into adulthood can be an uncertain, challenging and in some cases a very distressing period of time.

Worryingly, research tells us that disabled young people who have undergone the transition from childhood to adulthood are experiencing poorer outcomes as adults than their non disabled peers. This shows that they are more socially isolated, less likely to be in employment, more likely to live in poverty and more likely to be victims of hate or harassment crimes.

In order to ensure that the Independent Living Strategy delivers on its pledge to make the transition into adulthood a seamless experience, NCH believes that disabled young people and their families at transition should receive:

- adult service provision tailored to meet the needs of the young person;
- more holistic advice and support;
- continuity of provision where appropriate; and
- the opportunity to enjoy the same choices and support as their peers.

'Society need to treat us as equal, not look at us as different, we have a right to live independently too'¹

¹ Unless specified all quotes are from young people living at NCH Kingfishers who took part in our internal consultation on the Independent Living Strategy.

NCH's key recommendations:

On the delivery of the Independent Living Strategy:

NCH believes that when the Government is implementing the Independent Living Strategy every effort must be made to ensure engagement with disabled young people is meaningful and not tokenistic, whilst being accessible and open to all.

On the Independent Living Strategy:

NCH believes the young person must be at the centre of the transition process.

NCH believes that a key worker is essential to navigate young people and their families through their transition period.

NCH believes that during transition young people should have an advocate.

NCH believes that adult services must meet the needs of the young person as an individual supporting them with their housing, transport and health needs - 'best fit' offer of provision will not do.

NCH feels that disabled young people need more support with education, training and employment but that the Government should also use work experience and volunteering as an opportunity to broaden the horizons of disabled young people.

About NCH's disability services

NCH² is the largest voluntary sector provider of services for disabled children and young people in the UK. We are 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 future.

We provide a variety of specialist services for disabled young people in the process of transition 16 – 23 years old; this is delivered via residential short breaks, supported accommodation and independence skills development, transition key working and leaving care projects.

NCH works on the basis that the child is at the centre of all we do. We work to involve young people in the decisions that affect their lives and ask young people about the issues that matter to them. Nationally, we involve our service users in the design and delivery of our services. We provide children and young people with opportunities to speak directly to policy-makers about the issues that concern them.

NCH services endeavour to remove the barriers that occur for young people at transition by raising aspirations about what adult life can bring, assist with

² NCH is one of the largest children's charities in the UK. We run nearly 500 services and work with more than 160,000 children and young people across the UK, some of the most vulnerable in our society.

relationships, communities and support access to training, employment and volunteering opportunities.

NCH response to Consultation

NCH's response to the consultation is based on our knowledge from our services across the UK in addition to the individual views expressed by young people who attend NCH Kingfishers supported living project in Stroud and their carers.

NCH Kingfishers

NCH Kingfishers is a supported housing project in Stroud, providing supported accommodation for seven learning disabled young people aged 18 – 25 years old. The service supports young people to develop independence skills for typically two years before they move onto their own tenancies with floating support.

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

The Kingfishers approach is one which is led and guided by the young person. Working closely together the young person is supported to develop the skills necessary to lead an independent life. This for example may lead to a tenant's desire to travel to a work placement or visit a nightclub. Here the approach is to work alongside the tenant to enable the young person to fulfil their wishes as safely as possible. Staff will support 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, during this time twenty one young people have lived at Kingfishers, all of them wanting to become more independent and the majority wanting to live in their own accommodation by the end of the placement. Seven of these young people are currently living at Kingfishers and are in the process of developing their independence skills at varying stages. Four of these young people have increased their independence skills and have moved on to supported living, Ten of these young people have moved on to their own accommodation, receiving a few hours of floating support each week.

When we asked the young people at Kingfishers why they valued the support they received from the project, they told us:

'When I moved here I had a risk assessment to show me what things I needed to learn, I then gained experience and now I am doing things for myself'

'The fact that I have had to pay bills, that I had to look after myself, not

have people run around after me.'

'Kingfishers have given me the chance to live in the real world'

'Staff help me to plan the learning around me, I am treated as an individual'

Consultation question 1: We would welcome views on how best to involve disabled people, at a national level, in the monitoring of progress of implementation of the Independent Living Strategy, for example by setting up an Independent Living Scrutiny Group.

If you are in favour of setting up an independent Living Scrutiny Group, do you have any views on who should be in the group and how the members should be selected?

Why is it important to involve disabled young people in this process? Our young people told us:

'I think my opinion is important'

'So you can put your message across and get feedback'

'Participation is important because I can learn how to manage things that I want to do, I am not being told what to do, I make my own decisions'.

NCH is of the view that all young people should be able to participate in decisions affecting them; individual decisions such as what they will do when they leave school for example, to decisions that affect groups of young people, like planning and designing the services that will be provided for them.

It is crucial that young people who use services are fully involved in their design and delivery, and are empowered to have their voices heard and to facilitate change both locally and nationally. NCH acknowledges the importance of young people's views, and this is encapsulated in our guiding principle of the child being at the centre of all we do. Services are often most effective when they are a direct response to need. Therefore, it is important that young people are engaged appropriately, inclusively and in accessible ways, in order for them to express their feelings and needs.

We are concerned that disabled young people's rights to the freedom of expression are not being upheld. Speech and language therapy assessment and intervention can enable disabled young people to have a voice, however there is a postcode lottery of access to the provision.

We need to invest in communication aids now, and the training and support for families and universal, social and health care service staff to competently use high- and low-tech communication aids. We need a greater commitment to producing information in accessible formats for children who do not use written or

verbal communication. If young people are going to be able to make a positive contribution, they need to have an effective means of communicating and support to enable them to do so.

We asked our young people and practitioners how they think disabled people can be involved with the implementation of the Independent Living Strategy, we now suggest the following:

- Talking to disabled young people directly.
- Making any questions you are asking young people understandable, this could be through for example, symbols, photos or pictures.
- Create interest for young people attending any meeting / event by making a video or DVD for them to watch so that they fully understand what is going on.
- Employ staff who can collect the views of young people, who are trained to work with disabled young people who are able to interpret their views, have the ability to communicate effectively with a person with learning disabilities and will listen to their views fully.

Consultation or involvement in any form of disabled young people in the implementation of the Independent Living Strategy must not be tokenistic, but one of meaningful, continuous engagement, where participants can see and understand its purpose and benefits.

It is important to engage with the widest group of young people, regardless of age, ethnicity, ability, gender or circumstance

Consultation Question 2: We would welcome views on current arrangements for promoting the involvement of disabled people and their organisations and the contribution these arrangements may make to the monitoring of the Independent Living Strategy.

Is this enough? Or do you think that more needs to be done at a regional and local level to involve disabled people in plans to improve services in the local area? If so, what should be done to enable disabled people and their organisations to be more involved?

Young people themselves have told us:

'I would like to be consulted, not treated as if I don't have a disability, we need different things'

'I would like to be involved at a local level but also consulted on a National level'

NCH facilitates groups to enable young people to respond to Government proposals. Our services offer numerous activities, including debates, meetings, training and workshops. NCH's membership of the Dare to Care campaign is another example of young people being supported to become active citizens in the workplace.

As a children's charity, NCH has both an obligation and responsibility to do all we can to open up and develop the interests of young people who use services in a local or national setting. For disabled young people their voices are often lost within strategies whose main audience are adults, we believe more needs to be done to address this.

All government documents that have an impact on disabled young people should be routinely translated into a form that is accessible to them.

Consultation Question 3: Is there a need for a 'network of networks' to facilitate the involvement of disabled people in the implementation and monitoring of the strategy?

This direct information could then be used to inform the annual monitoring of progress on the strategy. Do you think this is a good idea?

In response to this question, NCH practitioners have told us:

'Definitely! Every disabled person who has any involvement in the strategy will have a different perspective.'

The sharing of these differing perspectives through a network will aid staff in supporting young people to understand the strategy'

Consultation Question 4: We would welcome views on current initiatives to build leadership capacity amongst disabled people, on whether further work should adapt the partners in Policymaking model, and/or whether there are other models we should consider.

Should the Government do more to help disabled people take the lead in making change happen and what is the best way to do this?

NCH believe that all disabled young people should be empowered to make decisions about their own lives and to have a stake in their local and national communities.

Through our services we have a number of examples of current leadership initiatives for disabled young people:

- Workshops which fully involve them.
- Talks from disabled people and discussing their achievements can be inspirational.

- Making a video for disabled people to watch and then discussing with support staff to discuss their views after watching.

Consultation Question 5:

We would welcome views on the best ways to assist implementation and monitoring of the strategy at regional and local levels.

What needs to happen at a regional and local level to make sure that the strategy works in each local area?

In response to this, NCH's practitioners from the NCH Kingfisher's project felt that the best ways to implement include:

- Taking time to introduce it properly and not rush it.
- Small group sessions.
- One to one work with people
- Make it understandable and accessible

Consultation Question 6:

Views on the Independent Living Strategy.

As a provider of transition services NCH and its service users are very interested in the strategy as a whole. We have addressed our areas of interest under the headings within the strategy. We have asked a group of our services users from Kingfishers to comment on the strategy.

Transition between Children's and Adult's services

NCH aims to help disabled young people achieve high-quality transitions from children's to adult services.

NCH services enable young people to develop appropriate levels of independence, roles and relationships through choice, and provide opportunities for social interaction, community participation and meaningful daytime occupation.

NCH believe that adult service provision must be tailored to meet the needs of the young person and there must be continuity of provision where appropriate

Planning services after full time education is complex and takes time; more time should be taken to appropriately align the needs of the young person with suitable provision. We know that 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.

We know that some young people, once they leave children's services, have little or no provision due to reassessment and the different model of eligibility criteria

that is used in adult services. This outcome can be incredibly distressing and destabilising to the young person and their family. This 'cliff edge' experience where services stop and this creates a sense of powerlessness.

Support must be put into place to prevent this, to assist the family as a whole to work together in the new environment of adult services and to deal with its implications.

NCH believes that adult services must meet the needs of the young person as an individual - A 'best fit' offer of provision could counteract the positive work and support that children's services had provided over a number of years. Thus, putting the young person in a more vulnerable and marginalised position.

NCH recognises that 'transition' means different things for different young people, for some it may mean a move towards independent living or a move into adult services. However with the later, it is still important to promote independence skills.

The different disability projects we run reflect our opinion that greater outcomes are achieved when a service moves around the young person rather than the other way round.

NCH Redwood House at Penhurst school

Provides a service for up to 6 young people under 26 years old with diverse and complex needs who have completed their education at Penhurst School (a mixed residential special school providing education, therapy and care for pupils with profound and multiple learning difficulties associated with physical disabilities) and works to support them in their preparation for living back in their home locality.

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 continue to develop their life and living skills and are able to access therapeutic services and appropriate medical care.

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 own 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 (especially in communication and mobility) resulting in her learning to 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.

Transition Support Programme

NCH supports the Transition Support Programme for 14-19 year olds, agreeing that access to an advisor or key worker, advocacy support and person centred planning from the age of 14 will assist young people through this period in their lives.

We believe that disabled young people need to have the ownership of their transition and future life plan.

One young person told us:

'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'

Key workers

NCH believe that co-ordinated advice, support and re- assessment of needs are what make the difference for disabled young people and their families during transition- a key worker is essential to this process.

The young people told us about their key workers, saying:

'My Key worker helps me with things on my mind, they are helpful and supportive. If I wanted to go to a Formula 1 weekend they could support me with planning'

'My Key worker is supportive, helps me a great deal, if I need to go to the Dentist which I don't like they help. I like working with my Key worker, they are great'

'My Key worker listens to me. I am treated as an individual'

NCH believes that a key worker is essential to navigate young people and their families through their transition period. This is due to the large number of agencies that can be involved with the transition process, the fact that there are

differing models of services, funding criteria and entitlements - in addition to numerous assessment requests.

Many young people and their families feel they are not in control of the transition process and are dependent on others to give them information, guidance and support. Generally there are a number of agencies and individuals involved with a young person when they reach this stage of their life: Children's Services, PCT, voluntary agencies, teachers etc. All these agencies will have their own information requirements, often asking similar if not the same questions. A key worker, should co-ordinate this, making sure that the young person and their family have a clear understanding of the options available to them.

At this point it is important for all agencies to recognise that they are one of many agencies working with the young person; this will ensure the young person is at the centre of their own transition process. A key worker would ensure this happens, focussing agencies on the young person and their needs rather than their service.

A key worker is also important because disabled young people and their families will previously have been dependent on services wrapped around their school life. Moving to adult services can be a daunting process. The differing models of services, funding criteria, entitlement and the number of different providers can be confusing at best and intimidating at worst.

Furthermore, the majority of young people will be re-assessed for services and provisions they access. Many such assessments could be unnecessary and from the point of view of the young person and their families it can be frustrating, particularly if they feel they have already provided the information to one agency and cannot understand why it is not simply shared with others.

A key worker could co-ordinate information requests whilst ensuring that reassessment requests are proportionate.

NCH support young people and their families by removing the pressure of the transition process whilst ensuring they are in control of and empowered by the process.

Transition Key Working

NCH Pembrokeshire Children's Centre has built on its Key Working Service for disabled children to establish a Transitions Key Worker posts, funded by adult social services.

The worker co-ordinates the transition planning and provides advice and information for the young person and their family. They continue their involvement co-ordinating planning and providing support after the transition from school until the young person is 25.

The key workers 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 which means the key worker ensures all agencies are focussed delivering services that fit around the young person and their needs, taking on board their views and opinions as a starting point not an after thought.

Key workers use various methods of obtaining and recording the young person's views and they are involved as appropriate in their own Family Support Plan (which is used for transition).

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

Advocates

Based on the views of some users, we know that transition can be a time of sadness; this is mainly because there is a break in emotional ties with paediatric services and individual carers who have provided them with continuity of support throughout their childhood. In addition, those individuals 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 is the first time they have been asked what they would like to happen in the lives. Up until this period their families, friends, carers and services may have decided what they wanted. It is therefore important to recognise that young people may be expressing different views about what they feel are the best options for them in their future. This is another reason why an advocate even at this late stage is important, it will be someone who can explain why their opinions are valid and assist them in developing them.

NCH believes 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 services recommend and what their family wants and or needs. The young person needs to be at the centre of this process and a key worker acting as an advocate would ensure this

Direct Payments

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

When we asked our young people about direct payments they told us:

'[They are]a good idea, I can choose a good support worker'

'It will give us more responsibility, we can manage the finances'

'It sounds a pretty good idea, we will be able to be flexible with hours and may have enough hours to do something you want, like see a Formula 1 race.'

Education, employment or training.

NCH 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.

We asked the young people a series of questions about this issue and they told us the following:

How have you been supported into education, employment or training?

'GIS [an employment agency for adults with learning disabilities] have supported me with getting a job and holding it down. It has been good doing just a few hours so that I can then build up to more. A slow process is good'

'I need to find a job; I am pleased that I have been found some work experience, being a member of staff is wow. GIS have helped me a lot.'

'I find it better to build it up with work experience, to do a little bit at a time, if things go too quickly I will just crumble'

'I have been supported by GIS to look at different work experience placements. I have had difficulty finding a placement I like because stables are often quite far out which makes transport difficult. I need safe routes to be able to access work independently'

What is the best thing about education, employment or training?

'Doing a job that I enjoy, and having gained experience at Garden Lynx. I am motivated to get there on time. I also have good, supportive employers'

'I work with a supportive team, they meet my level of needs and step in if there is an issue'

Are there any a down sides to education, employment or training?

'When I worked in a job where the hours changed a lot, this did not help me as I never knew where I was'

'Travel is hard to get to work placements and roads can be very unsafe to cross'

'The options are too limited'

Do you need additional support to stay in education, employment or training?

'I would like to do a full days work'

'I need support to get a local job and to be able to get there easily'

'I need something to fall back on'

'I always will need some sort of backing with a job, I need support'

'People like GIS help with things like the label of having a learning disability, employers sometimes see the label and don't want to give us a chance'

NCH believes that while many disabled young people may have additional support needs when in education, employment or training, they must have the same opportunities as their peers. Disabled young people like their peers want to and can contribute fully to society and their local community.

Without this access we know, as already mentioned, disabled young people can experience social isolation and a lack of opportunities leaving them lacking in confidence with low self esteem. This can mean that they are at risk of poor mental health and or being dependent on benefits with few opportunities or aspirations.

It is essential that the government recognises that education and communication are essential components of social inclusion.

Volunteering

Another way of supporting young people into the workplace can be via volunteering. Most young people will have experience of work experience or volunteering through their school life or other extra curricular activities. It is therefore important that disabled young people have similar opportunities.

We asked the young people about volunteering and they said:

'Being a volunteer would help me to feel happy as I am helping others out'

'Being a volunteer – I am giving something back to the community, it builds my confidence and will help me with my future.'

With this in mind, NCH agrees that more emphasis should be placed on young people moving from full time education into further education and paid work. However, we also feel that the Government should use work experience and volunteering as an opportunity to broaden the horizons of disabled young people - Being in the work place for the first time could be incredibly daunting if the young people have not experienced it in the past.

An example of how volunteering is promoted in one of NCH's services can be seen below. The benefits of this has been to provide the young people who have just left the service as a user with a constructive alternative to further education and paid work, thereby smoothing their transition into the 'adult world'.

NCH Yew Trees

Yew Trees is a residential short term breaks project for young people aged between 16 and 21 years with a learning and/or physical disability.

Yew Trees provides short term breaks, flexible and crisis support to young people and their families. Much of the care is based around activity groups e.g. youth club type activities, sensory story telling, cooking and craft activities, independence skills, massage and relaxation drama, football and walking.

Other new groups are constantly being developed e.g. music and movement, creative expression and more recently an Open College Network pilot scheme. Many groups are based in local community facilities - some run throughout the year, others are time limited and groups can vary from 5 young people to 16, depending on individual and group needs.

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 have three officially cleared volunteers with learning disabilities; one young man who has recently left the project has his own blog on the NCH Intranet!

There is great emphasis at Yew Trees on empowering and supporting young people as they go through their transitional time, having to adjust to adulthood and the many changes that are taking place in their lives. Yew Trees ensures young people are valued, their contributions welcomed and their achievements recognised.

Supporting young disabled people to become independent users of transport.

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 is the key to their independence.

We asked the young people a series of questions about public transport.

What are your experiences of using public transport?

'Since being at Kingfishers I can now catch the bus, it is wow, I had not done this before'

'I started independent travel quite young, my parents did not really trust me but once they saw I was able to manage they did'

'At 13 I learnt to use the London underground on my own, I self taught myself, it felt good not to have to rely on anyone, I learnt through experience'

'I caught the train to Cornwall once, I felt like I had something. Sometimes it gives me a sense of freedom; I can do what I want'

'Being able to travel on my own makes me feel an independent person'

Why it is important for you to be able to travel independently?

'It is important because my parents won't be able to be around for ever, I need to be able to do things for myself'

'It is important to travel independently because it means that I can keep having new experiences and I have the freedom to go anywhere'

What are the problems you have with public transport?

'Other passengers have got angry on the bus, I felt scared and worried about what may happen'

'I don't like it when I can't sit down, I feel annoyed as I find it difficult to stand, they are too crowded'

'It is a problem when buses are late, over all it is a nice experience; it is brilliant to have a free bus pass to go anywhere.'

'Some bus shelters are not very well lit, also if it is raining and there is no bus shelter you get very wet'

'I feel safer when there are lights for night travel'

'I would feel safer with more CCTV cameras on the bus and more Police on the streets'

How are you treated by people who work on public transport?

'Some of the drivers know me which is good; some drivers are not very polite or helpful. I once saw a bus driver who would not help someone get on the bus in a wheelchair'

How could you be helped more on public transport?

'We need easier to read timetables; I don't always understand the 24 hour clock. If you find it difficult to read picture clocks are good'

'Timetables need to be basic for beginners'

Finally, we asked those who work with the young people at Kingfishers about the importance of disabled young people travelling independently.

'Bus travel is a common area that most young people need support with initially but this support although replicated for each young person, can move at different speeds depending on their abilities and motivation.'

One young person may need staff support on the bus for a number of weeks but no support at all with walk from the bus to (e.g.) college.'

Whereas someone else may demonstrate confidence on the bus but has limited road safety knowledge so needs support with the walk to college.'

We know that disabled young people's concerns about public transport are no different from the concerns of other young people; they want safe, efficient, clean transport that they can use at their convenience.

The level of Independent travel differs for each young person, not all disabled young people can use public transport alone or cross main roads without assistance. Young people must be supported to develop appropriate levels of independence through choice - young people must not be prevented from obtaining any level of independence simply through the fears of others.

Those working within public transport from transport 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 and do all possible to assist them in a non-stigmatising way.

Meeting the housing needs of young disabled people.

One of the biggest uncertainties for disabled young people in transition is around housing, where they will live and with whom. Many disabled young people are able to live independently, with support, home adaptations if it is located in the right area.

The public must be more aware of people with disabilities living in the community and not in residential settings, by doing this, greater community engagement will occur between disabled and non disabled people. Adult services must work hard to allocate disabled young people the correct provision which is suitable and can cater for their individual needs. A 'best fit' offer of provision could counteract the positive work and support that children's services had provided over a number of years. Thus, putting the young person in a more vulnerable and marginalised position.

We asked the young people whether they had any housing issues. They said:

'There is not enough to go round'

'we should be able to but our own place'

'They need to build more, giving more young people chances and opportunities, it should not have to feel like a lucky dip'

'Everyone should have the chance to get their own place'

We asked those working with the young people at Kingfishers what problems they have with disabled young people accessing appropriate housing.

'We know that, the majority of the young people face difficulties when it is time for them to leave Kingfishers; they often have to be made homeless which feels frightening and can be a worrying time for them.'

The young people then have to wait for quite some time before a property is offered to them; often the properties are unsuitable due to where they are positioned or due to the condition of them. '

Health

Young people begin to take responsibility for their health needs when they leave school and disabled young people are no different, they want to take control of or self manage their health needs. This can simply mean being able to visit the doctors independently or feeling that they can speak up in medical appointments (an advocate could also assist in these occasions.)

Health is obviously another major area where disabled young people wish to gain more control, just like the issues of housing and transport – visiting your GP independently is another important step towards independence.

The young people told us their feelings on this matter by saying:

'It is expensive to pay private but it is important to have a good service, you only get one set of teeth'

'The information that Dr's give you at appointments can be a lot to take in, I need to support to understand what is being said. The Kingfishers way is good because you take a form with you, this has that info on that I need to get across and a space for the Dr to write down what they have said. I can then take this info back to staff for them to support me if I need to; it means I can go to my own appointments independently'

'It would be good to be given the chance to learn how to attend appointments on my own from an earlier age so that I could have got the practice'

'It is important for Dentists and Doctors to be patient and give us time. I want to be able to do this for myself'

'I need to be able to practice attending appointments with support so that I can learn how to do this for myself'

'Sometimes I have to wait too long for appointments and sometimes it is hard to get through on the phone'

For further information please contact Emma Scowcroft, NCH Policy Officer on 020 7704 7122 or emma.scowcroft@nch.org.uk

20th June 2008

