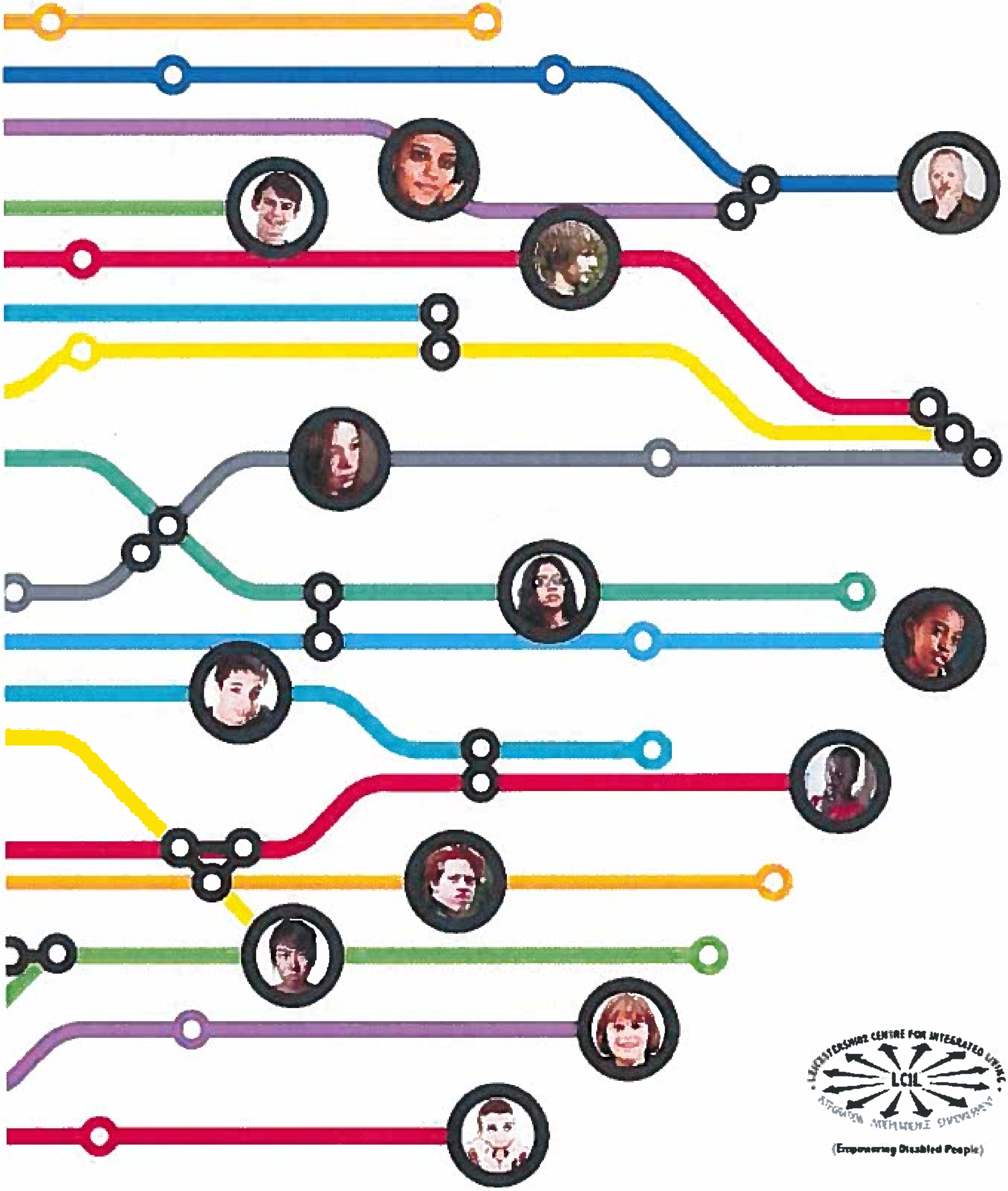
Transition: Executive Summary

A report on the experiences of young disabled people moving from Disabled Children's Services to Adult Social Care



LEICESTERSHIRE CENTRE FOR INTEGRATED LIVING
LCIL
(Empowering Disabled People)

Transition Report: Executive summary

1. Introduction and rationale

Right to Control (RtC) in Leicester is one of 7 national trailblazers, funded by the Office of Disability Issues (ODI). Nationally there has not yet been consideration within trailblazers of what young disabled people want in their lives and how RtC could support their independence.

The Transition project was funded through a 'stretch' bid to the ODI by Leicester City Council. The Leicestershire Centre for Integrated Living (LCIL) was chosen to manage the project.

The main report is based on key issues raised by young disabled people, and illustrated by quotations from them. **You are warmly invited to read the main report to experience what young people said in context.** Most quotations have been omitted from this Executive Summary for the sake of brevity.

2. Right to Control and Transition

The foremost aim of the project is to make sure that a variety of young people from different communities who have different disabilities have their voices heard, about what matters to them.

The term 'transition' in this context refers to the move of young disabled people from Disabled Children's Services to Adult Social Care. This usually occurs when the young person reaches 18 or older, according to the individual's stage of development.

Transition for young people, their families and carers, has generally been a time of concern and can be stressful, as the young person's needs and eligibility are re-assessed by a variety of adult services.

It is important that the opportunities for independence presented by RtC are appreciated and understood by young people themselves and by everyone else connected with a young person's transition, early enough for everyone to anticipate and feel well prepared for the transition itself.

Our project has therefore included meetings with a range of people, in order to inform what needs to take place for young people to understand, access and benefit from RtC effectively.

3. Procedure of data collection

3a. Journey of the project

This was not a randomised project and had to be conducted over a short span of time. Discussions were often open-ended, allowing the young people to talk about things they thought were important. We also met a range of adults involved in the transition process, in order to capture their viewpoints and experience.

A large amount of data has been collected through interviews and focus groups. The main report includes quotations that represent young people's views and highlights issues for service providers to consider. These may be areas where service providers could improve their services further by adapting their models of service delivery to fit in with young people's needs and aspirations.

The 5 funding streams of RtC are:
- Adult Social Care (ASC)
- Housing Related Support (HRS)
- Disabled Facilities Grant (DFG)
- Access to Work (AtW) and Work Choice
- Independent Living Fund (ILF).

3b. Criteria for interviews and focus groups

We met with young people who have a wide range of disabilities. We did not follow any criteria on levels of disability, i.e. mild or complex. If a young person considered themselves to have a disability, we listened to their views. None of the young people we met were receiving RtC, even though some were of qualifying age. The reason for this is unclear, though many young people do choose to continue their education. The adults we met also volunteered their time to take part. We feel that all the people we met made their contributions openly and transparently. We are grateful for this, and for their commitment to the project.

4. Case studies

A series of 10 detailed case studies appears in the main report.

5. Right to Control thematic analysis

Theme 1: Adult Social Care

I would like to have a **Transition Box**, which contains everything I need to know to help my son to make the best transition possible. (Martin, father of David, 21)

Communication

Communication is the biggest issue for parents, families and carers. They are the people who have the largest stake in what happens in their young people's lives, and it also affects them directly. There is a need for consistency in information and that it should be timely. Additionally, teachers and tutors feel that they have good information about students which is not used elsewhere.

Parents and families feel that they need the whole picture. One parent described this as the need for a 'Transition Box' which contains everything required for the young person to make the best transition possible. There was considerable frustration that transition generally was commonly not an holistic process for young people. Young people themselves understood far less about the mechanics of the transition process and viewed it as the day to day consideration of where they might go next in life.

Adult Social Care (ASC) and Housing Related Support (HRS)

Some young people may qualify for funding from ASC if they meet the criteria. For those who do not, but who do still need some support with activities such as travelling or cooking, would Housing Related Support (HRS) be deemed suitable, and would it be available? The division between what could be funded by ASC and what by HRS is unclear to some people.

Service access issues

The single point of contact (SPOC) may be viewed as difficult to access by some disabled people, including deaf people, people with learning disabilities, and people with mental health issues. Drop-in sessions, for some, would be helpful. We were told by a council officer that people could drop in and see a social worker if they went to Greyfriars (the Social Services building) reception - "but we do not promote this".

Assessment by age

There is well documented assessment by development, demonstrated by the fact that young people with profound and multiple learning difficulty (PMLD) can access children's services until they are 25. However, choices for young people with PMLD seem more restricted than those for other disabled youngsters, and young people with PMLD have to transition to adult services at some stage. This can involve, from a parent's perspective, unnecessary assessments such as fitness for work, and some loss of the funding used to help meet the young person's needs.

Additionally, some adult services may not be sufficiently development related to meet the needs of young people with PMLD.

The Resource Allocation System (RAS)

The RAS software works out funding for an individual. We discovered that it is locally weighted, so there is an element of postcode lottery in its operation. This does not guarantee parity of funding if an individual, of whatever age, relocates.

Conclusions for Theme 1, Adult Social Care

Young people...

1. Want more consistent, timely and accessible information prior to transition about the options open to them.
2. Want to know that their needs in relation to socialisation can be met (for detail, see Theme 2).

Parents, families and carers...

1. Want consistent information in accessible formats about all aspects of transition early enough for them to help ensure that transition is more successful than stressful.
2. Want consistency in information and advice from professionals.
3. Want one point of contact, or a key worker, in relation to all aspects of their young person's transition.
4. Want clear explanations of decisions made about their young person's funding.

Teachers and tutors...

1. Want detailed information about transition options and how to access them, in accessible formats, early enough for these to be useful in the classroom.
2. Want more use of their profiles, reports and assessments on individual students as part of the transition from special school to FE college, and as part of ASC and other funding stream assessments.

Theme 2: Independent living

> I know what I want to do and I'm working on it, but I didn't think it would be so hard... Mum is there for me – but it would make me feel better if I was independent and it would be better for her. (Stella, 18, FE college student)

The Independent Living Fund (ILF) and the Disabled Facilities Grant (DFG)

As the ILF is currently expected to end in 2015 and is not taking on new clients, this funding stream is effectively lost to young people and to RtC, so we expect a range of unmet need unless this can be taken up elsewhere in the system. Would ASC be a possible choice? As Housing Related Support (HRS) is also not taking on new clients, the pressure on ASC is potentially severe. Effectively, one third of the RtC funding streams can currently offer no practical benefit to young people.

Young people and their parents, families and carers seemed to know little about the DFG unless they were already receiving it. We met with a few young people whose homes had been altered to meet their needs, to great benefit. Parents, families and carers seemed to know little about adaptive technology and showed great interest, though the cost of some simple items was prohibitive to some.

Some of the rest of this section demonstrates some of the needs of young people which could be met by the ILF and the DFG, were funding available.

Independent living skills

> I stayed in the (independent living) flat at college for one night. I really enjoyed this – so I did it again! I would like to have my own flat. Mum's trying to get sheltered accommodation for me ... (Catherine, 21, FE college student)

A number of young people had received opportunities to gain experience of independent living through overnight stays in supported environments. Young people were very enthusiastic about trying out the skills learned in school or college and at home. These skills are part of the curriculum for students in special schools and for students whose FE college timetable includes foundation studies.

However, the frequency of opportunities is limited due to the level of demand, as is the funding available for support staff. This means that some much needed practical experience is not available to some young people and accommodation in short supply can end up being under used.

Some students were able to appreciate the positive differences their independence would make to other family members as well as to themselves.

Young people...
1. Want more practical opportunities, overnight and at weekends, to try out their existing independent living skills, and to try out new ones.

Parents, families and carers...
1. Want to feel secure that their young people could survive on their own.

Teachers and tutors...
1. Want existing independent living facilities to be able to be used to capacity, and for additional facilities to be available to meet the need.

Transport and travelling

Travel training was available to many but not all young people who needed it. Those who missed out tended to be on more academic courses. Some students were interested in learning to drive a car but this skill did not appear to be provided for. Young people generally wanted to travel independently. Some had issues with public transport, either with the negative attitudes of some bus and taxi drivers or some passengers. It is clear that travel training has to be about more than just understanding bus timetables and paying your bus or taxi fare.

Having, or not having, a bus pass was an issue for some students in relation to travel costs, including getting to or from college.

Young people ...

1. Want to travel independently, and want travel training.
2. Want to be able to afford to travel.
3. Are interested in learning to drive a car to give them greater independence.
4. Want bus and taxi drivers to show respect.
5. Want less hassle from other bus passengers.

Socialisation

> They saw me as an individual. They didn't see me as a disabled person in a wheelchair.
> (Stella, 18, FE college student)

Making friends and going out

We discovered that a large number of young people do most of their socialising in school or college, simply because these are able to provide a more flexible, adult environment which is safe and supportive for young disabled people. Schools and colleges are natural meeting places. Travel arrangements are already in place.

The biggest barriers to young people meeting out of school or college were cost, distance, difficulties with public transport and, in some cases, concern or fear about attitudes to disability outside the school or college community.

One important factor for young people was having a safe and secure environment, one in which they felt they could be themselves.

Young people who went into the wider environment tended to have strong views about their experiences and could list and score places they'd visited for accessibility and quality of service. Some young people were not anxious to receive help and had the confidence to ask for it. In these cases, asking to help was crucial as unasked help could disrupt existing skills and be counterproductive. Services too were expected to ask rather than assume for best results.

The attitudes of the general public are extremely important to young people. The bullying which takes place in some educational environments is also a feature of being in a public space for many young disabled people and, for some, its effects can debilitate. Over time, this can result in reduced confidence, increased levels of anxiety and a reluctance to try out new places.

Alternative forms of communication, like mobile phones, are popular because some young people have significantly less opportunity to meet friends and make new friends out of school or college time. If families can't ferry them about, or if friends live too far away, or if young people can't travel independently, these are the only opportunities to keep in touch.

Young people do want to go out and about with their friends, shopping or to the cinema or bowling, and into town at night, but there are restrictions.

A young disabled person might think twice about going into town in the evenings to meet people and make new friends. What information is available to young people which advertises venues which are disability friendly, which they can use with confidence? What initiatives are there in the city to encourage venues to take a positive approach to understanding disability equality and to attracting business from this community?

The implications for RtC are significant in relation to the socialisation aspect of funding. How can this best be assessed to reflect individual young disabled people's needs? How can systems ensure that assessments for this operate equitably across the range of need?

Young people ...

1. Want to go out – and stay out late!
2. Want to meet friends - and make new friends - outside school or college.
3. Want people and services to ask rather than assume where help is concerned.
4. Want places to socialise which are accessible, safe and enjoyable places to be.
5. Want less hassle – both unfriendly and well meant - in public places.

Life, love, sex and having children

> I have a boyfriend, but I do not ask him to care for me. I want him to see me as a person, not a disabled person.
> (Linda, 18)

Young people want their own families as well as friends. Having children features sooner (females) or later (males) for many. Some put their careers first; a few already have girlfriends or boyfriends and plan a future together. One young woman had even decided what kind of birth she wanted. One young man wanted a male partner.

Some families were secure with their young person's developing sexuality.

Young people ...
1. Want sexual relationships as well as friendships.
2. Want support, if they run into difficulties.
3. Want choices, such as whether career or having children comes first.
4. Want children when the time is right.
5. Want choice about relationships.

Parents, families and carers

Our experience with parents provided a few examples of the need for support and advice for families. Some parents and carers, not uncommonly, demonstrated over-protectiveness. Some wanted choice over who the young person had contact with. The main concern here was exploitation, abuse or unwanted pregnancy.

RtC funding streams can include funding opportunities for young people to socialise, to become independent, and to live separately from their families. Providing the right information and support for parents, families and carers to understand more about young disabled people forming sexual relationships as they grow in maturity could help to increase their confidence and willingness to support a young person who wants to take more responsibility for themselves.

Parents, families and carers ...
1. Want guidance and support in relation to young people's developing sexuality, especially if young people have learning disability.

Theme 3: Education, jobs and training, going to university

> I want to do work experience and go to college. I'm learning computer skills and languages, French and Spanish. I'm good at Spanish.
> (Valerie, 13, special school student)

Education

Most students see the connection between the courses they are following and moving on to more education or training or getting a job. Most students' timetables are personalised. Their last year at school or college is very busy as this is a focus for transition.

Course flexibility

It seems that the education system, especially in FE colleges, is flexible enough to support a student working at different levels, or one who needs to take more time, or to repeat courses, in order to achieve the needed qualifications. Students gave examples of how their needs were taken into account during the courses and at examination time.

However, for some students operating at the higher levels who most likely came to college through mainstream education, life skills courses such as travel training which were available to Foundation level students at special school, were not always available to them. Potentially, these are barriers to a student being able to achieve independence at times when their other, probably more academic skills, are maturing well.

Curriculum: Course content

It is clear that teachers and tutors are very keen to have access to up-to-date and relevant course materials for the life skills and citizenship types of course. They feel that they are failing their students in not being able to provide this type of detailed information relating to current developments in transition and RtC. Further partnership working between education and statutory services may be the answer.

We strongly support the inclusion of young role models from employment and higher education who could share their experiences. Teachers and tutors say that there is a significant lack of information and people to fulfil this crucial role in curriculum delivery and development.

The Right to Control is based on young people making choices. Joint working on curriculum development between education, social services and the other RtC funding providers could ensure a safer foundation for a smoother Transition process, and prepare the way for more young people to choose the Right to Control as their preferred route to independence.

The developing Information Strategy for transition

Professionals from the statutory sector also wish there was sufficient capacity to enable them to have early contact with young people in schools, to facilitate the transition process. They are very aware of the need for good information, and the Transitions Partnership has developed an Information Strategy, which takes an holistic approach, to fill the information gaps.

It is in the interests of both social and education services that the curriculum is developed to reflect current issues, so that knowledge about transition becomes a practical part of what young people learn about.

Our view is that young people themselves know least about transition – and that this could be remedied comparatively easily by the implementation of the proposed Information Strategy.

Person-centred planning (PCP)

Young people themselves are becoming more and more familiar with the process of person-centred planning (PCP) from an earlier age, and families are generally supportive of the process. If practical up-to-date knowledge is made available within schools and colleges about transition options and Right to Control, these can be applied within person centred approaches to show the young person and their family how independence can be achieved.

Additionally, parents would appreciate the value of having a single point of contact or a key worker in relation to transition and RtC. As parents and families can be the biggest influence on young people's choices, and potentially the biggest barriers to them achieving optimum independence, this is a key issue to be addressed.

Expectations post-18

For many students on Level 2 or 3 courses, the expectation is that they will go to or stay on at FE college or, from college, will seek employment or a place in a university.

For others, the motivation may come as a response to negative attitudes to disability from education and from employers and, ironically, may lead to greater motivation to succeed.

Taking a year out

Some disabled students may wish to take a year out in order to gain wider life experience or to follow up a personal ambition. For instance, if a young wheelchair user wants to experience Camp America, would some financial support for this be an appropriate use of RtC?

We encountered virtually no evidence of the idea of young disabled people taking up 'year out' opportunities, yet the potential benefits to the young person of gaining life skills and possibly job experience are significant. The challenges this poses to initiatives like RtC are as yet unexplored. In theory the independence available through RtC would be ideal for young people with these or similar ambitions.

For some young people and their families, the future after college is more uncertain. Parents, families and carers of young people with profound and multiple learning disability (PMLD) seem to have less knowledge about post transition opportunities, yet RtC could well be the appropriate choice, with appropriate budget management arrangements in place and a wider choice of services.

100% Health funding

If a young person is assessed as 100% Health funded, it is not yet fully clear how this could work for young people who also have education, employment or social care needs. If parents, families or carers are to support young people and young people themselves are to take up RtC in these circumstances, this information needs to be available to them early enough and in a clear and unequivocal form, to help them to make decisions.

Disabled students in mainstream schools

Some young people and their families felt there was a lack of support and opportunity available to disabled students in mainstream schools.

In particular, at the age of 16, essential services, such as speech therapy and physiotherapy, are discontinued and are difficult for the family to have reinstated. This seems to be age rather than needs related, and so does not make much sense to parents and families.

Bullying and discrimination

One strong element that featured in relation to mainstream schools was the potential for the disabled young person to experience bullying. Young people with hidden disability in mainstream education tended to choose keep their disability hidden. Their concern was to avoid, at all costs, negative disability related attention from their peers.

One young man with a potentially serious but hidden disability did not even consider himself to have a disability. To him, disabled young people were the ones who were taken out of class to another classroom – i.e. young people with learning disability – and he didn't want to be associated with them in the minds of his peers.

Furthermore, it became clear that bullying and negative attitudes to disability can cause a degree of self-hatred in young disabled people. There are two issues here. One relates to the continuing need for attitude change in schools, colleges and within society generally. The other usually but not necessarily has cultural roots and results in similar negative impacts.

Leicester city schools already have the successful ABC (Anti-Bullying Campaign) Awards and an electronic system for recording and addressing different types of bullying in schools. Both these approaches are now rolling out across schools in the city. What can be done in Leicester to ensure that bullying and negative attitudes, from whatever source, do not prevent young disabled people and their families from accessing RtC in the future?

Inclusion – and isolation

Several of the young people we interviewed had not met with someone with the same disability, impairment or health condition as them until they were in their teens. There was a sense of the isolation of the young people, without the opportunity to meet with and relate to others **who could share this aspect of their identity**. All the young people in this situation wished they had met similar others much earlier in their lives and viewed this as a missed opportunity to exchange information and to learn from others' experience.

We met with young people at an inclusion youth group, expecting it to provide opportunities for disabled and non-disabled young people to meet in a social environment. What we found was young disabled people meeting with each other, supported and facilitated where needed by youth workers and young disabled volunteers.

There was a wide range of activities available to the young people, in which they could interact with others in an environment which was free from the pressures of home, the classroom, and the need to be assessed. Having volunteer young disabled people as helpers also provided role models for the younger members.

Issues for Deaf young people

Education for deaf children in Leicester follows the auditory approach which means that the choice for bilingualism is not actively encouraged. Many deaf children and their families cannot access free sign language courses which are offered in nearby counties like Nottingham and Derby.

However, most deaf young people attend mainstream schools and have support where needed. In this, they are likely not to be able to meet with other deaf young people in a social situation. The Hearing Impairment Service provides one day per term for young deaf students in Years 7, 8 and 9 to meet together and share experiences, though the social aspects are limited as these times focus on much needed knowledge and skills.

We met some teachers that work with deaf children. On hearing about deaf sports clubs one teacher questioned why a young deaf person would need to meet with others like themselves when they could mix with hearing young people. As there is no mental health service specially tailored to meet the needs of deaf children or people in Leicester, we feel that the possible implications of a lack of opportunity for self-identity and peer support may require further consideration.

The potential impact here on RtC is the potential for additional support, required if young deaf people experience the difficulties referred to above, which could also delay or prevent them taking up RtC, possibly delay their entry into employment and reduce their life opportunities.

In addition, we noted that the accepted form of access to some services may not be suitable for some disabled young people. Access to Work requires initial contact to be made over the telephone. We think that this would not support the independence of Deaf people, even with a textphone service available, or people with learning disability, or people with mental health issues, who might benefit more from initial face to face contact.

Moving on: Transition out of college

Colleges are aware of knowledge gaps in their staff relating to transition into and out of college. Given the importance colleges, parents and families place on the role of education in preparing young people for life outside, these gaps become significant. Local authorities have differing practices, so this is a local, rather than a national, responsibility. It is also an ongoing one, as the rapidly changing environment could easily lead to good information becoming outdated quickly.

This reinforces the need for schools and colleges to have full, accessible and up-to-date information about transition opportunities to assist them to better 'bridge the gap' between statutory services and young people trying to plan for their futures.

Proposed developments

We have reviewed the proposals for an integrated and holistic Information Strategy, produced in partnership with Disabled Children's Services, and we believe that this will help to address many of the current information gaps.

There is a proposal to fund an Information Officer, to implement the strategy. We welcome this development and, as long as the person in post seeks proactively to meet with young people and their families, services (including Health) and service providers, and schools and colleges, to identify and plug information gaps with accessible and timely materials, the benefits to all will be significant. This means that the Information Officer will need to have the explicit support of all partners, and be empowered to make demands of them.

Such a post could also result in less irrelevant and out-of-date information being in circulation or, particularly, found on the internet.

We understand that one special school and one FE college are seeking to create a post of Transition Officer. In each case, if funding is available, the person appointed will be responsible for ensuring the successful transition of individual young people into and out of that school or college, with benefits all round.

As parents and families will often ask the school or college for information and support when things are unclear, having a dedicated person available who can provide this clarity and also access to up-to-date information (tracking) about an individual's progress through transition would be an immense benefit and confidence-raiser all round.

Young people …

1. Want to know how RtC could improve their lives and help them achieve their aspirations in life and work.
2. Want more personalised independent living skills where these are lacking.
3. Want freedom from bullying and discrimination, and for non-disabled people to understand more about disability equality.
4. Want the opportunity to meet with others like themselves at an earlier age.
5. Want places to go outside school and college where they can meet friends, make new friends and not be made to feel 'disabled' or out of place.
6. Want support in the transition out of education, to paid employment.

Parents, families and carers …

1. Want more information about RtC to help them understand how RtC could increase independence and opportunities for their young person – and possibly for themselves.
2. Want to know and understand the rights they and their young people have and how these can best be applied.

Teachers and tutors …

1. Want real, accessible information to enable them to include RtC in the independent living curriculum in a practical way.
2. Want more opportunities to involve parents, families and carers in young people's progress, development and futures, to help them appreciate the capabilities the young person has and to encourage healthy risk taking.
3. Want to understand fully how a young person's wider needs can be met if they have 100% Health funding.

Employment and training

> I live at home. I am bored at home on my own 4 days a week. I work as a volunteer in a charity shop 3 days a week. I want to do full time work.
> (George, 25)

The majority of the young people we met wanted employment and had ideas about what that could be. Some had had work experience, or work trials via the Leicester Works initiative, and others were looking forward to these. Not many were aware of the support available to them to find work, though the Connexions service and Remploy services (through Leicester Works) were best known about and valued.

Work experience, work trials and work placements

Good quality work experience is much valued and sought after. Most students had some idea of what employment they were looking for if not exactly how to achieve it. The occasional young person had the benefit of access to a family business, some wanted to take the self-employment option and overall, the choices were very varied. Young people became bored with long periods at home and wanted careers, pay, and the independence these could provide.

Hardly any students mentioned university as an option. Some had had experience of work and valued this opportunity. We had no adverse criticism of work experience, and much enthusiasm.

Support for young people seeking employment

The Leicester Works initiative

We became aware that some young people were part of the Leicester Works initiative, which is a partnership between Leicester City Council which provides work placements, Leicester College which provides workplace skills support, and Remploy which provides workplace mentoring and is the employment broker in the partnership. Recently, University Hospitals Leicester joined the partnership as a work placement provider.

Learning disabled students in their final year at Leicester College can apply for placements, which they enjoy. They get the experience of preparing for and being interviewed for work placements, supported employment experience in 3 or 4 different 3-month placements, and a report or reference from each placement. Support in the workplace, whether it's a placement, work experience or paid employment, is a key issue for students and families alike.

This is therefore a key issue for Work Choice. The level of mentoring and support in the work place can be the difference between a young person remaining employed, developing their skills and learning new skills, and them leaving employment, losing self confidence and reducing the likelihood of them being able to access paid work again. Similarly with Access to Work, young people need to know how they can access what they need to perform fully in paid employment.

In FE colleges, students are being trained and supported to be work ready, through Leicester Works or other initiatives, yet it seems that at times the opportunities at that point are unclear, as is the referral process from college to Work Choice. Teachers and tutors in FE feel strongly that for some students there is a gap between becoming work ready and finding employment, which can lead to skill levels becoming reduced and confidence waning.

A role for social enterprise

One social enterprise has been established to work with different special schools to bridge the gap in aspiration, taking a personalisation approach. They aim to employ disabled people as trainers, mentors and coaches to others like themselves, with a focus on disabled people getting jobs. The organisation also provides post-employment mentoring.

An interesting development to us was that the organisation was starting to offer accreditation to people who offer services to disabled people, including 'train the trainer' or peer support approaches. This approach, of 'professionalising' services, has the potential to provide quality assurance standards and can benefit employees and clients alike. If an organisation advertises opportunities for accreditation, this could help young people to distinguish between them and other providers when making decisions within RtC.

We met with 3 organisations in total which were very well positioned to deliver in response to RtC though none as yet had received any RtC business.

Quality assurance of services and value for money

There is a growing range of services in the city which will continue to proliferate as the market expands. What standards should disabled people, of whatever age, expect when looking to engage a particular service? Who can they complain to effectively if there is an issue? Is the service provider a member of a registered body? How will disabled people know which services offer the best value for money?

These questions are as important for young disabled people as they are for others taking on the management of their own budgets for the first time, even with support, and we feel that as yet there is only minimal availability of the kind of information which would assist them in making decisions. This situation may also put some young people off taking on the responsibility for their own support and care.

Without exception, the social enterprises and voluntary sector organisations we met with showed a high level of knowledge of the broader issues, were well prepared to offer a personalised range of services to their clients, and had developed or were developing strong links with statutory services. An issue they had in common was the lack of clear and specific information about RtC to enable them to work more closely with their clients.

Support from families / Cultural considerations

Where young people mentioned that they got a lot of encouragement from their families, they had very positive outlooks. Some young disabled people have the family support they need to develop their confidence and enable them to have positive outlooks and experiences. Those who may not have had sufficient support may need more encouragement in trying different services or in taking on RtC, and may benefit from more advocacy.

For some students, their future is influenced by cultural considerations. Some female students from Asian backgrounds who have learning disability spoke of their career interests but expected to be married soon after they completed their college education, possibly to a partner from abroad. It was unclear whether they were aware of their rights, and one teacher spoke convincingly about the apparent lack of choice for young Asian women with learning disability.

Young people...

1. Want good quality work experience, work trials and work placements.
2. Want support in work experience and in maintaining paid employment.
3. Want more information about the range of job coaching, mentoring and employment support available, how to access this and how to judge good provision.
4. Want information about Access to Work, what it's for and how it operates.

Parents, families and carers...

1. Want more information about what support is available to young people to help them find paid employment.
2. Want to know how best they can support their young person into paid employment.

Teachers and tutors...

1. Want to be able to link directly with Work Choice to enable work ready students to access paid employment in a smooth transition.
2. Want reliable information to be able to include Work Choice and Access to Work in the curriculum in a practical way.

Going to university

> I went back to education because I wanted to do something rather than just vegetate. One of my major goals was to get to university. People were, at one stage, very unoptimistic about me – but I like a challenge.
> (John, 31, unemployed graduate doing voluntary work)

Hardly any young people mentioned going to university, yet a number of the young people we met were succeeding at Levels 2 and 3. Meeting with young people who had been through the university system, it was clear that gaining entry to university and succeeding whilst there is not straightforward if you are disabled.

The young people we met who had been to university reported a number of barriers they had to overcome. For some the barriers are not academic and relate to, for example, a lack of life skills such as independent living skills, or the perceived need not to move away from existing support networks.

For a young non-disabled person, the choice of university can be narrowed down to factors like whether there's a good local football team, theatre, mountain range, social life and so on. For a young disabled person, the choice of university is limited by factors such as the accessibility of the course, the accessibility of the physical environment, the availability of support and support networks, knowledge of how to access support, and the attitudes of university staff, lecturers and fellow students – all these before they consider wider personal or social interests.

On arrival at college or university, some young people, as the result of experiencing prejudice previously, refuse needed support because they do not want to be identified as a disabled person. In this way, the negative attitudes experienced at home, in their local neighbourhood, in school and at college can transfer to the young disabled person's adult life, influencing their view of themselves in a negative way and possibly limiting their life chances.

One item we did come across was the insistence of a local university that young disabled people did not come to them with pre-knowledge about the Disabled Student Allowance (DSA). Rather, if a student presented themselves to the university's student services as disabled, they would then be informed about the DSA and how to access it.

This implies the possibility that not all information relevant to a disabled young person about university is readily available to them. Apart from the possible impacts of this, it raises the issue of whether or not universities and student unions will be prepared to make available timely information to disabled students about the opportunities RtC could provide after university.

Beyond university

Even for young people who have gained higher qualifications like a degree, the difficulty of access to financial support remains a barrier to them attempting paid work at all, or to them building up to working over 16 hours a week and, if that doesn't work out, having to try to reclaim the benefits lost.

Most young people, after university, want to use their time positively. If they are unable to obtain paid employment, volunteering can provide the opportunities they need to operate in a work environment and learn the skills that employers are said to value. It's not unusual for volunteering to be viewed by young people as a 'stop gap' between university and employment. However, if disabled young people in this situation are not able to obtain paid employment within a reasonable timescale, they are at the same risk as other young people, of becoming dependent on benefits and of losing some of the knowledge and skills they have already gained.

For disabled young people with degrees, post-university is the time when RtC could feature strongly. If young people, prior to university entrance, have not come into contact with RtC and what it could provide, there is a need for university student support staff and for RtC funding streams themselves, especially Work Choice and Access to Work, to provide both timely accessible information and a presence, so that support into employment is readily available.

Volunteering, though beneficial to voluntary organisations, young people and society for a number of reasons, is not geared up to moving the young person on into employment, and there is the possibility that they will become 'stuck' at this stage and benefit dependent. It seems that there is a 'second transition' for young people post-university when they are once again seeking effective guidance and support to enable them to move on in life.

Young people...

1. Want fewer barriers in the UCAS (university entrance) system.
2. Want a full set of independent living skills to complement their academic achievements.
3. Want more variety in their choice of available, accessible university.
4. Want more confidence that the support available to them locally can also be available if they choose to study away from home.
5. Want people at university, whether peers or staff, to see the person first, not the disability.
6. Want the support needed post university to help them make the 'second transition' to paid employment, possibly through RtC.
7. Want some flexibility around access to benefits and building up to working in excess of 16 hours per week.

Parents, families and carers...

1. Want the security of knowing that support levels can be the same if their young person wants to study away from home.
2. Want to know how best to support a young disabled person before, during and after university.

Theme 4: Housing Related Support

I would need help with times and dates – I'm crap at timekeeping.

> I'd need someone to point me to do my washing. I'd need help with the ironing as I'm scared of getting burned.
> (Catherine, 21, FE college student)

A wide range of young people could see themselves living in their own place but few had an understanding of what support they might need to keep their independence, maintain their tenancy or pay their bills. We identified a wide range of support that young people would need to maintain their independence, such as support with keeping to a schedule or routine, with managing a bank account, or with entering into contracts. However, at the time of this project, Housing Related Support (HRS) reported that they were already at maximum capacity and did not have any available spaces left for new clients.

There is therefore a significant gap in services for young disabled people who turn 18. In this respect, RtC is missing a key element of the package that can enable young disabled people to be independent. It may be that some knowledge gaps for some individuals can be identified that schools and colleges can assist with. However, if ongoing support is required, we found no evidence of forward planning. Using funding reserves to meet such needs is ultimately too risky.

Young people…

1. Want support to help them <u>maintain</u> their independent living, having gained skills at school, college and at home.

Parents, families and carers…

1. Want clarity about what HRS would be available to their young person.
2. Want information about possible overlaps with ASC provision.

Teachers and tutors…

1. Want the information necessary, in accessible formats, to enable them to include realistic HRS opportunities and scenarios in the classroom as part of the independent living skills curriculum.

6. Additional non-Right to Control themes

These additional themes may not have a direct relevance to RtC. However, they brought up important questions that may indirectly affect how people access RtC or how it is delivered. This is why we felt it important to include them. Right to Control cannot exist in a vacuum. More detail can be found in the main report.

<u>Theme 5</u>: Examples of best practice

We came across many of these and some appear in the main report within other sections. Here, Example 1, in Housing Related Support, shows how potential conflict of interest can be avoided. Example 2, in Housing Options, shows how a service can engage in effective forward planning. Example 3, of a non city school met by chance, shows how higher levels of support and funding can benefit young people whose local authorities cannot meet their needs.

Theme 6: Young people's ideas of managing Right to Control

A few real life examples show that the various options for managing a budget like RtC, composed of several funding streams, need to be included within education, prior to real life experience, to prepare young people.

Theme 7: Disability, BME and society

Some illustrations of cultural differences we met which could adversely affect a young disabled person's choice, independence, and self belief.

Theme 8: Myths and concerns about Right to Control

Some points relating to the confusion we found about benefits, personalisation and what RtC means for a young disabled person, and good practice arising from co-operation between 2 city schools which has the potential to resolve some of these issues through their work with both young people and their families.

Theme 9: Conflict of interest and the young person's choice

A short series of examples of how families may unwittingly restrict young people's choices, and their taking up of RtC, through lack of knowledge or understanding, or through the negative impact of some media reporting.

Theme 10: Safe spaces

Some brief thoughts on the need not for safe spaces as such, but for all spaces to be safe for disabled people, and the potential impact of RtC on disability equality.

Finally...

Our sincere thanks to everyone, especially young people. You gave your time and effort so freely to contribute to this report. We couldn't have done it without you.

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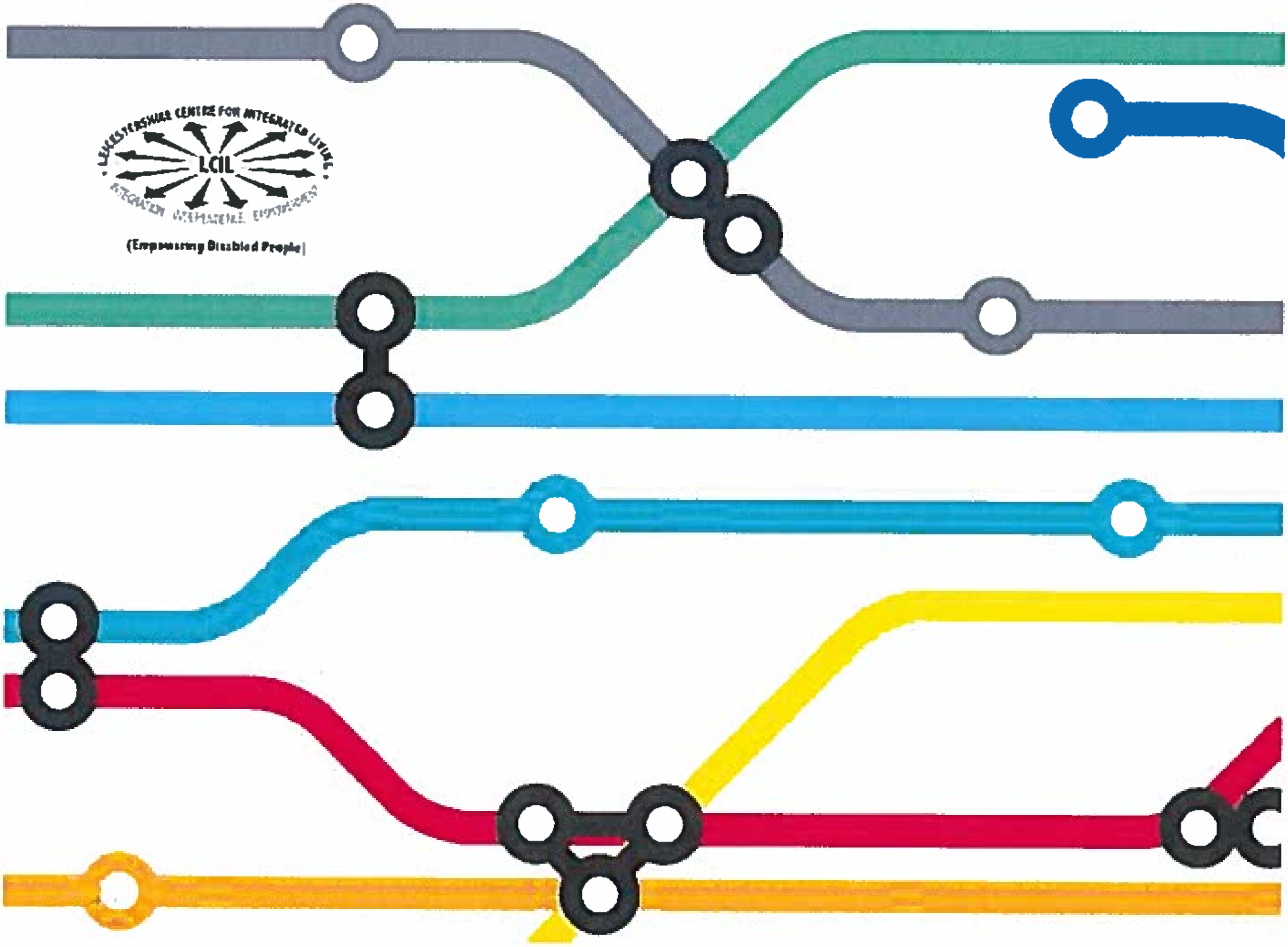

(Empowering Disabled People)