

‘A Better Future?’: Young adults with complex physical and communication needs in mainstream education¹

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Introduction

Little thinking or debate around disabled students being able to access mainstream education and qualifications has actually sought to take into account the views of those students themselves, particularly those with the highest levels of physical and communication needs. This paper presents findings from in-depth interviews with young adults with complex physical and communication needs expressing their views and experiences of mainstream education. Participants discuss what access to mainstream opportunities mean to them and how opportunities for informal learning are just as important to them as being able to learn the same subjects and gain the same qualifications as their peers. By presenting our findings using the authentic voices of those involved in this piece of participatory research, an added dimension is brought to understanding the needs and experiences of disabled students with complex needs in mainstream education.

Background

Schooling can make a significant difference to the quality of life opportunities disabled people encounter as adults (Bjarnaason, 2003; Casey et al, 2002). Comparative research finds that disabled people who have attended mainstream, as opposed to special, education tend to be

more likely to be living interdependently and in employment (Gray, 2002). However, the segregation of physically impaired young people into special schooling continues to be the norm. According to recent OFSTED reports, the proportion of pupils with statements of Special Educational Needs (SEN) in mainstream schools has not been affected by the government's inclusion framework and only 1 in 10 mainstream secondary schools are deemed to be fully accessible (OFSTED, 2004).

The increase in the number of parents appealing to Special Educational Needs and Disability Tribunals similarly reflects the difficulties many disabled young people encounter when trying to realise their potential. Concerns have been raised that many LEA's deliberately refuse disabled children the assessments and provision to which they are legally entitled knowing that only a minority will appeal against their decisions (Gold, 2003). Indeed, the Disability Rights Commission recognises that education providers routinely break the law in discriminating against pupils and students because of their disability (DRC, 2005).

Encountering barriers to doing the same things that other young people do defines many disabled young people's experience of social exclusion (Morris, 2001). School remains the main opportunity for most children and young people to make friends and learn about relationships and for many disabled children school is often the only opportunity they get to spend time with others of their own age except siblings (Murray, 2002). It is easy for adults to forget that for children and young people, friendship is the main motivator for going to school (Morris, 2002). Yet many disabled young people who have managed to gain access to mainstream education report that they often feel left out, are made to feel different, are bullied and experience social isolation (Murray, 2002; Gray, 2002) and 26% of 11-15 year old disabled young people, compared to 14% of non-disabled 11-15 year olds, describe finding it quite or very difficult to make friends (Morris, 2002). Young people with communication

impairments and high support needs find themselves to be even further disadvantaged in their opportunities for building relationships (Murray, 2002). Accessible leisure opportunities inside and outside of education are crucially important in enabling disabled young people to make and spend time with friends and can contribute to a more inclusive society by making disabled people enjoying positive experiences visible outside of 'special' settings (Murray, 2002). Current education policy, however, barely recognises that from a young person's perspective, friendships are a main motivation for going to school and social isolation may be a key barrier to their getting the most from their experiences in education (Morris 2002).

In terms of the opportunity to gain mainstream qualifications, recent research finds that 61% of pupils with statements of special educational need in special schools were not entered for GCSE qualifications compared to 4% of SEN pupils in mainstream schools (Audit Commission, 2002) while 24% of disabled people aged 16-24 have no qualifications at all compared to 13% of non-disabled people of the same age (ONS, 2003). Complaints to the Qualifications and Curriculum Authority regarding special arrangements for GCSE and GCE's (QCA, 2004) indicate that the barriers students face are occurring at many levels. Ultimately, however, narrowed opportunities for the realising of potential mean that at aged 18 young disabled people are only 40% as likely as their non-disabled peers to go to university (DRC, 2005) and, as adults, over seven times as likely as non-disabled people to be out of work and living on benefits (Labour Force Survey, Summer 2003).

About the Research

The RITE research project was initially designed to investigate the transition from school to Further Education and independent adulthood for young adults with complex physical and/or communication needs. The RITE Research Project was conducted by researchers from the

DARE Foundation and the London School of Economics in conjunction with the ACE Centre Oxford and was funded by The Gatsby Charitable Trust. The impetus for undertaking the research came about because there had been little investigation into the educational experiences of people with physical impairments and/or communication needs who did not have learning difficulties.

Involvement in the RITE Research Project involved participants taking part in an in-depth interview and completing a face-to-face questionnaire. In undertaking the interviews, participants were presented with a list of 16 topics which had been decided upon by the researchers in discussion with advisory groups of disabled people. Participants were asked to choose 4 of these 16 topics that they would like to talk about. Within this structure participants were free to discuss the issues they felt were of most importance. By far the most commonly chosen topic was 'education'.

In total, excluding 12 sets of parents, 33 disabled young adults took part in the research. 16 were young people aged between 17 and 23 with an average age of 20. 17 were 'post-transition' aged between 25 and 42 and an average age of 31. 19 participants were male and 14 female. 25 of the participants self identified as white, 2 as Asian, 1 British Indian, 1 African/Caribbean and 1 mixed parentage (3 participants did not complete the questionnaire and so this information was not collected from them). Participants came from all over the British Isles but the majority from the South East, Midlands and North West of England and were recruited through a variety of informal sources such as adverts placed in newsletters for organisations of disabled people. All of the participants self-identified as having complex physical and/or communication needs, mostly due to neuro-muscular conditions such as cerebral palsy. All but two participants were wheelchair users and 14 participants used other forms of assistive technology in addition to their wheelchair such as switch controls or computer access devices such as adapted keyboards. In total 19

participants had a mild to severe speech impairment and 8 of these 19 people used a communication aid such as a text writer or VOCA (Voice Output Communication Aid). 26 participants stated that they required personal assistance for day-to-day living.

Most of the young people who took part in the research were still in full-time education and had experience of both special and mainstream education environments. All but three of the post-transition participants in the project had finished full-time education. Many had also experienced both special and mainstream education though fewer post-transition participants had experienced mainstream education than young people.

In Participant's Own Words

For many disabled children, regardless of their academic ability, a place in a mainstream school and the opportunity to gain mainstream qualifications is something that must be fought for and won. One of the main reasons that many people described as a reason for their wanting to take part in the RITE Research project was because they hoped that in talking about their experiences they might help to create a greater awareness of what it is like to be disabled and people might change some of the ways they thought about and treated disabled people. This was important to people because of some of the ways they themselves had been treated and difficulties they had encountered. Because the young people who have contributed to this research so often find their voices ignored and their abilities and potential denied, this paper is comprised, predominantly of their own words.

Special education is still the most dominant form of educational provision for disabled young people. 25 of the 33 young adults taking part in the project had, at some point, attended a special school or college, some through choice, some through lack of choice:

My choice of GCSE's and choice of A levels was severely affected, even my choice of school, my choice of secondary school was hugely affected as only one school in the area was accessible for wheelchairs.

If you don't have the choice between going to state school, private school, boarding school or public school then your academic opportunities are limited in that you haven't made that choice...Everybody wants the best for their children. If, like in the U.K, you have a system where it is not really clear which one is best, where each one offers a different thing, a different type of education, then you should have an opportunity to access all of those types. I am not saying that my parents would have sent me to a private school, I am not saying they could have afforded to, I am just saying that it would have been nice to have had the choice, for being restricted for something other than the fact that I am sat down.

Though most participants had some aspirations to access mainstream education because it was thought of as a gateway into a wider world of mainstream opportunities, some participants were keen to stress their positive feelings about special education:

Despite what a lot of people might say I actually think that special education is a good thing...I think special education enabled me to grow as a person, develop from a child to a young person without the barriers of mainstream kind of life.

However, many other participants felt extremely let down by the quality of learning they had experienced in the special schools and colleges they attended:

Socially it was very good; academically we didn't do very much. So I acquired some social skills but nothing really that expanded my mind.

I would see one (teacher) and that one would do everything. It was like primary school.

The nondescript way they teach is dull. They only had lots of detritus to share. It was akin to having nursery teachers.

At the heart of peoples dissatisfaction were the low expectations of their potential and abilities that they felt they had encountered in special education:

As I went through my childhood, through special school, around the age of 13 to 14 I began to realise that I was missing out a lot. Around that age many of my (non-disabled) close friends and people around my age used to bring back homework in different things, different subjects about what they used to do at school and I thought it was really interesting and we used to bring back paintings... My friend said you really ought to approach the headmistress of the school and we went to her office, she opened the door and we went into the office and I said 'Could we do something more interesting?'. So she said, 'Like what?'. Well I had heard about science and some of my friends (in mainstream school) were doing science and I thought it sounded interesting. She said 'There are 2 things; number one, we don't have the staff and number two, I don't think you are capable of doing it, but anyway I have got a great idea.' So I said 'great'. Ok, it was not going to work out the way I wanted it to but she had got a great idea. So she goes 'There is a guy coming next week and he is a stamp collector', and that was her answer to my education!

They assume that kids in wheelchairs can't do much so they don't expect them to do much so they don't provide them with access to do things.

You had an educational programme which focused on physical needs and low expectations and if you challenged that then they felt it was easier for them not to raise your expectations, to give you more opportunities.

Low expectations inevitably had an impact on how some

young people felt about their abilities:

When I was younger I wasn't really into the academic side of it...I wasn't interested in writing or reading or anything like that because I thought I couldn't do it.

I was written off. A lost cause. I was labelled. There was no one of influence who understood things I could be capable of. I did feel so tiny minded in this world. Occasionally it did occur I really am retarded. It did not occur to them I was not.

Beyond Special Education

Many of those taking part in the study, particularly those who had been out of full-time education for some time, described the longer term impact they felt their experiences of special education had had on them:

I began to realise what opportunities I could have had, I realised that I could have been much further on academically at a much earlier age and probably have done things more quicker.

I felt that it slowed down not only your academic ability but also, I think, the mere fact that you were not, you were kind of cut off from some of the other mainstream things in society as well. So the mere fact that you are actually categorised as 'specialised', for me, means that you are being cut off. It is like being a branch to the main part of a tree; you cut that branch off, it is not going to get all the nutrition from the rest of tree, from the rest of the roots... it really did kind of handicap (sic) you more than your actual physical disability.

I think due to my speech impairment, I could not prove myself to the teachers. The teachers did not realise that I could actually speak and my brain was in full working order, I only had physical disability, which happens to include a speech impairment, not a learning disability. Even though I would communicate with my family and

friends, the teachers would not encourage me to communicate verbally with them and I was too young to understand that I had a greater potential than they realised.

Mainstream education

“I can’t say mainstream education for me was like a walk in the park, it was really, really tough. But I loved it. There was one of the main problems I had was because of my lack of education in the past. For example you know with GCSE Maths you have to do things like fractions? I didn’t even know how to add or multiply.”

Many participants, when discussing their educational experiences, described how important and fundamental to their sense of self-esteem and future possibilities, mainstream learning opportunities were for them. Mainstream education was identified as the primary route through which physically disabled young people could demonstrate their ability, gain access to the ‘real’ world, mix with non-disabled people of their own age and equip themselves with the knowledge and skills that they identified as being necessary to live independently as adults:

When I was very, very, very young - I was a youngster about 8 or 9 - I remember sitting where you are sitting down and I looked up and I thought one day I would like to go to a normal school and go to university. So it was kind of a dream. The idea of being able to expand myself more, that was really important to me, even at that early age.

I needed to achieve, I needed to break that special needs mould... I needed to work hard because it was the only way I was going to escape from spending the whole of the autumn term making Christmas decorations. There is only a certain amount of snowdrops a man can make before he gets completely fed up with life. No, seriously.

However, many of the parents and young adults we spoke with described how difficult and fraught had been their experience of trying to find a mainstream school willing to give them a place:

Because they didn't want her they were sort of, bringing up excuses and having this meeting and that meeting, and they were just so petrified of taking her and we had a meeting with the teachers and they were coming up with such stupid excuses: 'What are we going to do if the bus is late?' Well, nothing, she just comes into the class late. You know, it was just stupid things like that really.

A number of parents had found it necessary to appeal to Special Educational Needs and Disability Tribunals in order to gain access to mainstream school education. For others, even once a place in the school had been secured, they had still experienced difficulties:

There was never an issue with the children; it was the adults who had the problem. It was the teachers. Because they didn't feel that they should be teaching someone who they thought belonged in a special school.

You had to continuously battle teachers and people's opinions, particularly when you first went to school, because everybody expected you to just be a sort of spastic (sic) and just sort of sit there and do nothing and be able to do nothing.

When I went for my interview, I had said what I have already achieved but when I went back they put me on a course called 'PAL' which stands for Progression to Adult Life. (Interviewer: What course did you want to study?) Business Studies. The group that they put me with, all of them have got learning difficulties which I haven't got... I asked them the first week back if I could change my course and they said yes but they would gently break me in. I thought, didn't you listen to what I have achieved? Already I have got A star GCSE in Child Development, Level 3 Mathematics and distinction in English for

Business.

In contrast, some participants felt concern that disabled students sometimes experienced a pressure of constantly having to 'prove' their right to a place in mainstream education. Asha is a young woman with complex physical and communication needs studying for A levels. Her mother worked for some time providing personal assistance in the mainstream school her daughter was attending and noticed how...

What is expected from disabled kids is far more than what you expect from non-disabled...for example, one of the things that used to be said about Asha is that she can't concentrate for very long. She is sort of like, you know, she is moving all over the place and she doesn't stay focused, you know, she is not looking at the front all the time. 'She can't look at the front for more than 10 minutes which means that she has got a very short concentration span' and stuff like that. But if you look at what the other kids are doing, the other 29, you will see that they are putting on their lip gloss, they are looking at a magazine, they are doing their nails, they are sending a text on the phone while the teacher is not looking... So I just felt that these kids have it really hard actually and it goes down on their statement; 'cannot concentrate for more than 20 minutes'.

Inclusion and integration

The ways in which people felt they had been included into the day-to-day life of the mainstream schools and colleges they attended was often a crucial factor in terms of how they felt overall about their experiences of mainstream education. A number of people described how, although attending a mainstream school or college, they had been taught separately from other pupils:

When I started at the secondary school I was fully integrated. As I moved in to the sixth form things started to

change... We (SEN students) were taught as a group with no mainstream students and then the staff expected us to mix at break time... One day I overheard some students saying 'The disabled students shouldn't be here because they are lowering the rest of the school down'... I thought, if you were in class with us you would know we were the same as you.

I hated it. I think most people did actually. I think we won some battles. They wanted us to stay in the (SEN) unit all the time and we said 'No, if we are in a so-called normal school, we want to go to normal classes'. And they wanted to walk us to class and we said 'No way are you doing that, we are going to classes on our own like everyone else'. So I think we actually won battles but it was difficult.

If classes weren't (physically) accessible then you would again be segregated and went to the special needs area and you would have to work in the special needs area and I don't appreciate that really. I want to be involved in everything and have the opportunity to be involved in everything... you want to be given the same opportunity to try things out because at the end of the day you learn from doing things not from thinking about them.

Being identified as 'special' and therefore 'different' was something that many of the young people spoke negatively about in relation to their experiences of mainstream education. Being treated the same as their friends and peers was very important to those who had gained access to mainstream education:

I did get the impression that some of them (teachers) were treating me different to what they treated everyone else. My friend pointed out 'Why is it that the teachers say hello to you and yet they ignore everyone else'. And yeah, I would like to be treated the same as everyone else but obviously that applies to society in general not just through education.

In front of everybody in the dining hall, the whole school, I

had these assistants walking around with rubber gloves...and I refused to let them help me and one of them said, well, I have to accept them when I go to the doctor...I said 'Yes, miss, but we are not at the doctors, we are at a mainstream high school in front of 500 other teenagers. You don't wear rubber gloves! That is what you do at the zoo!'

People can be cruel and if you are different then they jump on your differences, even if you are wearing the wrong kind of clothes or whatever, yeah. You have got to wear the right kind of clothes to be accepted. It is just that you have to do the same kind of things also in a normal way to be accepted.

A number of participants who had attended mainstream schools and colleges described being picked on and bullied:

I think special school was very safe, very protected and then I moved to mainstream which was very big, massive in fact...and that led to children being unprepared and bullied. I was bullied for one and I know a lot of other children that were bullied at that school.

We had this label 'P2' which was the special needs class. Because we had that label we were picked out and bullied.

You go to a mainstream school and it is very real and kids are really hard and I had some pretty horrible experiences. In actual fact the mainstream I went to, very quickly, the whole idea was fun but this was a really, really rough school.

The barriers that some participants had to overcome in order to realise their educational potential were substantial but surmounted by participants' will to succeed, enthusiasm for learning and the positive encouragement of family and teachers:

I thought it would be good to do CSE's because I hadn't been to a mainstream school before. He (my teacher) said 'No, that is rubbish, you have the ability to do that', so he did a programme of doing GCSEs and A levels and within 3 years, from not being able to read or write, I was able to do my 7 GCSEs and A levels.

I began my education in a mainstream school and this is where I met Mr G, who changed my life around. He was the first person I met who did not make any assumptions about my disability. I had an incredible amount of support from him and my other teachers at mainstream school. It seemed as if the more enthusiasm I expressed, the greater they wanted to support me. The harder I worked the more I improved. After a while learning became easier and my confidence grew. I felt human and alive.

Informal learning

Little existing research has given much consideration to the social experiences of young people with complex physical and communication needs or the lasting impact that the segregation of disabled children has on their lives and social opportunities as they grow older. Participants in the RITE research project talked openly about their formative social experiences and the importance of their being able to have the same social opportunities as non-disabled people:

One of the things that I always felt I missed out on was, like, when you talk about access to learning, you have to talk about access to informal learning as well as formal learning. So, for example, school used to finish at 3.30 and my taxi used to be there waiting for me at 3.30 and really that's when school began because you needed to be down the chip shop and the arcade. I suppose one of the worst things about my education when I was younger was missing out on the informal bits.

It is not just about doing exams after all, school, that is not

what it is just about. You know, there is lots of other thing as well. It is about making friends and building, learning how to form, relationships with people so it is not just academic work, is it?

Despite any negative experiences, many participants talked about the opportunities that mainstream education had given them to meet and make friends with people of their own age who were not disabled and came from different backgrounds:

The best thing by far was meeting non-disabled people...It was about being integrated into society and having access to mainstream opportunities and that's it really, with a little bit of learning thrown in I suppose. But the actual learning was the least of my interests; I had better interests than that.

I think if I didn't have any friends that would have made a big, big difference because my friends, that is what has kept me positive, even though when things were going wrong...I have always known that my friends are there and at the end of the day that is what is most important to me, is my friends.

Yet, this is not to say that all participants found making friends in mainstream education easy:

There is a difference between people being friendly and proper friends. At the moment they are being friendly but not real friendship. They don't phone me up, invite me out, invite me to the cinema. So I think they need to know that I can do things and if they think I can't do them then there is maybe a way round it so don't presume I can't do it. People think that because you are disabled you always need lots of help, you don't.

Support Issues

When talking with people about their experiences in

mainstream education, issues of having access to appropriate levels of support and how that support was delivered were referred to time and time again. The right support was crucial for people to be able to access the curriculum, successfully demonstrate their ability and be able to feel integrated into the life of their school or college. Unfortunately, getting access to the right support was cited by many participants as one of the worst aspects of their experiences of mainstream education. For Finn the benefit he felt he gained from attending a mainstream school was offset by the effort he had to make in enabling others to help him meet his physical needs:

Effectively it was either go to a school that wouldn't cater for my educational needs or a school that wouldn't cater for my physical needs so I was sort of stuck...I was spending an awful lot of time educating my teachers and my people who were supporting me in what I could and couldn't do and actually it was taking more time and I wasn't getting as much out of my education as I should do because I was spending half the time teaching the teachers.

Conversely, for Sam, a mainstream college was far better able to respond to his needs than the special college he had initially attended upon leaving special school:

I told them that I needed one-to-one help in the classroom, I told them that I needed to do all my college work in college because I would be too tired when I got home and they made sure that that happened... because I have a lot of spasms, for me to spend 4 to 6 hours on a computer typing as well as using the mouse, it is too much and the special needs college would not accept that, they wanted me to do it all by myself. The sixth form college accepted it and said 'Well, you know yourself better than we do' - which is true - 'You tell us what you need and we will sort it out', and to be fair, they did.

A number of participants, however, voiced concerns that some mainstream institutions, while keen to include

disabled students, were unable to provide them with the support they needed:

When she got to college... there wasn't sufficient support and even now, almost at the end of the school year, she is not getting the support that she needs. There is many a time she is left unsupported and sat there because she can't physically access what she needs to be doing and I just don't think provisions are adequate... she doesn't get consistency of support either ...she has a different person with her every day... She enjoys going to college and being there but if the environment is not right then she will lose interest.

Others felt that personal assistance had acted as a barrier to social opportunities and informal learning:

Although it was necessary I would have preferred sometimes that the teaching assistants...weren't so obvious because I felt like it was making me different again. It all comes back to the idea of difference.

She has to be with somebody, although she is 19, which I don't think is right. Wherever she goes there is a member of support staff with her. She is not allowed to go out and integrate which is not normal; it is even more restrictive than it was in special school.

This is one of the difficulties. The majority of assistants in schools are mums...in terms of the impact on your social life with your peers, it is not a good idea to have your mum with you always even if she is not really your mum.

Appropriate support in a mainstream environment was also highlighted as often lacking in relation to students taking exams:

I should have got more support to access exams. I didn't get any support at all.

When I was taking my exams one of the things that helped

was I could choose who I had to scribe for me because it is stupid, like if I say three quarters and someone says 'How do you write that down?'

It helps if the person who is scribing for you knows a bit about the subject...because otherwise you are kind of disadvantaged because you are actually having to do additional work in having to explain things to someone. I would say getting the right person, when they are helping you with work, is very important for obvious reasons, particularly in an exam...you have got to have the right support worker.

Realising potential

It is hard to over-state how important to many participants was the idea that mainstream education could offer opportunities for personal development that special school simply could not offer and what this meant for people:

I see education as a way of developing not just mentally but developing the person as well... it gives you immense confidence and helps you in life in general.

It was relieving to be in with the rest of the world ... I thrived.

It was fantastic, it was like a whole new world.

Emotionally, you know in my mind, I began to grow up into my own person which was kind of reinforced by going to university.

I think because I had this label 'disabled' very little was expected of me, especially pre 15. It wasn't until I got to university that people started to say 'You can do this, you can do that'. Before it was 'You can't do this and you can't do that'.

Now that all the support issues are resolving themselves

at university this is becoming a positive, very positive, experience for me now. It wasn't but it now is.

Conclusions

For the majority of those who took part in this study, gaining access to mainstream education and qualifications was identified as a key opportunity for disabled people to realise their potential, develop self-confidence and social skills, counter low expectations and prove their abilities to others. The accounts of participant's experiences remind us that disabled young people are frequently denied access to mainstream education and qualifications because of physical and attitudinal barriers. They also suggest that the meanings that disabled young people attach to their participation in mainstream educational settings are not sufficiently understood, respected or acted upon by education providers or policy makers.

For many participants the social opportunities afforded by participating in mainstream education were of equal, if not more, importance than educational opportunities. Where many people felt special schools to be insulated and inward looking, gaining access to mainstream education was seen by participants to be a key opportunity to learn about the wider world. Increased opportunities to form relationships with a greater diversity of peers and adults were identified as being key to enabling disabled young people to improve their confidence and inform personal development. Accounts of participant's experiences remind us that mainstream educational settings may not be sufficiently aware of the barriers that disabled students face in terms of their being able to make the most of the social opportunities that mainstream education can provide nor the impact that such barriers may have on disabled students sense of self and well-being.

Being able to access appropriate personal and educational support within mainstream educational settings was also identified by participants as being key to

their being able to realise their potential, especially so where institutional barriers (physical and attitudinal) further disabled students. The accounts of participants highlight how appropriate support for disabled students in mainstream educational settings can be a crucial determining factor in how students experience the reality of mainstream 'inclusion'.

Participants who described positive experiences of mainstream education highlight its potential to model a world where disabled people are given the same opportunities and afforded the same value as non-disabled people. Without exception the young adults who took part in the RITE research project wanted access to the same world that we all live in, not a 'special' world for 'special' people where labels and experiences serve as a constant reminder that disabled people are not just excluded from sharing many of the same opportunities as non-disabled people but also the same rights. Education policies which fail to recognize the social context within which they exist and the relations they may be helping to sustain do not just fail disabled students, they fail us all.

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¹ This Paper has been developed from the soon to be published final report of the RITE Research project. For more information please contact The DARE Foundation, 01273 711 006.