



the **Building Bridges** project

Young people and friendships: What matters to us?

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CONTENTS

Acknowledgements	3
Preface	4
Section 1: Rationale and methodology	5
Section 2: What are the patterns of friendship among young people with a learning disability in transition to adulthood?	9
Section 3: The risk of social isolation	14
Section 4: Experiences of bullying and hate crime	20
Section 5: The role of family	26
Section 6: Developing aspirations: The role of education and work	30
Section 7: Conclusions and recommendations	37

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PREFACE

There is little research that focuses upon the friendship patterns and social isolation of young people with learning difficulties; and still less research that enables young people with learning disabilities to have positions of control and decision-making within research processes. This research project aimed to challenge the assumption, often inherent within academic research, of the academic being the expert. C.A.R.P. Collaborations employed and trained 8 young people with lived experiences of the research topic in order to gain effective, valid data and recommendations to further the social inclusion of people with disabilities.

The evidence and conclusions are based upon qualitative data undertaken with 85 young people with learning disabilities aged between 14 and 28 living in the Gwent region of South East Wales. All of these young people were at significant risk of social isolation and almost all did not see friends outside of structured activities or education settings. Additionally, the research participants faced high levels of social segregation with little participation in mainstream community life and few opportunities for paid work and financial inclusion. They faced a complex web of barriers to having a full social life that ranged from systemic discrimination within the education system and employment practice; to inaccessible public transport and difficulties in using communication tools that are needed to maintain and grow friendships. Two thirds of participants had faced bullying within their transition years and most were heavily reliant upon their families for socialising opportunities.

Given this complex picture there are a series of recommendations to be made. These include reviewing current education outcomes for young people with a learning disability and providing alternative routes to employment such as implementing supported employment models; facilitating friendships within inclusive community settings and educating non-disabled people about disability and the effects of bullying and hate crime. There are also some wider issues for society as a whole to contemplate and act upon regarding the continued segregation of people with disabilities and their systematic exclusion from mainstream social and civic life.

SECTION 1: RATIONALE AND METHODOLOGY

About the D.R.I.L.L. Research programme

The Disability Research on Independent Living and Learning (DRILL) programme is the world's first major research programme led by disabled people. Funded by The Big Lottery Fund, it runs across the UK for 5 years, and aims to fulfil 4 outcomes:

1. Increase knowledge about key issues and produce new evidence of what works.
2. Empower disabled people to ensure they have direct influence on legislation, policy and services.
3. Ensure disabled people have increased well being, independent living, choice and control through participation in DRILL projects.
4. Exert positive influence on policy making and service provision through the coproduction of robust research findings.

About the research project 'Young people and friendships: What matters to us?'

Community Action in Research and Policy (C.A.R.P.) Collaborations is a social enterprise dedicated to furthering social inclusion through undertaking innovative research and policy influencing. They submitted a successful partnership proposal to the DRILL research grant programme in partnership with The Building Bridges project; a service that provides holistic support to young people with additional needs and their families during transition to adulthood. Young people using the Building Bridges service suggested the topic for research and were involved in the proposal.

The research aims were to:

1. Explore the patterns of friendship and social isolation with young people with a learning disability in transition to adulthood.
2. Discover what helps and hinders friendships to form and be maintained.
3. Examine how friendships are linked to participation within community activities.
4. Assess whether young disabled people are at risk of social isolation; and identify what contributes to isolation and what can relieve it.

The peer research team explained the project in terms of finding out what support is needed that leads young people to move from the experience of 'existing' and into the experience of 'living a full life', or what enables young people to move from 'all I did was play on my xbox alone in my room' to 'I go to the pub on Fridays with my friends - we have weekly pool contests'. The peer research team said we were looking at friendship patterns and how they contribute to 'Having fun' and 'having a happy fulfilled life' and how a loss or lack of friendships can create loneliness and 'unhealthy lives'.

Rationale behind choosing this topic for research

According to Sense data from 2016, 38% of disabled young people felt lonely most days. In evaluative research undertaken in partnership with Building Bridges, C.A.R.P. Collaborations found that young people who were part of the Building Bridges project could explain exactly what 'lonely most days' meant; through their own reflections upon the change in their social life since having support to make and keep friends. Having friends means that:

'I'm not alone now. I felt incredibly alone. I started suffering from OCD, anxiety and I had my learning difficulty and I was all alone.'

And loneliness brought low self esteem with it:

'Since joining Building Bridges I realised I was not so bad'.

These descriptions painted a bleak picture of the transition experience. They also pose a fundamental question regarding social inclusion; why is it that most, (by no means all), non-disabled young people's life trajectories include apprenticeships or further learning, sexual relationships, networks of friendships and a variety of options whilst this blossoming of social life and participation in the adult world does not appear to be a common experience for disabled young people?

Social life and friendship are often seen as trivial; particularly within the eyes of social researchers who feel there are more weighty problems to investigate. However, social lives and community participation are crucial; to both well being and identity and were the most important social issues highlighted by the young people themselves.

What was the role of peer researchers in the project?

C.A.R.P. Collaborations staff team are all academically trained, non disabled and aged over 45, so whilst they held research capability they did not have the lived experience and knowledge that young people with a learning disability have themselves. This research project therefore involved employing eight young people in paid peer researcher work placements, training them in research skills to co facilitate focus groups with other young people across the Gwent region, undertake peer interviews, interview practitioners and to fully participate within analysis, report writing and dissemination of findings.

The peer researchers have had the opportunity to work towards a 6 credit Level 2 qualification (validated by Adult Learning Wales and Agored Cymru) in Social Research Skills and were recruited on the basis of their enthusiasm and interest in the research questions and for their personal experience of having a learning disability and experiencing the transition process. The peer research team skills were fundamental to the whole research process; from ensuring focus group activities were engaging and asking insightful questions in focus groups, to picking up issues that were missed by the academic research team and interpreting themes in the data.

This report was written by academic researchers, but with the peer research team having fully designed the structure, stressed the key analytical points for each section and developed the recommendations.

Where has the research been undertaken and with whom?

The fieldwork has been undertaken across the Gwent region, ensuring representation of each county area (Torfaen, Caerphilly, Blaenau Gwent, Monmouthshire and Newport). Additionally focus groups were held in 3 settings that serve the Gwent region; making a total of 8 regionally representative focus groups. In total these settings have been two specialist schools, two specialist colleges, two disability sports groups and two community youth clubs.

The fieldwork has consisted of activity based, creative method group work that has lasted up to 2 hours, one to one interviews and interviews with practitioners in each setting. The research team has worked with a total of 75

young people with a learning disability aged between 14 and 25 and 10 aged between 26 and 28.

Ethical considerations

The research project gained ethical approval via the DRILL programme ethics committee. Parental consent was sought for young people aged between 14 and 16. All young people were given easy read leaflets about the purpose of the research prior to arrival at each site, and signed an easy read informed consent agreement before the research questions were explored. All participants were given the option to stop their involvement at any point.

The peer researchers received work agreements and contracts fulfilling all necessary HR procedures and obligations. They also had job coach support from the Building Bridges project and employer supervision and contact with C.A.R.P. Collaborations. To ensure positive employment experience both organisations had regular contact and work in close partnership.

SECTION 2: WHAT WERE THE PATTERNS OF FRIENDSHIPS AMONG YOUNG PEOPLE WITH A LEARNING DISABILITY IN TRANSITION TO ADULTHOOD?

This research project set out to explore the nature of friendships and mapped the different activities that participants undertook during their week. We found 2 very distinct patterns of friendships.

2 patterns of friendships

1. Very limited socialising opportunities outside of school.

Approximately two thirds of the participants only had friends within school or college and had scarce socialising opportunities during evenings, weekends or school holidays. Some of these young people attended segregated youth clubs, with regularity varying from weekly to monthly, but this would be the only non-education based socialising opportunity that they had. Other participants did not socialise with peers at all outside of school:

‘I am aware that out in the community there isn’t a lot there for young people. Some don’t go out at all ... never leave their bedroom.’

College teacher

‘Many people don’t have people they know outside of school or college.’

Participant aged 16- 19

‘We enjoy ‘chilling out’ usually with our school friends, but sometimes we don’t get to see each other that often. At home we mostly play on the X-Box, alone.’

3 boys under 16

2. A very busy life filled with a lot of structured activity

Approximately one third of participants had friends at school or college and socialised during evenings, weekends and holidays through structured activities. These participants did not see friends outside of the activities they undertook, or outside of the school or college they attended; so whilst they had many people that they knew, they only had contact with them in specific settings. Almost all of the activities that these participants undertook were within segregated provision.

‘I do wonder at times, with some young people being so busy is there time or space for them to make new friends? Or even to think about what they need to do to keep the friends that they have. It seems to be they don’t have the space or time in their lives sometimes to think all of that through.’

College lecturer

Both of these patterns of friendship left young people vulnerable to social isolation. The first pattern of friendship relies heavily on family relationships to compensate for a lack of social networks and in transition years siblings and cousins reduced their contact with family as they became more independent. Within the second pattern of friendship young people became isolated once they cease to undertake an activity; usually because of age limits of the provision or because the provision stopped. Neither pattern of friendship included unstructured time to grow and develop existing friendships and both patterns led young people to be heavily reliant upon social media to maintain contact. In instances where young people did not have access to social media, social isolation and the lack of friendship development was particularly acute.

What stops young people from having contact outside of structured activities?

There were numerous factors that acted as barriers to developing friendships:

1. Difficulties in using public transport and long distances between friends who attend specialist education provision stopped school or college friends from seeing each other, outside of their education context.
2. Parents either not able to give lifts between friends houses or not recognising the closeness of friendships. This was particularly an issue for young people in relationships with people they knew from education settings, because some felt that their relationships were not taken seriously and they did not see each other outside of school or college. This was also a difficulty within youth settings as one youth group leader explained:

‘Isolation is a huge problem that children and young people with a disability face. For many of them X [segregated youth club] is the only opportunity or outlet that they have. There may be some other sports based opportunities, but for socialising and meeting friends this is the only chance they have. So, for instance, if young people are in a boyfriend/girlfriend relationship, then it may only be here that they have any time to be together.’

3. Some young people were not allowed access to social media by their parents. This significantly reduced their opportunities to maintain friendships.
4. Some participants did not have the knowledge of how to keep in touch outside of face to face settings. For example, one young woman explained she did not know how to make a phone call on her mobile phone, others said they had never asked for friends phone numbers and did not know their own phone numbers.
5. There was a general lack of understanding about the skills and process needed to maintain and develop friendships. This was not at all a question of capacity, but rather, that the level of social isolation and pattern of friendships participants had always experienced was also one of isolation and structured activities. Therefore, they had missed out on informal learning that non-disabled peers may take for granted regarding the processes of social relationships and growing independence.
6. Friendships patterns are dependent upon local segregated services. With the exception of the Building Bridges project in Monmouthshire, there was a distinct lack of community connecting or access to mainstream activities. Therefore the activities that were available to young people with a learning disability varied according to local funding priorities, Big Lottery projects and volunteer services. Participants were vulnerable to social isolation according to funding patterns and availability of specialist services within their area:

‘There should be more access for young people and there should be more clubs available for them to attend.’

3 boys aged under 16

Who was described as a friend?

The majority of the participants described numerous people as friends who may not be ordinarily be perceived as a friend. For example, some participants described close family members as friends:

‘My dad is my friend.’

‘My grandfather was my friend.’

‘Family can be your friends.’

Participants also described a range of paid staff as friends, including education support staff, personal assistants and youth workers and a minority added family acquaintances, such as neighbours, that they occasionally spoke to.

The research team struggled with how to assess levels of isolation or evaluate other people’s friendships. Discussion included problems of definitions because as peer researchers pointed out, if people have limited socialising opportunities then ‘everyone becomes a friend’ and individuals may not have described themselves as isolated because of different definitions of ‘friend’. In terms of research analysis, we decided to suggest that young people with a learning disability may not perceive themselves as isolated because they often use a definition of friendship that includes people paid to be in their lives and family members. If a definition of ‘friend’ was used that did not include family or paid staff, many participants could be described as isolated.

The role of social media within peer relationships

Social media and online gaming played a pivotal role in many participants’ lives. There was evidence that this led to two different outcomes with regards to friendship. Firstly, it increased some young people’s (mainly boys and young men) isolation and disconnection with their local neighbourhood:

‘Young people are isolated, particularly where they may be involved in gaming.’

College teacher

‘I don’t feel lonely, as I have lots of video games.’ [seeking clarification, we found these were online games]

Young man aged 16- 19

Secondly, social media enabled friendships to be maintained:

‘There is a slim chance of meeting them [friends] face to face. It’s easier to do it online.’

‘It’s easy to keep in touch on Facebook, but it’s harder to meet up in person.’

Professionals working with the participants expressed some concern regarding their understanding of friendship and personal emotional safety:

‘I do have concerns about young people such as X who spends a lot of time of Facebook and says that he is in touch with a lot of ‘friends’ ... I do wonder what his understanding is about friendships, about who those Facebook friends might be and whether or not he is too open.’

Youth leader talking about a 25 year old

A minority of young people were not allowed to have any social media accounts by their parents which increased their social isolation

Concluding observations and recommendations

Within both patterns of friendship, social relationships were confined to specific places and structured activity, with little informal or unstructured time within friendships. Young people with a learning disability had not had the opportunity to learn the skills for maintaining or developing friendships and therefore had little contact with friends outside of activities, as a peer researcher explained:

‘It seems to be an activity based social life.’

Many participants used a definition of ‘friend’ that included family and paid staff, which is not a definition that is generally shared across different social groups. There was anecdotal evidence that this could be a sign of social isolation, although this was a complex assessment to make.

There are multiple factors that contribute to young people with a learning disability experiencing limited social networks outside of structured activities and these lead to the risk of social isolation, which is explored further in the following section.

Social media has a pivotal part to play in enabling communication between friends although the use of social media also raised issues of emotional safety and understanding of different types of friendships. There was anecdotal evidence that online gaming contributed to isolation in face to face personal interactions.

SECTION 3: THE RISK OF SOCIAL ISOLATION

The previous section highlighted how the patterns of friendship leave young people with a learning disability vulnerable to social isolation. This section explores in more detail the factors that contribute to the risk of social isolation and young people's explanations as to why friendships are so important.

Why are friendships important?

Whilst this may appear to be a question with an obvious answer, often service provision focuses upon "individual need", "successful placement" or "appropriate care package" as mechanisms of support. Rather than approaching the research questions from a service provision viewpoint, the research explored with participants what friendship meant and why it is important in life.

We found 5 overarching beneficial outcomes to friendship:

1. Friendships offered the opportunity to experience sustained emotional well-being. All participants linked friendships to positive emotions.

'You feel happy with your friends.'

'They make you feel calm, they show you love.'

'They make you feel supported, proud, happy, confident and caring.'

'They help your self esteem.'

'Very often when we are alone we feel vulnerable. So when we aren't with our friends we don't feel good.'

2. Friendship offered a feeling of belonging and group identity.

'It's good to have friends as you can be a part of a group and then you can do more things than you can just do on your own.'

'They give you a sense of belonging. They give you a sense of sharing and having a shared experience.'

‘They make you feel like you have a place, they make you welcome.’

3. Friendship offered learning opportunities. Through being in a group and mutual support friends enable each other to learn new skills or undertaken new activities:

‘You go on adventures with them.’

Friendships are a source of mutual help and personal support.

‘[they] Stick up for you and you stick up for them.’

‘They are caring and there when you need them. They share things with you.’

‘They ask if you are ok and support you. You can also be a good friend by supporting them.’

‘They trust you and can talk to you. You can say things to friends that you can’t say to your parents.’

‘Good friends help you if you are being bullied. They stand up for you and are supportive.’

5. Friendship can enable use of community places and spaces (depending upon other factors such as accessibility and transport).

‘You can go to the pub with your friends or just out places with them.’

These 5 aspects to friendship are likely to be familiar reading and nothing new. However, when compared to the aims of most social care provision, the importance of friendship becomes a point for critical analysis. Much health and social care provision has these very aims as a service outcome; emotional well-being, sense of belonging, learning new things, personal support and use of community places. But support for building and maintaining friendships is often not the mechanism (or ‘intervention’) that is funded to enable these outcomes to be met.

Making and sustaining friendships can be perceived as trivial when compared to, for example, meeting individual need, creating a continuing health care package or securing day care provision. Rather than friendship being perceived as one outcome of service design, the research findings suggest that if service design focused purely on making and sustaining friendships many other outcomes could be met.

What support did young people need to keep in contact with friends?

Whilst friendship was clearly important for positive wellbeing; young people described how they needed support to make and maintain friends. Unanimously young people said they needed practical help, emotional support and communication skills to maintain their friendships. Participants in all focus groups cited a range of people who gave them this help; specifically parents and other family members, social workers, advocates, support staff, bosses, colleagues, carers, activity/youth leaders, and teachers. Some of these people acknowledged the role they had to play in enabling friendships to be maintained:

‘I know here [holiday disability sports club] that there some attendees who are just waiting for the holiday periods to begin so that they can come here, as they have little other opportunities to make friends. I give young people my work contact ‘phone number and I encourage them to keep in touch. So with some of them they will contact me just to say hello, or to find out what’s going on with sessions, or if there is something that they are concerned about or unsure of.’

Disability sports leader

However, young people said that they need far more help if they were to see their friends more and identified emotional help, practical help and communication skills as the things they needed help with.

Emotional help

1. ‘Learning about patience’ and understanding the social processes between people.
2. ‘Being taught what to do if something goes wrong when you are out meeting a friend.’
3. Having good advice.
4. Encouragement because it takes confidence to go out alone.

5. 'To not be anxious.'
6. To know how not to be moody, or angry.
7. 'Help to say that we are sorry and that it's about negotiating and not just getting our own way.'
8. To know how to solve differences:

'Staff here [college] help us with thinking about what friendship is and help us to solve arguments'.

Practical help

1. With using public transport: 'Being taught how to use a bus.'
2. Getting lifts: 'lifts from family members.'
3. Help with knowing eligibility for a bus pass and how to complete the form.
4. To learn to keep a diary and an address book.
5. 'Showing us how to find information about what is on.'
6. 'Showing us where things are happening so that you get to places'
7. Financial literacy - 'Having money' 'We need money to be able to do things.'
8. Help with understanding timetables: 'Knowing about bus times.'

Communication skills

1. Help to know what your own phone number is and reminders to share numbers: 'having phone numbers'
2. 'Help to know how to text and reminders to make sure we text our friends.'
3. 'Knowing how to book a taxi.'
4. 'Help to know how to socialise.'
5. 'Having the skills needed to use the technology.'

Most participants had some help at specialist schools and at youth clubs to learn some of these skills, but usually not until they were in the 6th form and in post-16 education. There appeared to be little progression in learning these skills nor any incremental learning from pre -16 education or pre -14 youth provision. Additionally, outside of youth clubs or transition projects and specialist education settings young people did not have opportunities to learn or practice these skills.

When do young people lose friends or become more socially isolated?

Participants discussed how transition of all kinds led to the loss of friends; citing examples such as moving house, ending a youth club or activity, moving

school etc. It was recognised that transition and changes in friendships were a part of life; particularly on the journey to adulthood. However, due to already limited social networks, low confidence in managing friendships and reduced availability of structured activities upon reaching adulthood, participants were at increased risk of isolation:

‘I’m not in school, or college and I have lost touch with people. But we do try and keep in touch on Facebook. I have a great set of work colleagues. [only sees them in work]’

‘I did have friends in school and college, but I don’t see them much anymore since leaving, as I live out in the countryside.’

‘In one year’s time I will need to find a way to keep my college friends.’
(22 year old young woman who only sees her friends at college)

Most participants used social media to keep in touch with friends from previous activities or education settings and described the main barriers to seeing them face to face as being the ability to use public transport, the availability of public transport, distance between each other and a lack of knowledge about what is available to do within the local community area. These latter two points were particularly applicable for those who had attended specialist or residential education provision; where pupils can live 30 or more miles from a school, and even further for colleges.

For those who had employment, issues around zero contract hours were also mentioned as a barrier to maintaining friendships because they prohibited being able to plan or keep to plans.

Conclusions and recommendations

The research data clearly showed that young people with a learning disability are at risk of significant social isolation and that the risk increases as they reach adulthood. Whilst they face many barriers to maintaining friendships the crucial issue appears to be having support to incrementally learn the tools or mechanisms of friendships from pre- transition years through into adulthood and having links to their local community. This issue was also discussed by group leaders in interviews:

‘We do have real concerns that young people are not able/don’t have the chance to form strong and lasting friendships, as they may have no other opportunities to meet up, outside of X [segregated youth club].’

Youth worker

‘[there’s] not at all [enough help], for helping young people with their social skills. It can be hard for them to make, and certainly to keep, friends, because a lot of the young people we see don’t have that developed understanding of how you go about doing that.’

Disability sports leader

The peer research team also felt that this was the crucial issue during analysis workshops:

‘I felt that people did want to have a social life, but didn’t know how to. There was a question for me about people needing the right tools to have a social life. It was unfortunate that they seemed to have a limited network.’

‘I agree that it appeared people wanted to have a social life, but didn’t know how to go about having one.’

‘School doesn’t tell you how to make friends. The Building Bridges project encourages people to get involved and interact. They help you plan things, even outside of the hours that staff are working.’

‘Yes, it is also an issue that no-one tells you how you should go about keeping friends, that is a real challenge.’

‘But they [participants] had no tools or experience of developing friends in an unstructured environment.’

SECTION 4: EXPERIENCES OF BULLYING AND HATE CRIME

How prevalent is the experience of bullying?

6 of the 8 peer researchers had experienced bullying, leading to four of them changing schools at least once. Bullying was discussed as an issue in 6 of the 8 focus groups and an estimated two thirds of the 85 participants had experienced bullying during transition years (14- 25 years old). It should be noted that usually the bullying experiences that young people shared related to their disability and participants felt they were picked on because of their disability.

Participants spoke about experiencing 5 different types of bullying behaviours:

1. Verbal bullying. This consisted of name calling and derogatory language:

‘Sometimes bad friends upset me, they pull faces at me and I feel like they hate me. They sometimes used to pick on me in school, use bad language’

‘Sometimes swear at you, pick on you, call people fat, are nasty to you, call you names.’

‘They sometimes swear at you, or call you names and think that they are ‘having a laugh’.

2. Physical bullying. More common for boys than girls, young people shared stories such as having their bags taken off them, being goaded to fight and being physically hurt such as tripped up or punched.

‘They abuse you, harass you and use you. They put pressure on you and put you in the middle. Boys will fight you and bully you and pretend that it is all a joke.’

‘Bad friends are people who trick you and ... make you fight. They are people who think they can do whatever they want to you.’

3. Spreading rumours and lies. More commonly experienced by girls, participants described how they were lied about and that there was little you could do to counteract rumours and gossip.

‘[they] whisper about you and say things that aren’t true.’

The aim of such behaviour was ‘to take friends away from you’ or to be expected to take the blame for other people’s behaviour.

4. Manipulation, exploitation and mate crime. Various levels of mate crime and bullying were described by participants. Common experiences included having people pretend to be a friend to order to take advantage, such as taking money or using a disabled person’s free bus pass:

‘They also use you for your free bus pass’

‘They think that they can get something from you and don’t care about you.’

‘They can take advantage of you.’

Participants also described how bullies would pretend to be a friend only to mock them once they were within the peer group and they would often leave them (running away) during group activities, or goad them to do things which were described as ‘banter’ but actually harmful and mocking. One example was of a group of young people who went for a day’s cycle ride to local woodlands, told the young person with a learning disability to go and find something in the wood and whilst he was away they loosened the wheel nuts on his bicycle wheels and left. (It should be noted that the age of these young people was over 16).

5. Cyber bullying. Some young people who had parents’ permission to use social media experienced cyber bullying; although this was discussed to a much lesser extent to the other forms of bullying described above.

Where was the bullying happening?

In school settings, bullying towards young people with a learning disability tended to be within mainstream schools rather than in specialist schools. In

many instances it led to young people who were bullied having to change school. Bullying in community settings was a complicated picture and generally followed 3 patterns:

1. Bullying perpetrated by young people who attended the same school as the target of bullying, whereby bullying behaviour occurred within school but also outside of the school in community and neighbourhood areas. In these instances, if the target of the bullying moved schools, the bullying would continue within the community settings.
2. Bullying perpetrated by young people in neighbourhood areas who had not shared a school experience. In these instances, the bullying dynamic had often continued for a long time, starting at nursery or early primary school age, and escalated over time. Some participants said they had grown used to it and because they had known the bullies all their lives they believed it was “just how it is” and described these people as friends.
3. Bullying within the family home perpetrated by siblings, other young people who were family members or their friends. This was described by a very small minority of participants and arose among those who were under 16.

What did young people do about bullying?

Almost unanimously young people felt that bullying was not adequately addressed. Schools appeared to try and tackle bullying but young people felt the target of the bullying was often seen as the problem and that most action was ineffective. They also felt they were often not taken seriously or were too scared to report it; particularly in instances where trust and belief in the truth of their experiences were called into question; such as when rumours had been spread about them, where they had been coerced to take blame for someone else’s behaviour, where they were goaded to undertake certain actions or where they had lashed out in response to continued bullying behaviour.

Young people felt that they could tell their parents, but that parents were limited to be able to do anything. Some parents restricted the young person’s freedom or internet use in attempts to try and reduce the possibility of bullying. Many young people moved schools in response to being a continued target of bullying, often from mainstream to specialist provision.

A minority of young people mentioned the police as a source of help but did not know how to contact them and felt that the police may not be interested because they have to deal with more important issues.

Participants felt particularly unable to do anything about bullying in community settings except to avoid certain areas, not go out or only go out with parents. Young people felt that there was no one else that could help with bullying and no other means of reporting it; suggesting that schools and parents were pivotal mechanisms of support and if support was not forthcoming the bullying would continue and there were no ways to stop it.

The impact of bullying

Bullying has a major impact upon the individuals who are the target and social relationships and cohesion. Firstly, participants explained how being the target of bullying affected their confidence and self esteem:

‘They made me think that I was a bad person.’

The lowering of self esteem was made significantly worse when the target of the bullying moved schools because of the bullying dynamic. Young people and peer researchers described how they felt they were to blame and brought negative behaviour onto themselves because there was ‘something wrong with me’.

Secondly, bullying contributes to increased social isolation because targets of bullying try and control it by avoiding going out, changing schools, avoiding activities and clubs and staying away from social media. All of these actions serve to isolate. It should be noted that because young people with a learning disability are at more risk of social isolation than their non disabled peers and because they tend to have limited social networks the personal impact of bullying and level of social isolation it creates is likely to be amplified.

Lastly, bullying has an impact upon social relationships and cohesion. In instances where young people with a learning disability are avoiding community areas, neighbourhoods become more segregated and the prejudice facing young people who have additional support needs becomes increasingly hidden.

What should be done about bullying and mate crime?

1. Increased facilitated social inclusion: Peer researchers felt that there was a lack of understanding and knowledge among participants about the nuances of friendship and the level of social isolation and segregation experienced by many participants added to their vulnerability to bullying. The team discussed how inclusion does not just happen but needs to be facilitated through community connecting and disability awareness education of the public and specific community members. Peer researchers commented:

‘I don’t think they know that not everyone who smiles at you is a friend.’

‘I found it intriguing, about people’s judgement about friends and maybe that their judgement about who might/might not be a friend wasn’t quite right. I always say, just because someone smiles at you doesn’t make them a friend’

‘When you’re alone a friend that bullies is better than no friend at all.’

‘A number of people [in the research] had been bullied and picked on and had to move school because of bullying. But people struggle to explain the emotions and feelings behind either good or bad friendships.’

2. Make better links between hate crime and bullying being undertaken in relation to disability. None of the participants wanted to criminalise other young people, but they did want non disabled young people to be better informed about hate crime, respect and more knowledgeable about disability. Peer researchers felt that:

‘More should be done to educate children about disabilities.’

From personal experience, one peer researcher cited the example of meeting up with someone who had bullied her in school. The person who had perpetrated the bullying apologised and explained that, largely because she had no understanding of what Asperger’s syndrome was, she had no idea about the impact of her bullying upon the peer researcher.

3. Easier reporting of hate crime. Many young people with a learning disability do not use a mobile phone for calls but instead as a mobile computer. An app to report instances of extreme bullying or hate crime would be effective.
4. Information about how to manage bullying is complicated and needs to be easy read and in audio formats so young people can understand it.
5. Young people need to know who to turn to in community settings and “safe schemes” that included local shops and other local facilities could help disabled young people feel safe in community settings.
6. Participants talked about positive and negative friendships in abstract terms rather than relating them to their own lives. Disabled young people need better education and information about how to interpret friendships in terms of negative and positive impacts within their own life experiences, which in turn would help to distinguish social nuances, such as how bullying can be disguised as “banter”.
7. Non disabled young people need to know about the consequences of identity related bullying. There are high levels of segregation in education and communities and young people who do not have a learning disability do not appear to be knowledgeable about disability and equality.
8. Increased joined up working between specialist organisations that work to support disabled young people in their communities and mainstream organisations. Many mainstream settings do not have disabled young people using their service and are therefore not skilled in facilitating inclusion.
9. Some specialist projects, such as Building Bridges, have successfully worked with staff in mainstream community organisations and services to share their knowledge of supporting disabled young people in community settings which has included how to recognize and tackle disability related bullying.

SECTION 5: THE ROLE OF FAMILY

Previous sections have already alluded to the importance of the role of family for young people with a learning disability. Whilst family can be assumed to be important to the majority of young people; for the research participants family had added significance and fulfilled a number of roles that the families of age equivalent non-disabled peers would not ordinarily have.

Family as a primary source of socialising

‘Family’ generally referred to siblings, parents and grandparents; with a minority of participants also including cousins and aunts as close family. All participants spent a significant amount of spare time socialising with family, and family played a crucial role for companionship amongst those who did not access many, or any, activities outside of school. Common activities undertaken with family members included playing on games consoles or online games with siblings of a similar age, playing with pets, going out to eat and shopping.

Socialising with family was particularly important during school or college holidays when a number of participants said that they did not see any friends because many structured activities were term time only. Most participants described going on holiday as their focal point for summer socialising; but young people whose families were unable to afford a family holiday described staying in the house until school or college restarted.

A minority of participants over 21 undertook voluntary work during the holidays if they could secure somewhere to offer them a placement.

Older siblings and grandmothers held a particularly significant role for socialising, with some participants describing how they would stayover at an older siblings house on a regular basis. More than half of the participants described how they spent time with their Nan, stayed over at their Nan’s house and saw their Nan during the week:

‘It was also really interesting that they picked the same family member. I would have expected it to be Mum or Dad, but it was the Nan.’

Peer researcher during analysis workshops

Where participants had experienced bereavement of a grandparent there was amplified loss and increased isolation because of the significant role the grandparent had played within their life, coupled with their friends' limited ability to give face to face support due to their own isolation and lack of informal time to be together.

Parents' facilitation of friendships

Whilst participants rarely saw friends outside of structured activities some did see friends when, or if, their parents were able to facilitate it:

'[We] are all friends outside of this group and this is supported by all of our parents also being in contact with each other and having friendships.'

3 boys aged over 16

'We have seen that the successful friendships seem to hinge on the parents being involved'

Youth worker

Young people were reliant upon support from parents to help with travel either through giving lifts or supporting them to get on the right bus at the right time. Parents also helped to arrange activities between friends or liaised with each other to enable stayovers. Where there were negative family relationships young people faced high levels of social isolation and loneliness.

Parental over protection and under protection during transition to adulthood

Due to limited socialising opportunities, parents played a significant role in their teenage and adult children's social life; sometimes being the primary source of socialising and sometimes being the facilitator of their social lives. Whilst parents had very little choice in this; the peer research team felt:

'There is an issue about the extent of family involvement in the social lives of young people.'

'It did come out that parents were very overprotective of some of the young people.'

Analysis discussions focused upon questions regarding the relationship between independence and relying on family for a social life. It was felt that family relationships were particularly problematic in instances where young people were over protected and not allowed out or have some freedom of movement when in other circumstances they had freedom to go out and be alone. For example, one young woman would travel to college on a bus but once she was home she was not allowed out or allowed to cross the road to go to the local shop. Another young man who travelled alone to college had had a GPS tag put onto his phone by his father and all his social media accounts were linked to his father's phone.

Many participants felt that their parents did not recognise their sexual or romantic relationships which limited the opportunity they had to be together outside of structured setting that they met at:

‘Your parents need to stand back and let you be with your boyfriend.’
19 year old female participant

However, there was also evidence that participants were aware that their families were being overprotective because parents were worried about how to support and enable them to develop their own social life and still ensure safety:

‘I was struck by the fact that lots of parents wanted to keep the young people safe.’
Peer researcher

The research team also had concerns about young people who appeared to not have enough support and were therefore vulnerable to exploitation and mate crime, as described in Section 4.

Conclusions and recommendations

The evidence in this section should not in any way be read as a criticism of parents or families. It should be noted that there is little, if any, support for parents in supporting vulnerable teenagers to adulthood and that parents of a young person with a learning disability have to balance differing concerns and priorities regarding appropriate levels of support, safety and an individualised route to independence; all within the backdrop of the threat or actual

experience of bullying, trying to guard against high levels of social isolation, fighting for education provision and sometimes also trying to secure social services support.

Family support and key working in the early teen years could enable different family members to work together towards independence safely and confidently. Key working could include incremental support for young people to develop and sustain the tools for friendship and better links between specialist and mainstream community services. These steps would enable an easier transition to adulthood and independence as well as improve social links between a young person and their neighbourhood. Parents would also then have support for addressing some of the complex issues they face including how to support independent living, further education, routes to employment and balancing safety with enabling independence.

SECTION 6: SUPPORT FOR ASPIRATIONS AND THE ROLE OF EDUCATION AND WORK

The research team had lengthy discussions regarding whether aspiration was relevant to a study on the pattern of friendships and social isolation. Whilst consensus was that aspirations were not directly applicable to the core focus of the research; aspirations are built or developed by the education system and the self confidence that can be built from inter-peer relationships. Additionally, aspirations leading to employment and participation within the workplace is a source of social validation, financial inclusion and socialising. For these reasons the team decided to include these findings within the report.

Participants' aspirations and support available to meet them

Only a minority of participants expressed any work aspirations and these included:

'Things that we would like to do in the future would be youth workers, or science teachers.'

2 boys under 19

'I would like to become a mechanic, I would like to become a Doctor and I would like to become a Chef.'

3 boys under 19

The other job aspirations participants cited were being a fireman, a lifeguard, a hairdresser, a beautician, a professional YouTuber and a librarian. The majority of participants did not have aspirations for their futures and could not tell researchers whether they wanted work and what work that might be.

The issues of low aspirations and a lack of support to develop aspirations were discussed in interviews with professionals and practitioners. It was recognised that there was little support to enable the participants to develop aspirations, and that there was no incremental development of aspirations during the journey through school:

‘It is an issue as we don’t really hear people talking about hopes and aspirations and for a number of our group, they have passed through school and college, so they are out there in the world. ’

College day provision leader

‘There are limited options [to support aspirations] unfortunately, [some] are going into another service, or others may be ‘signed off’ by Social Services, if no other service is available.’

College lecturer of 21 year olds

‘It [development of aspirations] should be encouraged in special schools. When young people go to college it seems that there are few opportunities. I don’t really know what their hopes or aspirations are as we never really hear young people talk about them, or talk about the future. That is a real shame, because if we gave young people opportunities, they would flourish.’

Youth club leader

The education system

Most of the research data regarding education related to the specialist school and college systems, except for data regarding bullying in schools, reported upon in section 4.

The picture regarding qualifications and opportunities to study for qualifications and job goals varied between the different fieldwork sites and the different education provisions that participants attended. However, there was evidence that the focus upon qualifications was very limited and most participants did not have a view of their future and did not appear to have much support in making plans to shape their future. Generally, most young people knew they were going to college or adult placement, but did not appear to have been actively involved in this decision and life after school was not related to aspirations or interests. There appeared to be a pattern of education that was very different to mainstream education that would ordinarily be experienced by non- disabled peers.

The pattern of education for the majority of the participants attending specialist education was as follows.

Work experience was not undertaken during years 10 or 11; but rather, the first opportunity to have work experience was in post 16 education, often at the age of 17 or 18 and usually the work experience was within the school or segregated placements rather than within the community.

They did not study for qualifications until after 16, and usually these were below GCSE level.

They left school at 19, having had some independent living skills tuition to support learning about using public transport, finances and budgeting, emotional health, cooking and hygiene and other key skills.

At 19, the participants generally started at college, but access to courses was very limited due to not having the qualifications for vocational study such as apprenticeships. Those who could access apprenticeships often needed part time study and these were not on offer. Of the 85 participants, not 1 had accessed, or was currently studying, on work related courses, such as traineeships, apprenticeships or other vocational study.

No one mentioned, or was accessing, supported employment or job coaching as a route to work based learning. Most were studying on segregated independent living skills courses, sometimes also studying for some core subject GCSE's and gaining work experience through voluntary placements.

There did not appear to be a pattern for when participants left college, and leaving college appeared to depend upon what other provision was available locally and the ability of the individual to secure long term voluntary work placements. The research included a few people aged over 25 who were still in part time study at college.

The role of voluntary work

All of the participants over the age of 17 had had voluntary work experience with wide ranging placements including community farms, gardening projects, waiter, receptionist, museum guide, peer and self advocacy, data administration for charities, shopping for older people with a charity, kitchen work in an older people's home, hairdressers, radio station, administration for local businesses, coffee shops, charity shops and dog kennels.

No one under the age of 16 had undertaken voluntary work and there were two patterns to undertaking voluntary work. Firstly, for those under 19, placements were very limited, short term, and hard to secure. For those over 19, and particularly those over 21, voluntary work was a way of having something to do during the days and tended to be longer term. There were some instances of schemes that involved the project being paid to undertake work such as gardening, and the project utilising the voluntary work of young adults with a learning disability to undertake the work.

The problems of securing paid employment

Only 4 of the 85 participants were in paid employment. It is well documented in education research that securing voluntary work experience is a good learning experience and enables understanding of the workplace as well as the development of soft skills. However, the level of voluntary work for those over 21, and the breadth of voluntary work undertaken, led the research team to question whether this was exploitation; particularly as participants did not seem to have any clear learning goals, personal development goals or incremental aspirations relating to the voluntary work that they were undertaking. Some young people undertook voluntary work in the hope that it would lead to paid work:

‘I am on a work placement at the moment. I would like to be in a permanent job and to get some money’

Young person aged 23

Some college staff however, reported that some young people undertook voluntary work in order to have things to do, but did not hold any aspirations to work:

‘We face a challenge with some of our young people in encouraging work as an option, or an aspiration, as some young people have been encouraged to believe that they should stay on benefits for life. We need to be encouraging young people into living independently and with that comes the option of employment.’

College lecturer

Many participants may have not been able to work full time and therefore the structure of the benefit system and permissions around part time work did

have a pivotal affect upon whether a young person with a disability is able to undertake paid work or not:

‘I think there is an imbalance between benefits and employment.’

Youth worker

The need for part time work coupled with low pay and zero contract hours affected young people’s financial inclusion and participation within the workplace.

Conclusions and recommendations

The peer research team had generally had poor experience of the school education system themselves; variable experiences of college, and personal experience of the cycle of endless voluntary placements prior to sessional employment with C.A.R.P. Collaborations. This conclusion therefore firstly gives voice to the peer researchers analysis based upon their lived experience before adding further analytical content from the academic researchers. Unanimously, the peer research team’s conclusion was that:

‘The education system is failing us.’

The peer research team highlighted three failings that led to this conclusion.

1. Schools use traditional teaching styles to focus upon high academic achievement:

‘Schools don’t focus on the outside world; they have too narrow a focus. They don’t apply teaching to real world scenarios and always put up barriers. They focus on exams as a guide to learning and don’t seem to care about the outside world.’

The academic researchers explored this issue further. There was an issue regarding young people with a learning disability access to GCSE and BTEC qualifications within the specialist system generally; and access to qualifications varied according to educational establishment. This led to young people who could study for qualifications not having the opportunity until they were aged over 19.

There needs to be recognition that not everyone will achieve qualifications, but there were no alternative plans or routes to employment; young people were not having their aspirations developed and there was not a clear alternative pathway from education to work or a fulfilling life. In terms of policy and practice development, there are questions to be raised regarding the lack of recourse to supported employment which is a well documented mechanism that enables meaningful employment and a link between aspiration, interests and paid work.

Research regarding the effectiveness of current Independent living skills teaching should be undertaken as a matter of urgency, given the difficulties that have been highlighted regarding use of public transport and the current levels of social isolation. Academic researchers also question why non disabled young people undertake work experience before the age of 16 and qualifications at age 16, whilst young people with a learning disability have to wait to be in post 16 provision before these opportunities are available.

Every practitioner and teacher within this research was clearly trying hard to secure the best future that they could for their pupils, but there did not appear to be any system that enabled the pupils to fulfil their potential or even recognise their potential. This two tier system could potentially be described as systemic discrimination; but there is a need for research purely focusing upon this issue in order to provide evidence of the finer details of this systemic discrimination and work with young people with learning disabilities to identify solutions and new practice models.

2. Segregation of young people with a disability is morally wrong and creates second class citizens.

The peer research team felt very strongly about the moral implications of educationally segregating young people with a learning disability:

‘I feel that being referred to ‘special’ (as in ‘special needs’, or ‘special schools’), is a derogatory term. But people have got used to it.’

‘I don’t like special needs schools, as they create difference. Children or young people shouldn’t be segregated. It’s like the experience of being in the environment as when black people were segregated and made to feel different in America up until the Civil Rights movement. It’s like the 1960s’ ‘When I was in school children were segregated according to ‘need’. I felt invisible.’

‘We were told by our teachers that we would never amount to anything’.

‘I think that the government see us as not having minds, as being buffoons’.

There appeared to be systemic expectations that education, and subsequently employment and developing interests, should be different for young people with a learning disability.

3. There is no progression or link between developing aspirations, college study and work experience.

There was evidence of dissonance between support for aspirations, work experience and college courses, and a general pattern that any educational placement is better than none. The peer research team discussed this issue:

‘Lots of the young people seemed only focused on the now.’

‘There doesn’t seem to be any linkage with aspiration and employment coming through? I didn’t get a sense today of progression for young people and that the whole idea of work is as an ‘optional’ thing.’

‘With this group I get a sense that if given a choice some people wouldn’t choose to come to X [particular college course].’

‘Yes. People appear to be stuck.’

‘There needs to be support for the journey to adulthood, so that it can be done in small steps. Also there needs to be work done with young people on aspirations and their social skills too.’

Academic researchers would add that colleges face a large challenge to develop work aspirations and support paid employment. If a young person has had no one to support them to develop their aspirations before the age of 19 the further education staff have nothing to build on, they are trying to develop aspirations from scratch. If this is the case, it also begs the question as to why schools are not working with young people with a learning disability upon their aspirations and to what extent are low expectations from professionals (and possibly parents) limiting young people’s potential.

SECTION 7: CONCLUSIONS AND RECOMMENDATIONS

This research set out to explore and answer 4 questions and the data evidence enabled some conclusions to be reached in relation to the original research aims.

1. Explore the patterns of friendship and social isolation with young people with a learning disability in transition to adulthood

We found that there are 2 patterns of friendships; one of which involves very little socialising with peers outside of education settings and another that involves many structured activities with peers outside of education settings. Neither pattern of friendship included informal, unstructured time with friends and young people with a learning disability were heavily reliant upon family for socialising opportunities and tended to use social media as a way of keeping contact in between structured activities.

2. Discover what helps and hinders friendships to form and be maintained.

Participants were clear that whilst some professionals and family members support them to keep their friends they need more support with understanding emotions, learning practical skills and implementing communication skills in order to maintain friendships. Difficulties in using transport presents a major problem for making friends, and having a limited social network with no informal time also inhibits acquaintances being able to become friends. Some parents appeared to be over protective which restricted young people's independence and opportunities to go out with friends.

3. Examine how friendships are linked to participation within community activities.

Very few of the participants accessed non segregated community activities. There was evidence that showed friendships enabled the use of community spaces, but many young people did not know what was available to them within their local community. There were high levels of segregation and therefore limited participation within mainstream community activities.

4. Assess whether young disabled people are at risk of social isolation; and identify what contributes to isolation and what can relieve it.

Young people with a learning disability are at high risk of social isolation; particularly as they approach adulthood. The risks arose from having limited social networks and therefore as transition occurred friends are lost from an

already limited group of friends. Additional isolation occurs through bullying dynamics. The level of segregation from the mainstream world appeared to impact upon opportunities to gain qualifications, develop aspirations and financial inclusion. In order to alleviate the level of social isolation researchers suggest implementation of the recommendations below.

Transition as a journey

Transition cannot be successful unless key learning and support is in place prior to the transition years. For example, feeling confident to be alone in ones' neighbourhood involves a series of small incremental steps that build upon each other. Similarly, aspirations do not appear at the age of 19; but develop, change and grow from primary years. There needs to be some key changes in practice whereby transition is perceived as journey and there is incremental learning of independent living skills from the primary years onwards.

The peer research team were clear about the value of a transition project that works holistically with them and their families to enable routes to independence and links to their community. Transitions work is well documented in social care research and practice evaluations and focused support for families could transform the experience of isolation that many young people described.

High levels of segregation and non participation in society

As a society we need to examine why the segregation of disabled people continues. The experience and data outcomes of employing peer researchers showed that in order to be effective we needed to work inclusively. The model of co-production needs to be applied throughout society, not just within social care or health services, but more effort at Government and local authority level is needed to create inclusive communities that enable people with disabilities to have active, valued roles.

The need for inclusive solutions within service provision

Practice needs to change so that friendship and community inclusion is a key outcome. This recommendation is not about specialist provision versus inclusive provision, but about crossing the barriers to inclusive provision and finding new models that enable specialist expertise to be used to upskill mainstream services and community facilities.

The need for meaningful employment

Four peer researchers who were involved in preparing two briefing papers, highlighted the following impacts of the project upon them:

- Having paid work experience that is otherwise hard to gain.
- Being paid for work. This is important because it means being treated as an equal and an employee so other labels become less important.
- Being included in decisions. This has enabled young people to gain confidence, realise that their opinion is of value and to learn to work together as a team.
- Gaining personal confidence to do things that are outside of your comfort zone. For example, going to new places, travelling on public transport and meeting new people.
- Learning new skills.

The data suggests there is an endless cycle of voluntary work. Some further research regarding inclusive employment practice and exploitation through unpaid work would be beneficial to understanding how to develop more inclusive employment practices and change mindsets regarding what is perceived as employability. The role of supported employment should be implemented as an alternative to qualifications and should accompany the development of aspirations.

Review public transport

Problems in using transport and the availability of transport posed one of the biggest barriers to keeping friendships and enabling community participation. County and region wide integrated public transport should be developed strategically and co produced with people of all ages with disabilities.

Review the education outcomes for young people with additional learning needs

This research was not about the education system. However, specific issues arose regarding aspirations; a dissonance between learning, voluntary work and paid work; unequal opportunities compared to non disabled peers and difficulties in independent living after attending independent living courses. This is not at all to suggest that education practitioners are not working hard to achieve the best they can for their pupils, but that potentially there is systemic discrimination in both mainstream and specialist provision that individuals in themselves cannot change. There is a need for a review of all education provision for young people with additional needs that includes the criteria that is used to assess successful outcomes for individuals with learning disabilities.

Messages from the peer research team to key decision makers:

Local Authorities

Learn to understand it.
To help us socialise in society.
Help provide information and support.
Be more understanding.
Enable us to become independent.

Funders

Learn from the report.
Fund more projects like Building Bridges that support community links and friendships.
Help other young people like us.

NHS

Understand additional needs better!
Learn that disabled doesn't mean incapable.

Non disabled young people

Read and respect it (the report).
Treat disabled people equally and how you would like to be treated.
We have feelings and are not invisible. Please treat us equally.
Don't ignore us!
Help bullies to understand their actions.

The police

Sort the bullies out! We shouldn't have to put up with it.

Help us to defend ourselves.

People with learning disabilities shouldn't be vulnerable to crime.

Regarding crime, disabled people shouldn't be more vulnerable to be stopped and searched than able bodied people.

Teach people with social problems to protect themselves and others.

Charities and other organisations

Be more aware of young people with disabilities.

Listen to us!

Provide support.

Help us get independent (jobs).

Welsh Government

Help us to be integrated.

Help people understand how difficult it is for us but how capable we are in jobs.

Include more disabled people in society especially in higher rate jobs to promote equality and fairness.

Education heads

Give us better work experience.

Provide a better system for special needs education.

Teach pupils to understand each other.

Teach teachers to help ALL their students.

Employers

Appreciate our TRUE potential and capability.

Make easy read documents.

Make the employment process accessible for all.

Adapt what you do.

Give me the chance to work. Don't overlook me because it's the easy option.

Family

Share with other parents.

How to support their children.

How to support themselves and teach their kids to do the same.