

Strengthening Protection for Disabled People: Case Studies

Revised Final Report, May 23, 2013

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INTRODUCTION

One year ago, in March 2012, the Equality Commission for Northern Ireland published *STRENGTHENING PROTECTION FOR DISABLED PEOPLE - PROPOSALS FOR REFORM*. In that report, the Commission called for significant changes in a wide range of areas relating to the law on disability in Northern Ireland. These changes would address inconsistencies in the legislation and are aimed at strengthening the rights of, and increasing protection for, disabled people, their family members and carers. The proposals would also harmonise and simplify the legislation, as well as ensuring it keeps pace with changes in the rest of the UK. The Equality Commission considers that people in Northern Ireland should not have less protection against disability discrimination than in other parts of the UK – whether that is discrimination in employment or in accessing goods or services. The changes proposed by the Commission would address that gap and have a significant impact on the lives of real people in Northern Ireland.

Collected in this report are sixteen examples, drawn from real peoples' lives, which show how each of the gaps and flaws in current disability equality legislation impact on the lives of disabled people; their families; and their carers in Northern Ireland. The case studies cover a wide range of individuals, families and experiences. They demonstrate how the Commission's reform proposals, if introduced, would make a tangible difference to the lives of the individual disabled people, to their families and those who care for them.

SUMMARY OF ISSUES

More than one in five people in Northern Ireland is disabled and being disabled brings with it significant socio-economic disadvantages. Disabled people are much less likely to be in work and find it a great deal more difficult to access services. Yet, the law in Northern Ireland lags behind that in the rest of the UK. The case-studies in this collection illustrate vividly the need for changes in the law as well as giving some insight into the daily struggles of those with a disability and those who care for them.

The cases cover a range of experiences. We hear from two people, who, having been left disabled by serious accidents have faced discrimination because service providers mistook the effects of their disability for intoxication. But they are not alone: those who are visually impaired and who rely upon their guide-dogs regularly experience unequal treatment. They find that service providers, instead of recognising the value of their dogs, regard them as a nuisance,

or a hindrance or worse. Travelling in taxis with a guide dog is especially difficult, with many service providers simply refusing to carry the dog in the car at all. Yet, as the law currently stands these people have limited means of redress.

Current statistics show that disabled people are twice as likely to be unemployed as people without a disability. Our case studies bear this out, with people reporting significant difficulties in either obtaining employment or remaining in employment because of discrimination. Intrusive, non-essential questions are asked on application forms and at interviews, putting many disabled people off from even applying. Many are left with a dilemma: to honestly disclose their disability and risk losing a fair chance at a job or covering up their disability and running the risk of later discovery. Disclosing one's disability can also lead to inappropriate conditions being placed on one's employment and even eventually to unfair treatment. Whilst many disabled people are highly capable of holding down a job, a number of them find that their disability is not recognised by the law in Northern Ireland. This means that, even if they disclose their disability, an employer is not obliged to make reasonable adjustments for them. Again, the law in Northern Ireland falls behind the changes introduced in the rest of the UK in the last few years.

The difficulties of holding down a job are shared by those who care for disabled people. Carers report harassment, lack of understanding and discrimination from employers. The failure in Northern Ireland to implement the key European decision of Coleman¹ leaves carers here in a much worse position than those in the rest of the UK. Our case studies show that carers suffer especially in the current economic climate, with many employers unsympathetic to the difficulties they face. Implementing the Coleman decision which protects carers from harassment and discrimination from employers would make a significant difference to carers' lives here, as our case studies show.

The problems faced by children with disabilities are also demonstrated by the case-studies which show the range of difficulties faced when trying to access auxiliary aids and services. At the moment and unlike the rest of the UK, disabled children without an identified special educational need have no right to auxiliary aids and services under the disability legislation. This is so even if they experience substantial disadvantage at school for a reason related to their disability. What our case-studies evidence is the stress this places on families who then have to

¹ Coleman v Attridge (case c-303/06) [2008] IRLR 722

provide additional support from home for their child in an effort to make sure that they do not suffer any further disadvantage. Families report that they feel that have to continually fight to obtain any small measure for their child, something which would improve with a change in the law.

As various studies show, people with a disability experience a wide range of forms of harassment, including verbal abuse. Our case-studies bear this out, demonstrating the need for a strengthening in protection against harassment. Disabled people should be able to effectively challenge degrading or offensive treatment when they are accessing day-to-day goods and services. But, unlike in Great Britain, there is no free-standing protection for people against harassment related to their disability when accessing goods and services, by private clubs or in schools. The extent of the incidence of harassment is borne out by a number of our interviewees who were too frightened of potential repercussions from employers, schools or service providers to appear other than anonymously in this publication.

Our case studies also show that there is significant prejudice and lack of understanding amongst employers and service providers when it comes to mental disabilities, especially in relation to those who have suffered mental health problems. Many of our interviewees also report that unless someone can see physical evidence of a disability, there is a presumption that nothing is wrong. Changes to the law, to harmonise it and bring it into line with that in the rest of the UK would significantly improve this state of affairs.

All of our interviewees are clear about one thing: the law needs to be changed in a number of ways. As one of those we spoke to put it: *“Why do we drive at 30 miles an hour in a 30 mile an hour zone? Because it’s the law. Why do we drive with seatbelts? Because it’s the law. If things aren’t working, you legislate and change it and then eventually it becomes the norm. But you have to have the legislation in place.”*

THE CASE STUDIES

1. The “Malcolm” Decision

1.1 *The Issue:*

The law in Northern Ireland prevents a disabled person being treated, without justification, less favourably for a reason related to their disability (‘disability related discrimination’). However due to a case decided by the House of Lords in 2008 (the “Malcolm” case²) it is now much more difficult for a disabled person to establish that they have been treated less favourably for a reason related to their disability. The Malcolm case effectively set the threshold for proving disability related discrimination (DRD) at the same high level as for direct discrimination.

So for example, a guide dog owner who is excluded from a hotel because it has a “no dogs” policy would not currently be able to pursue a case of DRD. This is because instead of comparing their treatment to someone who did not need to be accompanied by a dog for a disability-related reason, the disabled person would be compared to all other dog owners. This is the change that was introduced by the Malcolm case. Since the guide dog owner was not treated any differently by the hotel - all dogs were banned from the premises - the Malcolm case means there would be no DRD discrimination in this instance. The Malcolm case was about housing provision but its effect has been widened to include cases relating to education³, other service providers and to employment cases.⁴ As a result of the Malcolm case, the level of legal protection for disabled people in the case of disability-related discrimination has been considerably weakened. The Malcolm case has another aspect which makes life much more difficult for those who suffer discrimination on the grounds of their disability in Northern Ireland. Prior to the Malcolm case, a service provider might have been deemed to treat a disabled person less favourably for a reason related to their disability, even if it did not know the person was disabled. The test which has generally been adopted by the courts was whether, as a matter of fact, this was the reason why the disabled person was less favourably treated. This was changed by the Malcolm decision, which established that the service provider is only

² London Borough of Lewisham v Malcolm [2008] UKHL 43

³ R (on the application of N) v Barking and Dagenham London Borough Council Independent Appeal Panel [2009] EWCA Civ 108

⁴ Child Support Agency (Dudley) v Truman [2009] ICR 576]

liable if they knew the person had a disability or could be reasonably expected to know that they did.

Steps have been taken in GB to address the impact of the decision in Malcolm by ensuring that disabled people have protection against both indirect discrimination and discrimination arising from disability. In addition, Parliament has amended the definition of disability thereby making it easier for disabled people to establish that they are disabled for the purposes of the legislation. However these changes do not apply to Northern Ireland.

The Commission is proposing that the law be changed to prohibit discrimination arising from a disability and to more clearly outlaw indirect discrimination. This will mean that a disabled person will not need to compare their treatment to someone else in order to prove their case. The changes would prohibit actions and policies that apply to everyone equally but which place disabled people at a disadvantage. This would mean that the guide-dog owner, for example, may be able to show that the hotel's policy was discriminatory.

1.2 Case Studies:

Gertrude J.

Gertrude has been visually impaired all her life and her vision has deteriorated over the years from having partial sight to being registered as blind. Seventeen years ago her vision had become so limited that she got a guide dog. Since then she has had a number of dogs and several experiences of discrimination as a result. Her first experience was the day before her first dog was qualified and it was in a gospel hall. Gertrude was refused entry with the dog but she stood her ground and argued her case, something she has had to do now on numerous occasions over the years.

Taxis are a particularly difficult issue, with drivers often refusing to take her and her dog or complaining about having to do it. *"I always have to argue my point and sometimes I've phoned the taxi place and told them."*

As Gertrude points out, taxi drivers will often take people who are drunk in their taxis, but they object to taking her and her dog. *"They shouldn't be judging me on those grounds,"* she says. *"It's actually affecting my freedom of movement."* Gertrude finds that the issue makes getting around even trickier for her. *"You're getting a taxi and you just have to hope it's alright, that*

the taxi man is not going to have an objection. I've had times where a taxi man has just taken off and not come near me. Now, if they do that, it's easy for other people just to get in another taxi. But it's not for me."

On one occasion when Gertrude was refused carriage by a taxi driver, she was going to a computer course for blind people. *"The driver actually put two blind people and me out of the taxi because he didn't want to take the dog. I had to go back into the place and tell them and then we had to ring the taxi company up. The driver still just point blank refused although the girl at the other end was saying you have to take the person. It is actually so frustrating that you don't want to take taxis. First of all to get the taxi you have to say 'I have a guide dog' and hope you get the right response from it."*

She also points out that using any transport generally is much more difficult for visually impaired people, which is why having a guide dog is so essential. *"The driver should come to the door if a person is blind as they can't just walk out the door and walk into any car. Sometimes they don't, they just toot the horn and you have to hope!"* She finds the manner in which taxi and bus drivers often behave unacceptable. *"It's the same getting on a bus – you get on with the dog and they just take off. I can fall but they just take off before you sit down where they should be more considerate to the person and be more aware of the disability."*

As a result of the Malcolm case, Gertrude cannot allege DRD in relation to the taxi driver's actions. She knows it is the fact that she has a dog that is an issue, yet, as she points out, taxi drivers will take other disabled people without complaint. *"If someone has got a wheelchair or a Zimmer and they put it in a taxi it's ok – but the dog is my aid, it is my aid to get about. So I don't see why, just because it's an animal they won't help."* Changing the law to bring it into line with that in England would make a significant difference to this situation: it would mean that it would be easier for Gertrude to challenge the actions of the taxi drivers under disability equality law. It would also make a significant difference to her quality of life.

"There's a lot of things like going into shops and trying to find your way around, you can't get assistance all the time and that can cause a lot of hassle. You are isolated a lot even in the ordinary community so everything you go to do you have to think 'is it worth doing it?' The safest place for you to be is in your house, really, the way things are at the moment."

Thomas

Thomas had been employed in a responsible post dealing with the public. Eight years ago whilst he was at work, a colleague offered him a sweet. In a freak accident, Thomas choked on the sweet and as a result his brain was deprived of oxygen. He was in hospital for 6 months and was left with a brain injury which means his speech is slightly slurred. As a result, he had to leave his job.

One day he went into a record shop in Belfast city centre to buy CDs as gifts. The shop was very big so he decided he would be better to ask for directions. He asked the security guard on the door where he might be able to find the CDs. The guard was not very helpful and just waved in a general direction which was of no assistance to Thomas. So he asked again and the same thing happened. Thomas asked for directions for a third time and at this point the guard asked him if he was stupid. Thomas replied that he was not stupid, but he needed to know where the CDs were. The security guard then pushed him out the door of the shop, saying he was drunk. Thomas tried to go back into the shop, but he was pushed out of the door again by the security guard. Thomas did not disclose his disability to the security guard at this stage. Instead he walked home, called round to his uncle who lives nearby and asked him to come back to the shop with him. When they got back to the store, his uncle asked the guard why Thomas had been thrown out of the shop. The security guard said it was because he had been drunk. Thomas' uncle then told the guard that Thomas was not drunk but that he did have a brain injury. He then asked to speak to the manager of the shop, who was very apologetic. Thomas said he wouldn't be back and walked out. The experience made him feel very angry – he was fuming as he walked back up to the house to get his uncle and back into town again. *“There is no training or awareness. All I got was a meaningless apology from the guy. They shouldn't be able to get away with it.”*

This was not a routine experience – in his experience, the staff in shops are usually quite nice and very helpful. So this was just a bad experience but it really was very unpleasant. He was treated as if he was drunk and as he says, he does not even drink. It has left Thomas so that he is wary of going into town on his own now. These days he carries a card that states that he has a brain injury as he finds that people always make negative assumptions about him. As he explains: *“When you have a brain injury, people assume you are stupid – and I am far from stupid!”*

Thomas' experience is a good example of the "Malcolm" case in action and emphasises why the law needs to be changed. As the law currently stands, Thomas' treatment wasn't DRD because the security guard would have treated anyone else whom he decided was drunk in the same way. But of course, Thomas wasn't drunk: he was refused entry to the shop and treated as badly as he was because the security guard mistook his disability for intoxication. Unless Thomas could establish that the security guard knew, or ought reasonably to have known, that Thomas had a disability, a case could not proceed for DRD. If the law were changed to bring it into line with the rest of the UK, the security guard's behaviour would amount to unlawful disability related discrimination.

If this happened, Thomas feels that he would have a right to be treated fairly and with respect. As he points out – *"It's not my fault I have a brain injury!"*

Kenny

Kenny had a similar experience to Thomas. Eleven years ago, Kenny was in a car accident in which he was seriously injured. Some of those injuries have had a lasting impact on him – he has suffered brain damage and walks with a limp.

One night he was out with a large group of friends in bar in the centre of Belfast. He had one drink and went out to get cash for the rest of the evening. When he came back in the security guard on the door refused him entry, telling him *"You're not getting in - you're too drunk."* Kenny told her he wasn't drunk, as he had only had one alcoholic drink. Still, the security guard would not listen and she told him again that she would not allow him entry. Kenny explained that there were a large group of his friends in the bar, but she still would not let him in. He then told her that he was disabled and that she was discriminating against him because he was disabled and because he walked with a limp. But nothing would change her mind. So Kenny and his friends decided to go elsewhere. Kenny is very clear that he was refused entry because the security guard thought he was drunk because of the way he was walking.

The incident really annoyed him, but as he says, there's no point in getting aggressive about it. *"I could have blown up and got on like a bull in a china shop but it's not going to get you anywhere. There's no point in that because you shouldn't touch alcohol if you're going to be like that. But I can't understand why if you're a guy with brain damage and you walk into a place that you're treated differently than your mates because you're not as quick or as fast as them or*

whatever.” Because of the way the law currently stands in Northern Ireland, Kenny’s treatment was not unlawful – the security guard on the door refused him entry because she thought he was drunk and she would have done the same with anyone else she thought was drunk.

Kenny does not object to security staff checking people out, but thinks they should be better trained. *“It’s good to have security staff keeping an eye in bars to make sure nothing escalates but they should have more knowledge of different people from different places in life,”* he says. He’d like to see the law changed. *“It would give us a better chance to get on with our lives, get on with people and be treated the same.”* He thinks a change in the law might also make people realise that some disabilities are less visible than others. *“Some people you can really see their disability and in some people it is hidden. I have a friend and we could go out and you can see how the stroke has affected him and people know and see that. Whereas with me I walk with a bit of a limp and people think I’m drunk. But I’m not drunk – I just had a bad accident.”*

Rose

Rose was diagnosed with Multiple Sclerosis (MS) four years ago. She applied for a job with a local public body as a clerical officer. Her case demonstrates the impact of the Malcolm case in a number of ways. Because it makes it much more difficult for people to make disability related discrimination claims, one impact of Malcolm has been to require people instead to try to argue that an employer has the obligation to make “reasonable adjustments”.

In the course of the application process Rose told her prospective employer that she had MS. She had an interview and was offered the post, subject to passing some tests and having her qualifications etc. checked. She went to see the Occupational Health department in the organisation. She told them that she had MS and they checked her records.

Rose duly started work and everything was straightforward at the start. However she found the work hard-going – it involved a lot of walking around to collect notes and so forth. For someone with MS, that can be difficult and very tiring. Rose tried to discuss the issue with her manager, but got a very unsympathetic response. For example, her manager forbade Rose from telling her if she wasn’t feeling well.

Eighteen months ago Rose suffered a relapse of her MS and she approached her manager to see if it would be possible for her to go and see Occupational Health again, to be re-assessed. This never happened and when Rose asked about it, her manager told her that they had already

made reasonable adjustments for one person in the department and they were not going to be able to make such adjustments for a second person.

Rose found that she got into trouble if she asked colleagues for help. *“The lifts were not working one day,”* she explains, *“so I asked a guy just to bring some notes for me. I was asked to come to the manager’s office and she said ‘Can I have a word with you’ and I just knew I was in trouble. And she said ‘never, ever ask again someone to do a favour for you’. But the person I asked for help – she wasn’t his boss, and his boss was ok with me asking.”*

Rose felt that she was left with no option but to phone in sick on the days when she was too ill to undertake the job, even though she really did not want to do this. At one stage she actually went into work sick so that her manager could see how unwell she was. After Rose was given a sick line from her GP for four weeks, she was referred by her manager to Occupational Health. They recommended that certain reasonable adjustments be made for Rose – these included ready access to a toilet, use of the lift rather than the stairs, walking to be kept to a minimum and for Rose to refrain from heavy lifting.

But Rose’s manager refused to implement the recommended reasonable adjustments – she just said that the job had to be done and that if Rose couldn’t do it, she would have to be redeployed. By this stage Rose had contacted Disability Action, who provided her with guidance and support in dealing with her employer. There was a series of meetings between Rose and her manager, but none of these were about helping Rose by introducing the reasonable adjustments that had been suggested by Occupational Health. *“It was just about redeployment,”* Rose says. She asked in those meetings for an explanation as to why when she wasn’t ill, but disabled, that her employer was forcing her to stay off work on a sick line rather than make reasonable adjustments to help her return to work. She was told that if she did not submit sick lines she might face disciplinary action for unauthorised absence. Rose suspected that the redeployment issue was a red herring – she believes the real aim was to make her redundant. As she says, *“I am not stupid. I read a lot and especially when you are off sick for months you start reading about disability and disability discrimination – and I realised that your employer can dismiss you if they cannot redeploy you.”*

Eventually Rose returned to work without a satisfactory resolution of the issue and after four months she was redeployed to what was a part-time post. Rose liked the work and found her new boss to be helpful and sympathetic. But, she had not asked for a reduction in her hours and

was able to do a full time job. Furthermore, Rose was still on her original full-time contract, but she was told that if she wished to receive her full-time salary, she would have to use her leave entitlement to make up for the extra hours. At this point, Rose went to see her union, who helped her challenge the decision using the internal grievance procedures. She succeeded in this, with the grievance panel accepting that it had been wrong of the organisation to effectively downsize her to a part-time post. Rose is now in a full-time post, although this is a temporary arrangement at the moment.

The effect of the experience on Rose has been significant. *“It made me feel angry and sometimes a bit sorry for myself. I was told off so many times for doing something wrong but I thought I don’t want to be a victim and want to do as much as I can myself,”* she says. *“You feel like you get more understanding from your colleagues, from the people around you but not from the people who have a duty of care.”*

However she says, the experience taught her to stand up for herself, *“I’m not expecting that people should treat me differently because I have a disability. But because they employed me with my disability from day one then I think they should have had to take it into consideration. I am a disabled person, I am being discriminated against. It feels like everything is being made harder for you.”*

Rose would like to see the law changed so that people like her who want to work can do so. *“I don’t want to be a victim,”* she says, *“I am trying to be as independent and as active as I can. OK, I cannot do some things that a healthy person can but I don’t want people to feel sorry for me, I want them to understand and people don’t understand about disability.”* She feels that changing the law might also help change attitudes about the nature of disability. *“Some disabilities are not obvious and I sometimes say that it would be better if I did not have arms and legs – I would get more understanding from people and they would be able to see that I was not well.”*

Edna

Edna is an older disabled person. She has been registered blind for more than 20 years. She has a guide dog, which she adores and who has been a lifeline for her. As she says, *“When I got my first dog I hadn’t been over the door on my own in years. I got my first dog and she and I sailed out, went out into the town. It turned my life around, gave me back my life and gave me back my confidence.”*

Recently Edna’s health has declined and she now has to go for dialysis three times a week to her local hospital. She describes her experiences travelling with her dog to and from the hospital as *“the most difficult issue of my entire life,”* adding that *“in my 70 years I have never been treated in this fashion ever before.”*

Edna was initially taken to and from her home in a taxi, contracted by the local Trust. However Edna felt that the driver made things difficult for her because of the dog, even though, as she points out she has previously travelled on trains, buses and even aircraft with her dog without trouble. *“I was treated very well by other taxi companies, on the trains, in restaurants. Never, ever before was I treated like not only a second class citizen but a third class citizen.”*

When Edna contacted the Trust about the issue, she found them apparently more interested in challenging her complaint than speaking to the taxi firm concerned. In fact, she was told that she could make her own transport arrangements if she so wished. But this would have cost Edna over £5000 per year and she feels that it is wrong for her to be treated differently just because she has a guide dog. Dealing with the attitude and approach of taxi drivers on top of all that left her very upset. *“I felt diminished and demeaned, I must confess that I felt really victimised to the extent that I felt that I was being penalised because I had sight loss and I was using a guide dog as my mobility aid.”*

The Trust seemed unable or unwilling to tackle the matter of the taxi firm’s behaviour. Instead Edna was, as she puts it *“bumped onto what was called an ambulance”*. Edna is the only renal patient travelling in this fashion. This vehicle is not really suitable - there is no heat in the rear where Edna and her dog have to sit, so she is freezing and there have been a range of other problems. Edna’s beloved dog has also suffered – hyperventilating and shaking whilst in the ambulance. It turns out this may be because the vehicle is being washed out with bleach, which burns the dog’s paws. *“So it just goes on and on,”* says Edna. *“It’s distressing for me but more*

importantly it's distressing for my dog and he can't tell me what's wrong. I just find it hard to cope with."

Edna believes that the difficulty with the transport has adversely affected upon her health. As she explains: *"Dialysis is not an easy treatment to have three days a week; it takes the best part of 5 hours each time and it is very draining and quite debilitating at times. So I was finding this quite distressing."*

"If my treatment in the dialysis unit was only for 6 weeks," she says, "I wouldn't have bothered even making contact even with regard to the first issue; I would have gone the 6 weeks and thought well thank goodness that's over. But I have to travel this way for the rest of my natural life and I am not prepared to do that. Why should I be treated like this? Why should I be treated and carried in such a fashion and made to feel that I am just a nobody?"

Edna is the only renal patient who is being transported to and from treatment in this fashion: she believes firmly that this is because she travels with a guide dog. The whole experience has greatly distressed Edna and her consultant has noticed an adverse impact on her mood and general health. However, because of the state of her health she feels she has been unable to get the authorities to address the matter. *"I can't because I haven't got the energy. When your kidneys are not working, you are not working. You are just going from day to day, it's really hard. I hate stepping out of here in the morning. I am fine when I get to the unit but it's the getting there and getting home. I just dread it. It is impacting on my dog now, a poor animal who can't speak and can't tell me. I depend on him to keep me safe, the poor thing."*

Because of the decision in 'Malcolm', Edna has no legal redress against DRD. Yet if the law were to be changed, it would make a significant difference to her life. It would allow her to travel to her appointments at the hospital without worry or anxiety and she would be transported in a manner that would not make her any more ill than she is as a result of the dialysis. She is the only patient in the Trust being transported like this and feels it is clearly an issue to do with the dog since others in the same position as her are travelling in comfort and heat in cars provided by the Trust. She has to continue facing the distress and difficulties of travelling like this three times a week for the rest of her life and being made to feel, as she puts it, *"like scum"*.

"This is the first time in all my life I have ever been treated like this and it is the first time in 15 years of working a guide dog that I have ever been treated or made to feel, well, just not worth

it, I feel victimised and penalised. I feel diminished, I feel demeaned, I just feel worthless – I really do. They have taken away all the confidence that my dogs gave me. But since I started going to the kidney unit I just feel I don't want to go out anywhere because I just feel so ground down and just not me anymore. It's awful, absolutely awful."

2. The Definition of Disability

2.1 The Issue:

The disability equality law currently defines a disabled person as "a person with a physical or mental impairment which has a substantial and long-term adverse impact on his/her ability to carry out normal day-to-day activities." The law defines an impairment as one which affects the ability of a person to carry out normal day-to-day activities but only if it affects that person in one or more of the following ways:

- Mobility
- Manual dexterity
- Physical co-ordination
- Through incontinence
- Ability to lift, carry or otherwise move everyday objects
- Speech, hearing or eyesight
- Memory or ability to concentrate, learn or understand
- Perception of the risk of physical danger

This list is known as the 'list of capacities' and it is quite limited in its application. It excludes a lot of people who are in fact disabled. There are many people with illnesses or conditions which impact on their ability to carry out normal day-to-day activities which do not include one of the above capacities. This means that they would not be defined as disabled and are therefore not legally protected by the law.

The Equality Commission wants the list of capacities to be removed completely from the definition of disability. This would widen the legal definition of disability to include more disabled people and better reflect the social model of disability. So, for example, someone with a less obvious disability whose condition impacts on their normal day-to-day activities which are not included on the "list of capacities" would no longer be excluded from the definition of disability and therefore from legal protection.

In GB, the definition of disability has been amended to remove the list of capacities in order to make it easier for disabled people to establish that they are disabled under the legislation.

2.2. Case Studies

Theresa

Theresa is a former nurse who is in the early stages of dementia. She also has heart problems for which she has to attend hospital and outpatient appointments. Theresa feels there is discrimination against people with dementia as they are not being overseen adequately by the health service. In fact, as she puts it, *“people with dementia are written off by the health system after diagnosis.”* As a former nurse, Theresa understands the pressure healthcare professionals are under. But, she says, once dementia is diagnosed, the level of healthcare drops and patients with dementia receive a different level of care than other illnesses.

Theresa’s illness does not necessarily fall within the definition of disability as currently defined by the law in Northern Ireland. She does not always have difficulty concentrating, learning or understanding, and does not always have trouble with memory. This is because she is still in the relatively early stages of the disease. Theresa’s view is that when people think of disability, they think of a physical disability and thus there is more focus on that. *“When a disability or illness is hidden,”* she says *“when there are no bandages, it is so much more difficult to get recognition and understanding. There also needs to be more of a focus on what a person can do, not what they can’t.”*

The law as it currently stands does not always recognise the effect on people in the early stages of dementia. People are disabled by the symptoms of the disease, but perhaps not sufficiently to fall within the legal definition of disability. This has a knock-on effect in how such people are treated within the health care system. For example, as Theresa explains, when the health centre writes out asking her to ring to make an appointment a number of things can happen. She might set the letter down and forget about it. Or if, as happens more usually, she rings the health centre straight away but rarely gets an answer, Theresa will then set the letter down meaning to try again but then forget that she has received it. So she does not remember to ring the health centre back and her appointment goes unmade. Similarly, when attending at outpatient hospital appointments for her heart condition, Theresa is not given enough time during the

appointments to allow the information she is being given to be absorbed properly. This is because of the impact of dementia – it takes her longer to process information.

In both examples, small adjustments could be made which would significantly help Theresa. So, for example, if the health centre sent out a letter with an actual appointment that Theresa could immediately put on the calendar, that would prevent her having to remember to ring back. When she attends the hospital, if her appointments could be made five or ten minutes longer, to give her time to absorb and understand the information, that would also help a lot. A more inclusive legal definition of disability would allow for these small, reasonable adjustments to be made to accommodate people like Theresa.

Theresa also feels that a change in the law would mean that more effective training and awareness would be required for health workers. In her view, there is significant ignorance and non-understanding of the impact of dementia – even though there is a lot of money spent on training health workers. Theresa explains what she means by using the example of a simple, every day task. “It takes 30 steps to make a cup of tea – forget one of them and there is no cup of tea: that’s the impact,” she says. She believes that this aspect of understanding is missing from health worker training.

Theresa is very engaged and vocal and is involved in the Dementia Strategy Implementation Group. Through the Group, she recently got a copy of a report of a conference attended by 200 health workers directly engaged in the field of dementia care. The report indicated a general consensus amongst participants that even after attending training, they don’t properly understand dementia and particularly its impact.

Theresa feels very strongly that people who are affected by dementia need to participate in the health service to help inform and design effective policies and training. She has written to the Health Minister advocating this in strong terms. Beyond the health service, Theresa believes there needs to be a group of people involved, informed and able to raise awareness and campaign on dementia.

She feels that things need to change both to increase levels of resources and information, and to support people who don’t have access to information, resources and support.

“It seems to be matter of who shouts the loudest rather than who is in most need,” she says. “I find it very difficult but can just about manage; but I have had training and am naturally a very

active and vocal person. So if it's difficult for me, what must it be like for other people who can't participate to the same extent? It must be impossible for them."

David S

David is 38 and was diagnosed with paranoid schizophrenia 18 years ago. He has worked in the past, but has experienced significant barriers and prejudice as a result of his mental health issues. He is very keen to get back into work, but finds it quite a struggle, due to the significant stigma and prejudice attached to mental illness. One of the problems he faces is that mental illness isn't always recognised as a disability.

David has had a number of experiences of discrimination at work because of his disability, but because his disability does not necessarily fit into the list of capacities contained in the legislation, he is not always protected by the law. This aspect of the law has a particular impact on those with mental health difficulties and David's experience is a good illustration of what it means in practice.

David got a job working in a delivery yard which also handled recycling. He had responsibility for environmental issues, deliveries and dealing with builders. He had not declared on the application form for the post that he had a mental illness, because he had learned over the years not to do that, if you wanted to actually get a job. In any event, his condition was well under control and he felt well enough to work. David was in the post for over two years when things started to happen in his life which put him under a lot of stress and led to him taking an overdose. David had to take four days off work as a result, but it was the first time off sick he had taken in the entire time he had been doing the job. When David went back to work, he had to meet with his manager to explain his absence and he had to disclose his condition and the matter of the overdose.

"First thing I got was a written warning for not disclosing a pre-existing illness," he says, "now even though I did have the illness, I wasn't having any of the symptoms. It was like having cancer and then you were cured, it's just that some of the symptoms came back."

But matters got worse for him after the return to work interview. David's manager decided that she should tell everyone that he worked with about his condition – she said that the fact that he worked with heavy machinery and had a mental illness made him a potential risk to himself and others. Immediately there was a difference in how his work colleagues treated him. *"There was*

a lot of whispering and staring,” he says. “Everybody in there had a call sign which is what they were known by, but suddenly everybody was calling me “schizo” and things like that. I wasn’t ‘David’ or my call-sign anymore I was ‘schizo’.”

His colleagues also cut him out of social activities. *“I used to be invited out with staff on nights out, but I wasn’t being invited anymore and people I thought were my friends were staying away from me because I had a mental illness.”* The name calling and bullying continued, but when David went to his manager about it her response was less than helpful. She asked him if it had really happened, or was he imagining it – after all, she said, he did suffer from a mental illness. *“So I was in a no-win situation. I couldn’t show anger with my colleagues. I couldn’t go to my manager who didn’t believe me and put it down to my illness instead.”*

Because David’s illness had abated, it did not affect his capacity to do certain things, as specified in the current legal definition. David applied for a supervisor’s job, but got turned down for it. When he asked for feedback about why he had been unsuccessful, he was told it was because he had a mental illness and he therefore would not be able to handle difficult situations. In the end, David left the job because things were becoming intolerable and the strain was showing at home.

“I was coming home wound up and my wife would say something to me and I would snap. It ended up affecting my relationship. So I ended up walking out of the job because I couldn’t take it anymore and of course because I had walked out, the dole office wouldn’t give me any money for 26 weeks. So that led to a lot of heartache.”

Whilst David’s treatment at work might have amounted to discrimination, the nature of the legal definition of disability in Northern Ireland means that it was not certain. His employer certainly regarded his condition as an illness rather than a disability. In the end, the combination of his low mood, his experiences at work and the uncertainty of the law meant that David left work without seeking redress for his treatment.

3. Protecting Those Associated With a Disabled Person and those Wrongly Perceived to be Disabled.

3.1. The issues:

3.1.1 Those Associated with a Disabled Person:

The legislation in Northern Ireland currently does not expressly protect anyone associated with a disabled person from direct discrimination or harassment. This issue was addressed by the European Court of Justice when it looked at a case brought by a working mother who had been treated less favourably by her employer because she had a disabled child. Mrs Coleman's case was that she had been forced to resign from her job after being harassed by her employer and having being refused flexible working which other employees were granted. Mrs Coleman's claim was therefore that she had been discriminated against by her employer, not because she was disabled, but because of her son's disability. The Court of Justice ruled that treating an employee less favourably because of their caring responsibilities for a disabled child was not permitted under European law.⁵ Mrs Coleman had to take her case because UK law as it stood at the time did not make it clear that it was unlawful to discriminate against someone because of someone else's disability. The law has been changed in GB to address this case, but not in Northern Ireland.

In GB, a person who has, for example, caring responsibilities for a disabled child, has protection against direct discrimination and harassment.

The Commission wishes the law in Northern Ireland to be changed so it is clearly stated that there is protection against direct discrimination and harassment in employment or when accessing goods, facilities and services for people such as carers, friends and families where that discrimination is due to their association with a disabled person.

3.1.2. Protecting Those Wrongly Perceived To Be Disabled

The law currently does not protect someone who is discriminated against because they are wrongly perceived to be disabled. This could occur, for example, if someone were to turn up for an interview in a wheelchair due to a temporary injury, such as a broken leg. If that person were to be refused the job because the prospective employer thought wrongly that they were in fact disabled that would not amount to unlawful discrimination. Or if someone with a short-term mental health problem (such as depression) declares that on an application form and is rejected because the prospective employer wrongly thinks that they are disabled, that is not unlawful. The Commission is recommending that the law be changed so that people who are wrongly

⁵ Coleman v Attridge, note 1 above.

perceived to be disabled will be protected against direct discrimination or harassment by employers, service providers, schools etc.

3.2. Case Studies

Peter and Maggie

Peter and Maggie's eldest child Joshua was born with a profound, life limiting, physical disability. Joshua also has a number of other conditions, including autism. Shortly after his birth, he went through a long series of operations and spent the first six months of his life in hospital. He was not expected to survive and remains highly susceptible to infections. Joshua's condition means that he has to be educated and cared for at home on a permanent basis.

Like a lot of autistic children, Joshua finds it difficult to sleep at night. This was made worse a few years ago by a severe reaction to a drug, which has left him frightened to go to sleep on his own. He will only settle if one parent is in the room with him and he wakes frequently during the night. This results in continual sleep disruption and deprivation for Peter and Maggie, who have two other young children and no respite other than each other.

Peter works for a large public sector organisation and as part of his job is sometimes required to work nightshifts. This created significant additional difficulties for the family, as it meant that Maggie was left to care for Joshua by herself at night. As a result, Peter applied for flexible working hours with his employer and provided details of the reasons, including supporting letters from doctors and other specialists. His request was centred on his need to be present in the evenings to help care for his son. He wanted to work the same hours, just not at night. In the meantime Peter had to use up his annual leave to break up the night shifts and enable him to help Maggie in the evenings. As Peter met the flexible working policy criteria laid down by his employer, his request was granted for one year, but was to be reviewed every few weeks. Not long after his request was granted, it was revoked. When challenged about this, the organisation said that continuing the arrangement was not in its best interests. It also said that the arrangement had impacted upon Peter's performance in some aspects. The organisation added that it was only ever intended to be a short-term solution and advised Peter to "sort out" his domestic arrangements. The organisation seems to take the view that it is up to Peter to manage his home environment no matter how challenging the circumstances. He has also been told that if he is granted flexible working on this basis, it would set a precedent for others.

However, Peter is aware that, just as in the Coleman case⁶, there are other members of staff in the same work position as him who have been given flexible working hours on a long-term basis, for different reasons. They seem to only have it reviewed once every year as opposed to the shorter review period that was imposed on him. He considers that he is very clearly being treated differently to his fellow workers. There have been other incidents where he believes that he was treated differently and less favourably than other members of staff. For example, he asked for annual leave and was denied it on the grounds that there was no-one else available to cover it, but leave was then granted to someone else in the same department. The pressure from the situation has caused him so much stress and anxiety that on medical advice he has had to take sick leave. Since then he has been visited by a superior where he was told that although the organisation did not wish to put him under any pressure, his job was “hanging by a thread”.

Peter and Maggie believe that they and their family are being directly impacted by the gap in the law. Because the legislation has not been changed in Northern Ireland in line with the Coleman judgment, the law does not protect the families of disabled people. Yet, just like Sharon Coleman, Peter is being denied the flexible working arrangements he needs and which are available to others he works with. Instead, Peter feels that he has to justify everything he is asking for, which has created a difficult situation with his employer.

Both Peter and Maggie believe that the consequences of this gap in the law are that it discourages people who have caring responsibilities for a disabled person from working. A change in the law would mean that dealing with Peter’s employer would be a great deal easier: at the moment they are both worried sick that he will lose his job as a result of the on-going disagreement over his application for flexible hours. *“Dealing with a situation like this puts huge pressure on marriages and families,”* they say, adding: *“What happens to the disabled child if they break down?”*

Peter and Maggie also believe that a change in the law in Northern Ireland to bring it into line with the Coleman ruling and with the law in the rest of the UK would also have a profound impact on many disabled people and their families and carers. As Peter says

“The needs of carers and families have to be considered and must be protected in legislation. This is particularly so if it is a child with a disability, as it is actually the carers rather than the

⁶ See note 1 above

child that need protection in the workplace. People should not have to justify a disability or a child's disability in arguing for support. The law in Northern Ireland needs to be updated – this just couldn't or wouldn't happen now in GB."

Seamus and Jacinta Larkin, parents of Kellie.

Seamus and Jacintha are the parents and carers of Kellie, who has quadriplegic cerebral palsy and no verbal communication ability. They own a house that they have specifically adapted to their daughter's needs. Seamus works in a public sector organisation in Newry which is moving towards centralisation of its posts into one place. Because of the demands of her caring responsibilities Jacintha works part-time in Newry for an employer who has several offices around Northern Ireland.

At present the Larkins are up at 6 o'clock to get Kellie up, toileted, dressed and fed to allow them to be into work about 9 o'clock. Because of their responsibility as carers for Kellie, and the significant adaptations they have made to their home, they both need to stay working and living in the immediate locality. However, they both find that this has impacted considerably with their work and subsequently their earning capacity.

Seamus is concerned that, if published plans materialise, his job will move from Newry to Belfast, which would cause him significant difficulties as a carer. His previous job was centralised to Edinburgh but the employer refused to consider any adjustment to its centralisation policy. Jacintha has been on a promotion list on numerous occasions, but has been unable to commit to take it up because of her responsibilities as a carer as promotion would mean relocation to Belfast.

Both Seamus and Jacintha find that their caring responsibilities limit them in what they can do at work. Those responsibilities also place significant additional pressure on them. For example, someone has to wait for the bus that takes Kellie to her special needs school, which prevents them from starting work before 9am. They have to use up their leave allocation taking Kellie to and from hospital, therapy and doctor's appointments, which can run to several times a month. This puts extra pressure on them, as Seamus explains, *"You can get into a burn-out situation and you are also conscious yourself that if you are not there, somebody else is having to do a bit extra."* If Kellie needs taken any distance, usually both of them need to go, in order to be able to lift her. *"You won't believe this,"* says Jacintha, *"but you could go to a hospital and they don't*

have a hoist. You could go to a children's ward and not have facilities to shower a child. So the two of us have to be there".

But neither of them can be reassured by the protection of the law as it currently stands in Northern Ireland, because the Coleman case, which does protect carers, has not been implemented in Northern Ireland. Both Seamus and Jacintha believe that without this legal protection life is extremely difficult, if not nearly impossible, for parents who are carers and who are also trying to hold down a job. To illustrate this, they give the example of Kellie being in hospital in Belfast for major surgery which caused significant stress for all of them. Jacintha had taken 3 days care leave to stay with Kellie in the hospital, but she ended up having to stay with her for seven days. Kellie was in the operating theatre for seven hours for reconstructive surgery on her hip and had serious complications afterwards. She also required considerable additional care as a result. *"Kellie was in a cast from the chest to the ankle on one side and from the chest to the knee on the other,"* explains Jacintha, *"and that set her back toileting wise and everything. Her confidence had taken a real knock and she didn't want anyone to see her like that."* Jacintha needed to be there because of Kellie's communication difficulties. *"Even when it came down to food it was left to the parents – all Kellie's food has to be liquidised as she cannot chew, if you give her normal food she would choke on it."* The experience was very stressful and upsetting for the whole family. Yet Seamus had to field calls from his employer, asking about when he was coming back to work.

"I know they have targets to meet but there has to be a bit of leeway somewhere along the line. I know people actually do try and bluff their way through things but my manager knows Kellie but he had to follow policy and procedure," says Seamus. *"Kellie was very ill at that time, she had to have a blood transfusion and it doesn't help when your manager is not empowered with discretion even though he was very sympathetic."*

But, as Seamus points out, *"if it was me or you that had been in hospital, it would have been treated by an employer as a lifetime event and would have been treated compassionately and with consideration. It would have been accepted that it would be a long-term recovery period. But if you are the parent of a disabled person who goes through that it's 'oh, she's out of hospital? Right, fine, when are you coming back?' So despite the fact that the person is 100% dependent on you, you are expected to be back at work even though there are no viable care alternatives."*

The Larkins' feel that part of the problem is a lack of awareness and understanding on the part of others as the legislation is weak. Everything is subject to "business need" and the lack of legal underpinning is a major problem. As Jacintha says, *"General appointments and things need to be taken into consideration. At the moment, your holidays, your time to yourself doesn't exist. All you want is the flexibility to be where you need to be for her. We don't have holidays, we don't go away, we don't have the leave – all our leave is used up in appointments and looking for things that can be done to improve her life."*

They both think that if the law was changed to protect carers, things would improve. *"You are in a current environment of de-regulation, if you don't have to do it, don't do it,"* says Seamus. *"If the law was changed, employers would have to take a more sympathetic and reasonable approach to the huge burden that many carers carry every day whilst still trying to hold down a job."*

"There needs to be some degree of enforceable reasonable adjustment for carers," he argues. *"Carers Passports are available but they are not worth the paper they are written on as the recommendations may not be applied if they are not legally recognised. Business need will always win over recommendations. You can have all the best well-meaning policies and procedures in place but it is how these are exercised that counts. As it exists, you just feel like throwing in the towel as frustration levels go beyond pressure and stress."*

4. Better Protection Against Harassment

4.1. The Issue

There is no specific protection in the disability equality law against harassment related to disability if it occurs somewhere other than in employment or in further and higher education. This means that there is weaker protection against harassment for disabled people when accessing goods and services than if they were harassed due to their disability whilst in employment or as a student in a college of further education. This is in contrast to the law as it relates to other forms of harassment, such as race, where there is greater protection against harassment outside the workplace. It is also different to the law in the rest of the UK which does provide such protection against disability related harassment outside the workplace.

The Commission would like to see the law changed so that disabled people have stronger protection against harassment related to their disability when accessing goods and services.

4.2. Case Studies

The Morgans.

John is 51 years old and married to Carmelita. They have four children, two of whom, Thomas (16) and David (14), have been diagnosed as having severe autism and significant learning difficulties. The disability manifests differently for each boy. Thomas has very limited speech and language whereas David has much better communication skills. However they both have similar types of behaviour patterns which are common in people with autism. These include lack of social awareness and no inhibitions, especially around other people and their personal space. David will wander up to complete strangers and start asking questions. He will hug and touch strangers and does not realise he is not supposed to do this. Thomas is more withdrawn, but his behaviour can also be unusual, especially in public places where he can freeze and stare. A significant feature of autism is the lack of capacity to learn to stop doing certain things or to realise their impact on other people.

The response of others to the boys' behaviour can be very challenging for John and Carmelita. This is particularly true of public places where, as John says *"my two boys look like perfectly normal boys."* This means that if they start exhibiting some of their behaviour in places like restaurants, people point, stare and often make remarks about how *"badly behaved"* they are.

People will sometimes make insulting and hurtful remarks about the two boys. On the last package holiday the Morgans took a fellow holiday maker asked John if he thought it *"right to bring people like that on holiday as they spoil it for normal people."* The man's wife later apologised for his remarks, but that was the final straw for the Morgans. They are fortunate in having a friend who has a house abroad which they can use sometimes. It is more enclosed and private and they are able to relax with the boys and not constantly worry about harassment from others. Yet very few service providers seem to understand that this is an issue for disabled people and those who care for them. A law which protected disabled people from harassment when accessing services would begin to impact on such attitudes, the Morgans feel. It would also change the way that service providers behave.

For example, taking the boys out for a meal is difficult, as John explains. *"If you take an autistic person into a restaurant and you tell them you are going to get something to eat and you go in and the placed is bunged and it turns out you have to wait – well, they don't do waiting or*

queuing up and they don't do the social etiquette rules of 'don't eat other people's foods'." So it involves quite a bit of forward planning. "What we would do is survey the places before we go in. So I would sit in the car, Carmelita would go in and have a quick look and say 'there's room, bring them in' so in we'd go. We tend to find – not all the time, but when we go into places we find if the boys are being the boys - well, that tends to draw attention." That attention can lead to harassment and hurtful remarks. The Morgans were once told by a restaurant owner, "People have a right to come out and eat their meals without having to look at people with a disability."

Yet, because the law is framed in the way that it is, people like the Morgans have limited legal redress. Probably the worst experience the family have had was when they went through airport security. Getting the boys through the scanner can be difficult, so Carmelita takes David and John takes Thomas, who is always more likely to object to something. John always sets off the airport scanner because he has a metal hip replacement, but they try to make sure that the boys have nothing on them that will beep as they go through the scanner. They also put the boys through the scanner first, so they can keep an eye on them. However, on this particular day, Thomas set off the scanner. John's first thought was to get through to Thomas before the guards started to search him, as he would not understand what was happening. However, because Thomas had 'bleeped', the security people insisted on dealing with him before they would let anyone else through.

John said to the security guards, *'Hold on, Thomas is autistic.'* But he was ignored, so he then walked through the scanner anyway which, he says, *"agitated them no end because of course I bleeped as well."* John said again *"please stop"* but instead the security staff were telling Thomas to put his hands out to be searched. Thomas did not understand what they meant and John tried again to explain this to the security staff but, once again, no-one acknowledged what he was saying. Instead, the security people tried to search John, who was still trying to explain the situation to them. *"And they are saying 'he has to be searched' and I'm saying 'Yes I know he has to be searched but he is autistic, he does not understand what you are trying to tell him.' The guard who was dealing with Thomas was again completely ignoring everything I was saying to him. Instead he was still insisting that Thomas put his hands out. Eventually I put my hands up, said very loudly 'Stop!' I then asked very loudly for a supervisor to be fetched and then I had their attention. I said 'I have told you several times he is autistic, please leave him alone. Sort me out and then we together can sort him out.'* And that resolved the issue." Meanwhile Carmelita was having another problem – David wears a hat all the time, to which he is most

attached but it had to come off to go through the X-ray scanner. He was not very happy about this and was causing a bit of a stir. So both boys and parents were frazzled and upset by the time they got through security. Yet, if the law were to be changed in Northern Ireland, the Morgans would have greater protection against harassment .

More particularly, service providers would have to ensure that their policies and practices, including staff training, met the legal standards. As John says *"In the end it could have been easier if they had been disability trained - they would have recognised our Thomas has a difficulty. And really in the end when he was standing there staring at him the security fella should have realised he had a difficulty and he should have been treated differently but he wasn't."*

John acknowledges that a lot of the harassment they experience happens because they take their boys out. *"When we talk about taking the boys away on holiday or taking them anywhere other parents of autistic children can't believe we do it because they just don't."*

But John feels that it is important that people understand what it is like to be disabled and to look after someone with a disability. *"The act of going out there brings yourself and other people face to face with the nature of autism and the difficulties of it. If we hadn't taken the boys away on holiday we would never have met airport security; if we didn't take them into restaurants we wouldn't meet people staring at them; if we didn't take them into restaurants we wouldn't be meeting people who say 'well I don't think you should be bringing people like that into restaurants,' you know? The less society sees less of disability, attitudes become even worse. So you have to make sure that you actually do get out there."*

John believes strongly that a change in the law is needed, to tackle those attitudes. As he says: *"Why do we drive at 30 miles an hour in a 30 mile an hour zone? Because it's the law. Why do we drive with seatbelts? Because it's the law. If you have legislation that means that if I got to an airport and I thought that the person facing my Thomas was not treating him properly then I would be able to say 'excuse me, you do realise that you are supposed to behave differently?' I'm a great believer that if things aren't working you legislate and change it and then eventually it becomes the norm. And it's the norm now that we recognise diversity; it's the norm now that we treat people well. Quite simply, you have to have legislation in place to protect vulnerable people like Thomas and David and the people who look after them like me and Carmelita."*

5. Pre-Employment Enquiries

5.1. The Issue

Job application forms sometimes contain questions relating to an applicant's health or disability. Sometimes applicants for jobs have to fill in a medical questionnaire. Those sorts of pre-employment enquiries can put disabled people off applying for jobs. However, the law currently does not prohibit such questions and therefore there is nothing to prevent employers from screening out disabled applicants at an early stage in the recruitment process. So for example, an employer can ask questions either on the application form, or prior to making a job offer, about a person's health or disability that are unrelated to the nature of the job or to any reasonable adjustments that may be needed.

The Equality Commission wants the law changed so as to prevent employers from asking questions about an applicant's health or disability prior to making a job offer except in specific limited circumstances. Employers would still be able to ask health related questions in order to establish whether reasonable adjustments are necessary during the recruitment process or whether or not the applicant is able to undertake a function that is intrinsic to the job. Employers would also still be able to ask such questions in order to monitor the diversity in their workforce. This would bring the law in Northern Ireland into line with that in the rest of the UK, where changes like these have already been made.

5.2 Case-studies

Philip

Philip had a professional job for more than 30 years with a large public sector employer, but had to take early retirement due to a disability which developed later in life. He spent a few years out of employment, but decided that he really wanted to try to get back to work. He saw a job advertised by another large public sector employer, a job for which he felt he was very well qualified. He sent off for the details and the application form, but was very disheartened when he read through the form, as it asked a series of questions about health and disability which were unrelated to the criteria for the post. For example, the form required applicants to list their previous employment history and give reasons for leaving. As Philip says *"I had to put down 'ill health' as my reason for leaving my previous post. I could have put something else, but I wanted to tell the truth."* The form also asked about career gaps, so he had to explain this and

put down the details of his disability, why he had retired and why he had not been working for a few years. The form also asked for details of his medical history and for periods of sickness over the last three years. It asked if the applicant had ever had to resign, retire or been dismissed from a post due to ill health. *“Now that’s a very direct question not related to the criteria for the job,”* says Philip, adding *“All of this is giving the message that you are going to be regarded less favourably than an able-bodied applicant.”*

There were further questions about disability on the form. Applicants were required to state if they needed reasonable adjustments for reasons related to disability in order either to attend the interview or to undertake the duties of the post if successful. Philip had no objections to those particular questions, but he did mind the answers being before the panel who might be interviewing him. *“That sort of an assessment should be made by a technical person,”* he says, *“the sort of person with the ability to make those judgments. The people who were at the interview weren’t the people with the skills to evaluate what was on the form about that.”*

The questions on the form nearly put him off applying for the job in the first place. *“When I first read the form, I thought, well, would I be wanted? The first message you get is: have you a sickness, have you a disability? Are you going to be more costly, are you going to be more time consuming? The whole implication from the form is, well we don’t want to employ you, even just with the questions about the sickness, never mind the disability.”* He thinks it wrong to lump disability and illness together, as the form appeared to do. *“I have been working now for the last seven months and I haven’t had one day sick yet. And during my 30 years at work before, I never had a problem with my sick leave. Except when I was leaving when I had to put the hands up and say it was time to go out sick.”*

Philip believes that the series of questions about his health and disability on the application form impacted his chances of getting the job. He feels it sends out a very strong message that you are going to be looked on less favourably than an able bodied person. *“Other people would have given up – some people wouldn’t even have put pen to paper. It was only because I was determined to get back to work that I thought ‘okay I will go through with this’.”*

Philip was shortlisted for the post and duly attended for interview. He wasn’t asked any questions at the interview about his disability. But those who were interviewing him had his application form in front of them, with all of his answers to those questions. Philip finished second in the interview, to someone he feels was less well qualified. Unusually the panel did not

appoint a reserve candidate, even though Philip later discovered that he had met the threshold for appointment. His letter of rejection also made him suspicious – it was dated before the date of the interview, although this was later explained away as ‘a clerical error’.

Philip decided he’d like to know why he had not been successful at interview so he asked for feedback, but the employer never came back to him. In the end he resorted to initiating Industrial Tribunal proceedings in order to have some sort of dialogue on the matter. *“What I really was looking for was a proper explanation as to why I was unsuccessful and why those questions were asked on the form.”* But because of the way the law currently stands, as he explains, he was unsuccessful. *“I started proceedings but even though in England you cannot ask questions related to disability on an application form, here you can. So I only proceeded to get the answers the employer had denied me. It is wrong that the law does not protect disabled people in this way.”*

Philip believes strongly that the process discriminated against him, but despite that, he bears those involved no ill-will. *“I wouldn’t have taken the case if they had come and spoken to me. If they had come and given me feedback it would have been an opportunity for me to talk to them and point out that I found their form discriminatory.”*

He is certain that the effect of changing the law would be significant - *“If the questions were taken off the form they would reduce discrimination. Those questions the way they are just reinforce discrimination. I mean I didn’t put my application form in until nearly the last minute. In part that was because of the questions – I found them really degrading. I didn’t know whether I should put myself through all of that hassle just to get turned down anyway.”*

Philip was very upset by the whole experience – *“It made me feel like a lesser person in society - not on an equal playing field with everybody else. I was just recovering mentally from getting my disability – I have never had anything like this in my life before. So I was having to adjust my whole life, my whole mental attitude to having a disability. I was just beginning to think of myself as normal person again, able to do normal things, which took a lot of adjustment and then the whole thing with the application form and the job interview just reinforces your view that you are not an equal person in society.”*

Changing the law would make a big difference to Philip– *“I would feel I was going into a process on an equal footing with others. You know, I am being asked to answer for being ill. They were*

asking me, why were you sick three years ago? Why did you suffer a disability and have to take time off work? I felt like I was being blamed.”

Philip also thinks a change in the law would help disabled people live more independently. *“I believe that people should be treated equally. I also hear every day that the government are introducing massive changes to the law to try and make disabled people get back to work. The government are saying, you don’t need help, you could be out working, but employers are saying, we don’t want you! Surely allowing these sorts of questions conflicts with policies on making disabled people more independent.”*

Philip did not let the experience prevent him from trying again for a job. He has been back at work now for seven months with a different employer, who he describes as excellent. *“They are better for me being there, I am better myself for being there, they recognise my disability, they don’t mind it, they respect that.”*

David S

David is 38 and was diagnosed with paranoid schizophrenia 18 years ago. He has worked in the past, but has experienced significant barriers and prejudice as a result of his mental health issues. He is very keen to get back into work, but finds it quite a struggle, due to the significant stigma and prejudice attached to mental illness. He is currently volunteering five days a week with a local charity, helping other people with mental health issues and providing advocacy on their behalf.

David has a good understanding of his illness and manages it as well as anyone could. As he says, *“I know when the early warning signs are and I know when I need to step away from the situation. I would also suffer from depression - I think that’s all part of it.”*

For years David had not disclosed his illness on job applications, because he found that doing so made it really difficult to get jobs. But when he saw a job with a call centre company who had a policy of employing disabled people, he decided he would disclose his illness when applying for the post. His experience as a result of that illustrates another kind of detrimental impact that pre-employment inquiries on a form or at an interview can produce.

David was pleased to find that he had been short-listed for interview, but during that interview, the panel started to ask questions about David's illness. *"One of the questions was would I be dangerous working with other people? You're in an interview situation so you are already nervous before you get into it, so you can't think of proper answers – you're totally lost and the question completely froze me."*

Whilst employers will sometimes ask such questions for the perfectly valid purpose of making reasonable adjustments, in this case the information led to specific conditions being placed upon David under which he would be employed. Once a week he was required to discuss his disability, how he was managing it and how he was feeling, in detail, with his line manager. This caused him a number of difficulties.

"Going into the job I was straight on the defensive," he says, *"I mean I suffer from paranoia as it is, and then I was put into a situation where I knew that everybody was judging me and everybody was watching my behaviour so it sort of exaggerated my paranoia."*

Having to talk about sensitive and personal aspects of his life to his line manager was very difficult, not least because his manager had no training in mental health. *"When you are talking about your mental illness, you are sometimes talking about things that you don't want to talk to even your family about. I discuss my mental health with professionals like psychiatrists and CPNs all the time. But these are trained people, people you have spent years with building up a trusting relationship. When you have just walked into a job you don't know the manager, you haven't built up that relationship. Yet you are being expected to talk about some of the most confidential things to someone you don't know, things you might not even talk to your partner about."*

David thinks the company's intentions were genuine and intended to support him. But, as he points out, *"Since the manager had no training, how could he ask the right questions? How do you explain to someone like that if you are feeling suicidal? What you find is that the weekly meetings become daily meetings and then you have the manager coming up to you during the day, asking, 'How are you feeling David? How's it going?'"*

A significant issue was that the company had disclosed to David's co-workers that his weekly meetings with his manager were for health reasons. "So," as David points out, *"that meant people were speculating as to what' health reasons' it could be. It made me seem so different to*

everybody – so it made it worse. And I suffer from paranoia anyway. It just made things a lot harder.” When David’s manager approached him during the day to discuss his health, he felt like he was being made an object of curiosity and gossip. *“You had everybody trying to listen in - it was in one of those call centres with small cubicles. I didn’t feel comfortable in the job and I didn’t feel safe. So I wasn’t concentrating on the job, I was concentrating on my behaviour and how it could be perceived. I didn’t feel safe to express myself or talk to anyone. I just sort of retreated into myself and didn’t talk to anyone – even though there were over 500 people on that contract.”*

David’s sense of isolation got worse as a result of this. *“I wasn’t David,”* he says, *“I was “the schizo” in my own eyes. I felt so different to everybody else because I was being treated so differently to everybody else. Because when you are in work you need to build up relationships with people and it just meant that I felt left out. It was almost like it was a shameful thing to have a mental illness.”*

In David’s view, it was lay people asking inappropriate questions about his illness which was at the root of the problem. Those questions on his form and at interview ended up meaning that he was employed on very specific conditions relating to his disability. That treatment meant he ended up being treated as he was at work.

David thinks that questions on forms about illness and disability make life very difficult for people with mental health issues. They can even make the illness or the disability worse, because people are forced to hide their disability. In David’s experience just mentioning the words “mental illness” on a form meant you were very unlikely to get a job. *“The whole way through my career, I’ve either had to hide the fact that I had a mental illness and try to stay in a job or when I have disclosed it, I have had discrimination. I have had people turn round and say they didn’t want to work with me because I had a mental illness.”* So David decided to stop disclosing his illness on job applications. But, as he points out, that also has consequences: *“You’re denying that you have a mental illness, you’re lying and you’re always concerned and worried that it could come out. It also meant you couldn’t see your doctor and you couldn’t see your CPN. You were missing hospital appointments because you couldn’t ask for time off; you weren’t taking your medication because the times you had to take it fell in working hours. So all the time you were becoming unwell because you were too afraid to disclose that you had an illness.”*

David believes that the situation would be greatly improved if the law was changed because, he says, *“around 47% of people with mental illness aren’t in work and a lot of people would be able to work but aren’t even being given a chance.”* Changing the law would give David and others like him a lot more confidence in applying for jobs. *“If I didn’t have to declare my disability, it would probably give me a better chance of getting a job and getting off benefits which is my main goal – my aim is to get back into work. But it’s hard, because you are going, look I need to get a job but I also know I am going to face this discrimination. So you sort of don’t bother, it puts you off applying.”*

Adrian

Adrian developed a mental illness around the age of 17 and was admitted to hospital and spent just over 6 months there. He was diagnosed with bipolar disorder. When he left hospital, he tried to return to school, but found it very difficult – his concentration was poor and he had been given large doses of medication whilst in hospital from which he was still recovering. Adrian is still on medication today.

With help, Adrian got back on his feet and obtained a number of NVQs. He then joined a mental health charity as a volunteer. He found that it got him out of the house, gave him a much needed structure and the opportunity to practise his skills.

Then a couple of years ago, he was passed information about a new pilot programme being run by a large public sector organisation. They were advertising jobs in mental health support and were specifically encouraging those who had experienced mental health issues to apply. The jobs were open to anyone, but it was made clear that applications from those who had mental health disabilities were welcome. Adrian really liked the sound of the job, so he applied. However, even with a programme such as this, designed to encourage applications from those with a disability, there were difficulties. Adrian found that during the application process – which was long and very drawn out – there were a lot of inappropriate questions asked about his disability.

“There was a lot of misunderstandings and confusion about what they were asking for. I had to go for an occupational health check and a police check – I don’t mind about that, I understand that, but the occupational health, you know, they want a lot of your history; you know - the gaps

in your history. But the occupational health people had not been trained in mental health issues.”

Because of the nature of the post, a number of checks and enquiries had to be made and Adrian had to become registered with a number of organisations. During one of these registration processes, he says, the questions became especially intrusive. He thinks this was partly because the organisation concerned had never had to register someone for work who had a history of mental health issues.

“It was bizarre, it really was,” Adrian says. “Like one of the questions they asked on the form was ‘How do you manage your illness/disability?’ So I said on the form ‘I manage my illness by receiving medication from my GP.’ But they sent it back and they wanted more information. It was a whole host of questions; they kept sending it back asking for more in depth, intrusive information. I just thought, well, if I had broken my leg they wouldn’t be asking me how I broke my leg, why I broke my leg and all of that.”

Adrian could not see the reasons for the questions he was being asked. *“I just thought that bit was like too much. They were asking me things like, “how would you be a risk to people?” To be honest with you, I don’t know why they were asking that question. I think it was a shock to them that they were getting people with the experience of mental health and they didn’t know what to do – they thought, here what do we say to this fella?”*

Adrian found the experience very degrading. He was also bewildered as to why he was being asked so many questions that he felt he had already satisfactorily answered. Luckily, he had help and support, in the form of an employment support worker.

“She sent a letter off to HR asking what was the purpose of those questions. She said, look, he has already given you enough information about what he has and how he’s managing it, that should be enough information for anybody but clearly it wasn’t, not for them anyway. But as I say, I don’t think they’d ever had anyone like me apply for a job like this before or if they had they hadn’t disclosed their background.”

Adrian has found that having had mental health problems is a barrier to work generally and particularly in the field of care and support for people with mental illness. There is, he says, a lot of discrimination which arises from lack of knowledge and awareness. But, as he says, *“I can see it from both sides. I try to get an understanding now – the resident’s perspective would be*

mine but I can see where all the organisation's policies and procedures come in. To be honest I think more people like me need to be employed for things to change."

Adrian's job is a permanent one, but it was the first job he had ever applied for. *"I was too scared before. I had heard so many stories about people getting turned down because of the discrimination. And a lot of the forms I saw asked 'Do you have a disability, please tick.' Even the questions put me off."*

Adrian firmly believes that the law should be changed to prevent people having to disclose their mental health background on application forms. *"If the law were changed, it would reassure applicants going for jobs that they're not going to be judged on the illness or numbers of days off sick. I have found that because of that a lot of people aren't applying for jobs – at the moment there aren't that many, because of the recession and stuff. A lot of the guys are scared enough about not being able to do the work without being stigmatised. They feel they'll be judged if they make a small mistake. If there is anything for people, it's a placement – but even there, people find themselves stigmatised a bit on those, because everyone knows who they are."*

Adrian thinks a change in the law would make a big difference to the lives of those who have experienced mental health difficulties. *"It would reassure people and give people a bit of confidence. They would know they weren't going to be grilled or interrogated about their past illnesses or health. Because of the huge stigma around mental illness, people just don't want to have to talk about it. It would help other people see past that illness and see the person just sitting there. And maybe give them a chance."*

6. Providing Auxiliary Aids and Services in Schools

6.1. The Issue

Although schools are currently under a duty to make reasonable adjustments for disabled pupils in order to avoid putting disabled pupils at a substantial disadvantage, this duty does not extend to the provision of auxiliary aids and services. Instead a child who is diagnosed as having a disability must go through the process of being assessed for special educational needs, which can take some time. Furthermore, as the law currently stands, not all disabled children are considered to have special educational needs. In such circumstances a disabled child has no

right to auxiliary aids or services in school, even if they experience substantial disadvantage for a reason related to their disability.

This is because the disability equality law currently does not require schools to provide aids and services to disabled pupils who are not considered to have special educational needs. An “aid” might be downloadable electronic lesson notes for a pupil with a visual impairment; a “service” might be a support assistant for a disabled student to help them push their wheelchair around school.

In all cases, disabled children are dependent upon the assessment of the relevant educational authority – usually one of the Education Boards – for the provision of aids and services in school. However, some disabled pupils will not have SEN, and some disabled pupils with SEN will still need reasonable adjustments to be made for them in addition to any support they receive through the SEN framework. The Equality Commission would like to see the law in Northern Ireland changed to bring it into line with the rest of the UK, where the law requires schools to provide auxiliary aids and services for disabled pupils. They must do so where this is reasonable and where not doing it places the student at a substantial disadvantage when compared to pupils without a disability.

6.2. Case Studies

Seamus and Jacinta Larkin, parents of Kellie.

Seamus and Jacintha are the parents and carers of Kellie, who has quadriplegic cerebral palsy. She has to use a wheelchair and she has no oral communication ability. The Larkins own a house that they have specifically adapted to their daughter’s needs. They are both able to communicate with and understand Kellie, who otherwise needs specialist technology to communicate.

The main problems that Kellie faces with her education are around her communication difficulties. Kellie is intellectually able and wants to push herself in school, but the barrier is her ability to communicate, for others to understand her, which causes frustration and de-motivates her. Whilst Kellie has a Special Educational Needs Statement, it does not cover nor provide for a communication system which allows her to indicate more than “yes” or “no”.

When Kellie was in primary school, there was a specialised communication system used to help her, but it was tied into funding that the school got from the Big Lottery. However when the funding ran out, there was nothing to replace it. Because of the existing state of the law in Northern Ireland, there is no compulsion to provide aids like this for children like Kellie. When Kellie transferred to secondary school, there was a delay in the equipment going with her and the license lapsed. That delay has meant that Kellie has no effective means of independent communication in the school and the school are trying to assess her abilities without the necessary equipment. Seamus and Jacintha feel that this has resulted in her abilities being under-estimated and her learning affected as a consequence.

Having Kellie assessed correctly has been a struggle, because of her communication difficulties and the absence of technology to help her with this at school. Kellie is reassessed every year so that her Special Educational Needs (SEN) statement can be adjusted if necessary. An educational psychologist came in to do the transfer assessment, but as Seamus says *“They don’t know Kellie and they are doing an assessment based on two hours. At the end of it the sweat is running off Kellie because she is trying her hardest to tell them what is inside. So the assessment of her intellectual ability is seriously flawed.”*

The key to unlocking Kellie’s abilities is the provision of a communication system which allows her to express herself at school. *“Kellie is being set up for life here,”* says Seamus, *“she’s in secondary school, it’s her life skills they are working on now and there is so much stuff out there she could be using. The real comparison I would make is Stephen Hawkins – he basically has unlimited access to computer technologies and he is playing a prominent part in world affairs because he has the mechanism of being understood where others don’t have. I think too when you can’t talk or can’t express an opinion everyone just thinks you are stupid.”*

But the provision of that communication system is not something Kellie is entitled to as the law in Northern Ireland currently stands. The impact of that on Kellie is quite significant. Without the communication system it is very difficult for her to be understood and to indicate that she has learned and understood the material she is studying. The Larkins feel that Kellie has already lost a year of education because of this. Kellie developed her own way of communicating with her parents, so they can see that when she has done something, it is done correctly. Yet when she goes into school, she can’t explain herself and it seems to her teachers as if she has got the answers wrong.

“She is coming home and she is saying ‘but mummy how can it be wrong, I know it?’ and telling me exactly what the answer is,” says Jacintha. “It’s not doing much for her confidence. She wants to push herself – and she has asked for more homework from the school. Then she will come home tomorrow and it will be all marked wrong. So she’s looking at me and I know she will say just put it in the bin. Then they think she doesn’t know it and they put her further and further back – crazy stuff. Then she gets really frustrated and she will sit and cry.”

Because of this difficulty with communication, people often presume that Kellie has an intellectual impairment, when she does not. The absence of the technical aid for Kellie means that she cannot communicate her learning and she cannot follow the curriculum at her pace. *“As things stand, she is in the class but she is really not taking part like she should be. It just limits her, full stop,” Seamus says. “It will get to the stage where she will not even want to be there. At the minute it’s just yes or no, that’s all she can really say now. You can’t ask her opinion on anything, but she has an opinion on everything which you will find out if you are able to talk to her using the technology.”*

Both Seamus and Jacintha would like to see the law changed so as to require Education Boards to provide aids such as the kind Kellie needs to communicate effectively. As Seamus says, *“the technology would open so many doors for her. If there was an obligation placed on the education authorities to provide this, then it would follow that you have to plan for it because you have to purchase it.”* If the law were changed as the Commission wishes, it would require schools and authorities to plan ahead in this way. Seamus understands the budgetary issues for schools, but feels that a legislative change is long overdue. *“If someone was to come to us now and say this cannot be got out of this year’s budget but it will be included in next year’s budget and it will be delivered, well then you would say it’s not ideal but it’s reasonable. But the education board are not going to do that, they have no intention of doing that – they know she needs it, but there is never going to be a budget for it because there is no obligation to provide it.”*

The Larkins believe that changing the law wouldn’t just affect their daughter. *“It would make a big change in the lives of other children with communication difficulties,”* they say, *“it would allow children like Kellie to develop their potential to the maximum rather than having to set the bar at the minimum, as the law currently stands. When Kellie was 6, she gave a presentation to Sure Start using a computer and a head switch. But years later that is gone and there is no*

replacement in place. The education of children with disabilities should not be a lottery. If you do not have equality of opportunity at school what does that do to your expectation for the rest of your life?"

Fiona and Robin.

Fiona's son Robin has a visual impairment which means he is partially blind. He also has other physical disabilities and has more recently been diagnosed with learning difficulties.

When he started secondary school, Robin shared classroom assistance with another boy. However, his parents found that they had to do a lot of work with him at home in order to keep his grades up. When Robin went into his second year at the school, his parents were growing concerned and as a result, and after several tests and reviews, Robin was diagnosed with specific learning difficulties. In particular, Robin struggles to process, and to listen and write at the same time. Because of this, they asked the school for aids, specifically a Dictaphone, large print notes and 50% extra time for exams. But Robin is not entitled to auxiliary aids such as these because the law in Northern Ireland does not make it compulsory, unlike the law in England and Wales. These aids were not part of his special educational needs statement. They have been loaned an iPad by the RNIB, but because of Robin's particular learning difficulty he finds computers etc. difficult to use.

However, his mother was determined to try to get him what he needed. She got in touch with SENAC - the Special Educational Needs Advice Centre. It is an educational charity which provides independent advice and advocacy on behalf of children and young people with disabilities and special educational needs.

With help from SENAC, Fiona had numerous meetings with the school who kept insisting that her requests for the additional aids for Robin were "unprecedented" and could not be accommodated. The school kept coming up with all kinds of arguments as to why the aids could not be provided for Robin. Even when the SEN co-ordinator in the school drafted a letter to be sent to the examining board asking for extra time for Robin in exams, the principal of the school disagreed with this view and responded saying that he had consulted with Robin's teachers who did not believe that he needed the extra time. The principal also said that it was a request which was coming from the parents, as if Robin himself did not want the extra time and as if they were trouble makers for requesting it.

“But Robin was only 13 or 14 at this stage and of course he was not going to ask the headmaster or teachers, or tell them that this was what he needed. But as his parents we know what he needs - he talks to us about that,” says Fiona. *“While all this is going on, we had to keep helping Robin at home and paying for tutoring for him. We want the support for him as we know he is capable and we want him to get his GCSEs.”*

The family feels that they have had to take on the entire burden of Robin’s learning. They think much of their burden should have been shouldered by the school and would have been, had the law been different.

As a result of the school’s refusal to provide aids, the family have been forced to take a case to the Special Educational Needs Tribunal, which has placed a further burden on them. *“We feel like we are constantly under pressure and having to fight for everything. We’re also worried about what people will think. The principal and the school have such power, and are just not listening to us as his parents,”* says Fiona. *“Their stock response is ‘he is coping well, what are you looking for?’ Yet the school didn’t even spot or recognise that Robin had a learning difficulty – it was us who saw that.”*

Fiona would really like to see the law changed so that aids like this were something children like Robin were entitled to, instead of families having to fight for them. *“If the law were changed, we wouldn’t have to take this to the Tribunal. What we are looking for aren’t big, expensive things – just notes in advance of classes and a Dictaphone so that Robin can process the class in his own time,”* she says. *“Instead we have had to fight and write letters and it is very stressful. It feels like we are being a nuisance. It was a huge decision to take a case to the Tribunal, yet we are only looking for the best for Robin. We are not being unreasonable.”*

With the help of the Equality Commission, who supported their case, the family did not in the end have to go before a Tribunal, as the case has recently been settled. However, if the law in Northern Ireland had been clear and certain and in line with that in the rest of GB, there would have been no need to take the case in the first place.

Catherine and James

Catherine’s son James has Asperger’s Syndrome. He was diagnosed with this as he was going into Primary 3, although he had been struggling and falling behind the whole of the previous year. This meant that James at that stage had no identified special needs. The consequence of

this was that he was not entitled to specific aids and assistance. Catherine found the diagnosis itself a shock, but what she found altogether more traumatic was the extent of the struggle she then had to embark upon in order to secure the necessary support for James at school.

His school were very helpful in recognising that James was having difficulties and that a diagnosis and an assessment of his needs were necessary. They felt he would need classroom assistance - preferably full-time - as well as some visual aids and charts. They applied for an assessment, but it took months for the educational psychologist to come out to carry it. This meant that James was now diagnosed but was not yet assessed as having any special educational needs. He would have to wait for the Board to determine if they would provide him with any support and they would also determine what the nature of that support would be. As a result, James spent large parts of P3 with no support in the classroom. The school - with the family's input - had implemented their own charts and visual aids in P2, but it was always a stop-gap provision.

However, when the Board's assessment finally came through it was another blow. Although the Board agreed to the charts and visual aids, they declined to award the classroom assistance. James is described as "very high functioning" – this means that whilst he does not struggle with language and can read very well, he has real difficulties with listening and maintaining focus. The charts and the other aids they had been trying as a short term measure did not really help. Nonetheless, the Board insisted that they had to be tried again officially through them for a term. When James was still falling behind they suggested more charts and systems, which only served to confuse and upset him.

The effect of all of this on James was significant. *"It was terrible really,"* Catherine says. *"James had gone from loving school to hating it and had a very negative experience for such a long time that it took a very long time to get him back into going and enjoying it and starting to learn again."* She adds that the stress of this has been terrible. *"I can understand why there are so many marriage breakdowns, because of the stress and arguments it causes."*

Frustrated at the lack of progress, Catherine decided to take a case to the Special Educational Needs Tribunal to challenge the Board's assessment. She started gathering up reports and information and getting ready for yet another stressful battle. In the meantime, James' paediatrician had recommended that he have an ADHD assessment. The appointment for that did not happen until the summer holidays, but James was eventually diagnosed as having ADHD.

Catherine forwarded the letter confirming this to the Board. A few weeks before the scheduled Tribunal hearing, Catherine received a phone call from the Board, telling her that in the light of the ADHD diagnosis, they had accepted that James did need classroom assistance. This meant, they told her, that there was no need to go to the Tribunal.

However, it was Christmas and well into James' P4 year when Catherine was told that a classroom assistant had been allocated to him. There was still a lot of wrangling over the actual number of hours per week he would be entitled to classroom assistance, but at least James could get to know the lady involved. The transformation in James and in those around him was immense. As Catherine says *"From then on we have had no trouble getting him to school because it was just a torment getting out in the morning. You would be trying to drag him out to the car and he would be screaming, not wanting to go which was horrible because he has always enjoyed learning and it was really ruining his experience of education which worried me – no child should have a bad experience."*

In Catherine's view, it took far too long to get anything done. *"You really felt like the education board were doing as little as they could and it was just a fight to get everything. We did get some hours in the end but that was after a long negotiation – it was too long considering someone's education was falling behind. Luckily he's a clever boy and he's catching up very quickly now he's had the help and he gets on very well with the classroom assistant which helps so he hasn't been that badly affected luckily. But from talking to other parents in the same situation I know it's only because the school were very sympathetic to autistic kids and it's just basically because of their knowledge and it's not a consistent thing throughout Northern Ireland at all. So I feel very lucky really that he ended up going to that school because I know if he had gone to one a few miles up the road it would have been a very, very different story."*

Changing the law would make a huge difference, she thinks: *"It would be much easier if the schools were legally responsible. At the moment everything has to go through the Board which takes such a long time. If it was the school that had the power to do it as soon as they had identified a child as having special needs then it could be implemented much more quickly."*

It would also help families and carers, who have to turn themselves into experts and campaigners in order to challenge decisions just to get their child a decent education. *"I hate to think that there are so many people suffering like we had to – it was a very bad experience really. We have got over it now a bit but it was traumatic. It was very bad and it was very hard"*

because at the time our other child was 18 months old and I didn't have any time for him either because I was shuffling paperwork and on the phone with people and arranging interviews and appointments. So the whole family suffered really, it was a really bad time for everyone. When you wake up in the morning thinking right, I have to fight all day it turns you into a really cynical person and it took a long time to let that wash away from me and start to just be happy again."

And yet, as Catherine points out, this is all over something that should be a basic right. *"Just because you can't see the disability doesn't mean that there isn't one there,"* she says, *"but unfortunately at the moment it's very much that if you can't see it no one believes it's there. It's time really that attitudes changed and if the law hasn't changed then how can attitudes change? You have to start really from the top with these things and shatter the illusions around them."*

7 Other Issues

7.1. Greater Protection for Disabled Tenants

7.1.1. The law currently does not require landlords to make alterations related to disability in common areas, even where this is reasonable, or even if the tenant pays for the alteration. So for example, if a tenant with a visual impairment offered to pay for something such as putting strips on the stairs, the landlord is not obliged to do this.

7.1.2. The Commission wants the law changed so that where a physical feature puts a disabled person at a substantial disadvantage, and they request that an adjustment is made, the landlord cannot simply refuse to do so. Instead, the proposed changes would require landlords to follow a set process, including consultation with other tenants in order to decide whether to undertake the alterations. That consultation would have to be undertaken within a reasonable time of the tenant's request and if it is found that the alteration is reasonable in order to avoid the disadvantage experienced by the disabled tenant, a written agreement must be entered into setting out the changes to be made and the rights and responsibilities of all involved. A landlord may require the tenant to pay for the cost of making the alteration and that may also be written into the agreement.

7.1.3. We were unable to identify any case-studies in this area, despite extensive enquiries and numerous approaches to stakeholder organisations, public representatives and legal service

providers. The relevant stakeholder organisations that might have specific knowledge in respect of this area identified other issues as being more pressing, such as social housing and homelessness. It was also suggested to us that there was anecdotal evidence that landlords were deliberately avoiding longer term tenancy agreements with disabled people so as to avoid most of the legal protection for tenants.

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Strengthening Protection for Disabled People: Developing Case Study Examples.

Information Sheet & Consent Form For Interview

You are being asked to take part in an interview with Aideen Gilmore, who is an independent researcher working on behalf of Brookhall Consulting Services Ltd. We have been contracted by the Equality Commission for Northern Ireland to assist with a project about the experiences of disabled people, their families and carers. This form explains what the purpose of this interview is, how it works, and how you are going to be involved. We want you to understand what you are being asked to do. This will help you decide whether or not you want to participate in the interview. Contact details for the interviewer and for the project are at the end of this form.

The aim of this project is to produce case-studies which describe the experiences of disabled people; their families; and their carers. This will assist the Equality Commission for Northern Ireland to make the case publicly that change is needed in the law on disability in Northern Ireland. We aim to produce and present clear case-study examples to illustrate the real-world impact of the current shortfalls and gaps within disability equality law in Northern Ireland.

INTERVIEW DESCRIPTION

This interview is being conducted as part of the work on a project being run by the Equality Commission for Northern Ireland called **Strengthening Protection for Disabled People: Developing Case Study Examples**. The interviewer will explain the details of this project to you before the interview begins and before you give your consent to be interviewed. Participation in the research is entirely your choice but your involvement is greatly appreciated.

PROCEDURES

If you agree to take part in this research, you will participate in an interview by answering a series of questions. You need not answer all of the questions you are asked. All you have to do is tell the interviewer that you prefer not to answer that question. You may also have no particular views on a question asked and you can simply tell the interviewer that you have no views you wish to share.

The interview will last for a maximum of 45 minutes, but you may bring the interview to a close at any time you wish.

AUDIO RECORDING

If you agree, an audio recording will be made of this interview. Audio recording is used because it allows the interviewer to best ensure that your interview is properly recorded and reported. The recording will be used by the interviewer to write up the interview and the recording will then be passed to the Equality Commission for Northern Ireland for retention by them in a secure place. After the interview, the recording will only be used by the researchers and by the research project team in the Equality Commission for Northern Ireland. It will not be shared with anyone else without your express written consent. Personal information obtained from you will

be processed by ECNI and Brookhall Consulting Services Ltd at all times in line with the requirements of the data protection legislation.

RISKS

We may ask you about some things which you may find sensitive or personal. Whilst we wish for your fullest co-operation, you are free to not answer any question if you do not wish to do so. All you have to do is to say “I don’t wish to answer that question.”

COST TO THE PARTICIPANT

There is no cost to you for participation in this interview. You will not be paid for participation in this interview. However, expenses for reasonable support which is necessary in order for you to participate in the interview process will be covered. This would include things such as interpreters’ fees, the production of materials in alternative formats etc.

WITHDRAWAL

You have the right to withdraw your consent or stop participating at any time. You have the right to refuse to answer any question(s) or decline participation in any procedure for any reason. You may also withdraw your consent after the interview by contacting the interviewer or the project at the email addresses/numbers below.

USING YOUR NAME AND YOUR PHOTOGRAPH

For this research and case-study booklet to be most effective, it is necessary to ask people to talk about their experiences openly. This means that your name, details of your disability and the barriers you have experienced will be used in the publication. Photographs of you may be taken and used in the publication. We want to show you a similar publication, called **Working Together to Close the Gaps** so that you can see how your details are likely to be used. We want you to understand fully that you are consenting to your name being used and that your photograph may also be used in the publication as well as what you say during this interview. Either we or the Equality Commission will check the text of what is printed with you before the publication is produced and you will have the opportunity to ask for changes to the text when we do that.

We also wish to make it clear that the Equality Commission for Northern Ireland will only be able to publish a selection of case-studies for publication, so it may be that your experiences are not published in the case-study booklet. However, your participation helps us better understand the experiences of disabled people, their families and their carers and the interview you give us will assist the ECNI in its work to improve the law on disability.

All materials produced as a result of this interview, including the recording will remain the property of the Equality Commission for Northern Ireland and will be securely stored.

YOUR CONSENT TO BE INTERVIEWED:

In order to ensure that you have read and understood the form, or have had its contents explained to you, a written consent form is signed by you, or your consent recorded, and given to the interviewer. You keep the information sheet so that you can read over it after the

interview if you wish. This sheet is available in alternative formats for that purpose.

Your participation in this interview is voluntary.

If you do not wish to participate, please tell the interviewer before starting the interview.

You will be asked to sign the attached form, or record it, to indicate that you have consented to take part in the interview and for your name and personal details such as your photograph and details about your disability to be used.

The interviewer will keep the signed sheet or recording, and you will keep this information sheet. You can withdraw your consent at any time after the interview has concluded up to six weeks after the date of the interview.

INVITATION FOR QUESTIONS

If you have questions about this interview or about the research, please ask the interviewer before proceeding. If you have any questions about this research project or the issues discussed, after the interview has finished and the interviewer has left, contact details for both the interviewer and the project are below.

CONTACT DETAILS:

INTERVIEWER – Aideen Gilmore

Address: 2nd Floor, 133 Royal Avenue, Belfast, BT1 1FG

E- mail: aideengilmore@googlemail.com

Tel: 02890 313315

You may also contact **Brookhall Consulting Services Ltd** on Tel no: 01179115756 or at info@brook-hall.org

PROJECT- Strengthening Protection for Disabled People: Developing Case Study Examples.

Equality Commission for NI

Equality House

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Textphone: 028 90 500 589

Fax: 028 90 248 687

Email: information@equalityni.org

PARTICIPANT AUTHORIZATION (this section to be retained by the interviewer)

I have indicated below my agreement to various individual aspects of this interview process and I am aware that I can choose to agree to only some aspects of this interview process.

I have read the information sheet about the interview/it was read to me. I know the possible risks and benefits which have also been explained to me by the interviewer. I have been given the opportunity to ask any questions about this process and to have those questions answered.

I have received a copy of the information sheet.

I agree to my interview being audio recorded.

I know taking part in this interview is voluntary and I have chosen to take part.

I consent to my name, details of my disability and the barriers I have experienced and my photograph being used for the purposes of this research, in any publication arising from it and any publicity prepared by the ECNI associated with it

NAME: (Print) _____

Signature: _____

Date: _____

Insert signature of parent /guardian for minors

Issue: protection against disability-related discrimination

1. If you feel comfortable doing so, please tell me a little bit about yourself.
2. Again, if you feel comfortable, could you share with me the nature of your disability?
3. I understand that you have particular experience of being discriminated against because of your disability. Could you describe for me, in as much detail as you can, your experience?
4. The law currently says that it is unlawful for a disabled person to be treated less favourably for a reason related to their disability, without justification. An example of less favourable treatment might be:

A woman with a disability which requires the use of a wheelchair applies for a job. She can do the job but the employer thinks that the wheelchair will get in the way in the office. He gives the job to a person who is no more suitable for the job but does not require a wheelchair. The employer has therefore treated the woman less favourably than the other person because he did not give her the job and the treatment was for a reason related to the disability – that is, the fact that she used a wheelchair.

However, because of a case decided a few years ago (the Malcolm case), that law in relation to disability-related discrimination is now being interpreted very restrictively in NI. This means that since the Malcolm case, claims that are based solely on disability-related less favourable treatment can no longer proceed. This is particularly significant in recruitment cases. So, for example,

An employee with a sickness absence rate which is significant applies for a job. The sickness absence is related to a disability. The employer discards the application immediately on seeing such absence. Prior to Malcolm case, an individual would have had a claim for disability-related discrimination, and whether the employer had knowledge of the disability would have been irrelevant – the issue would have been whether the employer was justified in its approach or not. After the Malcolm case the individual has no claim unless it can be successfully argued that the employer ought to have known about the disability and therefore made a reasonable adjustment for him.

Another example of the impact of this is:

A person worked as a part-time receptionist/administrator. She has epilepsy. She is absent from work on a number of occasions for reasons connected with her disability. She is telephoned persistently to enquire when she would return to work, causing her extra stress. Her employer terminates her employment on the basis that there is no further work for her. Before the Malcolm case, the individual could take a case on the basis that there had been less favourable treatment for a reason relating to her disability – i.e. the need to be absent from work and that there had been disability discrimination. After Malcolm the individual would have no claim for disability-related less favourable treatment.

A further example might be:

A group of deaf people who use sign language is refused entry to a disco. The door steward assumes that other customers might mistake communication using sign language as threatening gestures. This refusal of service is for a reason related to disability. It is likely to be unlawful even though the disco would have refused entry to any person who made similar gestures. Before the Malcolm case the group of deaf people would have had a claim for disability discrimination. Following the Malcolm decision, there would be no discrimination in this scenario – the group of deaf people would have no claim for disability related less favourable treatment.

How do you believe you have been impacted by this?

5. How did your experience make you feel?
6. The Commission is proposing that the law be changed to prohibit indirect discrimination and discrimination arising from a disability. This means those individuals in the examples above would all be able to take a case. If these proposals were adopted, and the law was changed in this way, what difference do you believe this would make to you? And to others who have had similar experiences?
7. Why do you believe this change in the law would be important?
8. Are there any other experiences you would like to share or comments you would like to make?

Issue: changing definition of disability

1. If you feel comfortable doing so, please tell me a little bit about yourself.
2. Again, if you feel comfortable, could you share with me the nature of your disability/your child's disability/the disability of the person you care for? (as or if applicable)
3. I understand that you have particular experience of falling outside the current definition of disability and list of capacities in the DDA (which I will explain in more detail later). Could you describe for me, in as much detail as you can, your experience?
4. The law currently defines a disabled person as "a person with a physical or mental impairment which has a substantial and long-term adverse impact on his/her ability to carry out normal day-to-day activities." The law states that an impairment is taken to affect the ability of the person to carry out normal day-to-day activities only if it affects that person in respect of one or more of the following ways:
 - Mobility
 - Manual dexterity
 - Physical co-ordination
 - Incontinence
 - Ability to lift, carry or otherwise move everyday objects
 - Speech, hearing or eyesight
 - Memory or ability to concentrate, learn or understand
 - Perception of the risk of physical danger

This list is known as the list of capacities. So for example someone with an illness, such as one related to mental health, which impacts on their ability to carry out normal day-to-day activities but NOT in relation to this list of capacities, would not be defined as disabled and is therefore not legally protected by the DDA.

How do you believe you have been impacted by this? (or what do you think the consequences of this are?)

5. How did your experience make you feel?
6. The Equality Commission is recommending that the list of capacities be removed in total from the definition of disability. This would make it easier for disabled people to fall within the definition of disability. So, for example, someone with a more hidden disability who is not affected by the list of capacities but whose normal day-to-day

activity is impacted would no longer be excluded from the definition of disability and therefore from legal protection.

If these proposals were adopted, and the law was changed to remove the list, what difference do you believe this would make to you? And to others who have had similar experiences?

7. Why do you believe this change in the law would be important?
8. Are there any other experiences you would like to share or comments you would like to make?

Issue: association and perception

ASSOCIATION

1. If you feel comfortable doing so, please tell me a little bit about yourself.
2. Again, if you feel comfortable, could you share with me the nature of the disability of the person you care for?
3. I understand that you have particular experience being discriminated against or harassed because of your association with a disabled person (association means for example as carers, friends or family members). Could you describe for me, in as much detail as you can, your experience?
4. The legislation in Northern Ireland currently does not - on the face of it - protect those associated with a disabled person against discrimination or harassment. However it needs to be updated because of a European case. In the example in that case, a woman who cared for a disabled child had been forced to resign from her job after being harassed by her employer and being refused flexible working which other employees were granted.

How do you believe you have been impacted by this? (or what do you think the consequences of this are?)

5. How did your experience make you feel?

6. The Commission is recommending that the law be changed so it is clearly stated that there is protection against direct discrimination and harassment in employment or when accessing goods, facilities and services for people such as carers, friends and families because of their association with a disabled person.

In the European case mentioned above, the European Court of Justice ruled that treating an employee less favourably because of their caring responsibilities for a disabled child was not permitted under European law.

So if the law in Northern Ireland was changed to make this clear, similar to the example above, an employee with caring responsibilities for a disabled person who asks to work from home on a temporary basis and is refused, even though other members of staff work from home regularly, would be protected by the new law.

If these proposals were adopted, and the law was changed to offer this protection, what difference do you believe this would make to you? And to others who have had similar experiences?

7. Why do you believe this change in the law would be important?
8. Are there any other experiences you would like to share or comments you would like to make?

PERCEPTION

1. If you feel comfortable doing so, please tell me a little bit about yourself.
2. I understand that you have particular experience of being discriminated against or harassed because you were wrongly perceived as being disabled. Could you describe for me, in as much detail as you can, your experience?
3. The law currently does not protect someone who is discriminated against because they are wrongly perceived to be disabled. So for example discrimination on the grounds of perception could occur where an employer rejects an applicant for a job because they arrived for interview in a wheelchair and the employer wrongly perceived them to be disabled. They were in fact recovering from broken legs in an accident but would have

no legal protection at present. How do you believe you have been impacted by this? (or what do you think the consequences of this are?)

4. How did your experience make you feel?
5. The Commission is recommending that the law be changed so that people who are wrongly perceived to be disabled will be protected against direct discrimination or harassment by employers, service providers, schools etc.

So for example, someone with a short term mental health illness, such as short-term depression, that is declared on an application form and whose application form is rejected because the potential employer wrongly perceives them to be disabled would be protected by the new law.

If these proposals were adopted, what difference do you believe this would make to you? And to others who have had similar experiences?

6. Why do you believe this change in the law would be important?
7. Are there any other experiences you would like to share or comments you would like to make?

Issue: protection against harassment

1. If you feel comfortable doing so, please tell me a little bit about yourself.
2. Again, if you feel comfortable, could you share with me the nature of your disability?
3. I understand that you have particular experience of harassment related to your disability. Could you describe for me, in as much detail as you can, your experience?
4. The law currently does not protect against harassment related to disability other than in employment or further and higher education. So for example, someone with a disability who is trying to access an everyday service like public transport but is harassed by the bus driver who makes a remark related to their disability, has no legal protection.

How do you believe you have been impacted by this? (or what do you think the consequences of this are?)

5. How did your experience make you feel?
6. The Commission is proposing that the law is changed so that there is a right for disabled people of protection against harassment related to their disability when accessing goods and services. So, for example, if someone with a disability was called a name or harassed by a restaurant server for a reason related to their disability, this would be protected.

If these proposals were adopted, and the law was changed to protect against this kind of harassment, what difference do you believe this would make to you? And to others who have had similar experiences?

7. Why do you believe this change in the law would be important?
8. Are there any other experiences you would like to share or comments you would like to make?

Issue: Pre-employment questioning

1. If you feel comfortable doing so, please tell me a little bit about yourself.
2. Again, if you feel comfortable, could you share with me the nature of your disability?
3. I understand that you have particular experience of being asked about your health or disability by a potential employer. Could you describe for me, in as much detail as you can, your experience?
4. The law currently does not prohibit pre-employment inquiries and therefore there is nothing to prevent employers from screening out disabled applicants at an early stage in the recruitment process. So for example, an employer can ask questions either on the application form, or prior to making a job offer, about a person's health or disability that are unrelated to the nature of the job or any reasonable adjustments that may be needed.

How do you believe you have been impacted by this?

5. What do you think the consequences of this are? (For example, do you think that the inclusion of health questions in a job application or medical questionnaire can deter disabled people from applying for the job in question? Do you think that prohibiting such questions would reduce discrimination by some employers against disabled applicants?)
6. How did your experience make you feel?
7. The Equality Commission is proposing that employers are prohibited from asking questions about an applicant's health or disability prior to making a job offer except in specific circumstances. So, for example, an employer would not be permitted to ask questions about an applicant's health or disability on an application form (unless it was necessary for the job, or to make reasonable adjustments or to monitor diversity).

Another example is that if the law was changed, it will not be permissible to ask questions that aim to establish how many days of sickness absence an applicant has accrued during previous employment prior to the candidate being made a conditional or unconditional offer of work.

If these proposals were adopted, and the law was changed to prevent such questions, what difference do you believe this would make to you? And to others who have had similar experiences?

8. Why do you believe this change in the law would be important?
9. Are there any other experiences you would like to share or comments you would like to make?

Issue: aids and services in schools

1. If you feel comfortable doing so, please tell me a little bit about yourself.
2. Again, if you feel comfortable, could you share with me the nature of your child's disability?

3. I understand that you have particular experience of your child who has a disability being denied access to aids and services at school. Could you describe for me, in as much detail as you can, your experience?

4. The law currently does not require schools to provide aids and services to disabled pupils who are not considered to have special educational needs. For example, an aid would be a downloadable electronic lesson notes for a pupil with a visual impairment; a service might be a support assistant for a disabled student to push their wheelchair around a school.

How do you believe you have been impacted by this? (or what do you think the consequences of this are?)

5. How did your experience make you feel?

6. The Equality Commission is recommending that an additional duty is placed on schools under the SEN framework to provide auxiliary aids and services for disabled pupils where this is reasonable and where not doing it places the student at a substantial disadvantage to non-disabled pupils.

For example, if the law was changed the duty on schools to provide auxiliary aids and services might mean that schools are required to provide extra equipment such as an adapted computer for disabled pupils.

If these proposals were adopted, and the law was changed this way, what difference do you believe this would make to you? And to others who have had similar experiences?

7. Why do you believe this change in the law would be important?

8. Are there any other experiences you would like to share or comments you would like to make?

Issue: protection for disabled tenants

1. If you feel comfortable doing so, please tell me a little bit about yourself.

2. Again, if you feel comfortable, could you share with me the nature of your disability?
3. I understand that you have particular experience of a landlord refusing to make reasonable adjustments to a common area of your building. Could you describe for me, in as much detail as you can, your experience?
4. Currently under the disability legislation, landlords and managers of rented property must not treat a disabled person less favourably than a non-disabled person. They also have other duties, for example, to make reasonable adjustments (though not physical alterations) to the disabled person's home.

However, the law currently does not require landlords to make disability-related alterations to the physical features of the common areas (e.g. stairs and hallways), even where this is reasonable, or the tenant is paying for it themselves. So for example, if a tenant with a visual impairment offered to pay for a reasonable adjustment such as putting strips on the stairs, the landlord is not obliged to do this.

How do you believe you have been impacted by this? (or what do you think the consequences of this are?)

5. How did your experience make you feel?
6. The Commission is recommending that the law is changed so that where a physical feature puts a disabled person at a substantial disadvantage, and they request that an adjustment is made, the landlord will have to engage in a process around this.

So for example, if a person with a mobility disability who would be able to use the stairs if handrails were installed on both sides requests that this adjustment is made, the landlord would then have to consult with other people affected by this. If the landlord then decides that the adjustment is reasonable to avoid the disadvantage caused to the person who has difficulty using the stairs without the handrails, they would have to enter into an agreement with that person setting out the rights and responsibilities around this (and the landlord may be able to require the tenant to pay for this alteration).

If these proposals were adopted, and the law was changed to make landlords engage in this process, what difference do you believe this would make to you? And to others who have had similar experiences?

7. Why do you believe this change in the law would be important?

8. Are there any other experiences you would like to share or comments you would like to make?