

## **Evidence to the Northern Ireland Assembly Education Committee on the proposed Special Educational Needs and Disability Bill (SEND)**

### **Introduction and Background**

1. The Equality Commission welcomes the opportunity to present evidence to the members of the Education Committee. Our evidence is informed by our engagement with a range of stakeholders, including disabled people and their representative organisations. Our response reflects our views as set out in our previous responses to the Department of Education's consultation on a revised SEN and Inclusion Framework in 2010 and 2012.<sup>1</sup> The Commission's role and remit is set out in Annex 1.
2. The Equality Commission for Northern Ireland (the Commission) is an independent public body established under the Northern Ireland Act 1998. The Commission is responsible for implementing the legislation on fair employment and treatment, sex discrimination and equal pay, race relations, sexual orientation, disability and age.
3. The Commission's remit also includes overseeing the statutory duties on public authorities to promote equality of opportunity and good relations under Section 75 of the Northern Ireland Act 1998 (Section 75) and to promote positive attitudes towards disabled people and encourage participation by disabled people in public life under the Disability Discrimination Act 1995.
4. The Commission's general duties include:

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<sup>1</sup> See [Equality Commission for Northern Ireland \(2010\): Response to the Department of Education for Northern Ireland consultation on \*Every School a Good School-The Way Forward for Special Educational Needs\*, 2010](#), [ECNI response to DE consultation on Review of SEN and Inclusion, April 2012](#), and [ECNI response to DE consultation on Review of SEN and Inclusion, July 2012](#)

- working towards the elimination of discrimination;
  - promoting equality of opportunity and encouraging good practice;
  - promoting positive / affirmative action;
  - promoting good relations between people of different racial groups;
  - overseeing the implementation and effectiveness of the statutory duty on relevant public authorities;
  - keeping the legislation under review;
  - promoting good relations between people of different religious belief and / or political opinion.
5. The Commission, with the Northern Ireland Human Rights Commission, has been designated under the United Nations Convention on the rights of Persons with Disabilities (CRPD) as the independent mechanism tasked with promoting, protecting and monitoring implementation of CRPD in Northern Ireland.

### **Executive Summary**

6. The Commission would advise Committee members that there are many aspects of the Bill which will enhance the support and protections currently available to students with special educational needs. In particular, we welcome the following proposed provisions in the Bill:
- the duty of the Education Authority to have regard to the views of the child;
  - the right of students aged 16 plus to appeal decisions at tribunal and to request a statutory assessment, as well as the right to bring a complaint of disability discrimination to a tribunal (clauses 9 &10);
  - the development of a pilot scheme for students under 16 to have the right of appeal at tribunal (clause 11).
7. The Commission would ask Committee members to give further consideration to the following issues and recommendations:

### **Code of Practice**

- we recommend that the proposed Code of Practice outline how students will be involved in the development of overall SEN provision;
- the Commission considers that the CoP should outline training measures for teachers/LSCs.

### **Provisions of Bill**

- we are concerned that the Bill does not specify reviews for students with a Statement/CSP at various transition points within their journey through education;
- we are also concerned that the Bill does not refer to children with SEN in pre-school settings;
- we would welcome clarification of the retention of SEN statements and what this means for the future use of CSPs;
- we recommend that published plans relating to SEN provision should include measures to enhance the quality of service provisions and experience of those with SEN;
- the Commission considers that the CoP should outline training measures for teachers/LSCs and monitor the effectiveness/outcomes of LSCs;
- we recommend that further consideration is given to the appropriateness of placing a statutory duty on health and social care bodies.
- we recommend that the proposed Code of Practice include timescales as to how long the mediation process will operate and outline clearly the relationship it has with regard to the appeals process;
- we recommend that arrangements to monitor the effectiveness of the provisions within the Bill, including the collection of disaggregated data, taking account of the multiple identities of disabled people, must be provided for in the CoP;
- we recommend that action to address our proposals for legislative reform in order to strengthen protection for disabled pupils in schools;
- we recommend additional reforms, such as access to case decisions, financial support and access to auxiliary aids and services, are required to enable SEND Tribunals to be more responsive to disabled people;

- we recommend that arrangements are put in place for collection of appropriate data to enable monitoring of the effectiveness of the Bill provisions.

## Specific Comments

### **Clause 1: The Commission welcomes the duty on the Education Authority to have regard to the views of the Child.**

8. Article 7.3 of the CRPD places an obligation on state parties to ensure that children with disabilities have **the right to express their views freely and that their views are given due weight** in accordance with their age and maturity<sup>2</sup> and to be provided with disability and age appropriate assistance to realise that right.
9. Further, the Preamble (r) to the CRPD requires recognition of children and their human rights, taking into account the Convention on the Rights of the Child, while Article 3 (h), CRPD General Principles, requires public authorities and state funded agencies to respect the evolving capacities of disabled children and respect for their rights to preserve their identities.
10. We recommend that the proposed Code of Practice (CoP) gives clear guidance as to how students will be involved in the development of their own personal learning plans (PLPs) including review and appeals process associated with the SEN Framework. The CoP should also make clear as possible the degree to which students' views should be reflected in all aspects of the SEN Framework, weighted against all other considerations such as the views of parents or guardian/teacher/educational authority etc.
11. Emphasis within the CoP should be given to the importance of accessible communication provision and the relevant support requirements of each individual with SEN in order to enable them to participate effectively within any decision making process that will impact on their educational experience and opportunities.
12. Furthermore, the CoP should highlight models of good practice demonstrating how students can be involved in their own reviews/appeals processes and in the development of support and learning places. For example, the development of peer support advocacy services to support students effective involvement in these areas.

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<sup>2</sup> Article 7.3 of the CRPD is also consistent with Article 12.1 of the UN Convention on the Rights of the Child.

## **Transition stages**

13. The Commission is concerned that the Bill does not specifically provide for reviews for students with a statement/coordinated support plans at transition stages 14 – 16 years and 16 – 19 years.

SEN Reviews should be provided for within the Bill aligned with the important transition points during a student's education thereby acknowledging opportunities for students' views to shape their educational experience. Our view is consistent with the purpose and objective outlined in clause 1 of the Bill.

## **Placement of Children with SEN in Pre-school Settings**

14. We are concerned that the proposed Bill does not refer to the placement of children with SEN in pre-school settings, and the transition planning arrangements.
15. Reports by the Education and Training Inspectorate (ETI) have highlighted a lack of consistency in procedures/protocols for assessing need and differential thresholds for intervention in relation to the assessment and diagnosis of SEN in Northern Ireland<sup>3</sup>. A 2007 ETI report noted particular difficulties with delay and shortcomings in the planning for and assessment of children's special educational needs in all types of pre-school provision<sup>4</sup>.

## **SEN Statements and Coordination Support Plans**

16. The Commission notes that no reference is made in the Bill to Coordination Support Plans and that SEN Statements are likely to be retained. We would welcome clarification as to whether Coordination Support Plans will continue to be used to identify individual SEN requirements.

## **Clause 2: The Commission welcomes the requirement on the Education Authority to publish plans relating to special educational provision.**

17. We recommend that these plans include:

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<sup>3</sup> Education and Training Inspectorate (2006): 'Report of a Survey on Provision and Outcomes for Pupils with Special Educational Needs in Post-Primary Schools' (Bangor: Department of Education). Available at: <http://www.etini.gov.uk/survey-on-provision-and-outcomes-for-pupils-with-special-educational-needs-in-post-primary-schools.pdf>

<sup>4</sup> Education and Training Inspectorate (2007): 'Special Educational Needs in the Pre-School Sector' (Bangor: Department of Education). Available at: <http://www.etini.gov.uk/index/surveys-evaluations/surveys-evaluations-pre-school-centre-and-nursery-school/surveys-evaluations-pre-school-centre-and-nursery-school-2007/special-education-needs-in-the-pre-school-sector.pdf>

- Steps taken to promote positive attitudes towards disabled students in line with the public authority ‘Disability Duties’<sup>5</sup> obligations and Article 8 Awareness Raising requirements to reduce negative stereo-typing of disabled people within CRPD in schools;
- measures to promote awareness of CRPD rights and disability equality legislation generally as it applies to schools and other SEN settings;
- disability equality and awareness training measures for teachers<sup>6</sup> and others responsible for and delivering frontline educational services, taking account of the multiple identities of disabled people, should also be outlined in the plan;
- arrangements for monitoring and review of the impact of the SEN plans;
- details of resources allocated to enable full delivery on the commitments made to SEN students within the plans.

**Clause 3: Whilst, in general, the Commission supports proposals to strengthen the statutory duty on Board of Governors so as to ensure appropriate SEN provision in schools, we are of the view that there are a number of issues that require further consideration.**

18. These include the following considerations:

- the degree of individual student participation in the development of PLPs;
- the extent to which the training needs of the learning support co-ordinator and teachers will be met;
- the level of awareness of both parents and students of the alternative dispute resolution mechanism;
- how the PLPs will be monitored and reviewed.
- the Commission has recommends that PLPs are reviewed at least on an annual basis.

19. As highlighted in our response to the Department’s Consultation on Every School a Good School – The Way Forward for Special

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<sup>5</sup> Further details are available in: Equality Commission for Northern Ireland (2007): ‘A Guide for Public Authorities – Promoting Positive Attitudes towards disabled people and encouraging the participation of disabled people in public life’, (Belfast: Equality Commission NI). Available at: <http://www.equalityni.org/Publications?subject=Disability&type=Guides&year=2007>

<sup>6</sup> In accordance with Article 24.4 (Education) of the UNCRPD.

Educational Needs 2010<sup>7</sup>, whilst we recognise that teachers are competent to make general assessments of educational needs for children, the highly complex and specialised assessment of children with SEN will require specialist training. We consider that without specific qualifications and training, there is a significant risk that Learning Support Co-ordinators may miss early identification of needs and appropriate intervention.

**Clause 4: The Commission welcomes the requirement on the Education Authority to request help where it believes health and social care bodies could help in the discharge of its duties.**

20. Whilst we welcome the fact that the Bill strengthens previous legislative provisions by placing a duty on the Education Authority to request help from the health and social care, as oppose to the previous provision that conferred a ‘power’, rather than a duty, to request, we note that the Bill does not place a duty on health and social care bodies to assist the Education Authority in meeting the special educational needs of students.

We ask Members of the Committee to note that where there is a failure to provide for a student’s special educational needs, due to inadequate health and social care provision, it would not be possible for the student or parent to seek redress at a SEND tribunal.

21. This matter has been raised by the Joint Committee on Human Rights in Great Britain which drew attention to the fact that the right of appeal was only to be available in relation to the education component of SEN provision<sup>8</sup>.
22. The Joint Committee was of the view that this gave rise to the prospect of a complex bureaucratic system in which challenges to

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<sup>7</sup> Equality Commission for Northern Ireland (2010): Response to the Department of Education for Northern Ireland consultation on *Every School a Good School-The Way Forward for Special Educational Needs*, 2010. Available at: <http://www.equalityni.org/ECNI/media/ECNI/Consultation%20Responses/2010/EverySchoolaGoodSchool-2010TheWayforwardforSENandInclus.pdf>

<sup>8</sup> House of Lords, House of Commons Joint Committee on Human Rights (2013): Third Report of the Legislative Scrutiny: Children and Families Bill; Energy Bill. Third Report of session 2013 – 2014. Available at: <http://www.publications.parliament.uk/pa/jt201314/jtselect/jtrights/29/2902.htm>

the health and social care aspects of SEN provision would have to be conducted simultaneously through different tribunals, procedures and processes.

23. The Committee recommended that the legislation be amended to ensure that there was one single avenue of redress in relation to all aspects of SEN provision.
24. The Commission has previously welcomed the Department's proposal to explore with the Department for Health, Social Services and Public Safety, the possibility of a statutory basis for the health provisions set out in CSP's and SEN Statements<sup>9</sup>.
25. We recommend that further consideration is given to the appropriateness of placing a statutory duty on health and social care bodies. We also recommend that guidance on effective multi-disciplinary working between the Education Authority and health and social care bodies is outlined in the Code of Practice, setting out good practice in partnership arrangements and the obligations for both education and health authorities in the delivery of SEN provision.

**Clause 8: Whilst in general the Commission supports provisions that help ensure the early resolution of disputes**, it is important that none of the proposals will, or in combination with other factors, unfairly deter individuals from bringing an appeal to a Tribunal or restrict their access to justice.

26. The Commission recommends that the proposed CoP should include the inclusion of timescales for the mediation process so as to ensure that engagement in mediation does not delay any resolution of complaints unnecessarily or limit in anyway the parent/student's right of appeal to a SEND Tribunal at a later stage.
27. The Commission is committed to the early resolution of disputes and is of the view that mediation processes, if applied effectively in dealing with complaints and discrimination disputes, can ensure an early, less costly and more informal resolution of complaints with meaningful outcomes.
28. However, as set out in our response (July 2012) we made it clear that a requirement that a person seeking an appeal must first

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<sup>9</sup> Equality Commission for Northern Ireland (2010): Consultation Response to the Department's consultation on *Every School a Good School-The Way Forward for Special Educational Needs*, 2010, <http://www.equalityni.org/archive/pdf/FinResptoESAGTheWayforwardforSENandInclus.pdf>

engage in mediation, should not result in further delays in terms of meeting the needs of the child with SEN. It is also important that effective safeguards are in place to protect and support vulnerable claimants, through the mediation process.

29. The Commission recommends that the proposed Code of Practice should include the inclusion of timescales for the mediation process so as to ensure that engagement in mediation does not delay any resolution of complaints unnecessarily or limit in anyway the parent/student's right of appeal to a SEND Tribunal at a later stage.
30. **Clauses 11 and 12: the Commission welcomes the proposal to extend to a child aged 16 plus rights within the SEN framework which were previously exercisable by a parent; as well as giving a child aged 16 plus the right to bring a complaint of disability discrimination to SEN in their own name. We also welcome the development of a pilot scheme for students under the age of 16, to appeal on their own behalf at a SEN tribunal.**

## **Other Recommendations**

### **Legislative Reform**

31. **The Commission recommends that the Department, in conjunction with OFMDFM, addresses legal gaps in protection for disabled pupils in schools against discrimination and harassment, including ; an additional duty on schools to provide auxiliary aids and services for disabled pupils.**
32. The Commission's proposals for disability law reform ***Strengthening Protection for Disabled People***<sup>10</sup> has set out a number of changes which are required in order to strengthen protection for disabled pupils in schools. In particular the Commission has recommended:

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<sup>10</sup> The Equality Commission for Northern Ireland (March 2012): *Strengthening Protection for Disabled People, proposals for Reform*. Available at: [http://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/Strengthening\\_protection\\_for\\_disabled\\_people0312.pdf](http://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/Strengthening_protection_for_disabled_people0312.pdf)

- changes to SENDO 2005 in order to place an additional duty on schools to provide **auxiliary aids and services** for disabled pupils, where reasonable; in circumstances where a failure to do so would put the disabled pupil at a substantial disadvantage compared to non-disabled pupils.
  - that the current residual duty on the Education & Library Boards under SENDO 2005 in relation to the making of reasonable adjustments for disabled pupils or prospective pupils, is extended so that it includes a requirement to provide auxiliary aids and services. This recommendation is in line with changes implemented in Great Britain under the Equality Act 2010 in September 2012.
  - wider changes are needed both to the Disability Discrimination Act 1995 (DDA 1995) and SENDO 2005 in order to address inconsistencies and strengthen protection against discrimination and harassment for disabled people.
33. For example, there is currently **less protection** for disabled pupils in schools than for disabled students in further and higher education. In addition, legislative changes are required in order to address the impact of the House of Lords' decision in *Malcolm*<sup>11</sup> in 2008 which significantly restricted the ability of disabled people (including disabled pupils in schools) to pursue complaints of disability-related discrimination.
34. Committee members should also be aware that 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. We refer the Committee to the disability case studies research report commissioned by the Commission (2013) which highlights the problems faced by children with disabilities when trying to access auxiliary aids and services.<sup>12</sup> Please see case study example in Annex 2.

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<sup>11</sup> Mayor and Burgesses of the London Borough of Lewisham v Malcolm [2008]UKHL 43

<sup>12</sup> Equality Commission for Northern Ireland (May 2013): Strengthening Protection for Disabled People: Case Studies Revised Final Report Prepared by Brookhall Consulting Services Ltd.

35. We recognise that responsibility for changes to the Disability Discrimination Act 1995 as amended is the responsibility of the Office of The first and deputy first Minister (OFMdFM), including responsibility for changes to the definition of disability. However, primary responsibility for ensuring effective protection for disabled children in schools against disability discrimination under the Special Educational Needs and Disability Order 2005 (SENDO) rests with the Department of Education.

### **Reform of SEND Tribunals**

36. In Northern Ireland, discrimination cases in the provision of school education which do not involve disability related matters are dealt with in the County Court; they are empowered to award all remedies available in the High Court, which includes damages for any loss and compensation for injury to feelings.
37. The Special Educational Needs Tribunal is not empowered to make compensation for discrimination or harassment. This means that there can be situations where one child could be harassed because of race and one because of disability and the first child can seek compensation<sup>13</sup>, whilst the second child cannot<sup>14</sup>.
38. The proposed changes will help ensure that Northern Ireland equality law **keeps pace** with changes which already have taken place in Great Britain or are due to be implemented.

### **Access to Case Decisions**

39. Currently SEND Tribunal decisions are restricted to the parties involved in the dispute. As a consequence, Boards will have access to all decisions, whereas only the individual complainant in a case will have access to the decision relating to their particular case.

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<http://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/DisabledPeople-CaseStudiesReport.pdf>

<sup>13</sup> See paragraphs 18-20 and 54 of the Race Relations (Northern Ireland Order) 1997. Available at: <http://www.legislation.gov.uk/nisi/1997/869/contents/made>

<sup>14</sup> See paragraph 22 (4) of the Special Educational Needs and Disability Order 2005. Available at: <http://www.legislation.gov.uk/nisi/2005/1117/article/22/made>

40. This places a potential complainant and their legal advisor at a disadvantage as they are unable to ascertain what case law has developed relevant to their particular complaint.

### **Access to Legal Aid**

41. We are aware that persons making a complaint to SEND Tribunal may be able to get legal aid to help them prepare the case but not to be represented at a hearing. Consideration will need to be given as to how legal aid will be assessed if the child or young person brings a complaint in his/her own name.
42. The Commission recommends that the proposed Code of Practice identifies the level of support that is required to enable a child or a young person to make an appeal.
43. The Code of Practice should also highlight what access to legal advice and assistance and other advice and information will be available to the child or young person in these circumstances.

### **Tribunal hearings**

44. The Commission has raised concerns to the SEN review, in relation to the physical arrangements made at SEND Tribunal hearings. The Commission is concerned that although the Department is aware of this issue, there are still outstanding issues in relation to the physical arrangements at SEND Tribunal hearings which have contributed to increase stress of disabled children when giving evidence in relation to a complaint.

### **Data collection to enable effective monitoring**

45. Article 31 of the UNCRPD places obligations on the UK and other Member States to ensure the collection and assessment of statistics and other data in order to enable them to learn more about the barriers that exist for disabled people and to better understand how they can put into practice the UNCRPD.
46. As set out in independent research commissioned by the Commission<sup>15</sup>, the availability of robust data, information and

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<sup>15</sup> Harper, C., McClenahan, S., Byrne, B., Russell, H. (2012): *Disability Programmes and Policies: How does Northern Ireland Measure Up?* Available at: <http://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/UNCRPDmonitoringimplementationFullReport0112.pdf>

statistics is central to evidence based policy making and to an effective monitoring process under Article 33 of the UNCRPD. Article 31 identifies the purpose of data and statistics collection and outlines the standards to be used for the collection, and maintenance and use of this.

47. One of the findings of the research in relation to the statistical and data requirements of the UNCRPD is that statistics on policies and programmes were very rarely disaggregated to give information on persons with disabilities or on the type of disability.
48. The research further commented that it was 'currently extremely difficult to measure the effectiveness of government policies in relation to people with disabilities' and this was 'due to a lack of co-ordinated and effective monitoring to quantify the impact of policy change'. The research also highlighted difficulties in that systems were not monitored or policed and where information was available, it was not readily accessible or available in formats required by disabled people.
49. The research identified that the collection of data was a priority area where the UNCRPD is not being fully implemented in Northern Ireland with respect to policies and programmes.
50. In light of this, we recommend that within the CoP, the necessary steps to improve data collection and analysis relating to disabled children in schools is outlined so as to ensure effective monitoring and review the impact of the changes to SEN provision set out in the Bill.

### **Concluding Summary**

49. Committee members will note that our observations and recommendations are made with the intention of securing greater equality between children and young people with SEND and those without disabilities. As well as seeking parity of treatment of those with SEND with their counterparts in the rest of Great Britain.

**Legal Policy and Research Division  
April 2015**

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## Appendix: Case Study Example

1. 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.
2. The Larkins are up at 6 o'clock in the morning 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.
3. 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.
4. 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.
5. 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.

6. 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.
7. 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.
8. 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.”*
9. 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.”*

10. 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.”*
  
11. 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.”*<sup>16</sup>

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<sup>16</sup> Equality Commission for Northern Ireland (2013): Strengthening Protection for Disabled People – Case Studies prepared by Brookhall Consulting Services Ltd, pages 21-23. Available at

