



Working together to close the gaps

Disability policies and programmes:
how does Northern Ireland measure up?

Equality Commission

FOR NORTHERN IRELAND

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The Equality Commission for Northern Ireland (ECNI) and the Northern Ireland Human Rights Commission (NIHRC) have been jointly designated, Under Article 33 (2) of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), as the Independent Mechanism for Northern Ireland to "promote, protect and monitor implementation" of the UNCRPD.

The Convention is an international human rights agreement that:

- recognises that we are all equal. It acknowledges that disabled people have the same rights as everyone else to freedom, respect, equality and dignity.
- brings together all our basic human rights in one place
- describes what needs to be done to make rights real

Acknowledgements

The Equality Commission is grateful to Elizabeth Zammitt, Collie McElroy, Lyndsey Ewing and Conor Maguire for giving us a deeper insight into their everyday lives and the challenges and achievements they have experienced, their input was invaluable to this publication.

Closing the gaps

Understanding the impact of public policy and programme delivery on the lives of individuals is essential.

And the word individual is so pertinent when considering how policies and programmes deliver to and for those with a disability.

To help increase our shared understanding, to fulfil our role as part of the Independent Mechanism for Northern Ireland to monitor the implementation of the UNCRPD and to keep legislation here under review, we are bringing together for the first time a robust range of data and evidence.

This has included commissioning research to look at gaps and key areas that need to be addressed in public policy and service delivery and considering existing information and studies as well as carrying out wide-ranging engagement and participation events. From this ongoing work we will establish priority areas for improvement that will have a real meaning for the individuals concerned.

Already we can see that research suggests that there are significant gaps for policy-makers, and these include

three cross-cutting issues around awareness, participation and data collection.

It would appear that there is a lack of understanding of the range of issues for people with disabilities and that this impacts not only on the drafting of policies but also their effective delivery.

Consistently through the range of work undertaken we have heard that while there have been limited improvements in some areas, like physical access to buildings, there are barriers still to be overcome. Many of these are non-physical and relate to the point of contact or accessing information for example from a public body. It appears that often, it is a lack of awareness of disability issues by staff or service providers that can lead to service failure.

This can be as simple as not making sure a document is in accessible formats or not giving someone enough time to fill in a form or to find a seat on a bus.

Underpinning this lack of awareness is a failure to understand the issues. People with disabilities have told us that they feel excluded from the policy-

making process and from participating fully in society.

It appears that this lack of visibility is also an issue in terms of how and what data is both collected and shared to better inform decision-making.

Here we present four of those stories of individuals and the challenges and achievements they have faced throughout their lives.

We will be asking Government to consider these and all of the experiences and information contained in our own and others' research projects as work continues to implement the Convention on the Rights of Persons with Disabilities.

Darren McKinstry
Director of Policy and Research





“

There was no one person or place I could go to for advice on how to adjust to my new lifestyle or to come to terms with this life-changing disability

”

'My disability does not define me'

Elizabeth's story

Elizabeth Zammitt is a mother of two and lives in Derry. Her own experiences of learning to live with a disability have given her insight into the everyday issues faced by disabled people – and a passion for promoting disability awareness.



Elizabeth describes her life at age 34, expecting her second child, as 'normal'. Within six weeks of the birth of her daughter, everything started to change.

"I was suddenly too sore to hold my newborn daughter; I needed assistance with everyday tasks and depended on my parents to help with everything while my husband was at work," Elizabeth recalls.

As Elizabeth's symptoms increased in severity, it took some months before a diagnosis was made. "I was relieved to be told that I had psoriatic and rheumatoid arthritis. I spent five long and difficult months in hospital," says Elizabeth.

"But everything changed, I was sent home from hospital in a wheelchair that would fit in neither the front nor back door of my house. I had to uproot my family from their home to move to a specially adapted bungalow. And until recently, I even had to conduct my banking business on the street because our local branch had no wheelchair access."

Elizabeth refers to the lack of information or 'sign-posting' to tell her who to contact for advice as a huge challenge. "There was no one person or place I could go to for advice on how to adjust to my new lifestyle or to come to terms with this life-changing disability."

Now a committed campaigner, Elizabeth uses her own experiences to help others by raising awareness of the barriers that she has faced - in fact she now advises many statutory bodies and groups on what issues they should consider to assist people with a disability. Her impressive

CV includes advising the Police Service for Northern Ireland, Derry City Council, Translink and ECNI. She is also a member of the REAL Network (Rights, Empowerment, Action and Lobbying).

She says, "I have attended events at Stormont, invited there by our politicians. It is a stunning building and I was impressed by its grandeur, but its lack of accessibility has not gone unnoticed!"

She is adamant that awareness raising is the key to making real change for everyone with a disability.

"I am reliant on a wheelchair but I will not let my disability define me," she says. "I'm still the same person, I still like Chinese food and still love Cliff Richard all these years later! It's only my joints that don't work so well anymore. I have a wonderful loving family who support me. They won't let me sit in the corner for someone to come along and dust me off every so often – I have a life and I'm living it!"

Her passion and commitment is raising awareness to improve the lives of those with a disability. Making a real difference is where Elizabeth sources her sense of achievement.



“

I decided to step up to the mark... I worked hard to push disability onto the agenda within my local branch.

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'My focus is on what I can do'

Collie's story

Collie McElroy from Newry is the father of three boys and worked in the freight business for 17 years. He is an ardent supporter of Liverpool Football Club. Collie describes his life as pretty standard until November 2006.



“I was up a ladder, at home, cleaning fascia boards and PVC windows. Unfortunately no one was holding the ladder while I worked,” he says. The ladder slipped and Collie fell from a considerable height. When he landed on his feet the pressure of the impact caused a ripple effect which broke his back.

“I was rushed to hospital, and spent three weeks in the Royal Victoria Hospital. It was a scary time - I had to have rods inserted into my spine. My recovery was painful and difficult. I learned that I'd never drive a lorry again. This was a massive shock to me. I had no idea what I would be capable of doing,” Collie remembers.

Collie's sons provided him with the inspiration and determination to get back on his feet. “It was my son's birthday shortly after the accident. I was determined to be home in time for the family celebrations. I worked really hard at learning how to manage stairs and the hospital agreed to let me go home in time to help my son blow out the candles on his cake.” Collie recalls.

“On a friend's advice, I completed some computer courses and started to focus on what I could do and began to accept what I couldn't”, Collie said.

Collie freely admits that before his accident he had never considered issues faced by disabled people, but now that he himself faced those challenges he thought he should try and make a difference.

Collie joined the REAL Network (Rights, Empowerment, Action and Lobbying). One of their ideas was to improve the effectiveness of lobbying political parties and suggested

members should influence from the inside by joining a political party.

Collie says, “I decided to step up to the mark and to join the Ulster Unionist Party (UUP). I worked hard to push disability onto the agenda within my local branch. Then I was asked to have the courage of my convictions and stand for election.”

Collie was nominated as a candidate in the 2011 Northern Ireland council elections. “I was unsuccessful this time around, but the whole experience was brilliant and I'll stand again next time” he laughs.

Collie is currently a member of the committee for the Peace 3 Southern Cluster Partnership. He's also involved in the Cub Scouts and his sons' football team. He even travelled to Nepal to visit a centre for people with disabilities.

“It's great to be involved in all these things. I enjoy the role and understand the importance of taking up my civic duty,” he says.

“It took me a while after my accident to accept that my life was going to be very different to before. I have faced so many challenges and achieved so much. I never dreamt I would be involved in the things I am now doing. So, who knows what I'll be doing in the next five years? I've accomplished so much since 2006 that my focus now is onwards and upwards!”

Challenges and issues:

Some examples

What UNCRPD says

Independent Living

People with disabilities have the right to live independently in the community. Countries must ensure that people with disabilities have the opportunity to choose where they live and with whom they live, and that they are provided with the support necessary to do this.

Education

People with disabilities have a right to education without discrimination. Countries must ensure that people with disabilities can access an inclusive, quality and free primary and secondary education in their own community. Countries must also provide reasonable accommodation and individualised support to maximise academic and social development. For example, it must provide suitable ways for an individual to communicate so that their teachers understand how to respond to their needs.

Work and Employment

People with disabilities have the right to work, including the right to work in an environment that is open, inclusive and accessible. Countries must take appropriate steps to promote employment opportunities and career advancement for people with disabilities.

What you've told us

"Sadly the status quo seems to be that there is what there is, politicians are sympathetic but lack the drive to challenge the system and put proper structures and opportunities in place for young people with severe learning disabilities (to live) a fully inclusive and independent life"

(Carer, IMNI Conference 2010)

"Education: equal access is not needs led but resource led. This starts the downward spiral in equality - Less chance of employment - live on benefits - no way out of the poverty trap!"

(IMNI Conference participant, 2010)

"ensuring that young people with SLDs (severe learning disabilities) find meaningful and rewarding work experiences suited to their needs - it can be a very powerful learning experience for the workplace as a whole"

(research Focus Group participant, Monitoring Implementation of the UNCRPD in NI, 2011)

At a glance key statistics

There are differing attitudes towards disabled people in Northern Ireland. Around 1 in 10 (8%) would mind working with someone with a learning or physical disability, while almost 2 in 10 (17%) would mind working with someone with mental-ill health (Equality Awareness Survey, 2008).

Two-thirds (66%) of respondents felt that it is very important to uphold the rights of disabled people (Equality Awareness Survey, 2008).

Awareness Raising

Countries must raise awareness of the rights, capabilities and contributions of people with disabilities. Countries must challenge stereotypes and prejudices relating to people with disabilities through campaigning, education, media and awareness-raising programmes.

Participation in political and public life

People with disabilities have the right to participate in politics and in public life, as well as to vote and to be elected.

Statistics, Data Collection; Access to Information

Article 31 of the UNCRPD introduces a new element to human rights treaties in that it requires countries to collect information about people with disabilities, with the active involvement of people with disabilities, so that they can better understand the barriers they experience and make the Convention rights real.

“Those that have been there need to be behind awareness raising.”

(research focus group participant, Monitoring Implementation of the UNCRPD in NI, 2011)

“Ask first – the person with the disability knows what the disabled person needs.”

(research focus group participant, Monitoring Implementation of the UNCRPD in NI, 2011)

“Knowledge is power!”

(research Focus Group participant, Monitoring Implementation of the UNCRPD in NI, 2011)

65% of respondents said we need more disabled people in the workplace (Equality Awareness Survey, 2008).

In 2010-2011, 9 out of 416 people appointed to board positions in NI Executive public bodies had a declared disability, representing 2% of appointments, a decrease from 3% in the previous year. (OFMDFM, 2011)

In 2010-2011, 42 out of 1,009 applicants for board positions in NI Executive public bodies had a declared disability, representing 4% of applicants, an increase from 3% in the previous year. (OFMDFM, 2011)



“ I am deaf and I have some problems understanding some big words. I need people to think when they are dealing with me ”



“Simple solutions make a big difference”

Lyndsey’s story

Lyndsey Ewing is 26 and from Greyabbey. She is a strong and fiercely independent young woman. She was diagnosed with hydrocephalus shortly after birth and underwent surgery for the first time at just 2 weeks old. Lyndsey has endured many operations throughout her life to keep her alive and well



Surprisingly, Lyndsey’s deafness was not discovered until she had reached P2. By this time, she had taught herself to lip-read and had created some words of her own. She was fitted with two hearing aids and went to a new school with a specialist hearing unit, where she was found to have a slight learning disability.

Lyndsey took up swimming, after moving school again and they worked to ensure she swam as part of the team. “A flag was used to alert me to the start of the race as I couldn’t hear the starting pistol. It seems a simple solution but it meant I was able to participate in a sport I loved.”

“I then went to Torbank for my last year at school and then headed off to Castlereagh College to train to be a chef” she said.

Lyndsey recalls “I got a few placements, but they didn’t really work out for me.” Lyndsey felt some colleagues thought she was ignoring their instructions, “Sometimes I didn’t know that people were talking to me.” Unfortunately Lyndsey’s health deteriorated and she feels that as a result of her absence she lost her job. “I was disappointed, but once again I’m stubborn and wouldn’t let it get me down.” she says.

“I passed my driving test after finding a registered accessibility driving instructor to teach me to drive, I like a good challenge,” she laughs.

Lyndsey loves tenpin bowling and she is quite good at it too! “My dad taught me to bowl, and now I help coach and facilitate competitions for Special Olympics athletes

in Northern Ireland,” she says. In fact, due to her hard work and dedication her local bowling alley is hosting a competition early in the New Year. “I hope my team score lots of strikes!” she laughs.

Lyndsey is currently recovering from an operation so her ability to do some of the things she loves is curtailed for a few months but it’s hard to stop this lady achieving what she wants.

“I am deaf and I have some problems understanding some big words. I need people to take their time to explain things to me. I also need people to think when they are dealing with me. I’ve been asked by medical staff to take my hearing aids out and then they ask me questions – but without my hearing aids I can’t hear. Or in shops and the bank I’m asked to speak to someone on the phone, but I’m deaf and I can’t hear them, it’s a bit silly really.”

For Lyndsey, simple changes or adjustments to provide accessibility and understanding is key to allowing her to integrate fully in life. A few minutes thought by others may well be all that is needed to provide Lyndsey with the ability to take on her next challenge - whatever that may be!

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it's important for Conor to get out to his centre and his job in the restaurant. He enjoys them both and it is his time with his friends.

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“It’s important to be able to work and socialise”

Conor’s story

Conor is 21 and lives at home with his mum and brother. He enjoys his job at a restaurant and loves football, supports Liverpool and watches all their matches on TV.



Music is a passion of Conor’s. At the minute he is a fan of Justin Bieber – he even has the haircut to prove it. But he also still loves Irish music and Michael Jackson and the way he danced - and Conor loves dancing too.

Conor was born in 1991 and he has Down’s Syndrome. He has grown up in a loving family, supported by extended family and a circle of close friends and neighbours.

He went to Glenveagh School and took part in the Special Olympics in 2003, bringing home a handful of medals. But now he is too old for the school system.

Maura Maguire is Conor’s mum. She explains how after Conor passed school age, she felt that there is no real system or process in place for people like her son. She acknowledges the work his old school did in preparing him for leaving and it was through them and another project that he secured his work placement in a restaurant. She knows that quite easily Conor could have found himself stuck at home.

Luckily, Conor’s day placements are close to home with minimal travel. Shortly after his 20th birthday, his mum lost her entitlement to a considerable amount of monetary benefits. This was not because Conor no longer required the same support, but simply because of his age.

Maura said: “It’s important for Conor to get out to his centre and his job in the restaurant. He enjoys them both and it is his time with his friends. I could completely understand how the loss of often hundreds of pounds per month could leave

a family in a position where they have to cut back. I was lucky we got our situation sorted out.

But just because your child with Down’s has reached adulthood means that person could be confined to home for most of their adult life.

We are very lucky we have such a good family support system and wonderful neighbours, many of whom consider Conor to be part of their families. He is loved by many people. He makes the most of every opportunity to socialise and family events and parties are important to him. He also attends a club on a Friday evening.”

Maura had to work her way through a benefits system which was not well signposted.

She had to support Conor by herself as her husband had passed away and she believes that the system should be made simpler.

Conor is full of fun, and has a good quality of life which keeps him entertained, fulfilled and safe. But Conor’s condition will not improve. He will be reliant on that family support for his whole life. A change in the benefits system to make it easier to navigate and to empower people like Conor to make decisions which impact on their lives with the assistance of those who care for them would be welcomed.

What we've done so far

In our role as Independent Mechanism for Northern Ireland and in our own work as the Equality Commission, we have, with the Northern Ireland Human Rights Commission, sought to engage with disabled people and other key stakeholders. This has informed and helped to shape our plans and activities and we are grateful to all those who have contributed. Here are some numbers to explain:

44

people provided their views through questionnaire responses received after the December 2010 conference.

There were

9

'Have Your Say' rights based training sessions held between March and June 2011 with a total of 98 participants attending. Training sessions were held in 5 different locations from Belfast to Newry.

145

delegates attended our joint IMNI conference on 1 December 2010.

The research "Disability programmes and policies: How does Northern Ireland measure up?" referenced the use of over

60

pieces of literature in its bibliography.

6

focus groups were held during December 2010 to February 2011

Over

50

delegates who could not attend provided their views to those facilitating the relevant workshop

What next?

The Commission will continue to undertake targeted and proactive engagement and partnership working on its proposals for legislative and policy reform with key stakeholders, in order to raise awareness of, refine and gain support for the Commission's proposals. It will support stakeholders' engagement on this issue. In particular, it proposes to engage with individuals and representative organisations in the

disability sector, as well as other stakeholders, such as trade unions and business sector organisations.

The Commission will also undertake targeted political and other engagement, in partnership with key stakeholders, to press for change and secure reform; for example with political parties, Assembly Committees, OFMdFM and other relevant Government Departments.

Be part of it...

Please visit www.equalityni.org/uncrpd to find out more about your rights under the Convention; our work to improve the situation in Northern Ireland and how you can participate. If you have any specific enquiries or wish to know more about our work in this field please email crpdenquiries@equalityni.org

To receive information about the work of the Equality Commission please sign up for our Newsletter www.equalityni.org/newsletter.



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