

How can we increase the community recognition and response to the human rights of people with intellectual disabilities?

Carolyn Stobbs

Travel Date: June 2018

Acknowledgements

Thank you to the Winston Fellowship Trust for this opportunity. I am grateful for the incredible opportunity, both for me personally and for the work in the human rights of people with intellectual disability.

Thank you to all the people I met in the United Kingdom, you made this the most enjoyable, interesting, and valuable trip. You were generous with your time, your wisdom and your willingness to share this with me. Thank you for all the resources and information you shared and all the fabulous “change the world” conversations. Thank you all for what to do for the lives of others.

Thank you to my friends and family who supported me with their encouragement and generosity. To the many people in New Zealand who put me in touch with UK colleagues and gave me ideas and encouragement.

Thank you to IHC for supporting me to take this opportunity.

This report reflects my own thoughts and ideas on how to increase the recognition of the human rights of people with intellectual disabilities.

Thank you to the people who gave their time and wisdom: Sally Warren, Jo Giles, Sammy Baker, Simon Duffy, Zara Todd, David Towell, Sam Smith, Heather Simmons, Austin McGuire, Shaun Webster, Marianne Scoble, Andrea Clark, Beverly Dawkins, Sarah Gilbert, Philipa Bragman, June Dunlop, Keith Etherington, Laura Broughton and the teams that work with them.

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Executive Summary

I went over to the United Kingdom with funding from the Winston Churchill Fellowship Funding to assist me to further develop the work IHC New Zealand does by designing and delivering:

1. “Off the Shelf” learning events and modules which promote the human rights of people with intellectual disability.
2. Resources - for individuals, families, and communities.
3. Learning events and modules developed collaboratively and in partnership with others e.g. providers, community organisations, family membership organisations.

I was supported by Sally Warren, the Managing Director of Paradigm in the United Kingdom.

I identified the following ways IHC could assist New Zealand’s transformation of the disability support system:

- Offer a consultancy that can design and deliver events and activities to meet specific needs of organisations/community groups etc.
- Successfully employ people with intellectual disabilities to design and co-deliver our work.
- Enable supporters (paid and unpaid support) for people with intellectual disabilities to be strong advocates.

The following has directly resulted from my work:

- A new programme for has been designed for people with intellectual disabilities and their whānau and supporters.

- A new design is currently underway for a programme with a focus on collaboration with people with intellectual disability in partnership with organisations wishing to explore their response to the human rights of people with intellectual disability.
- The consultation of an Advisory Group for the Community Advocacy programme has begun.
- Applications have been made to present at relevant conferences which will enhance the human rights for persons with intellectual disability.
- Online resources to enhance the message and learning about human rights for people with intellectual disability is being developed.
- Programmes have been designed and are being delivered for organisations who provide services to the community and will now be more able to provide that service to people with intellectual disability.

Introduction

In June 2018 I travelled to United Kingdom to explore ways to improve the work that I do as the Team Leader of the Community Advocacy Programme for IHC New Zealand¹. When I applied to the New Zealand Winston Churchill Memorial Trust² Fellowship for funding the New Zealand Government had announced in 2011 their intention to transform the disability support system based on the vision and principles of the Enabling Good Lives project³. A nationwide transformation of the existing disability support system is currently under way.

¹ IHC is New Zealand's largest provider of services to people with intellectual disabilities and their families. The organisation was founded in 1949 by a small group of parents who wanted equal treatment from the education and health systems for their children with intellectual disabilities. More information can be found on their [website](#).

² The New Zealand Winston Churchill Memorial Trust is administered by the Department of Internal Affairs. Information about the Trust is located on the Community Matters [website](#).

³ Enabling Good Lives is a partnership between the disability sector and government agencies to ensure that disabled people. New Zealand Government recognised the need and broad direction for change to the disability support system through the New Zealand Disability Strategy and the UN Convention on the Rights of Persons with Disabilities, and the Government response to the Social Services Select Committee inquiry into the quality of care and service provision for people with disabilities. More information is available through the Enabling Good Lives [website](#).

I applied for the Winston Churchill Fellowship Funding to assist me to further develop the work we do with people with intellectual disability, supporters, staff, and disability support service providers, family organisations, community organisations, local and central government organisations, and agencies by designing and delivering:

1. “Off the Shelf” learning events and modules which promote the human rights of people with intellectual disability.
2. Resources - for individuals, families, and communities.
3. Learning events and modules developed collaboratively and in partnership with others e.g. providers, community organisations, family membership organisations.

There is a concern about how people with intellectual disabilities engage with the new approaches designed to maximise personal choice and control. There is a need to increase capacity in organisations and individuals accessing or providing support to people encouraging personal agency through supporting people to make decisions about their own lives. Throughout our work, we hear about the significant barriers people with intellectual disabilities experience in having their human rights recognised and responded to in all aspects of their lives. Our work is addressing the United Nations recommendation (2014) that New Zealand should take immediate steps to revise the relevant laws and replace substitute decision-making with supported decision-making⁴.

IHC Advocacy has the unique opportunity to work with individuals, organisations, and communities to build capacity in recognising and responding to the human rights of people with intellectual disabilities. The proposed government changes to the way supports are delivered has issues for people with intellectual disabilities, as for many people, having

⁴ Summary report on improving disabled people's exercise of legal capacity [website](#).

choice and control over their lives is something that has been denied for many years. Our work with people with intellectual disabilities and those people who support them raises awareness of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)⁵ and the importance of making those rights real in everyday life. It is essential that people gain an understanding of UNCRPD. It asserts their right to be treated equally under the law, to get the right support to make decisions about their own lives, and to have personal agency.

⁵ UN Convention on the Rights of Persons with Disabilities (CRPD) [website](#).

Why go to the United Kingdom?

The proposed transformed New Zealand disability system aims to give disabled children and adults and their families greater control and choice over their supports and lives⁶. The vision is based on disabled people having greater choice and control. The principles of how disabled people would like to live their lives include self-determination, with the system investing early, being person-centred, being easy to use, supporting disabled people to live an everyday life like others at similar stages, able to access mainstream services, being mana enhancing, and building and strengthening relationships between disabled people, their whānau and community. In the future, disabled children and adults and their families will have greater choice and control over their supports and lives, and make more use of natural and universally available supports. This significant change was at the heart of everything I went to explore in the United Kingdom.

I currently lead IHC's Community Advocacy Programme. This programme has been recently developed to assist all people in communities to better recognise and respond to the human rights of people with an intellectual disability. We work to enable people with an intellectual disability to have a say in their lives, to be supported to be active and valued citizens in their community. I studied the ways targeted organisations in the United Kingdom currently work in the following ways:

1. Offer a consultancy that can design and deliver events and activities to meet specific needs of organisations/community groups etc.
2. Successfully employ people with intellectual disabilities to design and co-deliver our work.

⁶ Ministry of Social Development Statement of Intent 2017-2022, page 22.

3. Enable supporters (paid and unpaid support) for people with intellectual disabilities to be strong advocates.

I observed that individualised funding began over 10 years ago with direct payments to individuals which gave some people the right to turn their social care service into its cash equivalent. Later, a further development came in the form of ‘Individual Budgets’ (or ‘Personal Budgets’) which meant everyone had a budget, but with several different options for managing that budget. There were opportunities to ask questions of a range of people who have experienced this change to systems and use this to design and develop resources that will support people and those who support them. I learned that significant change has occurred for some people.

The Experience

For much of the time I was based with Sally Warren, the Managing Director of Paradigm in the United Kingdom.⁷ Sally leads the ‘Ensuring an Ordinary Life for All’ national network comprising of 42 organisations. Sally has co-authored the Reach Standards and launched Reach Support for LIVING.⁸

I met with many more people than planned. Please refer to [Appendix 1 - Travel Diary](#) for all the details of my travel. As interviews took place, people would make suggestions and contact colleagues to arrange for me to visit. People were very generous with their time and it was encouraging to talk with so many people with such a passion for human rights and ways to ensure people with intellectual disability are recognised as full citizens. As a very practical learner, it was important for me to experience the delivery of workshops, to meet with people and be part of activity where I was able to ask questions in real time.

With a strong commitment to hearing and responding to the voices of people who this work is about, it was important for me to meet and talk directly with people with intellectual disability and those whānau and people directly supporting them.

I learned more than I could ever have expected. I returned with excess baggage of notebooks filled with drawings, diagrams, quotes and thoughts and many lightbulb moments.

⁷ Paradigm is a leading learning disability training and development agency. More information is available on their [website](#).

⁸ Reach Support for LIVING offers a set of voluntary standards. Originally launched in 2002 and now in their third edition, Reach was created to ensure that supported living focuses on ensuring each person is able to live the life they choose with the same choices, rights and responsibilities as other citizens. The Reach Standards remain the most widely recognised standards across the UK in relation to supported living. More is on their [website](#).

Key Learnings

My experience encouraged creative thinking and I was able to directly link activities I was participating in and translate them in to ways of working on my return. I identified the following ways IHC could assist New Zealand's transformation of the disability support system:

- Offer a consultancy that can design and deliver events and activities to meet specific needs of organisations/community groups etc.
- Successfully employ people with intellectual disabilities to design and co-deliver our work.
- Enable supporters (paid and unpaid support) for people with intellectual disabilities to be strong advocates.

Consultancy for events for organisations/community groups

We had developed the co-production area of our work in a way that I now understand will be better termed as partnerships. These partnerships were developed with organisations and membership groups who wished to develop their responses to the rights of people with intellectual disabilities.

We know that more needs to be done to tackle negative attitudes to individuals with intellectual disabilities, and to break down barriers that prevent people with intellectual disabilities from being accepted within society, and from accessing a wide range of opportunities and experiences taken for granted by people. These aims are enshrined in the UN Convention on the Rights of Persons with Disabilities, which promotes a rights-based perspective instead of, for example, the charity model so long applied to people with intellectual disabilities.

This experience gave me an opportunity to develop new ideas on how co-production can occur in this space. This means, that within this partnership, we look at ways in which people with intellectual disability can be fully involved in the development and activity of partnerships. We developed processes in which people with intellectual disability could be co-developers in learning. The value in processes where people with intellectual disability work alongside our partners to assist them to understand ways in which they can improve their connections and service to people with intellectual disability. This work takes skilled facilitation and our team are working on process and facilitation skills that ensure quality learning and respectful and shared understanding.

Where we can provide an opportunity for people in organisations and groups to experience working directly with people with intellectual disability, they will have the chance to understand the value of involving people with lived experience. They will learn that simple adjustments not only make a difference for this group of people, but for many others.

The voice and skills of people with intellectual disability is essential for this work. I encourage organisations to think about why they would not want to involve people with intellectual disability in the design and development of their policies and procedures.

Organisations and people offered practical advice and tools on who to decide where to focus our work, and where we could be most effective. My questions explored ideas around focussing in on people when they were in training for their role (i.e. Social Workers or Nursing), or do we start at the top to ensure change? Overwhelmingly, the response was “everywhere”. I was encouraged by stories of opportunities taken where there was a connection with an individual that created a space to work. It appears that where you create a spark, it should be followed and that this was a successful way of working in communities.

I explored ways to encourage organisations to look at who isn't in the room when decisions are being made or discussion is taking place. In the past, it may have been easy to accept “we don't have time” as a response, I think it is important to assist organisations to look at how they ensure that other human rights issues are responded to and respected in their organisation and ensure that they can see that human rights are for all people. Keeping the focus on ‘human rights are for all people’ has been strengthened from this experience. I feel I can draw on more examples of opening spaces for all people which only enhances. It doesn't take away.

This experience has strengthened both my commitment to collaborative approaches to this work. Are there opportunities for people with intellectual disability in this partnership? If not, I believe we should not be doing it we need to ensure that this is not just an “awareness” opportunity. We must continue to ask “and what next?”.

In the UK, co-production has become the expected practise and it was encouraging to see this, it is good to see that this is increasingly so in New Zealand. Why would anyone want to make policies without the people they are about?

What is planned?

- Develop our programmes capability as a trusted consultancy that can design and deliver events and activities to meet specific needs of organisations/community groups.
- Share stories that highlight partnerships with supporters and people with intellectual disability and their communities.
- A new design is currently underway for a programme with a focus on collaboration with people with intellectual disability in partnership with organisations wishing to explore their response to the human rights of people with intellectual disability.

Employ people to co-deliver our work



Figure 1: Sammy and Carolyn talk about how to include people's voice

My experiences on this journey changed my thinking significantly. I had developed a fixed view of ways in which people with intellectual disability could be part of the development and delivery of this work. I realised that the employment of one person to become a member of our team, could lead to reflecting the experience of one person. There are many varieties of views within a community and a danger of not getting a diverse perspective.

I learned many new ways to include the expertise of people with intellectual disability in genuine partnership roles that would give a wider pool of experiences. I continue to advocate strongly for the acknowledgment of people with intellectual disabilities lived experience to be acknowledged as experts and that they should be compensated appropriately, in the way any other expert is compensated for their work.

An Advisory or steering group will be one way in which the work is designed and developed and I am currently exploring ways in which this could work best for everyone involved. I strongly believe for it to work best, is for me to not to decide how it works best! Co-design is

not just bringing people in an idea that you have and I experienced this in action during my trip.

It is important to have people with intellectual disability as an integral part of partnership with groups and organisations, as discussed earlier. To provide opportunity to have people involved in a learning environment with an organisation will give a better understanding of issues, alongside practical experience for everyone in communication and making adaptations to include people.

I was excited to have an invite to the opening of an art exhibition called Power Struggle by Laura Broughton. Laura's introduction exhibition as the new artist in residence at the Health and Social Care People's Academy reminded me of the creative ways in which people tell their story. Laura's art was a fantastic way of telling a story about her place in this world and I committed to ensure that creative ways for telling a story would be included in our future work.

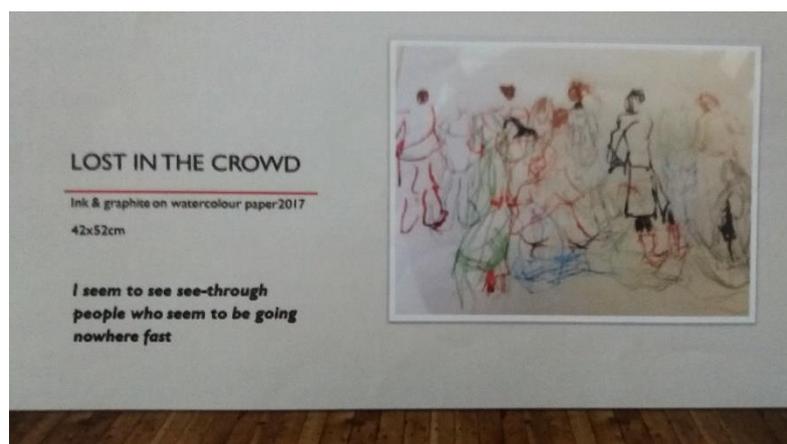


Figure 2: Lost in the Crowd watercolour at Power Struggle Exhibition at London's South Bank University

What is planned ?

- Develop an Advisory or Steering group. Work has begun to identify a group of people who can advise our work in a way that will include the voice of people with intellectual disability. It is essential that the composition and development of this group ensures that the voice of people is a genuine attempt to have disabled people at the centre of what we do, that they are acknowledged as experts and that their contribution is valued.
- Programmes have been designed as a collaborative process where people with intellectual disability are, as part of a learning process, able to share their experiences, expertise and knowledge of being included in their communities. Discussions continue on how they will be recognised for their expertise.
- Development of online resources to assist people with intellectual disability learning about supported decision making.

Enable supporters to be advocates

In New Zealand Whānau and supporters have been strong advocates for people they care about. We had looked at the impact of our current work and people with intellectual disability had expressed the importance of having good support and strong advocates alongside them as significant for them to have ability to be agents in their own lives. The experience of a more person-centred approach to disability supports from the UK has helped me to think about approaches and design of learning experiences which will support New Zealanders with intellectual disability and their supporters to embrace this opportunity for more choice and control in their lives with more knowledge and confidence.

Paradigm UK's Great Support Movement gave me several ideas on how we could connect supporters to each other as an important part of developing strong advocates.



Figure 3: Planning Live training with Paradigm in Swindon (1)

There are many opportunities using online tools and social media to connect supporters and I have joined existing groups and am currently looking at what is working well, with a view to contributing to rather than replicating.

I am exploring how we could assist supporters in different parts of New Zealand to develop leadership groups this would be a valuable way of supporting advocacy and ensure its work has a wide reach.

To work nationally is a challenge, and travelling the UK taught me that geography should completely change the way we think, and we should tailor our work to the area, this would mean using local community champions, with lived experience of intellectual disability

Many of the learnings from this fellowship are already in to place. We have been working with the Ministry of Health to design and deliver workshops for people with intellectual disabilities and their whānau. These workshops are called “Let’s talk about Choice” and will ensure people gain an understanding of supported decision making, the UNCRPD and ways to support each other.

These workshops, using a co-production approach will both increase capacity of supporters and disabled people to talk about choice and control together, with skilled support. Therefore, strengthening the voice of both disabled people and their supporters. This approach acknowledges people and their whānau as the experts in their lives, with our team as the facilitators of the discussion.

Families and support people can only advocate for people if they are sure of the person’s wishes, this includes all people.

Our invite to these workshops explains our approach to partnership in these relationships, and our vision that communities can support each other:

“Let’s talk about ... Choice

*This workshop will help you to talk about making choices,
advocating for yourself or people you care about, support
each to prepare for the future.*

*We will spend time working in groups and give you time to talk with
your peers and your whanau about what’s important to you.*

*We will explore ways to support each other to make choices
and how we can talk through things when they feel tricky.*

*Everyone can build on their knowledge of rights and
responsibilities so that we all know why it’s important.”*

I attended a training session on Planning Live with Paradigm. This workshop was to train professionals working with people and their families as table facilitators for a Planning Live workshop. I have used some of the principles and structures of this workshop to ensure our “Let’s talk about Choice” workshops provides the opportunity for people to support each other when planning for how they will plan for more choice and control in their lives.



Figure 4: Planning Live training with Paradigm in Swindon (2)

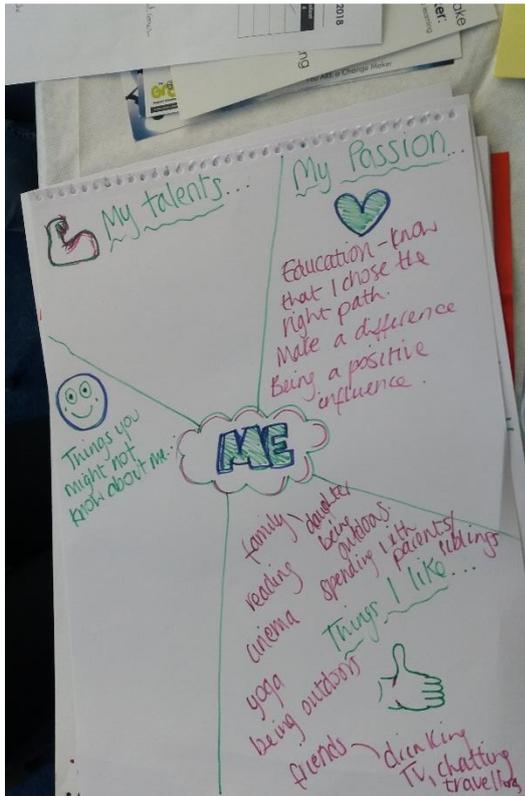


Figure 5: Example of a Planning Live worksheet

We could ensure that we have an up to date toolkit and provide training on how to campaign ensure we are using local people to campaign and to develop community activism. This was reinforced by my visits with Mencap and Ace Anglia, where I was given strong advice to keep well connected to communities, people with intellectual disabilities and their supporters.

I was encouraged by examples of advocacy and self-advocacy that kept real, rather than slick approach. People's voices in ways that they wish to be heard is essential for true involvement of people and their whānau. An example we filmed on a sunny afternoon following a workshop with Paradigm UK.



Video 1: an example we filmed on a sunny afternoon following a workshop with Paradigm UK.

IHC supports conference presentations. Opportunities to submit to conferences both in New Zealand and in Australia will be made for 2019/10. These will include conferences held by Australasian Society for Intellectual Disability, New Zealand Disability Support Network, New Zealand Association of Counsellors, and National Rural Health Conference. A list of conferences is regularly updated and explored by the Community Advocacy Team and approaches made to a variety of organisations. I have had the opportunity to share my learnings with IHC Programmes Management Team and Staff from Idea Services (IHC's service arm). My focus in these has been on encouraging the voice of people with intellectual disability, and ways in which this can be valued and implemented. I am fortunate that my role means that advice gathered from my learnings is sought regularly by people and their supporters.

What is planned?

- Support the groups to be actively engaged and build relationships within their communities to organise and host conversations.
- Provide a space for people to share information and ideas with others in similar group.
- Ensure an up to date toolkit and provide training on how to campaign to ensure we are using local people to campaign and to develop community activism.
- Opportunities to submit to conferences both in New Zealand and in Australia will be made for 2019/10.
- A new programme for delivery for the Ministry of Health through Mana Whaikaha and Local Area Coordination has been designed for people with intellectual disabilities and their whānau and supporters.
- Applications have been made to present at relevant conferences which will enhance the human rights for persons with intellectual disability.
- Development of online resources to enhance the message and learning about human rights for people with intellectual disability.
- Programmes have been designed and are being delivered for organisations who provide services to the community and will now be more able to provide their services to people with intellectual disability.
-

Conclusion

The Community Advocacy team works in a variety of settings. This means that the learnings from the Winston Churchill Fellowship are shared regularly in a range of places. The findings from this Fellowship, put in to practice have a wide-reaching impact. Currently IHC Programmes is exploring how the use of technology could enhance this work. We hope to look to several opportunities with on line learning, social media, podcasts, and webinars that will amplify this important human rights message.

For many years people with learning disability were excluded from public participation. Today, with the growth of self-advocacy and national and international instruments such as the New Zealand Disability Strategy and the UN Convention on the Rights of Persons with Disability, increased government departments, organisations and services are requesting participation of Disabled leaders who have a learning disability. To achieve participation on equal terms there needs to be recognition of access requirements and the provision of reasonable accommodations.

Appendix 1 - Travel Diary

Date	Activity
4 - 13 June 2018	Based with Paradigm with Sally Warren
Monday, 4 June 2018	<ul style="list-style-type: none"> • Andrea Clark and team at ACE Anglia Stowmarket, Suffolk • Laura Broughton's opening of Power Struggle Exhibition at London South Bank University, her supporters including Choice Support
Thursday, 7 June 2018	Paradigm workshop to train trainers in Planning Live for teachers and social workers in Swindon
Tuesday, 5 June 2018	David Towell Paradigm Associate
Monday, 11 June 2018	Beverley Dawkins, CE Generate,
Tuesday, 12 June 2018	<ul style="list-style-type: none"> • Jo Giles Paradigm • Sammy Butcher Paradigm
Friday, 15 June 2018	Sarah Gilbert, Head of Campaigns & Activism, Mencap
Wednesday, 20 June 2018	<ul style="list-style-type: none"> • Marianne Scobie Glasgow Disability Alliance, Glasgow • Austin Maguire Thera Glasgow
Thursday, 21 June 2018	Simon Duffy Centre for Welfare Reform
Friday, 22 June 2018	<ul style="list-style-type: none"> • Coalition of Care and Support Providers Catherine Garrod, Self-Directed Support Scotland Jess Wade • The team at Thistle Foundation Keith Etherington June Dunlop and team In Control Scotland and participants at European Network on Independent Living
Monday, 25 June 2018	<ul style="list-style-type: none"> • Sam Smith C-Change Glasgow • Zara Todd Disability Activist and Winston Churchill Fellow
Tuesday, 26 June 2018	Heather Simmons C-Change Glasgow
Thursday, 28 June 2018	Shaun Webster and team of resource developers Jane, Paul, Richard, Craig, Leepi, Durbali and CE Philpa Bragman Change Leeds

Appendix 2 – References

IHC is New Zealand website: <https://ihc.org.nz/>

The New Zealand Winston Churchill Memorial Trust Fellowship website:
<https://www.communitymatters.govt.nz/ask-us/?q=Winston+Churchill>

The New Zealand Ministry of Social Development (MSD) website:
<https://www.msd.govt.nz/>

The New Zealand Ministry for Vulnerable Children, Oranga Tamariki website:
<https://www.orangatamariki.govt.nz/>

The Ministry of Social Development Statement of Intent 2017-2022 link:
<https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/corporate/statement-of-intent/2017/soi-2017-2022.pdf>

Enabling Good Lives Project website: <http://www.enablinggoodlives.co.nz>

New Zealand Disability Strategy website: <https://www.odi.govt.nz/nz-disability-strategy/>

The Office for Disability Issues website: www.odi.govt.nz

UN Convention on the Rights of Persons with Disabilities (CRPD) website:
<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

Summary report provides an update on work by the Office for Disability Issues to identify improvements for disabled people exercising their legal capacity or decision making:
<https://www.odi.govt.nz/summary-of-progress-on-improving-disabled-peoples-exercise-of-legal-capacity/>

Paradigm, learning disability training and development agency. <http://www.paradigm-uk.org/about-us/>

Reach Support for LIVING voluntary standards: <http://www.paradigm-uk.org/reach-standards/>

Appendix 3 – Details of Illustrations

Image Label	Date	Location	Image Owner
Figure 1: Sammy and Carolyn talk about how to include people's voice	June 2018	Carolyn Stobbs Sammy Butcher	Paradigm UK
Figure 2: Lost in the Crowd watercolour at Power Struggle Exhibition at London's South Bank University	June 2018	South Bank University, London, United Kingdom	Carolyn Stobbs
Figure 3: Planning Live training with Paradigm in Swindon (1)	June 2018	Paradigm, Swindon, United Kingdom	Carolyn Stobbs
Figure 4: Planning Live training with Paradigm in Swindon	June 2018	Paradigm, Swindon, United Kingdom	Carolyn Stobbs
Figure 5: Example of a Planning Live worksheet	June 2018	Paradigm, Swindon, United Kingdom	Carolyn Stobbs

Appendix 4 – Details of Videos

Publisher: ParadigmUKTV

Published on 17 Jun 2018

Video hyperlink: <https://youtu.be/EvTnjYclhaA>

Description:

This short poem has been created following Paradigm's 'Mind the Gap' workshop on June 1st 2018.

At the start of the workshop we invited people, self-advocates, family members, support workers, commissioners, CEO and CQC colleagues to state what Support for LIVING (Supported Living) is really about. What is it we believe in?

We then went on to identify the gaps between these beliefs and current practice.

IMPORTANTLY we then went on to committing to action to close these gaps.

Category: Film & Animation