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Inclusive Leadership by Disabled People in Australasia

Fellowship Report 2018

Developing Inclusive Leadership in the Disability Movement: Lessons and Learning from Australia and New Zealand

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Summary

During her Fellowship Zara visited six cities in Australia and New Zealand and met with seventeen organisations and sixty-four individuals to find out about what supports and promotes leadership development and what the UK could learn from the practices and approaches taken in Australia and New Zealand.

Key Findings

People and organisations struggle to identify what supports inclusive leadership, but there are things organisations which are successful in cultivating leadership have in common. These include:

- being open to new people and ideas
- creating opportunities where there are mixed levels of experience and where learning from each other is promoted
- mentoring
- giving people space to talk about their impairment experience
- consistently providing development opportunities
- seeing engagement and development as a long-term process
- expecting inclusion

Recommendations

The recommendations from my Fellowship fall into five key action areas. Broadly, the recommendations encourage the disability sector to:

- **create space** - creating space and opportunities for new people to get involved
- **mentor** - acknowledging mentoring and creating opportunities for mentoring to occur
- **build-in capacity building** - forward planning to include capacity-building elements in projects and bids
- **create routes** – developing career paths and structures within DPOs which support the retention and development of future leaders
- **celebrate disability leadership** - publicising leadership by disabled people, and understanding what the barriers and supports to leadership are for disabled people

About the Author

I am a disability human-rights campaigner based in the UK and identify politically as a disabled person and as an intersectional feminist. At the time of writing this I have been campaigning for disabled people's rights since the age of ten and been actively involved in disabled people's organisations (DPOs) in the UK and internationally for over ten years. I have a BSc degree in Psychology and a Masters degree in Identity, Culture and Power.

I have worked advising government and civil-society organisations on disability policy and inclusion and have worked for a number of DPOs and NGOs in the UK focused on youth and community engagement. I also have fifteen years' experience delivering inclusive youth- participation opportunities.

I have held leadership positions in a number of organisations. At the time of writing this I am one of the directors of the disabled women's collective Sisters of Frida. I am passionate about making spaces, policies and organisations more accessible and inclusive.

During my journey around Australia and New Zealand I met more people and organisations than I can document in this report. I am therefore slowly but surely doing profiles of the people and organisations I was fortunate enough to meet. The blog can be found at www.zarasadventure.wordpress.com

I am also active on social media and can be found on Twitter via @toddles23

Image 1 Zara with Robyn Hunt

Image 2 Zara with Disabled People's Assembly

The Social Model of Disability - What's that?

The social model of disability is the philosophical and theoretical approach which dominates how the disability sector in the UK understands disability and how disability fits into society. The social model of disability was developed by disabled people in the UK as a means of explaining the discrimination and barriers that they faced without blaming themselves.

Traditionally in the UK disability was understood from a medical perspective, meaning that disabled people were seen as the problem that needed to be fixed and were expected to normalise themselves via medical intervention in order to be able to access society.

Due to the disadvantages disabled people faced in UK society in the late nineteenth and early twentieth century the country saw a boom in charitable trusts and organisations set up to support disabled people in recognition of the obstacles they encountered. These organisations traditionally focused on disabled people as objects of pity in order to get donations from the public to run their services and intervention. Within the charity model of disability non-disabled people were seen as the experts in disability.

The social model of disability sees disability as a social construction which is caused by barriers in society which disable an individual with an impairment. These barriers fall into three broad categories:

- Environmental
- Attitudinal
- Institutional

Under the social model of disability everyone in society has a responsibility to remove barriers in order to achieve equality for disabled people. The social model of disability sees disabled people as having the same right to have a say in their lives as non-disabled people.

For more information on the models of disability, please visit
https://www.inclusionlondon.org.uk/disability-in-london/

SECTION 1: INTRODUCTION

Why Disability Leadership?

The journey to this Winston Churchill Memorial Trust Fellowship was sparked by chance meetings, in 2010 with a young disability activist from New Zealand and in 2011 with a disability activist from Australia who had a learning disability. In both cases I met remarkable disabled women who were being supported to access leadership opportunities within their respective disability movements without a fanfare. As somebody who is active in the disability movement in the UK I was intrigued as to how these leaders had been supported to develop and grow.

My own path to leadership has been fraught with challenges and mainly down to luck. I know from working within British and European DPOs that the majority of disabled people who are active in DPOs never make it to leadership positions because there is not a clear path into them and there are not many opportunities to develop the skills, experience and confidence needed to progress. This has led to a shortage of disabled leaders with the skills and confidence to deal with the hostile environment many UK DPOs currently find themselves in. This got me thinking about what we could and should be doing in the UK to support new and diverse leadership within the disability movement and my Fellowship application was born.

When I began researching what was happening in Australia and New Zealand to promote an open and inclusive approach to leadership I discovered that not very much was written down so it was difficult to ascertain how disability organisations in the two countries had been working to support the calibre of leaders I had met. From the sheer diversity of leaders representing Australia and New Zealand it was clear that something different from the UK was happening when it came to disabled people’s leadership.

My intention through my Winston Churchill Memorial Fellowship was to take the learning from Australia and New Zealand to develop programmes and initiatives in the UK and Europe which would support the engagement of a diverse range of disabled people in our organisations and in particular in their leadership.

During my eight-week Fellowship trip I went to two countries and six cities (Sydney twice, Melbourne, Hobart, Wellington, Brisbane and Auckland) and I met with seventeen organisations and sixty-four individuals, some with or through organisations, as well as individual disability-rights activists.

Before I begin this report, I must issue readers with a health warning in that everything written within it is my interpretation of what was shared with me by those individuals and organisations. Thus, this report is one of many possible interpretations and I recognise that this interpretation is informed as much by my own experience as by what I was told.

I met with a lot of people and saw and discussed more ideas and practices than I could ever hope to do justice to in a report with a limited word count. I have therefore chosen to highlight eight examples of practices I felt were interesting and effective in supporting inclusive and diverse leadership in the disability sector. I have selected examples from both countries and a variety of interventions, from individual adjustments to leadership courses and beyond. The highlighted practices can be found throughout the document (and are also indicated on the contents page).

Image 3 Graphic from QDN

To try and make the document more accessible I have included a glossary of terms at the end.

Why I Chose Australia and New Zealand

Whilst on my Fellowship journey I met a lot of people who expressed surprise that somebody from the UK was coming to Australia and New Zealand to look at disability leadership, partly because of where they placed the UK in the field and partly because of how they viewed the development of their own disability sector. However, Australia and New Zealand were natural choices to explore the topic of leadership, partly because of my interactions at an international level with people who would struggle to reach leadership positions in the UK because of age, impairment and background, but also because of the shared English language. Moreover, in Australia and New Zealand, unlike the United States, there appears to be a broad acceptance/adoption of the social model of disability. Taking a social-model approach to disability was a key factor in choosing where to examine practice as the social model is the position that most disabled people’s organisations in the UK work from. This similarity would aid bringing back the learning and ideas and potentially implementing things.

In addition to the same language and philosophical approach, Australia and New Zealand and the UK at the time of my visit all had centre-right governments and strong international reputations around disability.

Another somewhat surprising similarity between Australia and the UK was the history of segregation of disabled people and the impact these structures and systems are still having on disabled people's life choices.

The more people I met with and the more organisations I spoke to in Australia and New Zealand, the more I realised that the interventions and approaches used which facilitate inclusive leadership are so embedded that those I spoke to often could not articulate the philosophical history behind those approaches. I would not therefore have been able to learn what I have without being able to immerse myself in the culture and communities as the Fellowship allowed me to do.

Through my research for my Fellowship I discovered that in Australia and New Zealand there were a number of long-term leadership programmes which appeared to deliver results so I set out to discover how and why they achieved this.

My Understanding of Leadership

For me, leadership is broad and multifaceted. It can be leading organisations, representing communities within society or coming up with new ideas and approaches. Leadership can involve the day-to-day managing of people within organisational structures, but it can also be inspiring and motivating of others in society. On some level I understand leadership to be about progress and motivating and managing change.

As you can see, for me leadership is wide-ranging and flexible, and as a result leaders can be very diverse in who they are and how they work, but on some level they are all listened to, trusted and respected, as well as taking responsibility for their beliefs, actions and approaches.

For me, leaders are not born but made through experience, motivation, space and opportunity. Through my Fellowship I have sought to understand what aids the creation and development of disabled leaders.

The Disability Leadership Institute

The Disability Leadership Institute offers a community for and run by disabled people where they can develop, learn and share leadership experiences. The organisation offers training and mentoring as well as a database of disabled leaders who can be approached for consultancy and events.

The Disability Leadership Institute was set up to support disabled leaders, acknowledging that there are many disabled people in leadership positions and that there are lots of barriers and challenges which impact disabled people’s leadership opportunities. To date one of the most interesting pieces of work which has been produced by the Disability Leadership Institute is an annual survey of disability leaders, exploring the challenges and barriers they face, but also documenting where disability leadership is strong, where it is developing and where there are areas in which disabled people are yet to reach leadership positions. This survey has enabled the Institute to identify barriers and strengths, but also to document and demonstrate the need for leadership intervention and support for disabled people.

The Disability Leadership Institute website has more information about its work at http://disabilityleaders.com.au/

SECTION 2: NATIONAL CONTEXTS

The UK Context

The United Kingdom has a strong history of disability-rights activism and is often seen as a leading country when it comes to disability issues. The disability sector has a long history and is very well developed. There are roughly around two hundred and fifty disabled people's organisations in the UK, including a large number of issue-specific ones, for example centres for independent living and organisations that campaign on just one issue such as education or transport. Most disabled people's organisations work across impairment groups and explicitly take a social-model approach to disability. Where impairment-specific organisations are found, they tend to be connected to the deaf community, those working around mental health or self-advocacy groups of people with learning disabilities such as People First.

A broadly adopted definition of a DPO in the UK is an organisation which is run and controlled by disabled people for disabled people. This is often quantified as having at least 50% of staff and 100% of board members identifying as disabled people.

In the last ten years, however, disabled people's organisations have been disappearing. There are a number of reasons for this, including the political climate, funding and lack of up-and-coming disability leaders who have the skills required to keep organisations afloat in challenging circumstances.

While I know of a couple of leadership programmes aimed at disabled people in the UK, anecdotal feedback I have received from some of those who have completed these programmes suggests they did not feel in a position to realise the skills that those programmes were exploring. This is partly because there are not generally follow-on leadership opportunities from these training courses but also because leadership programmes in the UK which are specifically aimed at disabled people are short in length (normally between three and six days over a period of six months to a year) and stand-alone. I am also aware from my research into these programmes that the majority are not very inclusive of people with learning disabilities.

In addition, the majority of disability leadership programmes in the UK which I am aware of are not run by disabled people's organisations..

Australian and New Zealand Contexts

The first thing to know about the contexts of both Australia and New Zealand is that they are remarkably different from the UK. There are obvious historical and cultural ties between both countries and the United Kingdom. However, both Australia and

New Zealand have distinct approaches towards disability rights that are noticeably different from each other and from that of the UK.

A feature common to both Australasian contexts and markedly different from the situation in the UK is the existence of substantial indigenous communities. These communities are and have been systematically persecuted, marginalised and discriminated against, and during my trip I saw little evidence, with a few notable exceptions, that disabled people from these communities were being supported to access leadership roles in DPOs. It is important that disabled people from all backgrounds are represented in leadership positions to give different perspectives on issues and also because many of the issues affecting disabled people are complex and intertwined with other identities a person may have.

In order to understand leadership and the development of leaders it is crucial to comprehend the contexts in which leadership develops and what structures and systems shape how leadership develops. A leader does not exist in a void.

In this section I will outline key elements of the Australian and New Zealand contexts to lay the foundations for exploring key factors which positively support leadership later in this document.

The Australian Context

Australia has a population roughly a third of the UK’s and is the size of continental Europe. It has a strong reputation on disability-rights issues. The size and geography of Australia mean that there is quite a lot of variation in disabled peoples experience across the country. These differences are further heightened by the fact that Australia has a federal governmental structure, with the national government, known as the commonwealth government, and then state/territory governments. Both tiers of government are involved in supporting disabled people and both levels of government are involved in supporting disabled people's organisations. The third tier of Australian government is local government. Local government supports DPOs to a lesser degree through small grants, and in kind through venue loan and partnership.

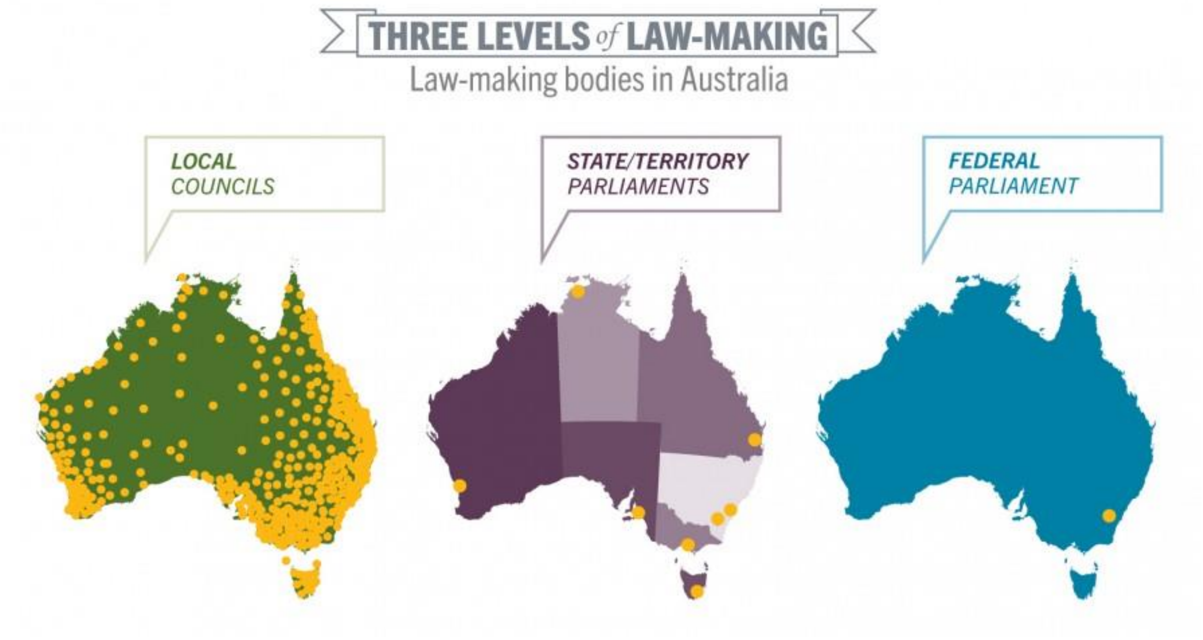

Image 4 Visual representation of levels of government [1]

Like the UK, Australia has a history of segregated provision when it comes to disabled people. there are still a considerable number of 'special' schools and residential units. While decreasing, there are still a number of large residential institutions.

To try and make support for disabled people in Australia more streamlined and market-based the Australian government are currently rolling out a new structure for support nationwide called the National Disability Insurance Scheme (NDIS). All of the organisations and most of the individuals I met with in Australia talked about the NDIS as a significant development for disabled people. There was both a sense of opportunity and significant concerns raised by everyone I spoke to. Although not the focus of my report, in annex 1 (Page 44) I have provided a basic overview of the NDIS because it has the potential to affect the disability context in Australia massively, including that of leadership.

I visited four states in Australia and the differences in funding and opportunities for disabled people were evident, even to a novice like me. Victoria, for example, had the most evidence of organisations and activists, and some of the best accessibility I found on my travels.

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[1] *from https://www.peo.gov.au/learning/fact-sheets/three-levels-of-law-making.html*

Despite the obvious differences between states there were many commonalities which sat in stark contrast to my experience of the UK. I believe these differences to be caused by a number of factors, the most prominent of which were:

- funding
- position of charity
- position of disability within society
- approach to disability politics
- geography
- disability-movement structure - the distinction between systemic and individual advocacy

Funding

The majority of the organisations I met with received funding directly or indirectly from state or commonwealth governments or both. This had several positive and negative consequences for disabled people's organisations.

On the plus side the funding gave organisations some stability to look at long-term capacity- building approaches around leadership and workforce. In addition government funding positively enables DPOs in Australia to get access to decision-makers and positions at decision-making tables. The power that Australian DPOs have to get involved in decision-making also attracts disabled people to engage with DPOs as their engagement has the potential to directly influence policy-making.

In addition to operational funding, disabled people’s organisations in Australia also had access to government funding through the equality and human-rights body to do representational work at international level. Annually there is a pot of money put aside to support disabled people to attend human-rights related events such as the conference of state parties for the United Nations Convention on the Rights of Persons with Disabilities. A list is published with the events for which applications for funding can be made. As well as this disabled people can put forward additional suggestions of events where there should be Australian representation. A number of the leaders I met with had utilised this funding to attend international events. What was interesting was that most organisations tried to send a delegation rather than a delegate, and many of the leaders I spoke to emphasised creating peer support and mentoring opportunities by ensuring that the delegations were of diverse experience levels.

The downside, however, was that the organisations tended to be quite small and some of the people I spoke to indicated it was difficult to see a space, funding or position for organisations which did not receive government funding. Some highlighted that the position of the existing DPOs meant there was no need for more organisations. However, I did meet a number of disability activists who chose not to engage heavily with DPOs because they perceived them as not having the freedom to be political or radical.

Position of Charity

Whilst there is charity and a charity sector in Australia, I saw little evidence of charity in the disability space in Australia. This meant that, unlike their UK counterparts, Australian DPOs are consistently seen and treated as the professional experts in disability by both society and the government. In addition, the weakness of the charity sector means that DPOs do not have to spend so much time or energy countering or correcting the charitable narrative. However, as well as a lack of charity there is also limited philanthropic funding available to DPOs to develop new or different services/projects or expand organisations. There are some DPOs in Australia which have been able to find additional funding through pursuing corporate and public-sector partnerships and philanthropy opportunities. Those organisations successful in finding additional funding opportunities were generally larger, with a more diverse range of activities.

Position of Disability within Society

Coming from the UK context, I found it refreshing to be in a space where disability and needing support is not overtly conceptualised in society as fraudulent. The Every Australian Counts campaign mobilised grassroots communities around the implementation of the National Disability Insurance Scheme. I suspect that, in part because of the success around the campaigning for the NDIS, disability is seen as something of national political interest, rather than a niche topic.

In addition, despite there being as many social issues around disability as there are in the UK, disability organisations in Australia seem to have an unusual position as civil-society organisations. Those working in the disability sector are some of the few that consistently receive government funding, which means disability organisations are some of the strongest voices within civil society as a whole. Consequently, disability issues seem to be more mainstream.

The Aboriginal Community

Despite disability currently being placed conceptually in a more positive position than in the UK, from talking to the First Peoples Disability Network it was apparent to me that negative perceptions of disability in wider society play a part in the systemic racism shown towards the Aboriginal peoples which is apparent across Australia. Prevalence of disability amongst the Aboriginal population is higher than in non-

Aboriginal Australia and yet the Aboriginal community is less likely to get access to key services such as health and education.[2] [3]

The discrimination faced by the Aboriginal People was also evident in DPO leadership where, outside First Peoples Disability Network, those identifying as part of the Aboriginal community were conspicuous in their absence from leadership positions.


Image 4 Meeting with leaders of First Peoples Disability Network

Geography

While there are distinct differences in the UK around how disability issues are addressed, the size of Australia means that the differences in approach are even starker. However, this also seems to create an acknowledgement that there needs to be a variety of organisations engaged in the topic. Although there are lots of political differences between organisations the sheer scale of the country means that organisations seem to be more willing to collaborate with each other as there is no way any organisation has the funds to meaningfully and consistently help all of the disabled people within Australia.

The challenges of geography also meant that organisations use technology such as Skype and webinars much more frequently to conduct business.

Although I should have realised this before commencing my trip I now see that by only visiting large cities my understanding of the Australian context is limited by study only of organisations working in metropolitan areas. I suspect that the impact of sparse geography on disabled people’s connection to disability organisations is something that I cannot fully comprehend as somebody who comes from a comparatively small and densely populated country. From conversations I had with organisations in Australia I suspect that disabled people living in rural and remote areas of Australia have very limited opportunities to engage in leadership opportunities.

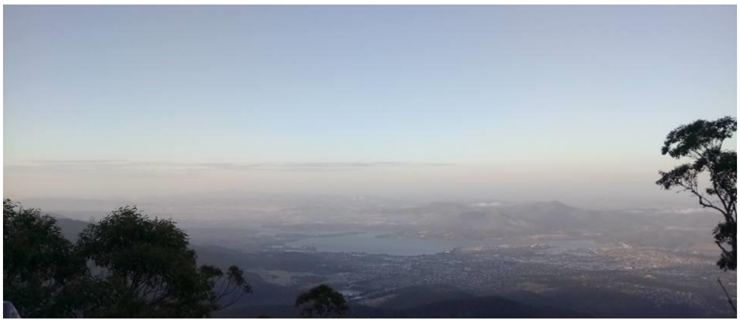
Image 5 view of Hobart from mount Wellington showing sparse geography of Tasmania

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[2] Government statistics http://abs.gov.au/ausstats/abs@.nsf/Latestproducts/4433.0.55.005Media%20Release12012?opendocument&tabname=Summary&prodno=4433.0.55.005&issue=2012&num=&view=

[3] http://fpdn.org.au/social-and-economic-wellbeing-of-aboriginal-and-torres-strait-islander-people-with-disability/

PWDA: People with Disability Australia

People with Disability Australia is one of the key peak bodies for disabled people in Australia. It provides systemic advocacy and representation on disability-policy issues at a commonwealth-government level and is based in Sydney. It works alongside other funded peak-body organisations to ensure that disability is on the table with policymakers.

People with Disability Australia works across all impairment groups and has a large membership of disabled people and their allies. This would appear to be in part because its funding arrangement means that it gets a seat round the table when big policy decisions are being made, so by being a member of the organisation you know that you can influence the development of policy.

What stands out about PWDA is its inclusive ethos and its willingness to support up-and-coming leadership across age, impairment and experience. Its ethos means that all opportunities are seen as development opportunities for the disability community, including board positions and opportunities to represent Australia internationally. This is not a new practice for the organisation but one that has been established over a long period of time and sets it apart from European DPOs, who are only just starting this type of approach.

PWDA, while following the social model of disability, has a relaxed approach to disability terminology, which has facilitated access to the organisation by those who have impairments but are not yet politically identifying as disabled people.

Movement Structure - The Distinction between Systemic and Individual Advocacy

One of the most surprising differences between the UK and Australia in the approach taken by disabled people's organisations is the very clear distinction in Australia between systemic and individual advocacy. This distinction was clear in the organisations, which tended to do one or the other, very few openly describing themselves as doing both. To judge by the organisations I met with, it would appear disabled people were more likely to be leading systemic-advocacy organisations. Understandably, there are more individual-advocacy organisations than systemic-advocacy organisations. In fact, a couple of people I spoke to about leadership indicated that there was a sense of non-disabled people being better placed to do individual advocacy because of the detachment not having lived experience gave them. Interestingly, a lot of the younger disabled people were frustrated at the lack of disabled people providing individual-advocacy support.

The role of parents of disabled people within this division sometimes seemed particularly uncomfortable as parents seemed happier within the individual-advocacy setting and yet their voices seemed to be influencing policy development in spite of limited engagement with systemic organisations.

The distinction between the two advocacy structures available to disabled people in Australia seems to aid collaboration within the disability sector as the distinct role separation means that the majority of parties appreciate what others bring to the table. The clear boundaries about what organisations do and do not work on, combined with the availability of government funding, seem to ease potential conflict and competition between different parties. That is not to say that there is no competition or conflict, but organisations seem to be able to negotiate common-ground positions with greater ease than I have experienced in the UK. With this ability to collaborate, disabled leaders appear to be broadly respected in their own right.

What is the Difference between Systemic and Individual Advocacy?

Systemic Advocacy:

Systemic advocacy is working on system and policy level to advocate for the needs of a group of people, in this case disabled people. The aim of systemic advocacy is to change the systems and structures which create barriers. In systemic advocacy individuals' lived experience is used to illustrate the need for change. Whilst systemic advocacy aims to improve the situation facing disabled people, it is not intervention designed to make any specific person's life better.

Individual Advocacy:

Individual advocacy is working with an individual to advocate for their requirements, supporting an individual to access what they need or want.

In addition to having this distinction between systemic and individual-advocacy organisations, Australia operates a tiered approach to its civil-society structures. What this means is that, as well as frontline organisations, Australia has a significant number of organisations which are termed 'peak bodies'. Peak bodies are generally second-tier organisations which act as umbrella organisations for different sectors. Peak bodies exist at both a territory/state level and at a national level. They exist to provide representation for organisations working on similar issues or in similar ways as well as doing representational work. Peak bodies also provide capacity-building opportunities for the membership.

Leadership in Australian DPOs

Australian DPOs have very strong leadership and all of the organisations I met with were actively capacity-building future leaders. Those in leadership positions were diverse in terms of gender, impairment and age, though there was an underrepresentation of people from Aboriginal communities.

When I asked people directly what supported the open and inclusive approach to leadership which I had seen, most of the organisations struggled to articulate how this was cultivated. However, after visiting a number of organisations commonalities in the approach to leadership became apparent to me. These included:

- long-term thinking about leadership
- mentoring
- the disability movement framed in a human-rights space by government
- the recognition by decision-makers of the importance of DPOs and disabled people’s voices in policy-making, giving DPOs positions of power which motivated individual disabled people’s engagement
- stable and long-term funding, which enabled organisations to bring in a diverse level of experience, particularly in governance.
- the use of governance structures as training grounds
- peer-support-led and inclusive leadership programmes and courses
- spaces to discuss impairment
- flexibility and adaptability around engagement
- people did not have to be familiar with the social model or at all politicised in order to engage with DPOs

Image 6 Meeting staff from Women with disabilities Victoria

The New Zealand Context

New Zealand has a population of around four and a half million spread over a geographic area roughly the size of the UK.

The New Zealand government is one of the few governments in the world to have actually produced an action plan on implementing the UNCRPD. However, one of the recurring narratives from my discussions with people in New Zealand was the fact that there was a considerable difference between what is written on paper and what happens in reality.

Whilst active segregation of disabled people is less apparent than in Australia, from the conversations I had with disability activists it was apparent that passive and active exclusion of disabled people from society was more commonplace, partly due to infrastructure challenges in the context of a small population spread over quite a large area. However, numerous people I interviewed also spoke of a cultural passivity which exhibits itself as a desire not to make a fuss.

The Disability Sector

In New Zealand there are relatively few disabled people’s organisations and they have relatively low membership in comparison to the percentage of the population who are known to have a disability. The organisations that do exist, with two notable exceptions, tend to be impairment-specific.

The Disabled People’s Assembly is one notable exception to this trend.

The other dominant disability organisation in New Zealand is called ‘Be. Accessible’. While it works predominantly on disability issues, it would shy away from describing itself as a DPO and avoids much of the philosophy and language associated with the disabled people’s movement in favour of ‘mainstreaming’ disability, and particularly the concept of accessibility.

Geography and infrastructure are major challenges to disabled people’s organisations working in New Zealand. Whilst there is state funding available to disability organisations, it is not evenly distributed, which has led to the dominance of a couple of organisations. The lack of diversity of voices within the disability sphere is of detriment to the sector as a whole, no matter how good or strong those voices are. What is noticeable particularly in comparison to Australia is the obvious presence of the charity sector. It was not clear from my time in New Zealand what the causal relationship between the charity and the disabled people’s sectors was.

Image 8 Meeting with Be.Leadership co-director Philip Patston

Image 7 Meeting disabled leader Matt Frost

Image 9 Meeting with Disabled leader Huhana Hickey

Support for Leadership: Matt Frost

Matt Frost is a disabled person working in the New Zealand government in policy- making. Matt is incredibly passionate and dedicated to his work. What makes his success interesting in the context of developing inclusive leadership is the innovative way in which he has been able to advocate for access adjustments to enable him to do his job. Matt is on the autism spectrum and can get obsessive about tasks and overwhelmed. However, he has been able to work with colleagues and managers to ensure that he can make the most of his skills and talent, staying in employment whilst not doing damage to his mental or physical health.

The accommodations which support Matt are unusual but incredibly simple and low-cost. Here are some examples of the adaptations he shared with me:

- if an urgent piece of work with a tight deadline comes in, his boss will buy him lunch to ensure that he meets his basic human needs
- there is a space in the office which Matt can go to, no questions asked, if he needs to calm down or needs to be away from excessive stimulation for a while
- he has an agreement with his colleagues that they will flag with him if he appears to be overly stressed because sometimes he finds it difficult to recognise threats to his own well-being

These adaptations support Matt in fulfilment of his leadership potential, facilitating his continued development as a disabled leader and a civil servant. Traditionally, many people with autism-spectrum disorders are excluded from employment and leadership opportunities because the barriers that they experience make it harder for other people to see and understand them. Adopting a holistic approach to access needs, where the disabled person is in charge of their narrative and adaptations to their needs, positively supports inclusive and diverse leadership amongst disabled people.

The Maori Community

The Maori community in New Zealand has definitely had an impact upon how disability and the disability movement is conceptualised. From the people I spoke I got a very strong sense that disabled people are ‘Wharna’ (family), and that motivated the approach of many activists to advocating for disability rights. However, having spoken to disabled members of the Maori community, I find there is a definite feeling of exclusion, underrepresentation and isolation, as well as issues around cultural appropriation for those of Maori heritage who are operating within the disability community.

It is important to acknowledge that the Maori community in general is discriminated against and this impacts all areas of their lives meaning that disabled members of the community face multiple barriers.

Leadership in New Zealand

The relatively small number of disabled people’s organisations in New Zealand, combined with the fact that four out of the five organisations I was made aware of were impairment- specific, meant there were limited options within the disability sector for disabled leaders. Most of the leaders I met operated as individuals rather than being connected to organisations. The positive consequence of the limited opportunities within the disability sector meant that disabled leaders had to find mainstream opportunities and pathways to develop leadership. This seemed to strengthen the leaders as it diversified their skills sets, connections and approach.

Be. Accessible leadership has around fifteen disabled people going through the programme per cycle. I met with eight or nine graduates from the scheme across various iterations and it was interesting to see where they had ended up as it often related to disability but was not in the DPO space.

There are a lot of strong disabled leaders in New Zealand but there is less of a sense of movement in comparison to Australia and the UK. However, all of the leaders I spoke to in New Zealand had a strong sense of being part of the disability family, and this seemed to come very much from Maori concepts of what joins people together.

Interestingly New Zealand has annual Attitude Awards (related to Attitude TV- see box on page 24) which celebrate the disability sector and disabled people’s achievements. They are broadcast on TV and are a public celebration of disabled leaders that is easily accessible to the mainstream community.

Attitude

Attitude is a media-production company based in Auckland which specialises in producing media content exploring disability, where disabled people lead the content. Attitude has a half-hour-long slot every weekend on a mainstream New Zealand television channel. One third of Attitude’s staff are disabled people, and in addition to producing documentaries the organisation runs and broadcasts an annual award ceremony for the disability sector in New Zealand.

Having a media narrative produced by disabled people available in the mainstream and to international audiences is significant when thinking about disability leadership. I met with Olivia, who is a disabled person working for Attitude, and she has found a very supportive employer for her own leadership development. In addition, she identified that the Attitude Awards allow disability leadership to be recognised and celebrated.

A significant number of the young disabled leaders that I met in New Zealand had engaged with the Attitude Awards. In its tenth year in 2017, the Attitude Awards seem to provide both recognition and motivation for young disabled leaders to engage in the sector.

You can find out more about Attitude and their documentaries at https://attitudelive.com/

Comparisons: Leadership Factors in Australia and New Zealand

There are many factors which influence leadership in Australia and New Zealand amongst disabled people’s organisations. In the tables below I explore factors which strengthened and limited inclusive leadership in the two contexts.

The Australian Context	
Strength	Limitation
Funding The funding Australian DPOs receive gives them the opportunity to develop leaders over time. Funding also allows representational leadership skills to have space and place as well as organisational leadership skills, all of which facilitates a more diverse leadership cohort.	Small DPOs Most Australian DPOs are small considering the areas and topics they have to cover. This means there are limited employment opportunities in DPOs to develop skills, although most organisations make up for this with voluntary opportunities. Innovation The relative stability of funding for the organisations I met with led to relatively traditional approaches to exploring disability rights. The challenges of delivering what was required from the funding meant that there was limited space to explore other approaches such as those connected to the arts.

Overt Mentoring In Australia all the leaders that I met with and spoke to talked a lot about mentoring those new to the disability movement. Whilst there are obvious benefits to individuals, a number of people I spoke to also highlighted the positive impact it had on representation as it enabled more people to enter coveted policy spaces.	Tall Poppy Syndrome Tall poppy syndrome is a social phenomenon where people who are successful are resented, cut down or criticised because there is a societal expectation that people should be modest about achievements. A number of the leaders I met with in Australia identified struggling with tall poppy syndrome, as a result being hesitant to take more prominent roles in organisations. Some had had their legitimacy as leaders questioned.
Openness to Those without Political Understanding of Disability All of the organisations I met with took a social-model approach to how they worked. However, most organisations were very flexible in what they expected in terms of understanding from those wanting to engage. Most organisations chose to use people with disabilities to fall in line with the United Nations Convention on the Rights of Persons with Disabilities.	Politics I met quite a few disability-rights activists who were frustrated with the lack of or passivity of disability politics in Australia. While this contributed to a collaborative approach to working with power structures, it meant that many serious issues were slow to be challenged, for example employment rates of disabled people.

The New Zealand Context	
Strength	Limitation
Long-term Leadership Programmes New Zealand has a number of leadership programmes lasting six months to a year, with follow-up support both specialist (aimed at disabled people) and mainstream.	Avoiding Disability Issues All of the leadership programmes I encountered, including the ones aimed specifically at disabled people, did not explore disability and how that impacts leadership.
Acknowledgement of Leaders There was widespread acknowledgement of disabled leaders, and disabled leadership is celebrated by the wider society through things like the Attitude Awards (see highlighted practice 2, page 14).	Passive Although there is strong leadership, there is a dominance of the desire not to make too much of a fuss, an expectation that things will change but slowly. While the passive- gentleness approach gets broad support and a buy-in from a wide range of stakeholders, the consequence is that the discrimination and inequality disabled people face is still situated with disabled people and not with society.
National Strategy on the Implementation of the UNCRPD New Zealand is one of the few countries in the world which have developed an action plan to implement the UNCRPD.	What Does it Mean in Practice? Although the action plan for realising the UNCRPD is great, all of those I met with highlighted that there was little to no evidence of the strategy being implemented.

SECTION 3: LEADERSHIP FACTORS

Key Factors which Impact Leadership

There were a number of factors and approaches which were mentioned repeatedly in my conversations with people and my visits to organisations. Some approaches were based on deliberately and specifically cultivating leadership, such as implementing leadership courses, but many factors I saw as having an impact were just a product of the way things had always been done or how structures had naturally developed. In this section I explore these elements in more detail.

Identity Politics

Across both countries the organisations I met with had clear branding around who they were, what they did and who they were for which was accessible to a wide audience. The organisations were clear about how and where they influenced and what the impact was. The organisations had positive narratives about what is on offer and how new people can get involved. This openness and clear communication about who and what organisations stood for meant that leadership opportunities and broader engagement opportunities became more prominent and accessible to those with less experience or who were new to the movement. There seemed to be a ’train them in house’ philosophy which meant in practice that, regardless of someone’s understanding of disability politics or even their own identity, if they expressed interest in getting involved the organisation would find an opportunity for them but would make sure there was the support and knowledge of more established leaders around to guide the newcomers.

Impairment DPOs

One of the first new concepts I came across in Australia was that of impairment DPOs. For someone coming from the UK and the social model of disability to start with the concept was jarring as it goes against one of the foundational principles behind most DPOs. It seems at odds with the social model, which starts from the position that disability is a societal construction where barriers transcend impairment distinctions. Disability is not caused by impairments, so the idea of an impairment DPO initially felt like the medicalisation of the disabled people’s movement. However, over my time in Australia I saw the potential of impairment DPOs to complement and support pan-impairment organisations and in particular diverse and inclusive leadership. Impairment DPOs seemed to:

- allow space for personal narratives, which can be lost when trying to find commonalities in a very diverse community
- give many of the leaders I met the confidence to enter pan-impairment spaces as a result of the peer support they received from impairment-specific DPOs
- reduce any sense of niche issues being neglected or not fully addressed within pan–disability DPOs as people had somewhere else to express views

- allow accessible leadership routes to be developed that were not trying to be all things to all people, but that would lead to the acquiring of leadership skills that might eventually transfer over to a pan-impairment context
- allow pan-impairment DPOs to work more strategically as people understood they were working as a collective across experience in those spaces
- allow double the chances and opportunities to get into decision-making rooms

Of course impairment DPOs also have the problematic consequences that the social model would anticipate. I saw and heard about duplication of work and division, particularly on topics which impacted on multiple impairment groups. It was fascinating to see how the hierarchy of impairment impacted the status and budget of impairment DPOs. A number of those I met highlighted substantial inequalities in voice and mobilisation connected to the existence of impairment DPOs.

Image 10 Ronelle Barker Director MDANZ

Future-proofing: Building-in Leadership-Development Opportunities

Only two of the organisations I met with had explicit leadership programmes. However, the majority of the organisations could identify the leadership-development opportunities within their organisations because they had explicitly built them in to projects and funding applications with long-term capacity building in mind. Cultivating leaders is a long-term game. One organisation I met with expressed it succinctly: ’We do not expect people to feel like leaders after one project but maybe after the third one they just might’.

The organisations I met with found ways into the organisations for new people from internships, projects and boards. There was an understanding that people did not need experience to get through the door and that the organisations would work with people to use and develop the skills acquired during their project experiences.

Mentoring

The impact of mentoring was one of the most inspiring and profound lessons I learnt from my Fellowship. In Australia and New Zealand the majority of organisations and individual leaders overtly acknowledged mentoring, both being mentors but also receiving mentoring. Mentoring was seen and talked about. Established leaders mentored in working hours, allowing themselves adequate time to mentor consistently but also facilitating a work-life balance. For mentees there was access to support and opportunities and the added bonus of not needing to ‘know everything’ to get into the room.

I do not know whether mentoring is just more common in general in Australia and New Zealand or whether it was something which the DPOs had embraced in order to be more accessible but many of the leaders I met with spoke of how useful they found it, both in developing new knowledge and approaches but also in giving the disability movement the power to get more disabled people into discussion-making rooms. Having more people in the room also had the added benefit of supporting and promoting continuity should people leave positions or organisations.

Another fascinating consequence I observed is that mentoring seems to facilitate the distribution and sharing of power and knowledge because it allows for people’s expertise to be acknowledged whilst also facilitating the opening-up of spaces to new people. Overt mentoring seemed to create supportive spaces in the disability movements, which allowed new leaders to develop.

Image 11 Meeting with Christina Ryan founder of the Disability Leadership Institute

Women with Disabilities Victoria

Women with Disabilities Victoria is a dynamic and thriving disabled people's organisation based in Victoria, Australia. Women with Disabilities Victoria undertakes systemic advocacy and representation, community women's empowerment programs and training. It is a large organisation (by DPO standards) which, as well as receiving state funding, is unusual in that it has diversified its income and partnerships by looking outside of traditional funding streams in order to pay for some of its innovative work with support from philanthropic trusts. Its Melbourne office is a hive of activity and there is a clear sense that this organisation is at the top of its game.

Particularly interesting are the leadership programmes which Women with Disabilities Victoria runs. They are striking because they overcome the challenges of Australian geography by working at a local community level. This localised approach has the positive by-product of facilitating local networks both during the training and afterwards. The programs run as partnerships with local government and non-government organisations. This increases the likelihood of concrete leadership opportunities being available to women as their community connections and networks grow.

What particularly stood out about Women with Disabilities Victoria leadership courses is that they are open to all disabled women and endeavour to overcome differences in skills and experience by using creative and inclusive methods. All training participants, regardless of their previous experience, are expected to sign up to the training's inclusive approach. This particularly supports the inclusion of those with learning disabilities into leadership circles because, rather than deeming certain impairment groups as needing specialist training, Women with Disabilities Victoria aims to create learning spaces which work for everyone.

There is also a strong sense of follow-up support from the organization who finish the programs by laying the groundwork for online and face to face networks to continue. This allows women to maintain the connections made through the program, foster new connections and to initiate their own ideas that are relevant to their communities.

In addition to the leadership courses Women with Disabilities Victoria has a biennial leadership award named after a former board member which provides prize money for women to pursue a leadership goal.

Leadership Courses

During my Fellowship I met with two organisations explicitly doing leadership courses, Be. Accessible in New Zealand and Women with Disabilities Victoria. Both organisations specifically target disabled people and offer comparatively (to the UK) long-term and intensive courses lasting between six weeks (regular contact, e.g. weekly) and a year (intermittent but intensive contact, e.g. a residential weekend every two months). Be. Accessible had run a number of iterations of their leadership course and as a result they had a clear idea of who their candidates should be and what existing skills and attributes they should have. Be. Accessible took a traditional approach to leadership training, focusing on an individualistic and introspective approach. Whilst disability is addressed in the programme, it is not explored in relation to leadership. The course is providing much needed access to leadership training for disabled people and creating a space and opportunity to acknowledge disabled leaders.

If the approach of running mainstream leadership courses and content aimed at disabled people intends to increase the number of disabled people in mainstream leadership positions, then it begs the question why are mainstream leadership programmes not globally open and accessible to disabled people? By addressing disabled people’s exclusion from mainstream training opportunities do we not risk perpetuating the challenge we are seeking to address?

Despite the above concerns it was clear from conversations with both organisers and participants in the New Zealand disability leadership programme that it was highly valuable in supporting and developing networks for disabled people and emerging leaders. These opportunities to connect to other disabled people seemed particularly valuable given the small number of disabled people’s organisations.

The leadership course I learned about in Australia felt very different to that of New Zealand, perhaps because the DPO sector in Australia is larger and more diverse, allowing for more entry points, which provide the opportunity to embed courses into specific contexts. The Women with Disabilities Victoria leadership courses were open to applications from any disabled women who expressed an interest and were adapted to people’s access needs. Their courses tend to run in local communities, and participants are expected to work in ways which are inclusive of all of the group. Disability is actively approached through creative means. The courses and approach to leadership seemed to facilitate getting new and diverse people into the organisation.

For disabled people’s organisations it is clear that we need to discuss how disability affects leadership, both in order to understand how disabled people operate as leaders but also what impact disability has on leading disabled people, especially if we want leaders who promote and support diversity and inclusion beyond their own lived experience.

Governance

The use of governance structures as a tool and opportunity in the development and creation of leaders was pronounced across the majority of organisations I met with. Organisations expected and supported their governance structures to be diverse in terms of age, impairment and experience. Many of those I spoke to described how they first started becoming active in organisations through the governance structures. Organisation leaders spoke of how they utilised the contact governance structures provided to capacity-build and develop future leaders and activists. The organisations which were explicit about capacity building through governance structures highlighted how diversity of experience levels aided the development of organisations by facilitating organisational growth whilst continuing to be open to new ideas and people.

Having a diversity of experience in governance systems also promoted mentoring opportunities, peer support and collaboration within the disability sector. Within some organisations diverse representation was further supported by having positions reserved for people with specific life experience, for example having a board position for someone under twenty-five years of age.

The opportunity to build confidence, experience and a working relationship with organisations through governance reinforced the concept of leadership and people’s belief in their ability to be leaders in a relatively safe space. Governance positions also led to people being recognised as leaders.

Image 12Meeting with Olivia Shivas Attitude TV

Muscular Dystrophy New Zealand

The Muscular Dystrophy Association of New Zealand was one of the only organisations which I met on my trip that identified itself as a charity. Interestingly, the charity at the point I visited was undergoing a transition under a new chief executive, Ronelle Baker, who happens to be a disabled person herself. The organisation under her leadership was seeing a transition from the traditional charity-model language and approach to campaigning and fundraising to a model more couched within a human-rights approach. Interestingly, this organisation has a rule that the majority of governance board members must have lived experience of a neuromuscular condition. Board members are elected from the membership and composition can vary. However, at present six members have lived experience of a condition (two of these board members are aged under twenty-five) and six are parents of someone with a condition. Ronelle is the first chief executive to have lived experience and this is bringing a different strength to the organisation. At present six out of twenty staff identify as having an impairment.

Where Muscular Dystrophy New Zealand really stood out was in dealing with an issue that challenges many disabled people's organisations, the issue of how to engage with disabled children and young people and also have space for the parents of disabled children.

Whenever a parent applies to join Muscular Dystrophy New Zealand they are asked for details of their child. That child is given status in their own right and has passive membership of the organisation. On the child's sixteenth birthday they are sent a birthday message congratulating them and informing them of their formal membership and voting rights in the organisation. In addition Muscular Dystrophy New Zealand has reserved a position on their board for a young person with muscular dystrophy aged between sixteen and twenty-five. Only members of that age can stand or vote for this position.

This approach not only assists the organisation in dealing with the potential conflict between parents and children but also provides young people with muscular dystrophy with a sense of belonging as well as a voice and sense of ownership of the organisation. The elected young person is given support by the board and the chief executive to carry out their role as a board member. I spoke to someone who had previously held the position and the current incumbent and both described how the support they had been given while being on the Muscular Dystrophy New Zealand board had encouraged them to take on leadership roles in other organisations.

SECTION 4: REFLECTIONS AND RECOMMENDATIONS

The UK's Strengths

As well as learning about innovative practices in Australia and New Zealand, the Fellowship experience gave me the opportunity to reflect on the achievements of the UK disability movement and the areas in which UK practice would be of benefit to disability organisations in Australia and New Zealand.

Accessibility

Physical accessibility was far more challenging in Australia and New Zealand than I had anticipated, particularly given the relative youth of the two countries in comparison to the UK. I believe this to be in part due to the propensity of Australasia to experience extreme weather and natural disasters. However, the major contributing factor seems to be the lack of legal protection available to disabled people to enable them to push for accessibility. Historic value was often used as an excuse for limited or no access. While occasionally used in the UK, there are well-documented cases of mediaeval buildings such as cathedrals being adapted to be accessible.

One of the most frustrating aspects of Australia and New Zealand's accessibility challenges was the lack of information available about access in the broadest sense. This often meant that attempting to access venues or events was hit or miss. When you do not have appropriate information, those who have access needs which cannot be compromised will tend not to take the risk. Therefore, they are less likely to access adaptations that have been made, making it more difficult to argue for adaptations to be made in the first place. Information about access does not cost a large amount of money but can make a massive difference to how and whether disabled people engage with society.

Travelling round Australia and New Zealand made me appreciate the accessibility features that we have incorporated into our public-transport systems in the UK. Beyond just physical access, the way in which we communicate information about transportation systems and how we make public transportation accessible for those with sensory and intellectual impairments really stand out in comparison to New Zealand, where public transportation structures are limited, and Australia where, despite the diversity between territories, there is generally a lack of accessibility features.

Employment

Another surprising observation from my travels was the lack of support available to disabled people to enable them to access employment. Neither Australia nor New Zealand have anything like the UK's Access to Work scheme currently, which means that several of the disabled people I met with were still waiting for adjustments to the working environment nine months to a year after starting employment. In addition, although I met specifically with an employment-focused organisation, there seemed to be hesitancy in collecting information about the representation of disabled people in the workforce, which is a key element in establishing disabled people's access to leadership opportunities.

Legal Protection

Whilst in the UK we perceive our legal structures and protections around disability to be burdensome on the individual and weak due to their inherently reactive nature, both Australia and New Zealand's legal protection around disability seemed cumbersome and unwieldy in comparison to the UK's approach.

Youth Work

Working with disabled children and young people was an area where Australia and New Zealand are still developing the structures and approaches. Interestingly, many of the leading Australian organisations are referring to work done in the UK to inform the foundations of their approach. There are definitely examples of good practice in Australia, but these are relatively new innovations.

Image 13 Me outside VALID's office

Image 14 Meeting Aine Healy NSWCID

YDAS: Youth Disability Advocacy Service

YDAS is based in Melbourne, Victoria, and offers individual and systemic advocacy for disabled young people. Interestingly, YDAS falls under the Victoria peak body for youth rather than disability. The majority of YDAS's staff identify as disabled people and the organisation is unusual in an Australian context because it directly engages disabled children and young people in decision-making about the organisation.

From my travels around Australia I found it apparent that youth participation with disabled young people is an area still under development, at least in comparison to the UK.

YDAS has a steering group of young people, the majority of whom identify as disabled. The steering group was well embedded into the organisation and there was clear evidence of its impact around what the organisation does.

The YDAS steering-group members I met with were overtly political in their beliefs around disability and inclusion, perhaps more so than some of the established DPOs I met with. The steering-group members came across as very comfortable within the youth context. However, from conversations I had across my trip it was unclear how much the DPOs, both nationally and within the territories, had reached out to embrace the expertise of the YDAS young people, potentially missing the opportunity to bring these young people into DPOs. YDAS was clearly a brilliant start for young disabled people's leadership in Victoria and hopefully other organisations will follow its lead.

Independent-living and Issue-specific DPOs

Despite the cuts in social care and the closure of the Independent Living Fund, I was struck by the impact that centres for independent living have on both the approach to community-based support and the ability to share good practice. The lack in both Australia and New Zealand of independent-living-specific organisations led by disabled people able to provide services is the challenge for disability activists and leaves achieving article 19 of the UNCRPD much more dependent on personal and familial motivation.

While Australia and New Zealand had impairment- and identity- (e.g. women, indigenous people, etc.) specific DPOs, on my travels I did not encounter any issue-specific DPOs. Having the ability to continuously follow up on the same issue consistently I believe to be a strength of having issue-specific DPOs. If one is constantly having to jump in and out of issues, this limits the development of technical knowledge, and it is difficult to maintain the momentum of change if staff are constantly having to deal with different topics.

In the UK the existence of issue-specific DPOs does not hinder other DPOs from engaging in issues such as education or transport, but it facilitates developing broader coalitions on issues (such as working with teachers on inclusive education) and provides more capacity in the sector.

Innovation

Lack of core funding and a hostile approach to disability-rights issues in the UK has led disabled people's organisations in the UK to innovate in their practices, focus and methods, frequently in order to stay afloat. This innovation has led the UK organisations to broaden the remit of the work and to look at other ways of progressing disabled people's rights rather than solely through policy, for example by exploring disability history and arts.

Learning for the UK – the Recommendations

From my interviews and observations throughout my visit to disability organisations in Australia and New Zealand I have garnered several ideas and actions which I believe to be worth exploring by disabled people's organisations in the UK and Europe.

Five key lessons that I have shared and will continue to implement in my own practice are:

- creating space
- mentoring
- building-in capacity building
- creating routes
- celebrating disability leadership

Creating Space and Demonstrating Impact

Creating space simply means having space within organisations for those with specific expertise as well as those who are new to disability activism. DPOs need:

- to become more open to new people – so that DPOs are places where ideas can be explored and developed. This means actively creating opportunities for the unknowns, going to new and different spaces to recruit and engage people
- to have membership categories for children and young people under the age of eighteen even if they cannot legally vote in organisational structures
- to have flexible opportunities available to support new people aiming to engage with the organisations
- to select, when recruiting for boards, one candidate who might need extra support or skills development. This is done by a lot of organisations in Australia as a means of capacity-building enthusiastic supporters so that they can become potential employees and future leaders
- to create more opportunities for non-politicised disabled people to learn in a safe space about philosophical ideas which DPOs expect them to subscribe to, such as the social model of disability
- to show the value of disabled people's organisations to disabled people and the impact that our organisations have, in order to actively engage more disabled people in the disability movement

Creating space is something that happens in both Australia and New Zealand, both consciously and unconsciously by individuals and organisations. In Australia most of the organisations that I visited had open opportunities on a frequent basis.

Open opportunities are ones where you do not have to have demonstrated prior experience or specific skills in order to apply. Most of the organisations I met with saw the opportunities within their organisation as a means of capacity-building people to become what the organisation needed rather than expecting everyone that came through the door to already have met a basic threshold. What this led to was a variety of people engaging in opportunities and activities, some with a lot of experience and skills and others who had never done anything similar before. This made disabled people's organisations learning grounds for everyone involved.

These interventions would provide opportunities for leadership development for younger disabled people, those with learning disabilities and those who have recently acquired their impairment. It is evident from Australia and New Zealand that these approaches also increase the general membership of disabled people's organisations and therefore strengthen their position when it comes to influencing society and policymakers.

Mentoring

Overtly embracing and celebrating mentoring:

- by creating open mentoring opportunities for those new to the disability movement, but also for those wanting to progress into leadership positions. At the moment progression within the UK disability movement depends too much on luck and who you know, rather than the skills you want to develop
- by existing disability leaders in the UK being open and explicit about the mentoring support that they are providing to other disabled people. Partly because this is already happening but without people talking about it, there is an extra burden on existing leaders. If mentoring was openly acknowledged, then some of the time spent mentoring could be done in working hours
- by creating opportunities for mentoring relationships to be formed, e.g. speed-dating leadership events, more mentoring schemes, and leadership and staff exchanges
- by asking, when mentoring, for additional spaces at events and meetings. The impact of this is twofold. It increases the number of disabled people in the room and it enables connections and learning to happen over time, rather than throwing leaders in at the deep end when someone retires or dies

In Australia and New Zealand all of the leaders I met spoke about mentoring and supporting other disabled people into leadership positions or skills development. Mentoring built up relationships between DPOs and also kept people engaged with the movement because it was partly based on personal connection.

Image 15 Meeting Karin Swift

Building-in Capacity Building

Ensuring that capacity building is planned for and embedded in all activities:

- by including capacity-building elements in all funding bids and all programmes, e.g. by providing training for trainers, workshops on advocacy, etc.
- by finding ways in which to engage over long time periods, rather than just in single projects, because one project might not develop a skill or sense of confidence but a number of projects might achieve that result for an individual

All of the organisations I met with which had strong leadership and were developing future leaders saw workforce and leadership-development opportunities as essential to the organisation's long-term survival.

QDN: Queenslanders with Disabilities Network

QDN is a medium-sized DPO which is a disability peak body for Queensland. Founded in 2002, it delivers systemic advocacy for the state on disability issues based on disabled people's lived experience and delivered by disabled people themselves. When it comes to leadership QDN has some interesting programmes to support disabled people across impairment groups in developing their voice and leadership skills in a wide range of areas.

Talking to the staff at QDN it became clear that for them it is key when developing leadership to look at the long term. This means they build skills and capacity-building opportunities into every funding bid so that every project offers the opportunity for disabled people to get involved and develop skills. QDN acknowledges that one leadership opportunity may not result in everybody feeling like a leader but over time the individuals involved develop the sense of having the skill, experience and confidence to see themselves and be seen as leaders.

QDN is keen that its leadership opportunities are open and accessible to all disabled people so materials are produced in a variety of formats such as plain English (easy read) and training is delivered in creative, accessible and inclusive ways which promote self-confidence and expertise.

Celebrating Disability Leadership

Publicising disability leadership both within the disability movement and within the general population:

- by profiling disabled leaders and their experiences so that these can be used to motivate and inspire others, but also to broaden people’s understanding of leadership and where disabled people can and are leading
- by conducting a survey of disabled leaders to find out what are the barriers and supports to disability leadership in the UK

This makes people feel that leadership is a possibility for them and also challenges society to reflect on where the disabled are. It also offers a challenge to civil society about removing barriers to leadership.

Creating Routes

Opening up career paths within the disability movement so those starting out can see how they might reach leadership positions:

- by providing professional development opportunities for staff within DPOs to develop their skills
- by unflattening DPO structures so that there are places to go
- by developing collaborations with civil society and the private sector to provide skill- development opportunities for disabled people so that they can come back into the disability movement at leadership level
- by offering the potential for sandwich years and internships to higher- and further- education students

At the moment many UK DPOs lose out on talent and potential leaders because development opportunities and progression routes are not clear.

Follow-up

As a result of the opportunity that the Fellowship granted me I have been able to present some interesting findings and experience to a wide variety of stakeholders invested in disability. I have also provided information and guidance to a number of disabled people’s organisations which are currently seeking funding to develop leadership opportunities in the UK.

I will be using the knowledge I have gained from the Fellowship to help me find funding and partnership opportunities to help develop mentoring.

Thanks

I would like to thank all of the individuals and organisations who gave up their time to meet with me and share their expertise. I would particularly like to thank the following individuals for their support and networking during my Fellowship trip:

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Thanks to my mum, Judy Todd for proofreading everything in this report (apart from this bit).

Finally I would like to give a special thanks to Kate Buchan, who accompanied me as my personal assistant throughout the trip and without whom the trip would not have been possible.

Image 16 Kate feeding a kangaroo

Glossary

Access to Work: UK government programme which pays for adaptions and support such as assistive technology and personal assistance for disabled people in the workplace.

Capacity building approaches: Interventions and support to build peoples skills, experience and confidence for example training, mentoring and shadowing.

Centre for independent living: An organisation normally run by disabled people which aims to support disabled people to achieve independent living through information, campaigning and peer support.

Commonwealth government: The central government of Australia, decisions here apply to the whole country.

Cultural appropriation: Taking something made by another culture like clothes, hairstyles ideas etc. and use it in a way that is considered harmful and/or disrespectful by people from that culture.

Disability: The limitations people with impairment experience because of the barriers created in society.

Disabled Peoples Organisation (DPO): An organisation run and controlled by disabled people in the UK this is commonly understood as 100% of the governance board 50% of staff and ideally the CEO/Director identify as disabled people. Outside of the UK what qualifies as a DPO changes a lot.

Disabled people and politically identifying as a disabled person: Disabled people is used by those with impairments to describe the fact that they are disabled by barriers in society. It does not reflect biological limitations or impairments. Politically identifying as a disabled person means that you see being a disabled person as a political statement. In this case you are saying that society creates the barriers which disable.

Governance: The systems, structures and processes which make sure organisations run properly.

Impairment: a long term physical or mental condition which can limit what someone can do.

Impairment experience: people can have the same impairment but everyone experiences their condition differently.

Inclusion: Inclusion means having an approach that understands and encourages people to be different. An inclusive approach values, respects and celebrates people equally.

Indigenous communities: Groups of people who are known to lived in a place or area first.

Issue-specific DPOs: Disabled peoples organisations which on work on only one subject like education or transport.

Independent Living Fund (ILF): ILF was a government fund which was used to support disabled people with complex needs to live in the community and have choice and control over their lives.

Multifaceted: having many different features.

NDIS: National Disability Insurance Scheme more information page 44.

Participation opportunities: Activities where people can get involved and have a say.

Peak body: an umbrella body or an organisations which supports and represents other organisations working on the same issues.

Philanthropic: A person or organisation which seeks to improve the lives of others by giving money and other forms of support.

Segregation: separating people because of difference

Territory: a large area of land which has its own rules or an Australian state

Section 5: ANex
Annex 1 NDIS:

What is the National Disability Insurance Scheme?

The National Disability Insurance Scheme is a new approach to supporting disabled people in Australia to lead ordinary and independent lives. The premise of the scheme is to give disabled people choice and control over the support that they receive so that they can live as part of their community on an equal basis with others. Support under the NDIS takes a person-centred approach, with each eligible person receiving a personalised plan. The scheme is open to disabled people under the age of sixty-five with a ‘long-term and significant disability’.

The National Disability Insurance Scheme is quite similar to the former Independent Living Fund in that it operates at a national level.

Key to the National Disability Insurance Scheme is the fact that it is framed as an insurance scheme as opposed to a benefit. Interestingly all of the available information I have been able to find on the scheme emphasises that it is there to meet disabled people's needs, as is their right.

Trial areas started rolling out the scheme from 2013. More territories had started the process by December 2017.

The key strength of the National Disability Insurance Scheme is the time being invested in capacity-building disabled people to take control of their lives and lead the process. A number of the organisations I met with were capacity-building disabled people to run training courses on the NDIS. This could be a stepping stone for those individuals on their leadership journey.

What is it replacing?

Prior to the establishment of the NDIS support available to disabled people in Australia varied massively between states. The NDIS was a huge innovation for Australia and a new approach to social-care provision. Traditionally Australia has worked from a block-funded service model which required disabled people to fit into the services that are available rather than there being services that are tailor-made to the individual.

The services that were available for disabled people varied massively from state to state, meaning the support that was available in one locality from a variety of service providers may have been non-existent in another part of the country.

How it was achieved

The NDIS was achieved after many years of campaigning by disabled people and their organisations. The Australian government started thinking about support systems for independent living, but nothing came to fruition until 2008 when the

Rudd government held a summit called Australia 2020. It concerned itself with big policy ideas for the future of Australia and it was at this summit that the father of two disabled children, Bruce Bonyhady, proposed what is now the NDIS.

While the government was exploring the proposal further, Bruce Bonyhady came together with the prominent disability-rights activist Rhonda Galbally to build a grassroots movement to support the idea. The pair also worked to bring together a number of peak-body organisations working to represent service providers, carers and disabled people and their families. This led to the formation of the National Disability and Carer Alliance.

The main work of the Alliance is the Every Australian Counts campaign, which used grassroots political activism - rallies, visits to MPs by disabled people and their families, media stories - to promote the need for the NDIS.

When the Australian government launched an inquiry into what reform was needed in the area of disability care and support, basically to explore whether the NDIS was needed, the National Disability and Carer Alliance made sure that disabled people and their families had a voice in the inquiry to argue for the establishment of the NDIS.

One of the things that was made very clear throughout the lobbying efforts was that the support systems in place were not working and if no alterations were made the costs would increase substantially. However, as mentioned above, the scheme has never been framed through an economic narrative. Instead communications about the potential of the NDIS followed a rights narrative

Through the work of the Every Australian Counts campaign the disability movement was able to establish cross-party support for the creation of the NDIS, with the promise of funding through an increase of 0.5% to the Medicare levy in addition to the diversion of money from existing commonwealth, state and territory social-care budgets.

For more information on the Every Australian Counts campaign visit http://www.everyaustraliancounts.com.au/

Challenges

Whilst achieving the creation of the NDIS was a milestone for Australia’s support systems around disability, its implementation has not been smooth, and at the time of writing this report (2018) continues to cause a great deal of frustration, anxiety and stress. It is still unclear whether the NDIS will achieve the momentum required to reach its potential.

One of the biggest challenges to embedding the scheme has been its rollout. Each territory has taken a different approach to the gradual rollout of the NDIS. In New South Wales, for example, the rollout has been done by area, whereas in Tasmania the rollout is being done according to the age of the participant, starting with children. In addition, the phased implementation of the NDIS has created a number of challenges for disabled people who need support.

Some of the challenges during the rollout of the NDIS include:

- the failure in some areas of existing service provision because the funding has moved to the NDIS model, which not all of the service users have access to. In other areas there is not the service provision to meet demand
- the transfer in some areas of certain systems such as wheelchair provision over to the NDIS with little thought being given to those who have yet to have their needs identified through the NDIS system
- the drive to meet rollout targets has meant that some NDIS participants are not getting assessments which comprehensively meet the support requirements
- issues with prices of services set within NDIS frameworks compared to the actual costs of running those services
- the speed of roll-out has resulted in some poorly planned and implemented processes
- some disabled people are in ‘thin markets’ where there is no competition for their funding because they live in a remote and lowly populated area or because they have what gets called ‘complex needs’ which won’t give the service provider a profit. This creates a need for a ‘provider of last resort’, however as state governments are moving away from service provision by the very nature of the NDIS, it is not clear who will be the provider of last resort.
- larger service providers are taking over smaller services which undermines the scheme’s promise of more choice.

Although in principle the NDIS is a positive move for Australia’s approach to disability support, it will take more time for the system to embed so that users have a consistent experience that truly offers choice and control.

As an outsider to this process I believe the question that will become more and more pertinent is what will happen to those who do not meet the NDIS threshold or eligibility criteria?

In conclusion, it is obvious that the NDIS is a game changer for disabled people in Australia if implementation can live up to the aspiration that drove its creation in the first place. In the interests of promoting disability leadership the NDIS has to support new disabled leaders to enter the disability movement who previously did not have the right support or the autonomy of choice to get involved.

More information on NDIS is available at the following:

https://www.ndis.gov.au/about-us/what-ndis

ANNEX 2 Organisational list

Below is a list of organisations visited or spoken to during the fellowship

Name	Description	Area	website
Accessible Arts	Accessible Arts is a peak arts and disability organization.	New South Wales (Australia)	http://www.aarts.net.au/
Australian network on Disability	A national, membership based organisation that supports organisations to advance the inclusion of people with disability in all aspects of business.	Nationwide (Australia)	https://www.and.org.au/
Attitude	a media-production company based in Auckland which specialises in producing media content exploring disability	Nationwide (New Zealand)	https://attitudelive.com/
Be.Accessible	Be. Accessible is managed by the Be. Institute, a social enterprise that aims to work across all sectors and communities throughout New Zealand.	Nationwide (New Zealand)	http://www.beaccessible.org.nz/
British council Australia	Australian office of the British Council	Australian branch of international cultural organisation	https://www.britishcouncil.org.au/
Children and Young People with Disability Australia (CYDA)	national peak body which represents children and young people (aged 0-25) with disability	Nationwide (Australia)	http://www.cyda.org.au/
Disability Leadership Institute	The Disability Leadership Institute is the professional hub for leaders with disabilities.	Nationwide (Australia)	https://disabilityleaders.com.au/

Disabled Peoples Assembly	The national DPO of New Zealand	Nationwide (New Zealand)	http://www.dpa.org.nz/
First Peoples Australia Disability Network	First Peoples Disability Network Australia (FPDN) a national organisation of and for Australia's First Peoples with disability, their families and communities.	Nationwide (Australia)	http://fpdn.org.au/
Muscular Dystrophy New Zealand	Charity supporting those with neuromuscular conditions and their families	Nationwide (New Zealand)	http://mda.org.nz/
New South wales council for intellectual disability	Advocates for the rights of people with intellectual disability	New South Wales (Australia)	http://www.nswcid.org.au/
People with Disability Australia (PWDA)	A national disability rights and advocacy organisation	Nationwide (Australia)	http://pwd.org.au/
Queenslanders with Disability Network (QDN)	A state wide organisation of, for, and with people with disability connecting for collective and affirmative action.	Queensland (Australia)	http://www.qdn.org.au
VALID (Victorian Advocacy League for Individuals with Disability)	Advocacy organization working with disabled people and their families	Victoria (Australia)	https://www.valid.org.au/
Women With Disabilities Australia (WWDA)	The peak organisation for women with all types of disabilities in Australia.	Nationwide (Australia)	http://wwda.org.au/
Women with Disabilities Victoria (WDV)	Is a disabled women's organisation	Victoria (Australia)	http://wdv.org.au/

Youth disability advocacy service (YDAS)	Advocacy service for disabled young people	Victoria (Australia)	https://www.yacvic.org.au/ydas/