Strengthening communities to deliver social change for people with disabilities: what role for government?

It's not all about the money. It should be about community…We want lives, not services, and it's still all about services.

Pippa Murray, IBK Initiatives

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In early 2014, I completed my Masters in Public Administration from the University of Sydney.

I was a proud recipient of The Graduate School of Government, Sydney University, NSW Public Service Commission Award in Public Administration. This is a travelling research prize that facilitated travel to England and Scotland, where I interviewed key people working in the field of disability.

This report does not necessarily reflect the views of the NSW Department of Family & Community Services, or The Graduate School of Government, Sydney University.

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RESEARCH QUESTION

To determine the role for government in enabling or building communities to deliver social change for people with disabilities.

- Where, why and how has it worked in the UK context?
- What can we learn from this for the implementation of the NDIS in Australia?

EXECUTIVE SUMMARY

The purpose of this research report is to outline the role for government in enabling or building communities to deliver social change for people with disabilities. Set within the context of Australia and the implementation of the National Disability Insurance Scheme (NDIS), this report aims to draw out success stories from across the UK that can be applied to the Australian context.

Qualitative data was collected between mid July and early September 2014 through semi-structured interviews with professionals from corporate, government, charitable[1] and social enterprises in the UK. The sample size was small – ten people – which allowed for a depth of questioning and exploration of success factors and perceived barriers. A thematic analysis (O'Leary 2005: 231) methodology was used to analyse the data.

The research findings elicited six key recommendations for government in enabling or building communities: Question assumptions used to define problems and set the vision for change; Foster community-led change and localised decision-making; Challenge traditional notions of workforce; Create structural reforms that facilitate innovation; Give control to people with disabilities, families and carers, in design and monitoring; and Understand what is working, why, and direct investment towards multiple approaches.

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[1] It should be noted that in the UK context, non-government organisations are called charities. Wherever this report refers to a charitable organisation, an Australian reader can take this to mean an NGO.

CONTEXT

Australian context: current state of play

There is an overwhelming recognition that investment in prevention and early intervention models can help to contain costs as 'Australia's population, like that of most developed countries, is ageing as a result of sustained low fertility and increasing life expectancy' (ABS, 2013). The rights of people with a disability have been recognised through legislative reform, including the *National Disability Insurance Scheme Act (2013)* and Australia's ratification of the *United Nations Convention on the Rights of Persons with Disabilities* (2008). It has been recognised that an individual should be able to choose, control and direct their support.

Governments across Australia are transferring services to the non-government sector as part of a shift from centralised service delivery to localised decision-making with devolved budgets and responsibility. New and innovative models of service delivery are replacing the traditional funder / provider relationship, including Public-Private Partnerships (PPPs), social benefit bonds, social entrepreneurship and philanthropy. The modes of funding are also shifting from block grants to service providers, to individualised funding based on assessed support need; direct payments; and self-managed funding models.

The National Disability Insurance Scheme (NDIS)

The NDIS represents the most significant social reform package in Australia since the introduction of Medicare in 1975. The Scheme represents the transition to a new market and model for service delivery that will substantially change the nature, focus, and funding of disability support service delivery (KPMG Report: 2014).

In Australia, projected populated demographics indicate that the number of people providing care and support for people with a disability is decreasing and a small decrease has a large financial impact on the formal (government-funded) system. The NDIS will address this shortage by providing an injection of funding ($19.3 Billion AUD over 7 years) that will assist 460,000 people.

But it is not simply about more funding. By the end of 2018 when the NDIS is fully implemented, state governments will no longer provide disability services. People with disabilities will get their supports from non-government providers and through self-directed, flexible and innovative models. Government will shift from being a 'provider' of services, to being a 'funder' - where money goes directly to an individual; a fund-broker / intermediary; or an organisation that delivers the service.

The success of the NDIS is highly contingent on the growth of new types of organisations, partnerships and innovative models, in short, the growth of a 'community-led response'. So how does government enable this change?

DESKTOP ANALYSIS

An analysis of peer-reviewed journal articles, practice guides and other documentation from Australian and international jurisdictions, illustrates key themes for building communities and the role for government. To make it easy for the reader, each point is followed by a number(s) that links to its source as listed in the bibliography.

What is meant by the term 'community'?

- **communities** can be strengthened by improving partnerships between government, non-government organisations, corporates, service providers, individuals and families (7, 13, 15, 16, 21, 27, 32, 33, 35)
- community can be defined as 'a group of people who all hold **something in common**, locality or geographical place, or people who are members of communities of interest' (http://www.healthknowledge.org.uk/about-us)
- the definition of community can be **rights' based**, recognising that everyone should be able to access the 'physical, social, economic and cultural environment, health, education, information and communication' (9).
- governments are increasingly using the term community to engage, partner and find new ways of driving social policy reforms through shared responsibility, **connectivity** and **localised decision-making** (8, 19).
- community is **inclusive** - it is about every individual, family, business, non-government organisation and social enterprise delivering together (36).
- building **resilient** communities means being able to identify changes at a local level which create greater inclusion and mutual support within our communities (15).

What is the role for government in building community?

- **Legislative change** - enact legislation that enables reform and modernises practice, recognising that legislation alone will not bring about change (11, 18, 21, 24, 27).
- **Engagement with community** - engage at all levels, recognising that the process is critical: deliberative democracy is important with strong citizen and stakeholder engagement; develop a deeper understanding of how innovations mature and develop; foster community brokerage and existing strengths of a community; make mistakes and learn from them; involve community in the design-phase: do not implement a top-down model (6, 7, 8, 9, 11, 13, 16, 17, 25, 29, 31, 33, 35).
- **Leadership and strategy** - lead, set the strategic direction, understand transformation, be opportunistic and focussed; clearly define government's role and responsibilities, particularly where there is shared responsibility across jurisdictions (2, 6, 9, 18, 19, 20, 22, 27, 31)
- **Workforce investment** - work to change the culture of the workforce in the direction of the reform; invest in staff to ensure they have the right skills to move forward; develop the skills of staff to become facilitators and relationship builders; support staff to listen and understand their communities (6, 7, 8, 9, 11, 12, 13, 15, 18, 25, 33).
- **Develop new partnerships, innovations and ways of working** - work with business / private sector; encourage philanthropy; change *what* is funded and the *mode* of funding (1, 2, 3, 11, 14, 15, 16, 17, 25, 26, 31, 35).

RESEARCH METHODS

In mid 2014 I conducted two (2) informant interviews with Kerry McGough (KPMG, May 2014) and Dr Simon Duffy (The Centre for Welfare Reform, July 2014).

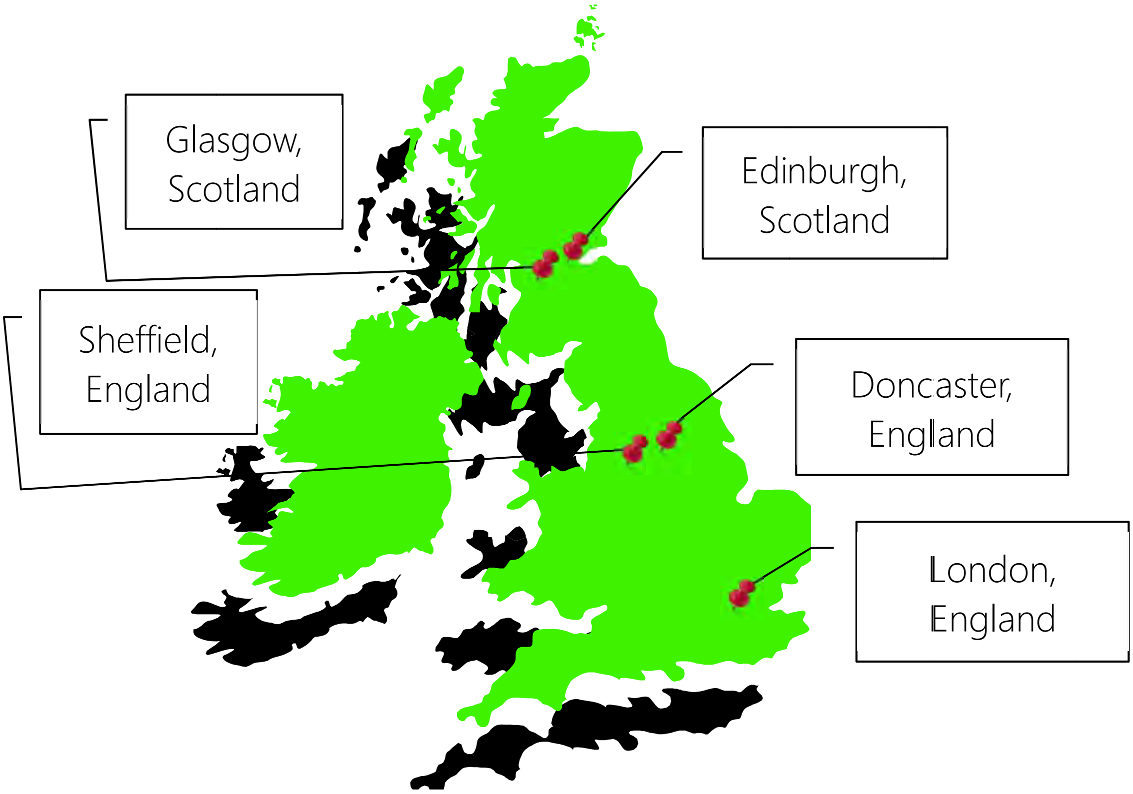
In July 2014 I completed a literature review and desktop analysis of documentation on community development and participation of people with a disability. I reviewed government reports; practice guides; and peer reviewed journal articles. I used this breadth of information to develop my interview questions.

Between mid July and early September 2014 I set up ten (10) appointments with professionals in the UK. I targeted a mixture of organisations from small to large and across a wide field: corporate, government, charitable and social enterprise.

Between 24 September and 15 October 2014 I conducted ten (10) face-to-face interviews in the UK with professionals working in the field of disability. Prior to meeting the interviewees I emailed a one-page summary document outlining my research question; the Australian context; and key questions (Appendix 1). This gave the participants the chance to think about what they wanted to share with me and helped focus and structure the interview. Each interview was recorded on my iPhone and transcribed within 24 hours of the meeting. The interviewees all agreed to being recorded and it facilitated a much more relaxed and conversational approach during the meetings.

In November 2014 I returned to Australia, collated my findings and wrote this report.

Type of organisation	Geographic location	No. of Orgs
Corporate	London, England	1
Independent think-tank	Sheffield, England	1
Family-led social enterprise	Sheffield, England	1
Peer support organisation	Doncaster, England	1
Government (Local Authority)	Edinburgh & North Lanarkshire, Scotland	2
Charitable organisation	Glasgow, Scotland	4



FINDINGS & RECOMMENDATIONS

The interviewees highlighted areas of best practice; outlined what they thought government could do differently or better; and shared stories to illustrate their views. This information has been grouped into six (6) key themes, illustrated by their stories and quotes. In summary, the future role(s) for government in enabling or building communities to deliver social change for people with disabilities should include the following:

1. Question assumptions used to define problems and set the vision for change;
2. Foster community-led change and localised decision-making;
3. Challenge traditional notions of workforce;
4. Create structural reforms that facilitate innovation;
5. Give control to people with disabilities, families and carers, in design and monitoring; and
6. Understand what is working, why, and direct investment towards multiple approaches.

1. Question assumptions that have been used to define problems, and set the vision for change

Each of the interviewees identified that problem definition is critical, because the way you define a problem influences what action you decide to take. For example, if you define the person with a disability as the problem, then it is likely you will try and find a solution to fix that person, rather than looking at the bigger picture, at what strengths or skills they have to offer their communities and how the community could be adapted. A number of the organisations worked from a strengths-based approach, looking at what people with a disability had to offer their communities. It took the focus off the person as the problem, and saw the possibilities for them to contribute to their communities in meaningful ways, and to ultimately belong.

> We need to stop modelling that we as public servants know the answers, have the solutions. We are all desperate to solve a problem we don't understand. Simon

> One of the biggest cancers we have in our community is loneliness. It's all about this. Strip it all back and this is where all the problems come from. My recovery comes from me giving back. If I give – I receive. Glyn

Glyn

Coming to PFG has changed my life in so many Positive ways. Help for me [illegible] And Professional, I have felt more myself and feel more Confident for the future. Here is so welcoming and they make feel so at Ease. [illegible] XXX

Thankyou to PFG for Helping me to live life again instead of just existing. PFG has gave me Hope was there was no Hope and enabled me to to live a fulfilled life once more. failure is not an option.

Comments from people supported through PFG

> We refer to the people we support as members. The first thing they do is fill out our skills audit form – 'what skills and gifts do you have to offer'? Kelly

Similarly, the interviewees identified that how you define a community will shape and influence the way that people with a disability are supported within their communities. IBK, a small family-based social enterprise, moved from an office location surrounded by other small businesses, to being located in St Mary's community centre, Sheffield. As people from different ethnic communities accessed the community centre, they started to learn about IBK and think about how they could include people with a disability in their communities.

> We have grown particular links with different communities without really trying actually – we've got Somali, Pakistani families, and they're all asking us for something, and they're all attracted to us because we offer a non-judgemental space. They wouldn't use this language, but they're asking how can we include people with disabilities? How can we make our activities attractive to disabled children? Pippa

Interviewees also described a culture of behaviour that encouraged the participation of all people in their communities, not just people with disabilities.

> Adrian has set up a group called Paces: cycling and walking – as part of that he set up a litter picking group – the members do it with the community – they're giving back to the community by regenerating the cycle paths, but also connecting our members with other people in the community. It's a combination of the members and community that has brought about community regeneration. John D

Another common theme reported by interviewees was a sense that we are social beings that need to belong, and a large part of that is reflected in where we live and the choices we have around housing. In North Lanarkshire Local Authority, people with a disability are overwhelmingly supported to live in their own homes. This is fortuitous as North Lanarkshire has many properties at their disposal, however it seems to have fundamentally started from the workers who decided to set the bar high and aim for every person to have their own home, their own secure tenancy agreement.

> There's more chance of being a citizen if you have your own house, it's a wider social inclusion agenda. You use the local shops, local gym, rather than being in the house down the road with all the special people. People expect this now, to be a citizen, to have the same expectations as everybody else. Morris

Similarly, in approaching the issue of unemployment for people with a disability, North Lanarkshire Local Authority did not approach the disabled person as the problem. They conceptualised it within a broader framework of unemployment in impoverished communities, with people with a disability as jobseekers like everyone else. They set the bar high, assuming that all people would work in the open labour market and receive a wage.

> Real jobs for real wages. This was our starting point. We spent some time in Liverpool, a service that was getting people jobs in the mainstream – more than 16 hours a week. We decided not to go for less than that. We got people up from London to work with us. They helped us to work out how to get people jobs. North Lanarkshire has third generation unemployment - it's quite an impoverished place. We've got people in the wider community competing for jobs. But the starting place should always be jobs in the real market. If there's 'Employability' initiatives locally, what are they doing to support people with disabilities – if they walk through the door. Are they geared up to support? Could people set up a micro-business to support themselves? Morris

North Lanarkshire also reported a culture of continuing to strive and overcome community resistance. For example, where some workers might have said that employment for people with disabilities was only possible in certain communities, or that it was lucky it had 'worked in Motherwell but it won't work in Airdrie' (Morris), the leadership and their teams just kept on going. They kept on challenging the status quo and ultimately this lead to real jobs.

2. Foster community-led change and localised decision-making

Many of the interviewees identified community-led solutions and localised decision-making as key to success. Overwhelmingly there was a sense that communities had natural leaders, but government needed to identify those leaders, foster them, and provide the appropriate structural reforms that allowed them to flourish. There was a strong sense that communities had been disempowered for so long by governments holding the money and decision-making power, that communities had lost the ability to find solutions.

> We keep expecting solutions to come down from government and in that very process of looking up to the solution, we degrade the possibility of finding solutions in the community. Simon

The interviewees also identified that further investment in small organisations working locally with families to build relationships and plan, could be very beneficial. Overwhelmingly the interviewees wanted governments to design reform strategies that supported innovation and provided for multiple solutions – not a one-size-fits-all approach.

> The issue with Direct Payments has been – here's the money, sort it out for yourselves. Most families don't know where to go to get help. Government pays for the worker, the accommodation, but no one is paying for the infrastructure work to get real planning off the ground. Pippa

Another key theme that was reported was creating the environment that allowed mistakes to occur and therefore supporting people to learn and build on that. Interviewees wanted the right environment that enabled communities to be organic and go through the steps of learning.

> We need to be ok with the chaos. We need to let people with disabilities try things out, fail, get up and recover. The whole society has to support that. It just can't be about the disability sector. Pippa

Many interviewees reported that they did not see more services or putting more money into a problem as the only answer. The solution was more about appropriate planning, working out how to make the money stretch further and on supports and activities in the community, not specialist services.

> It's not all about the money. It should be about community. We had a transition program – but it was all about government saying we need to help children move from children's services to adult services. We want lives, not services, and it's still all about services. Pippa

> We decided to spend money on people that could do things with other people, rather than spend money on buildings and buses. Morag

> When our program started, we realised that if people got together and made friends then their money would go so much further – and it was also building their social capital - this is what people wanted. Vicky

3. Challenge traditional notions of workforce

The workforce responses can be envisioned along a continuum, realising that the sector is at different points of development from block funding to individualised supports; from respite units to individuals supported in the community; and from people accessing specialist supports to those being supported completely in the mainstream. The themes expressed by all interviewees reflect this continuum. They described how staff needed to change now to meet the needs of the people they support; outlined the role for employers to support staff through the change; and fundamentally, they described the move from a traditional notion of 'workforce' with government / charity as the employer of staff, to people with a disability as the employer, hiring individuals on the basis of skills, likes, interests linked to their goals and aspirations.

Charities were doing a range of activities to try and change the existing workforce and move people in the direction of what people with a disability and their families were saying they wanted. For example, at Choice, Steven described a culture of change that was fundamentally about:

> …releasing staff capacity – so they go into the field more, more time with families; sharing our learnings – communication between the Board, governance groups, support staff and families; and making internal communications more clear with face-to-face briefings for staff'. Steven

At Inclusion Glasgow, Aileen described a culture where individuals were hired because they had the right values and could make decisions:

> People learn experience on the job – give staff the autonomy to make decisions and don't send everything up the line. But staff also need to use their initiative and not get into a rut. Aileen

Similarly, through the respite program in Edinburgh, Vicky described how:

> …we are getting people that are graduates, studying to be social workers, people that are doing this because this is the job that they love! Our workers need to be invisible. We don't want the staff member to be parading about with their badge and uniform. Our passion is to help people integrate into the wider community.

In North Lanarkshire, the interviewees described a management team that were proactive in ensuring that staff were working with individuals with a disability based on common interests, not simply because they were qualified as a support worker:

> Once staff 'get it', that their job is better in the new world, most of the staff get more satisfaction out of the job they're doing now. It's about linking staff to individuals based around what they want – common interests. Morris

The language used by many of the interviewees was also telling, in terms of understanding how far that organisation had moved along the continuum of choice and control for people with disabilities. At Inclusion Glasgow, Aileen described an organisational culture that demonstrated how people with disabilities had the power, choice and control to make decisions, rather than the workforce that supported them. 'Right from the CEO to finance, we're all paid from the people. We don't talk about 'service users'. We talk about the people we work for (Aileen). This was also exemplified by Inclusion Glasgow's administration assistant describing people with disabilities as 'the people we work for' (Erin), rather than clients or service users.

There was also a sense that change was good and giving people with a disability more choice and control held the organisations to account. As Steven described at Choice, if people are happy with the support we provide, they'll continue to stay with us - if they're not, they'll vote with their feet (Steven). The interviewees overwhelmingly described a culture of action. Whether they were the CEO of a large organisation or a manager in a Local Authority, they all had vigour, drive and understood the vision for change. They all agreed that things needed to change and it was really about 'rolling up their sleeves and getting on with it' (Simon).

4. Create structural reforms that facilitate innovation

The interviewees identified that there was a role for government in creating the structural reforms that allowed practitioners and people with a disability, the freedom to innovate. This was exemplified through five key areas: new provider frameworks; individualised funding linked to a person rather than a service; person-centred planning that facilitated the development of technological solutions; new ways of measuring outcomes; and an environment that enabled risk, rather than tried to manage and control every aspect of a person's life.

The North Lanarkshire Local Authority described how they established their strategic framework for providers, purposely creating a pool of providers that could deliver supports across a wide spectrum to drive their vision of inclusive supports in the community:

> There's no specialist providers e.g. Autism specific, physical disability etc. In theory, any of the 18 should be geared up to support someone with specific needs - it should relate to the impact of the disability on that person, rather than funding a disability specific service model. Part of my role is to work with these organisations, to make sure they're doing all the things we want. They exist to work themselves out of a job. We want them to help people become community connected. It's not enough for someone to have a clean flat with milk in the fridge. It's bigger than that. Morris

The key to success was how the vision was implemented. Providers identified the need for open and honest working relationships with government, with flexibility in how supports were delivered; measured; and reported.

> When we meet with our Local Authority [our major funder] there's no power struggle – it's a very open and constructive, informal meeting. It's so refreshing to feel like we're at the same level. David

> Our Local Authority doesn't try to fit people into boxes – they support preventative action – e.g. if a carer dies, the Local Authority will put in paid sleep overs for two months to support the son or daughter, until they get back on their feet. Aileen

The move from block grants to individualised funding was also seen as a fundamental and necessary reform, to shift the power and decision-making to people with a disability. In practice, many interviewees identified that this was the catalyst for change:

> It's not always about well-orchestrated change by government, it's about groups of people coming together to drive the change. Change comes about when individuals get their Individual Service Funds. Steven

Similarly, the process of moving from block grants to individualised funding, challenged providers who had always planned in terms of the cost of services (respite, or in-home care), to think about planning in terms of a person's life. This took a long time to permeate the culture of the Local Authority, but was well worth the challenge:

> It was difficult [in the beginning] to attach money to an individual that was not about services, for example it used to be ten hours of home care costs this much, therefore that's how much money the person needs for their future home care needs. But this [process of change] was 16 years in the making – it didn't happen overnight! Morris

Changing the funding mechanism had also facilitated more innovative solutions, often driven by a desire to make a person's individual service fund stretch that bit further. Many of the interviewees described how technological solutions were replacing services previously delivered by staff.

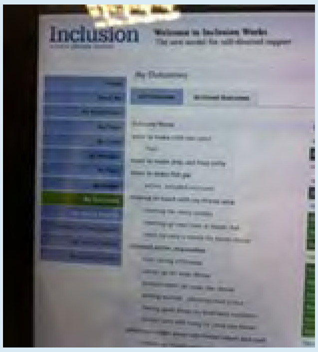
> Approximately 3,000 pounds per year provides technology for someone to sleep alone, rather than a sleep-over which would cost triple that. Do you need someone sleeping in your house overnight, or could you use technology to summon that support if you need it? Morris

> At the moment we have people getting sleep-overs, but that's money that they could use to do things throughout the day. We're looking at how technology can enable some of that risk – assistive technology can really help. It's about planning for this – we wouldn't withdraw the over-night support straight away. Aileen

What was most interesting about the technological solutions was that it went further than saving money – it was actually improving people's lives. Choice had engaged Bucks New University to conduct research looking at the health outcomes for people with a disability through the use of technological solutions. What they discovered was ground-breaking:

> The research, Better Nights, found that taking waking night staff out and replacing them with Assistive Technology also resolved in better health outcomes for people with disabilities. They had better sleep patterns as there wasn't someone awake in the house to help them out. They were no longer paying for someone to have the lights and heating on all night.
>
> Sarah

SDS Technology



At Inclusion Glasgow, they had implemented a new technology called SDS (Self Directed Support), aimed at integrating every aspect of a person's individualised package; focused on how each element was assisting the person to achieve their outcomes. Message boards, policies and procedures, accident and incident reports, time sheets, staff diaries and outcomes tracking. For example, each outcome was broken down into smaller goals so the person and their support workers could easily see how every activity was contributing to the longer term goals.

The interviewees reflected a general consensus that the disability sector needed to continue striving for new ways to measure outcomes that are based on people's lives, not the services they receive. There was also an expressed need for greater dialogue between sectors - government, charities and investors – so that reporting was meaningful across sectors.

The organisation Corporate Citizenship, works with a global group of companies to implement Corporate Social Responsibility reporting. Their work is focussed on supporting more companies to measure the impact of their investments and in doing so, to truly understand how their investment relates directly to outcomes in that particular community:

> We need to ensure that companies don't over report. Some companies try to claim outcomes in communities for which they are not really responsible'.
>
> Jon L

Interviewees from the smaller organisations outlined how time was a barrier to reporting:

> We don't have time to put the stories out there, we're doing so much that we're not getting paid for, that we don't have time to tell the government our stories. Our families know what we're doing, but no-one in government seems to know.
>
> Pippa

> Our funders need to create a relationship with our organisation – come out and see what we're doing. Spend time with us. Sit and have a cup of tea with people. Then go back and fill in their books. They know how they want the information – they can turn it into what they want.
>
> Lisa

The larger organisations had invested in training for staff on outcomes based practices, changing the way their staff assessed and reviewed outcomes to try and direct practice into creating meaningful lives for people with a disability, rather than just 'ticking boxes' on what activities a person had achieved. Inspiring Scotland was working with the organisations they supported to create a culture of constantly questioning what they were doing and was it having the desired impact:

> We spend a lot of time at the beginning of the fund – setting the baseline, describing the outputs and the outcomes. It really helps the organisations to be able to tell their story and what change they'll make and then this helps them attract more funding. The organisations need to self-evaluate – they need to be doing this as they go along – they need to want to improve. We try to encourage a culture in our organisations where they're constantly looking and asking, is this working? Celia

The fifth and final area under structural reform was risk enablement. Many of the interviewees described how they had worked hard to change their staff's attitude towards risk, so they moved from 'managing' risk to 'enabling' risk. There was also evidence of a fundamental shift in power to the person with a disability, rather than the funder:

> Everyone thinks 'they own the risk', no-one really things it's the person's choice - that they can hold the risk. The risk of not having a life is worse! Morag

Most organisations had criteria outlining what people could spend their money on, with the only prohibitions being 'gambling, illegal activities, or anything that would bring the [funder] into disrepute' (Claire). But despite these broad criteria, it was the leaders of the organisations that ultimately set the right environment to enable risk:

> The planning is where you manage / enable risk. Everyone is involved – the person with a disability; their family; social workers'. Morris

> We need to get the right staff so they're not over-protective of the people they are working for. There's always ways around things, even with risk. We talk with staff, why do you think it couldn't work - think about other ways of seeing things. It's about getting the trust of everyone involved in the process. Aileen

And nearly all the interviewees described how important it was that decisions were made close to the person with a disability. In practice this meant empowering staff on the ground to make decisions, and not pushing everything back up the line for approvals. North Lanarkshire had spent a lot of time changing their internal approval process, to ensure their front-line staff could make decisions:

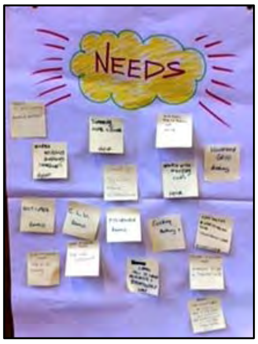
> The systems we had before allowed front-line staff to send things up the line, and we were the keepers of the budget. We've given front-line staff the budget, so they know what they're working within. If there's a disconnect, the only place it can be resolved is at the local level. Morag

Similarly, an example from Neighbourhood Networks exemplifies how risk enablement is about giving power and autonomy to people with a disability, rather than seeing the paid worker as the solution to every problem:

> A member (person with a disability) was moving house and the Community Living Worker had reported to their manager that they couldn't attend a staff meeting because they had to be there to provide support, to make sure that nothing went wrong. The manager had replied by saying, if the only reason it's happening is because you're there, then it's wrong. You shouldn't be there, then it won't happen, and then the members will learn how to plan better for next time.
>
> David

5. Give control to people with disabilities, families and carers, in design and monitoring

Interviewees expressed how meaningful engagement needed to occur with people with a disability, to ultimately shift the power to them as the decision-makers. Many organisations outlined the success of peer-led solutions, where people with a disability or their family members / carers were working alongside other people to bring about changes in their lives.



For example, at North Lanarkshire Local Authority:

> We've enlisted support from carer organisations and 'Champions for Change' – getting them to tell their stories, so it's not just the voice of the Council worker. People with lived experience of the change [can tell their stories] – here's the good and bad bits. Carers listen to carers.
>
> Morag

Similarly through the respite program in Edinburgh:

> Our pilot group of families decided to take a leap of faith into the unknown and then they began talking to other families, educating them [about how it had worked] and expressing how their son or daughter was really enjoying this.
>
> Vicky

People with a disability were also playing a key role in the monitoring of services, providing their input into how supports could be improved. At Choice Support, London, 'Experts by Experience' is a program where over 400 people with a disability accompany inspectors from the Care Quality Commission on inspection visits. As Steven explains:

> We hold the main contract for the Care Quality Commission to provide people who have experience with receiving services. We recruit and train them and they're also paid above award wages for their work.
>
> Steven

Similarly in Glasgow, Inclusion was running a peer monitoring program called 'Inclusion Ears':

> People with disabilities interview the person receiving support, talk to their family members and report back. This is a good way of monitoring because it's transparent. Aileen

A number of respondents also reported how critical it was to listen, and that this culture of listening permeated all levels, from service delivery to policy makers:

> It's not enough to just listen once to what a person wants – it's about unpicking that' [and getting to what they really want]. For example, if you could live with anyone in the whole world, would you pick living with yourself or living with somebody that you've lived with for 40 years because they were the best of a bad bunch? Morris

And likewise from Steven,

> ...we need to talk to people more, spend time with staff and talk to families. Often our ideas are quite similar; we just need a way to understand each other. Steven

6. Understand what is working and why, and direct investment towards multiple approaches

Inextricably linked to community connectedness and localised decision-making, was a strong sense that governments needed to understand why some individuals, families or communities were able to support people with a disability to thrive. The Real Wealth model (Murray, 2010) identifies five broad categories that are essential in building family resilience – spirit, people, community, assets and gifts.

By developing a better understanding of how people develop and maintain capabilities across these five areas, governments can direct investment towards the right areas.

Some organisations expressed their ability to be flexible, to respond to the changing needs of their members, was integral to success. PFG, a peer support group in Sheffield, struggled to describe what it was that they provided. Precisely because they were so agile, the supports they offered and the members that came to the group and offered their skills and expertise were constantly changing:

> Our group started with about five people – they used to meet in church halls, park benches, wherever they could find space. Then we got a property and we got started. It's all about the members. It's grown from them. It's always changing because it's people-led. Kelly

IBK Initiatives reported how their strength lay in their small size, as they could easily link families up to support each other and when they were interviewing for Personal Assistants, they could ask questions relevant to the people with a disability they were supporting, rather than recruiting based on generalist skills:

> We already know when we're interviewing someone whether they're the right fit and who they'll be able to support, as they have the same interests. Pauline

The interviewees also reported that just because a model was working in one community, or even with one family, did not mean that it could be simply replicated. It was the process of developing a solution, listening, building and learning by trial and error that was key. The Local Authority in Edinburgh expressed this as:

> You can't replicate, it's about ownership, getting to the roots of why it's working. We need to make sure the systems and processes don't get in the way of the personalised approach. Anne-Marie

Similarly Pippa expressed how important the process was when working with families:

> You need to sit down and peel away the layers of the onion – work to bring down the families' stress. You can't go into a community and replicate – it's got to be organic. Pippa

There was also a strong sense that 'people in the community could find their own solutions' (Simon), by seeing and experiencing different models, different ways of doing things.

A key finding was that there seemed to be a tipping point around inclusion. Many of the interviewees were aware of the need to constantly challenge what they were doing, to refresh, to rejuvenate, and to make sure that they were not simply creating another 'service', based in the community. At North Lanarkshire Local Authority, Morris expressed this as:

> We're keen to try and avoid the creation of specialist groups for people with disabilities – the best barometer [to determine if it's working] is people telling us themselves. We don't want the local gardening group that everyone now attends to be a substitute day service. If someone goes to a local theatre group and they get a good reception…then word spreads and then lots of people go and the balance shifts. So we're really keen to try and avoid garden centres becoming day centres.

Neighbourhood Networks in Glasgow also recognised that if they grew much larger, then they would need to split into smaller organisations. The strength of this model was because the Community Living Workers they employed came from the same communities they supported.

> We're employing well-connected people, connected to their community, with a knowledge of it. We don't want them to lose their community connectedness and we don't want the members becoming reliant on them. David

Inspiring Scotland

Traditionally, the bulk of funding for the voluntary sector comes via earned income and grants. Inspiring Scotland's work is based on a complementary but different model. The central concept of Inspiring Scotland is to provide better social services to Scotland by strengthening and expanding the charities that provide those services (Isserman, 2013).racking. For example, each outcome was broken down into smaller goals so the person and their support workers could easily see how every activity was contributing to the longer term goals.

> Inspiring Scotland was formally launched in 2009 – our approach is strategic investment. We raise money from investors, government, high net worth individuals, trusts, foundations, corporates and together all these investors 'buy into' tackling a social issue. Each venture (the charitable organisation) has a dedicated Performance Advisor who works alongside them. It's about transformational change – helping ventures to move from 98% grant funding to 75% income-generation. The organisations that have minimal, short-term investment seem to benefit just as much as those that get longer term support. Celia

Neighbourhood Networks

The Neighbourhood Networks are 'modelled on the principles and practices of KeyRing, who pioneered the model of Living Support Networks to enable people labelled with a learning disability to live in their own homes. They work with local communities to support and empower people who may be described as having a learning disability' (page 1: Neighbourhood Networks Information Pack). Most of their funding is provided by government through the Local Authorities in the form of block funding to support people with low needs who are not in receipt of a personalised budget.

A Network has around 9 people who live near each other and are known as 'members'. Members usually have their own homes or tenancies or are working towards this. Each Network has a Community Living Worker, who lives in or around the same area as members. Support is flexible, which means it is there when members need it, not when they don't. Members often help each other and learn to do things for themselves.

NN has a flat structure, with a Director and two senior managers (Heather and David). Network Managers have up to 5 networks each and support 21 networks across Central Scotland. Each network has their own Community Living Worker (CLW) who work a maximum of 16 hours a week – very flexible – they live in the area they work in.

CONCLUSION

This research is the culmination of a journey. It started back in 2010 when I completed a leadership program and realised that I wanted to do more study. I enrolled in my Masters and steadily worked away for two years, juggling work and full-time study. I relished the challenge and found that I was achieving more at work, in a shorter period of time, because I had to.

I then won the travelling research prize and was again pushing myself to new limits - working out who I wanted to speak to, how I would conduct the interviews and on a practical note, how I would get around the UK without getting lost!

Every person I met with shared their personal and professional insights and told me about their individual journey.

I learned that it's ok to make mistakes, to try new things, to challenge the status quo and to aim high.

I remain committed to improving the lives of people with a disability in Australia, and I can't wait to look back in another 30 years time and see how far we've come.

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APPENDIX

IBK Initiatives, Pippa Murray, Tuesday, 30 September, 10am

Australia: the National Disability Insurance Scheme (NDIS)

The NDIS represents the most significant social reform package in Australia since the introduction of Medicare in 1975. The Scheme represents the transition to a new market and model for service delivery that will substantially change the nature, focus, and funding of disability support service delivery[1].

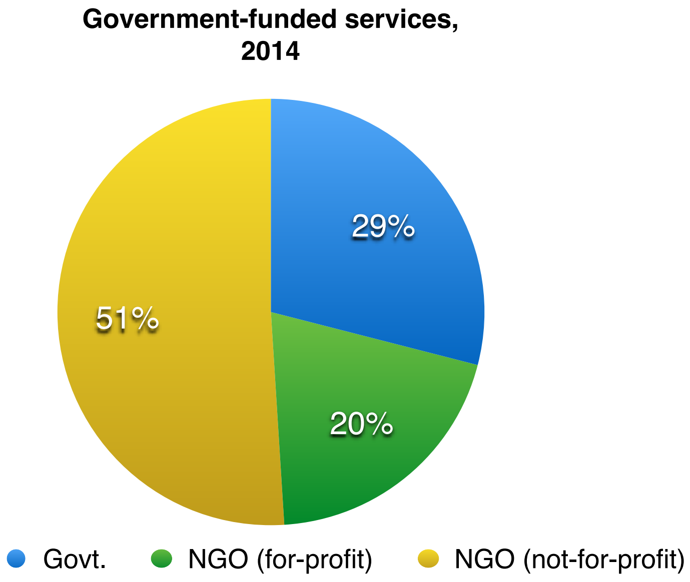
In Australia, projected populated demographics indicate that the number of people providing care and support for people with a disability is decreasing and a small decrease has a large financial impact on the formal (government-funded) system. The NDIS will address this shortage by providing an injection of funding ($19.3 Billion AUD over 7 years) that will assist 460,000 people.

But it is not simply about more funding. By the end of 2018 when the NDIS is fully implemented, state governments will no longer provide disability services. People with disabilities will get their supports from non-government providers and through self-directed, flexible and innovative models. Government will shift from being a 'provider' of services, to being a 'funder' - where money goes directly to an individual; a fund-broker / intermediary; or an organisation that delivers the service.

The success of the NDIS is highly contingent on the growth of new types of organisations, partnerships and innovative models. In short, the growth of a 'community-led response'. So how does government do this?

Government: current state of play

- Re-auspicing services to the non-government sector
- Public-private partnerships (PPPs)
- Recognition of the need for innovative models (social benefit bonds); social entrepreneurship; and philanthropy
- Localised decision-making, devolution of budgets
- Investment in prevention and early intervention models (aiming to contain costs)
- Recognition that an individual should be able to choose, control, direct their support
- Individualised funding (based on assessed support need) and direct payments, self-managed funding (both models in their infancy)



My research question:

What is the role for government in enabling or building communities / partnerships to deliver social change for people with disabilities?

- Where, why and how has it worked in the UK context?
- What can we learn from this for the implementation of the NDIS?

Interview questions - IBK Initiatives

- What does the word 'community' mean to you in the context of your organisation?
- How does IBK enable, lead, grow 'community' according to your definition?
- How did IBK, the social enterprise, begin?
- Your projects indicate that you work with Local Authorities. What type of work do you do with them?
- Do you have any other intersections with the UK Government or policy makers?
- Do you think there is a role for Govt. in being a partner, driver or in helping to establish social enterprises?
- How can Government drive change without stifling innovation and creativity?
- What gap(s) are you filling in the market place? What makes your organisation thrive?

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[1] 'Interim report: Review of the optimal approach to transition to the full NDIS': KPMG, 16 July 2014

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