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Reimagining futures in the Australian Disability Sector

Abstract

The opportunity to reimagine the future for the disability sector doesn't come around often but in Australia in 2010 it did occur. A timely mix of public outrage over high levels of unmet need, abuse and neglect, alignment of activists, a compelling campaign and sufficient political will provided the conditions for a major social policy reform known as the National Disability Insurance Scheme (NDIS). The promise was for an entitlement based, social insurance scheme which would provide individualised funding on the basis of need, existing networks of support, and aspirations for the future. While the level of unmet need for specialised disability supports in Australia has decreased dramatically, a major challenge remains for the NDIS in being a transformational rather than transactional reform.

Gelegenheiten die Zukunft des Behindertensektors neu zu gestalten, bieten sich nicht oft; aber 2010 in Australien eröffnete sich eine Solche. Auslöser dafür waren eine Mischung aus öffentlicher Empörung über das hohe Maß an ungedeckten Bedarfen, das Sichtbarwerden von Fällen der Misshandlung und Vernachlässigung, der Zusammenschluss von Aktivisten, eine überzeugende Kampagne und ausreichender politischer Wille. Zusammengenommen schufen diese Elemente die Voraussetzungen für eine große sozialpolitische Reform, die als National Disability Insurance Scheme (NDIS) bekannt wurde. Versprochen wurde ein auf Ansprüchen basierendes Sozialversicherungssystem, das eine individuelle Finanzierung auf der Grundlage des Bedarfs, bestehender Unterstützungsnetze und individueller Erwartungen an die eigene Zukunft vorsah. Zwar ist der ungedeckte Bedarf an spezialisierter Behindertenhilfe in Australien drastisch zurückgegangen, doch besteht nach wie vor eine große Herausforderung für das NDIS, dass es sich eher um eine transaktionale als um eine transformative Reform gehandelt hat.

1 Introduction

The context for this paper is the emergence of the National Disability Insurance Scheme (NDIS), a major social policy reform underpinned by the promise of choice and personal control over the future for individuals and their families. Launched in 2012, the NDIS is a social insurance scheme, similar to Medicare – the Australian national health system, rather than a disability support funding scheme. Provision is made for individualised disability funding on an entitlement basis using actuarial algorithms to calculate costs over a lifetime. It replaces the block funding arrangements managed by the 8 states and territories which was widely recognised as a fragmented, broken system (National People with Disabilities and Carer Council 2009; Productivity Commission 2011).

Many in the Australian disability sector – individuals, families, service providers, advocates, academics and members of the community were and continue to be inspired by the possibility of people with disability imagining and shaping their own future. Many more people now receive specialised support based on an individual plan, with opportunities for review and appeal. However, to date the NDIS has failed to deliver on choice and control and the promise of being able to shape one's own future. Instead, these constructs have been rationally and politically defined rather than understood in the context of relationship and personal agency. Nowhere is this more evident than in the absence of language and opportunity for “dreaming” and “visioning” in the planning and implementation processes of the scheme. The NDIS documentation and processes indicate no expectation or evidence of individual aspiration. It is no surprise then that individual plans tend to reflect a closed, rather than open view of the future for people with disability, particularly in the context of media headlines of NDIS sustainability concerns and cost blow-outs.

This paper draws on the field of futures studies to explore how a reform that holds such promise can be falling so short of the dream so fast, and how to find our way back. Specifically, it discusses two initiatives, a non-government sector scenario building process (2009) and post graduate research later undertaken by a member of that team (2017), using the framing of the Three Horizons model to understand the challenge for the NDIS in being a transformational rather than transactional reform. The “Blue Skies” scenario made a brighter future for people with disability seem possible but Causal Layered Analysis or CLA (Inayatullah 1998; 2004), the primary methodology used in the subsequent research project, revealed tension and dissonance between the vision for a brighter future and reality for people striving for a decent life under the NDIS.

Is it possible that CLA as a tool might provide a path at both individual and system level for revealing then reframing the dissonant beliefs and narratives that underpin current reality, in order to reconstruct a brighter way forward?

2 Three Horizons

In drawing on futures studies to understand the relationship between past, present and future, the three horizons model with three overlapping circles or waves offers a relevant frame of reference. Horizon 1 represents business as usual – present reality steeped in history, lived experience and dominant discourses around disability and power. Horizon 3 represents the future with many scenarios possible, including the radical, the pragmatic and everything in between (Curry & Hodgson 2008).

Horizon two is positioned between horizons 1 and 3 and is the space of social change effort and reform. It is the space of uncertainty, choice and possibility. It is the space that beckons when business as usual is no longer fit for purpose and some brave individuals are willing to let go of what they know and step into the unknown. Horizon 2 is also the space where the actors, individual and systemic, are still likely to revert to old patterns of behaviour without progress, if the vision offered by Horizon three is not compelling or the path is too challenging. The challenges may take the form of overwhelm if choices are too many, doubt and discouragement if dissonance is too great, fear of abandonment or retribution for treading a different path.

Elise Boulding (1995) suggested one of the greatest challenges to being able to create the future one prefers is the inability to reimagine, in other words, to generate mental images of a future not yet experienced. In the field of peace studies, the ability to imagine a world without violence or war is considered critical to being able to create it (Boulding 1988; 1995; Polak 1961). Both Boulding and Polak suggest that people are not born with this capability and that it must be modelled, taught and practiced. Similarly, in the disability sector people are rarely called upon to generate images of a preferred future and the dominant discourse is one of tragedy instead. People become well-practiced at describing the negative images and experiences of disadvantage associated with having a disability, particularly when it comes to entry and planning process in the specialised service and support system.

In telling the story of people with disability and their family as part of the campaign for NDIS reform, the dominant discourse was of people living lives of isolation, poor health, and exclusion. The images were compelling and effective. Unfortunately, they kept much of the sector rooted in Horizon one rather than inviting movement to Horizon three and a range of possible futures.

3 The Blue Skies Scenario: A vision for a brighter future

Creating the conditions where individuals and families are willing to consider a range of possible futures

In 2009, the disability sector was unaware of the possibility of major policy reform, the NDIS, that would emerge from the recommendations of the Productivity Commission Inquiry into “Long Term Disability Care and Support” two years later. Various disability sector stakeholders were aware that (a) continuing with business as usual in a deeply flawed disability service system was not an acceptable way forward, (b) that activist groups and individuals were tired, discouraged and largely absent from the conversation, and (c) that vision for the future in the disability sector was absent or bleak.

The first seeds of the blue skies scenarios emerged in 2008/2009 when thirteen key disability sector stakeholders decided that the task of system change in the disability sector was bigger than any of them as individual lobbyists, advocates or academics. In a state where more than 80 % of the people with moderate to profound disability were without any support, they were no longer able to justify waiting for the system to respond. While amongst their own constituencies, they could each generate angst and blame of others for the situation, they were unable to affect the scale of system change required. Moreover, they were starting to recognise the limitations of expecting the government to drive change and had started to look for leadership at a grassroots level.

The idea of creating an alternative vision for people with disability, their family and supporters came quickly. The work of building trust and finding common ground between people more familiar with being in adversarial relationship with each other, took nearly two years. The relationship between parent advocates and service provider representatives was critical in this first stage and key to success. The parent advocates were fierce in their relationship with a system that had failed to support their family member over a lifetime. Service providers represented the “nameless, heartless, useless” system they had been compelled to live with (Robinson & Chenoweth 2012). The early conversations were endured rather than enjoyed but, in each actor’s willingness to remain in conversation, they came to a place of mutual respect and found enough common ground and shared value base to work with.

As they were working toward common ground, the members of the group started introducing some of Meg Wheatley’s living system ideas (Wheatley 2006) into the work, and learned and practiced the art of hosting conversations around powerful questions, e.g. “what would it take to create a disability service system that meets the needs of all Queenslanders?” Early feedback indicated that the real question was “how do we create a genuinely inclusive community”.

3.1 The scenario building work

It was based on this foundation that the original blue skies circle spent three days together at Walkabout Creek in Brisbane, building a series of scenarios for a better future for people with disability, their families and supporters. A community development scenario building approach was used as structure.

The process worked for two reasons: The first was the amount of preparation by key members of the group to get the right people at the table. The group comprised prominent systems and individual advocates, people with disability, peak body and service providers, academics, a deputy director general, a member of the office of the Minister for Disability Services, and parent advocates. Group membership, by design, included representation from regional Queensland, young people, and people outside of the disability sector. Each of the participants had established themselves as leaders in a relevant context – yet the grouping had no precedent. It was an unexpected alliance!

The second reason it worked was the process itself. The three days started with a sharing of personal stories – a transparent and deliberate attempt to build trust and respect. From the beginning, the stories shared were so deeply personal and generous that common ground came quickly and a deep trust in each other followed in time. While there were a few changes to composition of the group, the culture that was established in those first few hours together set the pattern for all of the work since.

Much of the work, both in the scenario building phase and the developmental work that ensued, drew on appreciative inquiry-based tools (open space, world cafe, and conversations that matter) and involved people coming together in hosted conversation circles. There is something special about working in circle on complex issues, where people are invited to bring in the best part of themselves allowing something to be created that would never have emerged if had they worked alone.

3.2 The launch

Pulling together a single vision from the three scenarios that emerged from the workshop flowed easily. While there wasn't the need to rewrite or add to the vision, the group quickly identified the need to deepen the clarity of the vision by developing a "principles and elements" companion document. This provided a useful opportunity to engage a broader range of stakeholders and together these documents formed a useful reference point for policy makers in and out of government.

The blue skies scenario, so-called because it suggested a brighter future, enjoyed strong support from the Minister for Disability Services, no more so than in her offer to launch the scenario and to use its principles as a key reference point for her 10-year plan for disability services cabinet submission.

The launch was initially anticipated as a gathering of 50-60 people with sandwiches on the lawn at Parliament House in September. 350 people responded to the invitation and the event was moved to the adjacent botanical gardens where it attracted significant media attention and community support.

3.3 The conversations

After the launch, Queenslanders were invited to initiate their own conversations on December 3 (International Day of People with Disability) around an element of the scenario that mattered to them. 138 people offered to host conversations across the state and were sent a “how to host a conversation kit”. Feedback was received from over 1500 Queenslanders who got involved in those conversations in all parts of the state. The data was shared with senior members of government on December 10 (International Human Rights Day) of the same year.

3.4 The follow-up

The work of the group following the December 3, 2009 conversations was largely behind the scenes and focused on using the vision to influence the Queensland 10-year plan for disability services, and the shape of the NDIS (formerly named the Long-Term Care and Support Scheme by the Productivity Commission at a national level). The early part of 2010 was also an opportunity to pause and reflect on who and what Blue Skies should/could be and a Charter developed in response.

3.5 The challenges for the group

When an idea captures the imagination and builds momentum on the scale of the Blue Skies vision, it is tempting to get a treasurer as well as some funding and to register a charity. The group certainly felt a surge of responsibility as stewards of the vision but thankfully resisted going down the incorporation path. They experienced the power that comes from holding a vision lightly and offering clear principles as a point of reference for people trying to navigate their way through the complex maze that is our human service system.

3.6 The outcomes

The vision was powerful because it was an idea whose time had come and because there were enough Queenslanders who cared enough about people and families to step up and demand something different. The power and authority of the vision didn't come from the blue skies group being a well governed organisation, or having money, or being of a particular political persuasion. Its power came from

being a gently held vision for the future that had no agenda other than wanting to promote and support a genuinely inclusive community. It was powerful because it invited personal responsibility rather than blame, and it offered supporters the chance to be at their best in their work.

The Blue Skies vision found its place as a platform for strengths based, community driven change. They met every month for a couple of years, focusing on various topics of shared interest – housing, developing a social diversity bill, and perhaps most significantly, engaging with the early stages of major reform – the National Disability Insurance Scheme. Members became individually active in the national NDIS Campaign (Every Australian Counts), a range of Advisory Groups at Commonwealth and State levels and working directly with government departments on the various work plans for implementation of the NDIS. Lobbying efforts around legislation and surety in funding were successful and the narrative was both well aligned with the Blue Skies Vision and optimistic. The NDIS enjoyed bipartisan support and a relatively smooth transition into being.

On the surface, the Blue Skies work appeared to have made a useful contribution to reform but in retrospect, the unfolding of the NDIS may have been better served with visible, community driven reminders of the vision throughout the implementation phase and beyond.

4 Implementation of the NDIS

For many Australians with disability, the NDIS has provided unprecedented access to support. However, it has failed to sustain focus on all three of the initial criteria for access – need (based on function rather than diagnosis), context (strength of support network), and aspirations (personal vision for the future). Perhaps as consequence, the language of visioning and dreaming have remained largely absent from the process, plans and conversations of NDIS participants. As a direct result of this observation, the author commenced independent post graduate research in 2013 to better understand the relationship between disability, vulnerability, and power to shape one's own future (Rose 2017).

The research was undertaken during the national implementation phase of the NDIS with the aim of exploring the connection between vulnerability and capacity to anticipate and shape the future. More specifically, it explored the following emerging questions

1. Given the impact of disability and vulnerability discourses on both service system and individual identity, how readily will people adjust to the reframing of future possibility offered by the NDIS?

2. Will stories of lived experiences of navigating the service system sit awkwardly with promises of choice and control offered by the NDIS?
3. If power is contextual then what shifts in power relations will flow from NDIS, as a new context, for the various stakeholders – people with disability, their families, their service providers?
4. Is it possible for the vulnerability associated with disability, projected or denied, to co-exist with power to shape the future?
5. Will people be able to generate the positive images of the future needed to imagine something other than what they have experienced?
6. Will people be able to not only imagine alternative futures but make and give effect to those decisions that will bring such imaginings to life?

Causal Layered Analysis, a tool from the field of futures studies (Inayatullah 1998; 2015) was used as group process for mixed groups of stakeholders across metropolitan and regional Queensland. These workshops explored the central themes of disability, vulnerability and power, with participants invited to reflect on the ideas, images and worldviews as they became visible.

CLA is a layered process of examining first the litany or most visible layer of a story; that is, the version seen in the media, reflecting the most superficial, often emotive, view of people with disability with stories of hardship and exploitation or, alternatively, inspiration at overcoming seemingly insurmountable obstacles. This is followed by a second layer, which is about interpretation or analysis of social causes, historical and political context and is often accompanied by blame of whatever part of the system is responsible. This may include the social service system as a whole, service providers or individual workers charged with keeping people free from harm. The third is a deeper layer, which invites examination of the impact of structure, discourse and worldview on the phenomenon being studied. In the context of this research, the third layer may be about the academic, rights-based or ethicists' view on the experience of disability. The fourth and deepest layer consists of analysis of the collective story – at myth or metaphor level – that drives the phenomenon, often unseen and unexamined (Inayatullah 1998; 2015).

Each layer was presented as a discussion prompt in the form of a question. People were invited to choose from a range of images and/or generate words, phrases or examples of what each of the three constructs (disability, vulnerability and power to influence the future) mean to them. The images and text were used to populate a CLA matrix, with the three constructs – disability, vulnerability and power – to influence the future at the top of each column, and the four levels of litany, social cause, worldview and image/metaphor at the beginning of each row using a standard template drawn on a whiteboard, wall or floor, for example

Table 2: CLA on Stakeholder understandings of disability, vulnerability and the future

	Disability	Vulnerability	Futures
Litany	<ul style="list-style-type: none">• Be grateful• Keep expectations low• You're on your own	<ul style="list-style-type: none">• There's no vulnerability here• Inclusive communities are the answer	<ul style="list-style-type: none">• There's no optimism here• The future is uncertain• Negative past constrains the future
Social Cause	<ul style="list-style-type: none">• Inequality in valued status and access to resources• System works for providers not people• No privacy in the service system	<ul style="list-style-type: none">• Inaccessible transport and affordable living arrangements• Insufficient support creates vulnerability	<ul style="list-style-type: none">• Access to supports as measure of success• Funding always linked to political cycle – uncertain
World-view	<ul style="list-style-type: none">• People with disability need protection• Systems are untrustworthy	<ul style="list-style-type: none">• Knowledge is power• Community is dangerous• Invisible is vulnerable• Surveillance is dangerous	<ul style="list-style-type: none">• Uncertainty is negative• Choice is overwhelming and risky• Choice is an illusion
Meta-phor	<ul style="list-style-type: none">• Eternal child• Life's a struggle	<ul style="list-style-type: none">• There will never be enough• Butterfly trapped in a cocoon	<ul style="list-style-type: none">• Life is a compromise• Dreaming is for children

The key findings from group CLA's included the following points:

- Numerous tensions and contradictions were noted in the comments of participants as data gathering unfolded.
- The strongest ambivalence was noted with regard to community, which was considered both a source of possibility and a source of danger.
- A lack of optimism for the future was associated with the idea that dreaming is “for children”.
- Feedback suggested that people value knowledge needed to navigate the system to access resources more highly than self-determination.
- People stated they were willing to adopt whatever mask (identity) needed to get what they or their family member needed.
- The discourse of disability as a social construct was used to explain disadvantage and exclusion, rather than as a platform for transformation.

- While some people had experienced success with attempts to influence their circumstances they had little expectation that this power would generalise to other contexts.
- Choice was considered by some to be an illusion.
- Vulnerability appeared to be a powerful driver of behaviour, though it was not always visible.
- Vulnerability was mostly understood in terms of power over, in the form of physical, sexual, emotional or financial exploitation at the hands of a potentially “dangerous” community.
- Fear of harm and homelessness were not verbalised but were implied in the narrative.
- The importance of enduring family relationships as a protective factor was raised, but there was no mentioning of other protective factors such as involvement with services, safer public spaces or greater civic mindedness.
- With regard to power, people with disability and their families were familiar with the idea of building social capital to help get good outcomes from the system but had little expectation that it guaranteed success.

5 Potential for Causal Layered Analysis to open up a range of possible futures

Inayatullah (2015) was significantly influenced by the work of Jungian psychotherapists Hal and Sidra Stone (1989). The central premise of their work was that we are all born vulnerable and that our personality develops as a product of how we protect our vulnerable inner child. A multitude of selves develop in response to our experience of being rewarded or punished for certain behaviours as we grow. They refer to our primary selves or ego as the window through which we see the world, selves that are invisible to us unless we discover the range of disowned selves that obscure the ego. Inayatullah (2015) associates this discovery with the process of revealing and deconstructing current reality that is necessary to open up future possibility.

Over 30 years of practice, CLA has become both theory and process for transformation. Developed in the 1980s as a four-layered process for mapping the external world – the discourses, the worldviews, assumptions and underlying myths, metaphors and images – CLA has become a valuable tool for mapping self-transformation. By revealing the multiple layers of self and exposing the vulnerable self the path is opened for individuals to not only see but integrate their multiple selves. Inayatullah (2015) deliberately situated CLA in the work of Hal and Sidra Stone in order to challenge a single view of reality; he wanted to open up the idea of multiple possible futures by introducing multiple lenses (or selves) through

which reality, past, present and future, could be viewed. Not only does such a process allow an objective view of multiple layers but it allows the complexities and contradictions to be viewed and examined. In the disability sector, such contradictions and dualities are readily apparent, for example the community as welcoming and inclusive versus the community as dangerous.

It is Inayatullah's (2015) view that the opportunity to examine such double-binds and discern whether they are helpful or constraining is an essential part of anticipating and shaping one's future:

"The challenge, as with all foresight work, is to move from fragmentation to the preferred future, the integrated way forward. By identifying the issues (the internal research question) and the double binds that restrict their solutions, individuals create alternative maps of the consciousness and then move toward a new metaphor, a new life narrative, and consequently an alternative future." (Inayatullah 2015, 14)

It was apparent in this research that revealing and reflecting on beliefs and world-views that underpin ones' experience of reality had the effect of softening them, opening a pathway to new narratives. It was also apparent that while many of the participants felt initial resistance to imagining a better future, they were happy to engage with images, texts and ideas to explain their experience of choice and control.

6 Conclusion

The National Disability Scheme has been the largest reform in the provision of disability supports that Australians could have imagined. The creation of the NDIS parallels our largest ever health system reform and has enjoyed bipartisan support in both design and implementation. It has also addressed, in fair measure, the deep well of unmet need for disability supports experienced before it existed. Currently, the NDIS is delivering in large part on the vision for an inclusive community developed by the Blue Skies team in 2009. It remains, however, at risk of being predominately transactional and administrative, rather than delivering on the transformation promised at both system and individual levels. In the framing of the Three Horizon model of future making, both system and individual are struggling to let go of the past – *business as usual* – as they continue to use the same service system and fail to bring "choice and control" to life. Rather than being drawn to a more meaningful vision of the future, we see individuals and families locked into patterns of engaging with the service system of the past. While the expectations of support are higher, people are still filled with uncertainty and anxiety on engagement with the system. Rather than bringing descriptions of a reimagined future with them to their individual planning process, they bring a wish list of supports needed to get by today and tomorrow.

At a system level, the pattern is similar – a return to *business as usual*. There is anxiety about cost blow-outs and ever-increasing centralisation of control over budgets and decision making, leaving little space for visions of a decent life by people with disability. Rather than face the future (Horizon 3), both system and individuals are still trapped in the beliefs and worldviews of the past (Horizon 1).

In conclusion, failing to extend engagement and ownership of the “Blue Skies” vision to the disability sector at a national level was a mistake. Failing to deepen and maintain a vision for a better future for individuals and families, in full sight as the NDIS was designed and implemented, was a mistake. It left no compelling reference point to steer by or evaluate progress of implementation. It let measures of success be reduced to numbers and costs, rather than stories of a decent life gained. We demonstrate what we value by what we choose to measure and, thus, we have unwittingly allowed the NDIS to become a transactional rather than transformational reform.

The Blue Skies experience in 2009 suggested that when people with diversity in life experience and systemic worldviews come together with shared purpose, compelling images of better futures can be generated. When individuals have the opportunity to reflect and reframe their own narrative, build their expectations of self-determination and engage with service systems more powerfully, their lives can change.

With regard to the question, “*Is it possible that CLA as a tool might provide a path at both individual and system level for revealing then reframing the dissonant beliefs and narratives that underpin current reality, in order to reconstruct a brighter way forward?*”, the answer is yes. It is not only possible but desirable that people be enabled (taught and supported) to reimagine their future rather than repeat their experiences past.

The Blue Skies scenario prior to the NDIS demonstrated that a compelling vision for the future can mobilise a whole community and allow us to face our future at both individual and systemic levels. A small piece of independent research inspired by the NDIS failing to deliver on that vision suggests that it takes more than vision and that the field of futures studies has much to offer. Causal Layered Analysis as one example, provides both theory and tool for revealing and reframing limiting beliefs and narratives, enabling a brighter future.

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