

Side By Side Advocacy –
Disability Royal Commission Team
Observations, learnings and recommendations



side by side advocacy

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Introduction

As the submission phase of the Royal Commission into Violence, Abuse, Neglect and Exploitation is drawing to an end, the Side By Side Advocacy Disability Royal Commission team has stopped to reflect on what we have learned about advocacy from the people who we have been lucky enough to join for parts of their journey. In particular, we have been reflecting on what has been different about the advocacy support we have provided to people affected by the Disability Royal Commission as compared with individual advocacy requests not relating to the Royal Commission.

Three learnings stand out

- 1) When advocates are afforded the opportunity and resources to plan and engage with people from a place of comparative strength rather than responding in a reactive fashion, long term positive change can more easily be facilitated in the lives of people with disability who have experienced violence, abuse, neglect and exploitation.
- 2) When advocacy is available in conjunction with emotional and legal supports, it is possible to meet people 'where they are' and support them to decide what would bring them a sense of meaning, release, and/or justice. This contrasts with triaging need on the basis of imminent risk of harm – a scenario that often happens where there are limited advocacy resources, significant demand and contact is made with an advocacy organisation at a time of crisis.
- 3) A common theme through so many of the conversations we have had with people who have experienced violence abuse, neglect and exploitation in institutional and segregated settings, is how humble their expectations are about what could begin to heal the harms done.

This submission will primarily focus on how we planned and delivered advocacy to people affected by the Disability Royal Commission and what we observed and learned from that experience. We also set out our conclusions and recommendations

It will also include reflections based on our previous experience of advocacy models and sector practices.

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Rationale

Our earliest discussions about how we might approach advocacy for people affected by the Disability Royal Commission, recognised that as a small, specialist advocacy organisation embedded within our community, we had a responsibility to ensure that we made the Disability Royal Commission accessible and meaningful for that community. Many members of that community would experience barriers to engaging with less specialised advocacy organisations.

Side By Side Advocacy specialises in advocacy for people with intellectual disability. We provide:

- Citizen Advocacy
- Individual Advocacy (including Family Advocacy and Self Advocacy as appropriate)
- Support for people to appeal decisions of the National Disability Insurance Agency at the AAT
- Disability Royal Commission Advocacy.

We are also researching ways that people with intellectual disability can better have their voices heard on management committees and boards via an Information, Linkages and Capacity Building (ILC) grant.

Our Citizen Advocacy Program – a proactive rather than reactive form of advocacy - started more than 30 years ago and informs our understanding the life experiences of people with intellectual disability.

Our organisational history means that many people within our extended community have

- complex communication, cognitive and social support needs
- limited access to, or engagement with, traditional or social media
- limited opportunities to engage outside of congregate or segregated
- either no unpaid relationships in their life or limited, fragile or low-quality unpaid relations.

As we know and research confirms, people with these attributes have an increased likelihood of being dependent on the persons and systems enabling, contributing to, perpetrating violence, abuse neglect or expectation.

Many have so normalised violence and abuse, that it would be unlikely to occur to them that such a seemingly banal and routine experience might constitute something worthy of sharing, let alone seeking to change.

With this in mind, we drew on the stories and experiences we had witnessed over our individual and collective decades of advocacy experience to develop a strategy that might include some of the most vulnerable and marginalised voices as part of this conversation.

These voices that belong to people so often characterised as ‘hard to reach’ are in many cases very easy to find but continue to be very easy to miss. They are all too often located in places where they lack the support or opportunity to be anywhere else. Choice and control are mostly alien concepts to them.

Many of Side By Side Advocacy’s long and ongoing connections are with people who grew up and lived in large institutions. Many still live in institutions of a more domestic scale.

We made engagement with this cohort characterised as ‘hard to reach’ our priority. We started with outreach and engagement. Any decision about whether to complete a submission to the Disability Royal Commission could come later.

We also began with the premise that if you are experiencing violence, abuse, neglect or exploitation, the priority must be safety.

If you have normalised violence, abuse, neglect and exploitation, you need to understand and believe that you have a right to be free of them before you might be in a position recognise the Disability Royal Commission’s terms of reference as having any relationship with your lived experience.

If you have normalised being silenced, or if being disbelieved is your expectation, you need the opportunity to believe there is a purpose in speaking up.

If being heard, understood and believed takes more effort than most people could imagine, you need time, space and compassion to build a safe and effective communication partnership before it is possible to even contemplate sharing your story.

With that understanding, we developed a strategy that we knew was likely to have a high failure rate in terms of the number of submissions we would facilitate. We understood that quantity of submissions was not the right measure for what we were aiming to achieve.

We determined that the goal of our outreach and engagement needed to letting people know that there could be something different, something more than their current life experiences.

When doing 'in-reach' into segregated and semi closed settings, our goal was to ensure that people had the pre-requisite knowledge for understanding what constituted violence, abuse, neglect and exploitation. We needed to convey to everyone we engaged with the message that they are important, that they have value. That the things that make life good for them are important no matter how much others may have sought to trivialise them.

What we observed

Trust takes time to earn – same time, same place, same people.

Meeting people where they are at works, but you cannot just do it once and expect people to talk.

Many people we spoke with who worked at Australian Disability Enterprises (ADEs) were sceptical the first time we visited. The second or third time we visited, many people began to engage and share.

One person explained that so many people came and asked them questions, or "told us stuff" then never came back. Another person asked if their work had

paid us. They only ever got asked what they thought when it came to audits. A number of other people only spoke to us once we mentioned (with permission) the names of others in their peer network we had assisted with advocacy support in the past.

In short, reserving trust is an understandable and appropriate response.

Gaining that trust takes time and resources. It takes being physically present, it takes consistency of advocates, it takes the time and skill to actively engage with communication styles which may be less direct.

Relationships are indispensable

Journeying together builds trust and a shared language. It allows an advocate to model what they want to see in the world. Whatever the person with disability wanted to talk about was validated. This allowed people with significant cognitive and/or communication support needs the time and space to move from the 'trivial' to the sophisticated articulation of their experiences, values and aspirations.

In some instances, this led to incredibly moving submissions to the Commission. One person went from being too ashamed to speak aloud about what had happened to them, to a recorded interview submitted under restricted privacy settings, to being a lived experience witness at a public hearing.

Another person progressed from wanting to make a submission about a bus driver who was mean, to talking about the intersections of disadvantage they experienced due to having intellectual disability, physical disability and being a migrant.

Yet another person attended a private session from the bed of a nursing home in Covid-19 lockdown. They had been discharged from a three month long hospital stay only two days prior. They were unable to sit, and so made the submission via an iPad held above their head.

A number of people completed private sessions using highly individualised communication styles. Some required a trusted communication partner to interpret for the Commissioner.

For some people, nurturing an ongoing advocacy relationship resulted in meaningful life outcomes that would not otherwise have been possible.

For one person, premature entry to a residential aged care facility was averted.

For one person, it was the sense of having left the abuse behind that allowed them to begin catching up on the life that had been taken from them.

For one person, it was the opportunity to build a support network of their own choosing that allowed them to flourish.

For another, it was being able to teach peers about their rights and what it means to have valued status.

For a few people, it meant choosing where they lived for the first time in their life.

For many people, it was re-establishing connections which had been severed by the actions of others.

For many families, it meant planning safeguards to protect from violence, abuse, neglect or exploitation in the future.

And for others it was simply the knowledge that advocacy is a thing which exists.

The seemingly trivial can be the most consequential

A number of people initially raised seemingly trivial advocacy requests with us. These would not be matters that would be perceived to relate to the Commission's terms of reference. With time, trust and further exploration, many of these people made some of the most consequential requests for advocacy we received.

This approach also modelled the message we wanted to convey, that each person deserves to be heard. If someone wanted to talk to us about how much better it was when they got chips for morning tea rather than fruit, we would listen. If someone wanted to tell us about a disagreement with a family member or house mate, we would listen. If someone wanted to tell us about having been imprisoned in an institution for more than 20 years, we would listen.

We were also mindful that this approach would not replicate what is so frequently the experience of 'easy to miss' people - that what you have to say only matters if it fits within a defined survey or study and/or if it triggers a formal complaints response.

In some instances, the initial topic raised, or advocacy request was a way of measuring our credibility. Why would anyone make themselves vulnerable without trust? After we had taken this seemingly small issue seriously, a much more personal issue would be disclosed.

In other instances, the matter only appeared trivial if judged against the wrong scale. Lives can be so precarious that the seemingly trivial can have massive personal or practical consequences. The 'trivial' was what made life worth living for that person.

The cumulative harm of ignoring the 'trivial' is one of the most pervasive forms of neglect and abuse witnessed. For a person who communicates informally, it might be that they are repeatedly told "we don't have any" when they ask for one drink rather than being offered an alternative for which they may not have the word. For another person, it might be that online grocery shopping is easier meaning that they never get to point out their favourite flavour of ice cream.

One person summarised this type of abuse so eloquently - 'my time isn't worth anything, but if I keep them awaiting, I get in trouble.'

Moving beyond purely reactive advocacy allows for lasting change

The possibility of a slower pace of advocacy afforded by our approach to Disability Royal Commission advocacy, allowed the time to be present with people. In many instances, this meant a relationship-based approach rather than an issues based approach.

When people did present with a crisis, that was illustrative of what we know to be a common experience of too many people with disability, we would offer advocacy support. As we addressed the crisis in a practical fashion, we would listen. As the crisis subsided, urgent issues would begin to emerge. Again, as we addressed those, we continued to listen. This pattern continued, and we

addressed issues that were irritating, and continued to listen. It was only then, that that people began to share what was missing in their life, what would constitute a good life. And often what was missing could be perceived as trivially small by any objective measure. It might be calling a friend or going for drive on the weekend. But a life devoid of such simple autonomy and basic human connection is at the heart of what it means to be institutionalised, to be objectified, to lack meaningful choice and control.

Advocacy that meets people where they are at – literally and metaphorically - works

Conflict of interest and the normalisation of an impoverished and segregated existence make the most vulnerable people even more vulnerable. Vibrant, diverse support networks keep people safe. Access to advocacy cannot be contingent on being able to ask for it in formal language.

Not everyone has the skills, safety or resilience they need to benefit from issues based advocacy. Some of the most damaging forms of abuse and exploitation are not the result of any single issue. They are the cumulative impact of systems and institutions that are predicated on assumptions that have no relationship with people's lived experience.

- Imagine being asked about your family and the support they provide every time you fill out another new client profile form, when your experience is that you were relinquished to institutional care as a young child.
- Imagine being asked to prove your disability every time you have an NDIS review even though the state whose care you were in never deemed you worthy of a diagnostic assessment.
- Imagine being asked to demonstrate your testamentary capacity by giving an average price of a house or car when you have never been allowed to choose where you live or to buy something as simple as some clothing without asking permission.

Imagine being presented with an abundance of glossy brochures, weblinks and other information in a style that you do not understand and/or cannot access but that everyone else in the room seems to assume that you understand.

We cannot expect one type of advocacy to work for all people with disability as if disability is any one single thing. To presume a person with complex support needs across multiple domains of their life can automatically access and benefit from short-term, issues based advocacy in the same way as a person with support needs in few domains, is to fail to recognise the individual nature of disability and to reinforce a deficits model of disability by expecting the person to change to fit with what is available rather than providing the person with the support they require.

We also cannot presume that information provided in plain English or Easy Read formats will suit all people.

We should be providing information in a range of formats – including person to person information sharing - and allowing time to build understanding.

We should be building capacity within and around people with complex support needs.

What we learned

Side By Side Advocacy's Disability Royal Commission advocacy efforts and historical experience has led to learnings relating to people with disability, and particularly people with intellectual disability.

People accessing advocacy

- frequently take time to trust an advocate – sometimes meeting on multiple occasions before advocacy can productively start
- may experience change at a pace slower than is measured by common outcomes tools
- may initially present with a small advocacy issue until trust is sufficient to share more substantial issues
- are likely to have experienced multiple traumas
- benefit from trauma informed specialist advocacy and the availability of complementary support such as counselling
- need advocacy that is easy to access

- benefit from a flexible advocacy style - including the option of face to face, in a familiar location, at a time that suits
- may benefit from supported decision making.

Other learnings are noted below.

- Crisis advocacy can lead to self- advocacy, but this requires the resources to continue along the journey with the person beyond resolution of the immediate crisis.
- Reactive advocacy fails the most vulnerable people who are dependent on others to realise they might benefit from advocacy or to facilitate their access to advocacy support.
- Self-advocacy can take many forms. For some people it may be learning they can ask a worker to “call Sarah”. For others it might be a 15 minute phone call to an advocate when they are not sure how to proceed or if they are at risk. For others it might be giving consent to regular advocate check ins or for issues to be followed up.
- In-reach works. We began to pilot in-reach efforts at the beginning of 2020/21 and the results began emerging in earnest in 2021/22. We have reached people who previously did not have access to advocacy. These people are now able to have more meaningful choice and control.
- Systemic failings have been magnified as Covid - 19, floods etc leave people more isolated. There is not ‘give’ left in the system and tight resourcing has left gaping voids.
- Advocacy takes time. Some services, families and people with disability are suspicious of the motivations of advocacy organisations and others who they do not know well. Trust and sharing take time.
- Repeat attendance at events resulted in increased participant confidence. We noticed that where participants attended more than one event, there was more participation, more questions and more sharing as confidence grew.
- Participants who were introduced to advocates by peers who had connections with the advocates engaged more readily than when advocates

introduced themselves or were introduced by workplace supervisors or other paid supports.

- Disability Royal Commission outreach has prompted people to address negative life experiences – including of a historical nature. Following these disclosures, people benefit from ongoing support.
- Many people with disability making a Royal Commission submission are experiencing ongoing abuse, neglect and exploitation and have multiple support needs.
- Making a submission to the Royal Commission can be one element of a healing. Redress actions are also important - such as restoring relationships, preventing further abuse, access to counselling.
- There is considerable unmet need with many of the most vulnerable members of the community experiencing neglect relating to basic health care and other needs.
- Many people with disability experience barriers to communication via technological means such as Zoom. Face to face communication and access to a physical meeting space are important for effective advocacy.
- Many people with disability in Side By Side Advocacy's service area have experienced a long history of institutional type living and have few if any freely given relationships in their lives. Many communicate informally. In these circumstances, they are particularly vulnerable to abuse and neglect.
- Our observation is that people with intellectual disability who have no freely given support network continue to be largely limited to congregate, service options. Advocates must strive to achieve the least worst option. The benefits of individualised funding that have been experienced by many people with disability have largely alluded this cohort.
- Many people who have lived in institutional type settings have experienced ongoing abuse and neglect such that their health and other needs are more complex and varied than may be anticipated for a person of their age and disability label.
- If some people with disability who need advocacy cannot come to us, then we need to go to them. This is long term work.

Conclusions

There are many more stories of abuse, neglect and exploitation that need to be heard. Many of those stories never made it to the Commission because of the impact of continuing violence, abuse, neglect and exploitation experienced by that person.

If we are serious about our obligations as signatories of the UN Convention on the Rights of Persons with Disabilities, the availability of advocacy is critical for people with disability including those with intellectual disability and complex communication styles.

The absence of freely given relationships and isolation for many people with intellectual disability in Side By Side Advocacy's reporting area leaves them in a state of ongoing vulnerability and in great need of access to specialist advocacy. Moving beyond issues based advocacy to assist people to work towards their goals and aspirations for a good life is needed.

Outside of Disability Royal Commission Advocacy, Citizen Advocacy Programs can play a substantial role in identifying people with unmet need and linking them with ordinary citizens. The citizen, in combination with the Citizen Advocacy Program Coordinator can be alert to the potential for problematic things happening that would go unchecked without ongoing advocacy. This proactive form of advocacy can be life changing for people with intellectual disability, help raise awareness of the life experiences of people with intellectual disability and contribute to communities being more inclusive.

Advocacy needs to take forms that meet the needs of all people with disability – including those that are hard to reach (although arguably easy to find but seldom heard). That includes all forms of advocacy currently available including proactive forms of advocacy such as Citizen Advocacy.

The availability of specialist advocacy that allows time and space for the building of trust, shared understanding and for supported decision making is critically important.

Not funding advocacy is a false economy. Where advocacy is not available in timely fashion, situations escalate and move into a situation of crisis. Recovery can take years if it happens at all. A comparatively small increase in advocacy

funding would have a disproportionate impact on the life experiences of people with disability and in moving towards an inclusive society.

Including and appropriately supporting people with disability, including people with intellectual disability, to be consulted, involved and take up meaningful decision making roles in community organisations is a further important step in increasing meaningful choice and control.

Recommendations

- 1) Provide sufficient advocacy resources to make it possible for advocates to provide advocacy support in a way that is useful to the people that need it. This would include allowing for face to face engagement and the time and space for the building of trust and for supported decision making. Trauma informed, easy to access, flexible specialist advocacy is needed.
- 2) Provide ongoing advocacy resources rather than short term, project based funding. Short term wastes skills, money and is not consistent with trauma informed practice. Short term leads to poor planning, losing trained staff, skilled people leaving the sector. It leads to wasted time scrabbling for funding and writing submissions. It leads to exacerbating anxiety and wasting time as advocacy organisations that are beyond capacity attempt to make referrals to equally busy colleagues. It leads to a lack of trust and the need for more time and resources to rebuild trust. It leads to wasted lives for people with disability and to lost opportunities both for people with disability and the community.
- 3) Make available ongoing resources - rather than project funding - to proactively build networks and capacity for people with complex support needs. Without this ongoing support and facilitation, the most vulnerable are likely to continue to access only the least worst disability specific, congregate options.
- 4) Recognise the critical importance of proactive forms of advocacy such as Citizen Advocacy that are about more than dealing with an articulated crisis and adequately resource such advocacy.

- 5) Recognise the importance of responsive, flexible advocacy in all its forms including Self and Family Advocacy.
- 6) Provide complimentary services such as counselling and legal services that have been available during the Disability Royal Commission to continue to be available.
- 7) Provide information from government in a range of formats including plain and Easy English as well as in ways that enhance accessibility such as larger fonts and hard copy. Provide resourcing to allow for those that engage with people with disability to provide information in meaningful ways.
- 8) People with disability, including people with intellectual disability, should have meaningful opportunities to provide feedback and make decisions relating to organisations that impact on their lives. For this contribution to be meaningful, it must be evidenced based and appropriately resourced.