Issues arising from the death of a 54 year old disabled woman living independently in South Australia. Author: Katharine Elisabeth Annear BAppSc(DisStud) MDisStud DEAI

What follows is a review of some of the issues relating to the systems surrounding people with disability in South Australia who may also be vulnerable to abuse and neglect. This is prepared in good faith as a private citizen who lives with impairment and disability and who has and does engage in systemic and individual advocacy both in a paid and volunteer capacity. Versions of this document have been shared with other interested parties and may be used to form policy responses and recommendations that are in the best interests of South Australians living with disability.

“In Kind” Supports under the Bilateral Agreement

In 2018 South Australia entered into a Bilateral Agreement with the Federal Government that set out the terms of transition to the NDIS and the financial contributions to be made by respective parties. The financial contribution made by South Australia effectively meant that most of the money related to providing services to people with disability was committed to the NDIS. This began to leave gaps and shortfalls in disability services that fall outside of the NDIS and eroded their supporting bureaucracies including the human capital and knowledge base that previously existed in within government departments.

It must be noted that not all service types have been transitioned to the NDIS and some may continue to be delivered by the South Australian Government until as late as 1 June 2023 (the review date of the current agreement). It is these responsibilities that must be the focus of some attention.

Under the Bilateral Agreement the Government undertook to deliver Specialist Support Coordination and Coordination of Supports for people with disability transitioning from existing state services to the NDIS. The phase out deadline of this arrangement is June 30, 2020. It has been reported by numerous participants, their nominees and advocates that although this ‘in kind’ support was stated in a participants plan they received no contact from Disability Services (SA) or upon making contact were told that the service was at capacity and no-one could be assigned to provide the support.

Of note the Bilateral Agreement states the following regarding quality and safeguarding:

32. The Parties agree that other existing Commonwealth and South Australian quality and safeguarding arrangements will be in place:
   a. for services for people with a disability delivered through service systems outside the NDIS;
   b. for matters which fall outside the jurisdiction of the NDIS Commission;
   c. to cover all existing clients that have not transitioned to the NDIS; and
   d. to cover all in-kind supports, which do not fall under the remit of the NDIS Commission because they are not funded under the NDIS Act.

Many of the vulnerable people with disability (those without natural support networks or advocates) who transitioned from Disability Services (SA) to the NDIS did so without access to information or decision-making supports which were to be provided by ‘in kind’ support coordination. One result of transitioning without informed supports is inadequate funding to meet the needs of the person with
disability, support coordinators and participants report up to 70% discrepancies in funding between similar clients with and without advocates. Receiving no support coordination in the first plan has also left participants without sufficient evidence to present for subsequent planning meetings resulting in underfunded second plans. Alternatively, some of these people had plans brokered and agreed upon by their existing service providers completely removing the element of ‘choice and control’ that the NDIS was supposed to deliver.

One of the things that must also be attended to with the ongoing ‘in kind’ arrangements (especially accommodation and behavioural supports) is the consequences of ‘institutional layering’. According to Nevile, Malbon, Kay and Carey (2019) ‘layering occurs when new policy goals are introduced whilst retaining existing rules or policy commitments. The NDIS introduced a new policy goal, more choice and control for participants, which means participants are able to choose their service providers as well as being involved in decision-making around the sort of supports they require. However, existing commitments (existing State and Territory government contracts) were retained and participants are required to use service providers funded under these existing contracts until the contracts expire.’ These authors also note that use of ‘in kind’ supports is more expensive and more restrictive. They encourage the use of causal loop diagrams, which focus on feedback and emergent properties, allow researchers to clearly map the, often multiple, effects of a particular set of policy decisions.

![Causal loop diagram](image)

Figure 1. Nevile, A, Malbon, E, Kay, A, & Carey, G. (2019).
Client Capture

It has been observed that some services providers continue to practice what is referred to as ‘client capture’ (David & West, 2017) whereby they provide a range of services (pre-planning, support coordination and subsequent direct supports) effectively capturing the client and their funding within the one organisation. David and West (2017), use various sources to establish a definition of “client capture”: the practice of locking service users into fixed schedules, activities and accommodation under the umbrella of a single service provider (pp. 336).

For example, a local service provider states the following:

We can help you understand the NDIS and:

- Plan for your future
- Guide you through the application process
- Identify what you’re eligible for
- Find support and services to suit you
- Prepare you for your NDIS planning meeting
- Help you track and meet key goals and milestones.

They are then able to offer a broad suite of services from accommodation, living supports, employment and leisure options whilst simultaneously coordinating supports via support coordination – also funded by the NDIS.

This client capture limits the relationships that a person with disability has outside of services provided by the organisation – and may limit their relationships to only ‘paid supports’. The services provided are often segregated; accommodation, employment, and leisure options exclusively for people with disability, restricting inclusion and limiting the formation of natural relationships within the community. An important part of Developmental safeguarding is a ‘wide focus on producing desirable social and cultural conditions for inclusion and protection aimed at ensuring the emergence of freely given and respectful relationships at all levels of the person’s life’ (MDAC, 2011). The ongoing provider imposed restrictions limiting client choice and control introduce and maintain exclusion and risk in the lives of people with disability.
Community Visitors Scheme

The establishment of the Community Visitors Scheme in South Australia was a milestone in Disability reform. The South Australian CVS has been instrumental in giving people with disability (particularly those living at the margins) a voice, pathways to changed circumstances, diversion from potential neglect and abuse, and escape from abusive and neglectful situations. However, in 2019 The South Australian Community Visitors Scheme had its scope limited. Their website states:

*As from May 2019, the Community Visitor Scheme no longer conducts visits to non-government disability accommodation service providers, Supported Residential Facilities or Day Options programs.*

The current Government believes that these settings are now subject to the NDIS Quality and Safeguards Commission and this should provide sufficient protection to vulnerable clients. This action was taken despite the findings of the Westwood Spice Review (2018) that:

**CVS provide local, independent support to vulnerable NDIS participants by:**

- Upholding an individual’s human rights and ensuring service provision is appropriate in order to prevent violence, abuse and exploitation.
- Supporting appropriate decision making reflecting the wishes of individuals.
- Facilitating local capacity building to achieve resolution of issues in services at the earliest possible stage.
- Adding to regulatory intelligence on services and systemic issues to the state or territory as well as to the NDIS Commission.

The Westwood Spice Review (2018) also found that CVS ‘*do have a role to play in safeguarding vulnerable NDIS participants.*’ And that ‘*This role complements and strengthens the protections offered by the COAG-agreed NDIS Quality and Safeguarding Framework (NDIS Framework), including elements enacted by the NDIS Commission.*’

As advice the Review offered the following:

*States and territories may wish to consider whether their Community Visitors have sufficient legislative authority to enter and inspect. The way this authority is provided, if administered by states and territories, should be a matter for those states and territories... This issue should be addressed through a policy decision/drafting practice in each state or territory.*

Given the above, would it not then be prudent for the Government to introduce appropriate legislative and regulatory change to enable the CVS to work within the NDIS framework and share vital information regarding the safety and care of vulnerable people with disability in South Australia.
**Work Force Issues**

The recent report *Working in new disability markets: A survey of Australia’s disability workforce* produced by the Social Policy Research Centre UNSW (2020) highlights significant issues within the NDIS workforce. It is already established that Disability Work is a low paid, highly casualised, at times unstable profession and this report concludes that working conditions are not necessarily improving under the NDIS. Of pertinence is the fact that many workers express significant concerns about service quality in the NDIS. Important findings to emphasize are:

- When reflecting on supervision and support, 59% of respondent workers agreed they had to make decisions about client safety, care and support on their own. Unsupported decision making was also prevalent among less qualified workers: over half of those with less than a Certificate IV level qualification said they had to make important decisions on their own.

- Home-based support workers in particular reported a lack of paid time in which to communicate and build rapport with colleagues, supervisors and senior managers. Consequently, many felt isolated in their job, which added to the stresses of their day-to-day work with clients. The lack of support and supervision they felt exposed them to uncomfortable levels of risk and were a major source of stress. Issues of violence and abuse were consistently raised in relation to perceptions of lack of support and adequate supervision.

As originally stated by MDAC (2011) in almost all cases of neglect and abuse in services the staff person does not set out to harm the service user. It is more the case that workers are ill equipped to deal with complex situations without supervision and decision-making supports. We must also allow for the fact that some people enter the workforce to access a vulnerable population. This is where, in part, worker screening plays a role in establishing a preventative mechanism for prohibiting undesirable workers from working with vulnerable people.

However, worker screening (even when correctly applied) is not a sufficient mechanism to prevent abuse and neglect. There must be multiple redundancies both formal and informal for a safeguarding system to operate effectively.

On the matter of screening workers, it is clear the South Australian Government is still responsible for screening NDIS workers until 1 July 2020. [The National Disability Insurance Scheme (Practice Standards—Worker Screening Rules) 2018]. There have been many issues with the South Australian Screening unit including lengthy delays in having screening processed and the very effectiveness of screening itself being brought into question. The current Government needs a better understanding of how screening forms only a part of a raft of mechanisms that ensure that vulnerable adults with disability are kept safe and free from harm. As can now be appreciated through multiple cases, a person can still ‘pass’ a screening and be a perpetrator of abuse and neglect.

On June 8 Minister Stuart Robert announced 'The NDIS Commissioner... will be granted additional banning powers to prevent people who may pose a risk of harm to participants from entering or re-entering the NDIS,'

This of course relies on those people being identified through multiple safeguarding redundancies in the systems other than just screening.
NDIS Quality and safeguards Framework

The NDIS Quality and Safeguarding Framework (Department of Social Services, 2016) ‘consists of measures targeted at individuals, the workforce and providers within developmental, preventative and corrective domains.’

This framework is well developed on paper but hard to see at work in the lives of people with disability. Much public emphasis has been placed on complaints and corrective mechanisms but little on the developmental and preventative mechanisms needed to keep people with disability safe.

When horrific details of the death of a woman with disability in her own home emerged people rightly asked questions about the checks and balances in place at the time of her death and a criminal investigation and several inquiries have been launched it the circumstances of her death. People also began to ask questions about how a woman could live in the community but not be connected to the community and how people involved in her life did not ‘see’ what was happening. It is reported that the woman entered the NDIS in ‘late 2018’. Within 15 months she had died.

It was the intention of the Federal Department of Social Services when developing the Quality and Safeguarding Framework that ‘participants will take part in a formal risk assessment during the plan development process. They will be asked a range of questions about their personal perceptions of their own safety, their informal safeguards and the level of assistance they need. There may also be questions about their experience managing their finances.’

The question must be asked, did such a risk assessment occur, in person, with the woman in question. Had it done there may well have been problems evident to a trained professional at the time of transition to the NDIS. Developmental, preventative and corrective safeguards could then have been brough into play to divert this person away from neglect and abuse and to increase her quality of life.

Conclusions

Given that in 2011 the MDAC delivered the report inclusion&protection: A dynamic safeguarding schema for South Australians with disability who are also vulnerable to neglect and abuse, to the then Minister, there should be a legacy of understanding within government that inclusion and protection of people with disability is everybody’s business. This business transcends jurisdictional boundaries and legislative frameworks. It starts at a neighbourhood and community level and extends to the United Nations and back down again. It is not just the domain of paid workers, be they support workers, NDIS Planners or Commissioners.

As highlighted earlier South Australia has seen an erosion of the expertise and knowledge base on disability and the lived experience within and around government. In the 2015 financial year the then Government abolished the Ministers Disability Advisory Council which had provided direct and expert advice to the Minister from people with lived experience. Over the course of the transition to the NDIS the South Australia has lost its Disability Policy Unit, the Senior Practitioner for Disability Services, the Principal Community Visitor (whose role was curtailed in 2019) and many of the hard working Government employees who supported reform, communicated with stakeholders, knew clients and championed the rights of people with disability. As a result of so much reform, mechanisms for reporting care concerns within state run facilities are not clear and nor are the mechanisms by which the Minister for Human Services receives notification of critical incidents or care concerns.
South Australia has a new State Disability Plan but are people with disability at the centre of determining their futures in South Australian? Can they be assured that the whole community is invested in their safety, quality of life and prosperity?

Returning people with disability to the centre of the conversation involves re-establishing some of the richness of input into the government, re-establishing and extending the reach of some services, creating new roles to ensure that vital information can and is shared between the state and federal governments.

The Government should work to ensure that there are correct channels and the right reporting relationships between government departments and entities, jurisdictions, the services sector and the community; and to have an enhanced developmental and preventative role aligned with the needs of people with disability through the mechanisms such as the State Disability Plan: Inclusive SA.
References


The South Australian Ministers Disability Advisory Council. (2011.) Inclusion&protection: A dynamic safeguarding schema for South Australians with disability who are also vulnerable to neglect and abuse.
