

Capricorn Citizen Advocacy

Submission to the Disability Royal Commission

This submission is by Capricorn Citizen Advocacy (CCA), a small not-for-profit disability advocacy program based in Rockhampton. CCA is an incorporated association and registered charity, run by a voluntary Management Committee.

Our submission focuses on three related issues arising from our front-line experience in central Queensland as an independent disability advocacy program with 23 years of service. It includes our responses to some questions listed in the DRC's Safeguards and Quality Issues Paper, issued in November 2020.

a) Failure of Safeguarding Organisations

Capricorn Citizen Advocacy is grateful for the seminal report by the Queensland Public Advocate; *'Adult Safeguarding in Queensland'*; Volume One (Identifying the Gaps), released in July 2022 and Volume Two (Recommendations), released in November 2022.

This commendable report is well researched. Its recommendations are very practical and address the currently fragmented and inadequate situation. Although several agencies in Queensland have responsibility to safeguard the safety and wellbeing of vulnerable ('at risk') individuals, very concerning examples of systemic failure and gaps can be observed. The creation of an "Adult Safeguarding Commissioner" will address this frustrating situation. We note that this recommendation by the Queensland Public Advocate has also been made by the Australian Law Reform Commission.

Capricorn Citizen Advocacy was consulted in a roundtable event held at Rockhampton on 22 March 2022 and we raised concerns about the current safeguarding system with Dr John Chesterman, Queensland's Public Advocate. The role of informal, community and relationship-based safeguards for at risk individuals was endorsed by the report's recommendations in Volume Two. Our safeguarding work is part of the Citizen Advocacy movement's *raison d'etre*; our focus is forming supportive relationships with vulnerable individuals. However, the legislative and governance frameworks within which Citizen Advocacy operates have key systemic weaknesses.

There is a welcome emphasis in the report's recommendations on building capacity, supportive interventions and prevention of harm. Nevertheless, Capricorn Citizen Advocacy believes that there must be far stronger consequences for clear cases of serious violence, abuse, neglect, and exploitation to deter perpetrators. Currently there are clearly insufficient professional, legal, financial, and incarceration penalties available to courts and regulatory bodies and this is combined with an apparent reluctance to use the available penalties.

NDIS Commission for Quality and Safeguards

In particular the powers of the NDIS Commission are insufficient to deal with hardnosed NDIS providers; both companies and individuals. The Commission cites its ability to issue compliance orders, enter into enforceable undertakings, seek court injunctions, issue infringement notices and seek civil penalties as well as suspending or cancelling registration or issuing banning orders. The introduction of ASIC rules regarding registration and identification of company directors will allow the NDIS Commission to prevent phoenix disability providers from thwarting banning orders or revocation of their registration.

Privacy legislation however is responsible for the lack of full disclosure regarding the breaches committed by individuals and companies as the Commission does not maintain a publicly available register of companies and individuals who have a pattern of non-compliance and high-risk activities.

This information is precisely what is required to assist NDIS participants to exercise informed choice and control regarding the employment of service providers. The Commission's 2021-22 Annual Report states it is working on a new complaints system but it does not confirm that the system will be co-designed with stakeholders. There should be a new consultative committee formed by the Commission focused solely on improving its incidents and complaints management systems.

Capricorn Citizen Advocacy believes that the NDIS Commission's activities are skewed towards providing capacity-building and education of NDIS providers at the cost of enforcement, compliance and the public holding of providers to account. The Commission claims in its annual reports that it takes "*protective action in serious cases of persistent and high-risk non-compliance*". Presumably this refers to revocations of registrations and banning orders. Detailed information on "persistent and high-risk non-compliance actions" is not provided publicly. NDIS participants and NDIS support coordinators are not privy to "protective actions" until many months after complaints by the Commission are received.

The Commission's lack of regulatory teeth has cost it dearly in terms of credibility. Its annual reports indicate it is focussed on worker screening, provider registration and dealing with thousands of minor complaints, whilst serious cases are not being prioritised or appropriately penalised. In 2021-22 only 177 of the Commission's 2,754 compliance/investigation activities regarding providers resulted in corrective action requests and banning orders; this is only 6.4% of these activities and only 2.3% of total complaints. There were only 2 revocations of registration issued by the Commission in 2021-22 although the total number of registered providers at 30 June 2022 was 19,739. Surely at some point in the near future, the sector can be regarded as mature enough for the NDIS to 'go in harder' with non-complying providers on behalf of NDIS participants who are 'at risk' adults.

The Commission states that in 2021-22 it prioritised; "*the completion of compliance and enforcement action targeting registered NDIS providers with systemic non-compliance with reportable incident notification obligations, as well as those identified as being at high risk of broader non-compliance with incident management and prevention obligations*". It is quite extraordinary that there is no information provided about the identity of these providers. Regular and timely publication of this information by the Commission is essential and would immediately result in better informed choices by NDIS participants, and quite likely go quite some way towards minimisation of the forms of harm being addressed by this Royal Commission.

The Commission's 2021-22 Annual Report states that; "*We receive, investigate, manage, mediate and resolve complaints about NDIS supports and services*" and; "*Actions we take are responsive and proportionate, according to our regulatory approach...*". Based on its experience with the Commission, Capricorn Citizen Advocacy believes that there is a culture of over preparedness by the Commission to give providers the full benefit of the doubt. In particular, it appears that very large providers with resources to contest findings have 'captured' the Commission, its staff being co-opted instead of acting to deter non-compliance and protect very vulnerable people by issuing stiff penalties. We have set out a case study below to illustrate this. This points out the lack of a due process in allowing the complainant to respond to the service provider's answers before the complaint is closed.

It is acknowledged that the Commission is only empowered to handle complaints about NDIS providers and as it is a new organisation it was not able to predict the level of demand of complaints to be investigated. However, as providers have such important roles in the lives of 'at risk' adults, Capricorn Citizen Advocacy argues that across the disability sector, stakeholders agree that the Commission needs to wield a much bigger stick with serious and continuing non-compliance.

CCA was advised anecdotally by a complainant to the NDIS Commission regarding a provider which had ignored the NDIS Code of Conduct, that the Commission explained to the complainant that there was a limit to actions it could take, not due to the seriousness of the non-compliance, but solely because of the thin market of providers in that area. If this is correct, it is a dismal example of goal displacement within the Commission, and one could argue – a serious abrogation of its duty.

Other Systemic Weaknesses

There is no single body responsible for ensuring complaints are investigated, no joined-up approach across organisations to ensure that complaints received by the incorrect body are actually referred to the other, no single cross-jurisdictional database, no single legislative framework, no recognised body of case law and no accountability or mandatory feedback to any representative advocacy bodies or disability peak bodies.

The empowering legislation of the Public Guardian, Public Trustee, Queensland Police Service, the NDIS Commission for Quality and Safeguards must require any safeguarding organisation to introduce a 'no wrong door' policy, and to develop and maintain a common database for any case involving 'at risk' adults.

Officers of the Queensland Police Service are trained to deal with domestic and family violence, terrorism, organised crime and child sexual offences, but not how to recognise and deal effectively with cases of violence, abuse, neglect and exploitation of 'at risk' adults. A serving QPS sergeant confirms that it would be very helpful for first response officers to be able to seek support from a specialist disability team within QPS. This team would be tasked with advising and assisting in investigating offences against 'at risk' adults, especially people who communicate non-verbally. This officer recalls a recent case where an abusive support worker was reported by his colleagues to the support provider's line management but to no avail. The colleagues then informed the abused person's parents who called the police. The police charged the support worker with assault and secured a conviction. The person who was being abused could not communicate verbally.

The investigation arm of the Office of the Public Guardian in Queensland is under-resourced and we have been advised informally that this unit is focussed on child safety complaints due to follow up actions by the State Government in response to recent child safety reviews enquiries.

There are very strong 'silo' cultures within the OPG, QPS and NDIS Commission which encourage serious cases to be referred with no responsibility taken by the referring agency to follow up the referral. No inter-agency protocols exist that guarantee full sharing of information between agencies about complaints and serious non-compliance by NDIS service providers, or other offenders which might include family members.

"At risk" adults are thus very vulnerable to buck-passing and the shrugging off of complaints by safeguarding organisations due to systemic gaps in both legislation and its implementation. An element of service providers are simply incompetent, criminally negligent and exploitative. No amount of capacity building will change their mindsets. There must be a very uncompromising and equally hardnosed approach by regulatory and compliance agencies to these providers; they must have no roles in providing disability services, until banning periods expire AND it can be demonstrated that they have undertaken appropriate corrective actions to prevent further activities that would lead to future banning.

The lack of support services and support coordination available to 'at risk' adults who are NDIS participants due to 'thin markets' of disability support providers, is very apparent in many regional and remote areas including western areas of central Queensland. There is no justification for the NDIS to keep talking about this as the problem was identified many years ago. The review of the NDIS currently underway must result in the introduction of better financial (NDIS Pricing Arrangements and Price Limits) and other incentives to disability support providers to ensure availability of in-person services in such locations.

The NDIS should also introduce a scheme that incentivises support coordination providers to build their own capacity to deliver their services in a remote context. Such providers must demonstrate a sound knowledge of the complexities of service delivery in regional, rural and remote locations, as well as an understanding of the role of family and other informal supports when no other alternative formal supports are available.

They should demonstrate a strong understanding of the logistical issues (distance, time, higher costs related to limited availability of support providers and non-registered providers involved in such things as building work) and cultural issues (family and community dynamics in indigenous communities or communities with high indigenous population). Support coordination providers participating in the scheme would also need to understand issues involved in employing family members and other matters that are only considered as suitable options in extreme circumstances.

Local Case Study – Capricorn Citizen Advocacy's Protégé – "MB"

"**MB**" was a young man aged 19 living in North Rockhampton when Capricorn Citizen Advocacy became aware of his situation during 2018 and subsequently engaged in its comprehensive process to appoint a Citizen Advocate to support him with advocacy related matters.

"**MB**" is now aged 22 and still lives at home with his mother and three brothers (all his brothers have disabilities). He was matched to a Citizen Advocate on 21 June 2019. **MB** has severe cerebral palsy, epilepsy, is profoundly deaf and is eligible for a cochlear implant (he can hear very high-pitched sounds). **MB** is unable to communicate verbally, is incontinent and has a wheelchair to assist with mobility. His mother says about 8 years ago **MB** was diagnosed with brain damage.

At home **MB** spends a lot of time quietly lying on the floor or on a mattress, sometimes watching TV, with the household's activities going on around him. According to **MB's** mother; *'He does not cause much trouble'*. **MB** is a very gentle young man who responds to kind words and behaviour. He giggles when is enjoying himself such as going on a walk or when he is watching a funny cartoon. The staff from his Special School who taught **MB** noted his sweet natured personality despite the regular physical pain he suffers and a severe lack of opportunities for him to connect with others and engage in enjoyable activities.

MB finished his education in 2018 and has since lived at home. One of his teachers contacted Capricorn Citizen Advocacy in 2018 before he left school. **MB** was then aged 18 and had been provided an extra year at school. His teacher was concerned about **MB's** future after he left school at the end of 2018.

MB's advocate; "**LW**" was a man aged 37 at the time of his appointment. **LW's** younger brother also had lived with cerebral palsy and with profound intellectual disability and **LW** understood the vulnerability of **MB**. **LW's** brother had died 4 years earlier, aged 32.

MB enjoys a game where he moves an object and the other person moves it back until **MB** gets tired. He has good fine motor skills and when was at school he loved sailing with Sailability in Yeppoon and getting splashed. He enjoys water play and going to the beach. **MB** loves to go for walks (he needs to have somebody push him in his wheelchair) and he enjoys watching cartoons. **MB** also enjoys spinning objects, lights that he can turn on and off, eating food (especially fruit and yoghurt) and drinking coffee.

MB hates high pitches sounds as these give him a headache. He sometimes has epileptic seizures. When **MB** is in pain from seizures, it is very distressing to see him twitching, hitting himself in the head and hurting himself. He regularly has convulsions but rarely sees the doctor and only receives Panadol for pain relief. When he was at school the staff would make appointments for his mother to take **MB** to the doctor and also take **MB** to the appointments. His mother and brothers did not attend his graduation. A teacher ensured **MB** was dressed in good clothes, collected from home, attended the dinner and received his certificate.

MB was approved an NDIS plan in October 2018 and a national support provider handled his support coordination. The planning appointment was conducted by an NDIS Local Area Coordinator who met with **MB's** mother outside the house. This LAC told CCA she could not bring herself to go inside as she was confronted by the appalling squalor in **MB's** home. **MB's** NDIS Plan did not mention his acute vulnerability to abuse, neglect, violence and exploitation and the need for preventative monitoring of his welfare.

CCA visited **MB** at home several times when recruiting his advocate. His living situation was a disgrace. **MB's** home was piled high in every room with various belongings and was dark and smelly. Two dogs lived in the house and **MB** has his face frequently licked by the dogs as he lay on the floor.

MB had no bedroom and slept on a mattress in the living room as his mother claimed he will not sleep on a bed. He was extremely thin with a sunken chest and was dressed only in a nappy all day. He had no pleasurable activities, regular outings or any visitors. One of his brothers was responsible for feeding, showering and toileting him. This was the case 12 months after **MB's** NDIS plan had been approved.

MB is unable to express his likes and dislikes using words, but his former teacher confirms that **MB** communicates using an iPad with Proloquo2Go (a speech generation app) and a sign-language. **MB's** occupational therapist recommended that he be provided two iPads by the NDIS, envisaging that **MB** would use the iPads to help him with communicating when he is hungry, thirsty, needs to be changed, wants to go for a walk, or is feeling sick. One iPad would be used by her and **MB's** support workers and the other one by **MB's** mother and brothers to communicate with him. **MB's** communication needs are complex.

MB also needed an electric bed, a hoist for the bathroom and bedroom, a transfer board, a new conventional wheelchair, a separate beach wheelchair and a gym mat to lie on in the house. He needed warm clothes, socks and slippers for winter.

Unsuccessful Complaints to NDIS Commission, NDIS Fraud Hotline and Office of the Public Guardian

Once the match between **MW** and **LW** started, it quickly became evident that **MB** was being exploited by his family, that his NDIS support coordinator was charging his NDIS plan without arranging any supports and that his NDIS service provider was not acting in accordance with the NDIS Code of Conduct.

CCA notified the NDIS Fraud Hotline on 06/04/2020 that **MB's** Support Coordinator (a national support provider) had been charging **MB's** plan for more than 12 months for work not done. The support coordination was being provided from Biloela; a town located two hours drive from Rockhampton. Not one service had been delivered to **MB** in 18 months other than delivery of continence aids (adult sized nappies). **MB's** NDIS plan included a standard \$2,376 NDIS transport item paid directly to the participant; in this case it was paid to his mother. **MB's** mother and his older brother used taxis to stock up at the bottle shop when **MB's** Disability Support Pension arrived each fortnight. **MB** however was not taken to medical appointments. The Fraud Hotline acknowledged but did not respond to the complaint by Capricorn Citizen Advocacy, other than to state on 23/07/2020; *"It is our policy, based on privacy and confidentiality principles, not to provide any information/advice/updates/outcomes on current matters. This means we are unable to access previous allegations for discussion and the specialist officer will only be in contact with you if they require any further information."*

In 2019 after **MB's** support coordination was moved from Biloela to Rockhampton, **MB** started to receive services (support workers providing him with showers, assistance with meals and some outside activities) but the service provider did not want to make a complaint about **MB's** living situation to the Office of the Public Guardian (OPG). It appeared to CCA that this reticence was based on a conflict of interest as **MB** was the source of significant income to the support provider. CCA then made its own complaint to the OPG on 07/11/2019. We also started plans to submit an application on **MB's** behalf to the Queensland Civil and Administrative Tribunal (QCAT) for an interim order to remove **MB** from his home.

CCA and his service provider both agreed that **MB** needed to be removed from his family and placed in a suitable supported independent living environment funded by the NDIS as there was evidence of financial abuse, neglect and exploitation occurring at home. **MB's** family are collecting **MB's** Disability Support Pension and a carer's payment for **MB** and there is a clear financial incentive to have all four sources of Centrelink income for **MB** and his brothers collected by a single household.

As **MB** cannot verbally communicate, a complaint to the police was not made.

CCA's complaint to the OPG dragged on for 18 months as the investigating officer was also assigned to child safety matters. The OPG's eventual decision was not to lodge an application for an interim order to QCAT on **MB's** behalf. Its reasoning was similar to the NDIS Commission noted below (which dealt with the provider). The OPG somehow found that counselling the family would suffice.

Capricorn Citizen Advocacy's third complaint was to the NDIS Commission for Quality and Safeguards on 27/02/2020 regarding the history of incompetence and substandard service by **MB's** support coordinator. The outcome of this was that the Commission's investigating officer noted that the provider had only admitted to logistical issues with their service and did not address **MB's** "at risk adult" status. The NDIS strangely accepted this response by the provider without question and did not request the complainant to verify what had been claimed. The complaint was dealt with by a conciliatory, 'counselling the provider' approach. There was no requirement for the provider to repay **MB's** NDIS plan several thousand dollars.

Our experience of the safeguarding organisations with which we have dealings; the Queensland Police Service, NDIS Commission, NDIS Fraud Hotline and OPG indicate that a significant rethink is needed. We agree with the submissions made to the DRC's Issues Paper on Safeguards and Quality by Disability Council NSW and Queenslanders with Disability Network. They both argue that stiffer penalties and increased investigative and punitive powers by the NDIS Commission against service providers who breach their responsibilities will drive behavioural change. We are convinced by our experience that regulatory bodies and providers alike can easily lose their primary focus on the safety and welfare of "at risk" adults.

Recommendations

- 1) An office of "Adult Safeguarding Commissioner" be created in accordance with the recommendations by the Queensland Public Advocate and the Australian Law Reform Commission.
- 2) The NDIS Commission for Quality and Safeguards be required via amendments to its legislation to:
 - a) Regularly publish a register of companies and individuals who have a pattern of non-compliance and high risk activities;
 - b) Ensure that its new incidents and complaints management systems will be co-designed with stakeholders, including independent disability advocacy programs;
 - c) A new consultative committee be formed by the Commission focused on overseeing and improving its incidents and complaints management systems.

- 3) That safeguarding bodies in every state including the new “Adult Safeguarding Commissioner”, NDIS Commission for Quality and Safeguards, Human Rights Commissions, Offices of the Public Guardian, Public Trustees and Police be required to develop a cross-jurisdictional database, information exchange protocols and a referral system of ‘no wrong door’ for complaints and incidents.
- 4) Federal and State privacy legislation and subordinate legislation be reviewed and harmonised to ensure that detailed information retained by the NDIS Commission on “persistent and high-risk non-compliance actions” by providers is provided publicly, including the names of individuals, status as directors of NDIS providers and information regarding the corrective actions enforced by the Commission. The aim should be to ensure privacy is respected in the case of NDIS participants but disclosure of relevant information to protect and inform NDIS participants is available regarding non-complying providers.
- 5) A specialist disability team be developed and staffed within the Queensland Police Service. This team should be tasked with training, advising and assisting first response officers in investigating offences against ‘at risk’ adults, especially people who communicate non-verbally.
- 6) The review of the NDIS currently underway be requested to introduce better financial (NDIS Pricing Arrangements and Price Limits) and other incentives to disability support providers to ensure availability of in-person services in regional, rural and remote locations.
- 7) The NDIS also introduce a scheme to incentivise support coordination providers to build their own capacity to deliver their services in remote contexts. The scheme should require support coordinators to demonstrate a strong understanding of the logistical and cultural issues as well as issues involved in employing family members as support workers.

b) The Status of Disability Advocates

It seems to be universally agreed, at least in principle, that effective advocacy on behalf of vulnerable people is a good thing. In practice however, disability advocates often encounter ignorance, confusion, obstruction, gatekeeping and even hardnosed opposition to their efforts.

The roles of an independent disability advocate include vigorously standing up for the rights of a vulnerable person, and to clearly be on their side and nobody else’s. A determined, skilled and knowledgeable advocate is an extremely valuable ally, whether or not the person who needs the advocacy has a disability.

Legislative Recognition of Advocacy

The NDIS Act 2013 states; *The “role of advocacy in representing the interests of people with disability is to be acknowledged and respected, recognising that advocacy supports people with disability by: (a) promoting their independence and social and economic participation; and (b) promoting choice and control in the pursuit of their goals and the planning and delivery of their supports; and (c) maximising independent lifestyles of people with disability and their full inclusion in the community.”* **Section 4, Subsection 13.**

The Act also defines ‘independence’ of advocates for a person with disability. It means a person who:

- (a) is independent of the Agency, the Commission and any NDIS providers providing supports or services to the person with disability; and
- (b) provides independent advocacy for the person with disability, to assist the person with disability to exercise choice and control and to have their voice heard in matters that affect them; and
- (c) acts at the direction of the person with disability, reflecting the person with disability’s expressed wishes, will, preferences and rights; and
- (d) is free of relevant conflicts of interest. **Section 9.**

The role and legitimacy of independent advocacy is also explicitly endorsed in the Australian Disability Strategy 2021-2031 (ADS) and the National Disability Advocacy Framework (NDAF). However, Capricorn Citizen Advocacy like other disability advocacy programs, wrestles with the uncertain and sometimes devalued status of its advocates. The role of disability advocates is very poorly understood and there appears to be little information (or training) about advocates provided by key organisations to their staff who engage with disability advocates.

As explained in appendix "A" to this submission, Citizen Advocates in particular are unpaid; as being part of a freely given relationship guarantees their independence. They are unencumbered by conflicts of interests that arise for employees of disability service providers, funding organisations or regulatory or compliance staff. They are informal or natural supports and not part of the client-provider paradigm.

Newly appointed Citizen Advocates soon experience their uncertain status with staff and management of NDIS disability service providers, support workers, support coordinators and team leaders. In Queensland, this also applies to the Office of the Public Guardian (OPG), the Public Trustee, Centrelink, Queensland Health, allied health consultants funded by the NDIS, and the staff of the NDIA itself.

Downplaying and even refusing to recognise the role of independent advocates is also experienced by advocates employed by other organisations providing independent disability advocacy. CCA knows of advocates who are ignored by the OPG. The intervention of advocates is also contested by some NDIS providers who believe that the appointment of independent advocates must be approved by the OPG. Early career staff in the disability sector are often untrained or ambivalent about the role and legitimacy of advocates.

One of CCA's Citizen advocates recently visited her "at risk" protégé who lives in her own home (see definition of 'protégé' in Appendix 'A'). She was told by a service provider that support workers working at her protégé's home were instructed not to speak to the advocate, citing (bogus) 'privacy concerns'. This refusal to share information or answer the advocate's questions was done in full knowledge that the protégé's family members had signed a consent form which not only approved the advocacy, but that the advocate and the protegee were already long-standing friends.

Staff of this service provider was belligerent regarding potential complaints by the advocate to the NDIS Commission for Quality and Safeguards. They threatened to lodge a counter complaint against the advocate about the 'breach of privacy' of their client. Fortunately, in this instance this conduct was dealt with effectively by the operation of the market as the protégé's family changed to an alternative service provider. It's remarkable that an NDIS participant had to exert their "choice and control" by changing providers because a service provider wilfully denied the participant's right to advocacy!

A new Head of Power for Independent Disability Advocates

The tragic story of Ann Marie Smith would never have eventuated if she had been regularly visited by an independent advocate who could have intervened on her behalf, to call her service providers to account.

The NDIS and Centrelink both have processes and forms for the appointment of various types of formal nominees. Disability advocates including Citizen Advocates sometimes need to be appointed as NDIS Nominees to be able to advocate on behalf of their protégé. CCA believes that disability service providers must continue to be excluded from being appointed as NDIS Nominees.

CCA also believes that is crucial that the status of disability advocates is accorded recognition and respect and be backed by a new head of power, being an Act of parliament. The Act must recognise disability advocates regardless of whether they are formally appointed e.g. appointed as nominees, or whether they act in an informal capacity such as an unpaid family member, friend, or neighbour.

The introduction of a 'Statutory Advocate'

The example of Anne Marie Smith illustrates the need for an independent '**statutory advocate**' to be appointed for any person who in the judgement of QCAT (or similar body in other jurisdictions), is very vulnerable, without capacity to effectively self-advocate and who lacks informal supports.

The '**statutory advocate**' positions would be legislated under the proposed new legislation and must be filled by people who are experienced and knowledgeable. The work of statutory advocates would be administered by the Office of the Public Advocate, which would of course need to be resourced to do so. This role could also be included with the expansion of the community visitor scheme which has been separately recommended by several submissions to the DRC.

National Conversation about the Importance of Natural Supports

Capricorn Citizen Advocacy fully supports the submissions made by other organisations that the NDIA and relevant sectoral partners conduct a national conversation around 'natural' safeguards including what natural safeguards are, and how they afford protection against abuse while also building a person's capacity and life choices. Citizen Advocacy can make a useful contribution to this conversation.

Likewise, CCA supports the recommendations made in submissions to the DRC's Issues Paper on Safeguards and Quality that NDIS planners or other appropriately skilled professionals routinely assess NDIS participants at the time of plan development as to what relationships they have beyond a paid support worker, and what activities in the wider community they are accessing.

These assessments will highlight the vulnerability of some clients in closed residential settings (e.g. "MB" discussed above) as well as "at risk" adults in supported independent living environments.

Recommendations

- 8) A new Act be introduced to formally recognise and endorse the important and ongoing roles, legitimacy and existing models of independent disability advocacy in Australia, regardless of their funding source.
- 9) The new Act should recognise Australia's commitment to international conventions and covenants and guarantee sustainable public funding of an independent disability advocacy sector, including the development of an intergovernmental agreement.
- 10) The new Act or the NDIS Act should provide for sanctioning, banning or suspension of NDIS providers who demonstrate a pattern of wilful refusals to engage with independent disability advocates acting on behalf of NDIS participants.
- 11) The new Act should ensure that all forms of disability advocacy, whether informal advocacy by friends, family and neighbours or-via formal appointments, whether by paid advocates or not paid (such as Citizen Advocates), are recognised as legitimate.
- 12) The new Act should recognise the crucial importance of independent advocacy for people with disabilities who lack capacity to effectively self-advocate and who lack unpaid supportive networks. As considered necessary, the appointment of a paid '**statutory advocate**' for each such individual be ordered by QCAT (or similar bodies in other jurisdictions).
- 13) A working party should be formed including representatives from the disability advocacy sector, QCAT, the OPG, the Public Trustee (and similar bodies in other jurisdictions) to develop the scope and responsibilities of the 'statutory advocate', including its role in supported and substitute decision making.
- 14) This working party also consider the development of a register of advocates as a safeguard against people in the community who may prey upon the vulnerable whilst calling themselves advocates. All registered disability advocates would be subject to NDIS Worker Screening (Criminal History Check) and vetted for their suitability. However, this registration process should not be totally exclusive, and provision should be made to recognise the vital and valuable role of informal advocates who are not registered (e.g. family members, friends, neighbours etc.) from acting as informal disability advocates.

- 15) The NDIS Commission for Quality and Safeguards should consult comprehensively with the disability advocacy sector before introducing a compulsory training module for all registered and unregistered NDIS providers concerning the importance, roles and legitimacy of independent disability advocacy and understanding natural/informal safeguards for vulnerable people with disabilities.
- 16) Laws and penalties need to be strengthened in the case of unconscionable conduct and predatory behaviour by any persons or businesses who deliberately target cohorts or individuals who are identifiable as potentially being unable to enter into a contract due to impaired capacity.

c) Funding of Independent Disability Advocacy in Australia

From 1999 to 2021 Capricorn Citizen Advocacy operated within the areas of Rockhampton Regional Council and Livingstone Shire Council, a population of approximately 120,000.

In mid-2021 the Queensland Department of Disability Services, Seniors and Aboriginal & Torres Strait Islander Partnerships changed its funding arrangements for disability advocacy. Without any consultation with the sector, it introduced the Queensland Disability Advocacy Program (QDAP) and invited competitive tenders from advocacy programs.

The government announced that all areas of Queensland would be covered by disability advocacy programs, including large metropolitan and regional populations centres like Logan/Beenleigh, the Sunshine Coast, Maryborough and Bundaberg which were not previously covered by advocacy programs. It did not undertake to review the funding basis, only stating that existing funding would not be increased. The new areas to be serviced under the new funding guidelines absorbed 28.74% of the existing funding base.

Capricorn Citizen Advocacy was successful in its tender. The new service agreement expanded our geographical coverage in central Queensland west to the Northern Territory border from 1 January 2022. CCA now serves a total of 12 local government areas and a population of 240,000, a service area which matches the Rockhampton service district used by the NDIA. This area covers 6,514 NDIS participants which is 5.6% of the state-wide total.

Our geographical area of service was multiplied by a factor of 24 and the population we serve doubled, but as a result of the funding decision, Capricorn Citizen Advocacy's already modest annual funding of \$180,000 was also reduced by 30% (\$60,000). Capricorn Citizen Advocacy was already the lowest independent funded advocacy program in Queensland prior to this decision.

QDAP's total funding base of \$6.5 million in 2022-23 (which includes \$1.7 million for specialist advocacy and a new disability hub). Capricorn Citizen Advocacy's share is only \$123,282 or 2.87%. CCA has now been forced to reduce its fulltime equivalent employees (FTE) from 1.4 to 1.1, relocate its office, sell its car, and even further reduce already tight operating costs, whilst expanding its service to include client-based individual advocacy.

This single example of Capricorn Citizen Advocacy's recent funding history illustrates a glaring mismatch between the current funding of independent advocacy in Queensland, particularly in regional areas, versus the long waiting lists and documented unmet advocacy needs of people with disabilities.

Independent Disability Advocacy - A Neglected and Poorly Funded Sector

The State, Territory and Australian governments have shared the funding of disability advocacy programs since the 1980's, with the advent of the Disability Services Act 1986. The Australian government funds 59 disability advocacy organisations via the National Disability Advocacy Program (NDAP).

However, since the inception of the NDIS in 2013 to the present, there has been years of buck passing, lip service and lack of engagement with the disability advocacy sector by both levels of government. Unfortunately, this has gone largely unnoticed by policy makers, disability commentators, NDIS stakeholders and the media.

The disability advocacy sector is so small, lacking in visibility and is incredibly poorly funded compared to the annual budget for the NDIS of around \$30 billion, that it remains very much an afterthought. Indeed, the DRC is our last hope that the sector will be elevated in priority to the point where it is allocated sustainable funding with the development of a genuinely respectful on-going partnership. Future funding of the sector must enable disability advocacy agencies to deliver outcomes relevant to their model of advocacy, to their cohort, and within fully funded geographic catchments.

Further afield, the NSW and WA governments recently refused to allow state funded disability advocacy programs to deal with issues related to the NDIS or mainstream services such as Centrelink funded by the federal government. These states aim in a highhanded fashion to force the hand of the federal government to take over future funding responsibility for all disability advocacy, even at the risk of vulnerable people being left without recourse to any independent advocacy.

The current mix of state and federally funded advocacy results from the historical variations in how programs initially gained their financial backing, not because of any agreed policy framework. Human tragedies like the death of Ann Marie Smith in April 2020 and many other sad stories of people who had nobody to stand up for them, demand that governments now must work together better to provide independent advocacy and safeguarding mechanisms.

It defies description that such a confused, fragmented and ill functioning example of public policy currently exists in our advanced and wealthy nation for such a vitally important service. Vulnerable people with disabilities need to be able to access high quality independent advocacy wherever they live however the current public policy settings and funding arrangements across Australia prevent this.

The problem can be addressed with some clear-thinking regarding Australia's commitment to the United Nations Convention on the Rights of Persons with Disabilities (CRPD), the development of a shared financing formula and intergovernmental agreement and an immediate and significant increase in funding.

CCA supports the submission to the DRC by Disability Advocacy Network of Australia (DANA) which cites rich evidence that the disability advocacy sector provides a valuable form of quality feedback to government services and points out there an economic return of \$3.50 per dollar spent on advocacy. DANA's submission refers to the 'patchwork' of inadequate and uncertain funding across the country for disability advocacy and the barriers that exist for many vulnerable people gaining any access to advocacy. DANA also recommends an immediate increase in funding and the development of a robust funding formula and CCA supports this unreservedly.

The important role and cost effectiveness of Citizen Advocacy comes from its early intervention and harm prevention role and its ability to also shine a light in dark places. Many Citizen Advocates point out examples of NDIS systemic waste, fraud and sharp practices and their work reduces the need for expensive legal appeals which add to the ever-increasing cost of the NDIS. CCA notes that Citizen Advocates are part of freely given relationships meaning Citizen Advocacy is a particularly low-cost model of advocacy.

CCA fully supports the submission by Queensland Advocacy for Inclusion (QAI) which sets out a cogent argument for an immediate increase in independent advocacy funding by the Queensland government to \$15 million per annum. Whatever rationale or formula is used, (either ABS demographic data, NDIS participant data, unmet need data or anecdotal information), the same conclusion is reached: independent advocacy across Australia particularly in regional Queensland is woefully underfunded.

CCA also refers to the recent Royal Commission into Aged Care Quality and Safety's finding that aged care advocacy needed a both a legislative head of power and increased funding. Recommendation One of the Commission's final report required a new Act to be introduced by 30 June 2023 and that one of the Act's objects (e) should be to; ***“provide advocacy and complaint mechanisms for people receiving aged care”***. The need for a legislative head of power is addressed in Section B of our submission.

In December 2021 the Federal Government announced an additional \$99.6 million expanding the National Aged Care Advocacy Program (NACAP). The additional funding of the NACAP will improve access to face-to-face and virtual aged care advocacy by doubling the workforce to support more than 15,000 additional advocacy cases. The Australian independent disability advocacy sector also needs additional funding as pointed out above.

Recommendations

1. That a working party of State and Federal Ministers including Treasury, federal and state public servants, DANA and independent advocacy programs from each state and territory develop a brief for an independent report and recommendations concerning an intergovernmental agreement addressing the funding of the disability advocacy sector.
2. That the current funding of existing disability advocacy programs in Queensland and other states (both State and Australian Government funded) be locked into five-year cycles rather than the uncertain 12 and 18-month cycles currently in place, which prevent funding recipients from proper planning processes, and which undermine the stability of the funded organisation. We note that this recommendation has been also made by the Queensland Public Advocate in its report: 'Adult Safeguarding in Queensland'; Volume Two (Recommendations 11 and 12), released in November 2022.
3. That disability advocacy funding remains completely independent and separately administrated from funding of the NDIS and the NDIS Commission for Quality and Safeguards.
4. The quantum of funding for existing disability advocacy programs in Queensland and other states be increased by a minimum factor of three as recommended by QAI regarding QDAP.

Capricorn Citizen Advocacy

T: (07) 4922 0299 | E: office@capricornca.org.au

M: 0409 220 072 | Web: www.capca.org.au

19 Willis Street, West Rockhampton, Qld 4700

PO Box 1175, Rockhampton, Qld 4700



We are ordinary people
doing ordinary things
of extraordinary importance

Appendix “A”

Explanation of Citizen Advocacy

Citizen Advocacy is a discrete form of disability advocacy that is quite different to other forms of advocacy such as individual advocacy or systems advocacy for instance.

Citizen Advocacy recognises, promotes and protects the interests of people who have cognitive disabilities, by facilitating and supporting the establishment of committed, one-to-one relationships between competent, resourceful community members (**Citizen Advocates**) and people with disabilities who are vulnerable, often socially isolated, and who have unmet needs (**Protégés**). Vulnerable persons with a cognitive disability, who are without family or friends, are especially in need of at least one loyal long-term ally who is single mindedly committed to them.

Citizen Advocacy provides a practical way in which ordinary members of the community can make a positive difference by providing long-term advocacy to a person with a disability so that they are no longer entirely alone and unprotected given their relatively powerless circumstances.

Strong relationships have been shown to be the strongest safeguard for protecting the very life of a person with a cognitive disability. Otherwise, such a person without a strong sense of consequence and perhaps ‘living’ within the confines of a service system, is completely exposed to the vagaries of that system and its ever-changing policies, agendas and identities.

Citizen Advocates and Protégés are carefully recruited, matched and supported by the staff at Capricorn Citizen Advocacy. Citizen Advocacy offices need paid staff because most Citizen Advocates would never get recruited and supported if the staff of a Citizen Advocacy office were not there to focus on this unique task that requires persistence, sensitivity and finesse. All Citizen Advocates enter into a freely given (unpaid) relationship with their Protégé and these relationships can often last a lifetime!

Many advocates have been faithful companions to their Protégés and have saved them from terrible situations. Many have saved the very lives of their Protégés, and sometimes on repeated occasions.

As a powerful form of disability advocacy, Citizen Advocacy has strong elements of:

1. **prevention** of situations and issues that will never arise because of their very presence and attentiveness,
2. **protection** against the actions of people and systems, and the negative consequences that need to be short circuited,
3. **image enhancement** amongst those around them who sees the Protégé feels great about having someone in their life just for them, and that the Protégé has a strong ally who will “go into bat” for them,
4. **competency enhancement** when Citizen Advocates assist their Protégés to better understand seemingly simple things like how to appropriately dress or respond in certain social situations; how to catch a bus; how to stand up for themselves; or how to get more serious help should that be required, and
5. **relationship broadening** that often naturally occurs when Citizen Advocates expand their Protégé’s circle of friends and acquaintances, including amongst their own family.

Citizen Advocacy organisations are free-standing associations, and they are always of a non-profit nature. While each Citizen Advocacy office offers information, advice and guidance to the Citizen Advocates it has recruited, it does not conduct the advocacy directly itself. Each individual Citizen Advocate does the advocacy, albeit with training, ongoing support, and follow up from the staff. Thus the name “Citizen Advocacy”.

It is a highly cost-effective response to the ongoing, rather than simply “issues based” needs of vulnerable people. It has been shown to reduce or entirely circumvent the call upon other forms of disability advocacy which are more often than not “at capacity” or cannot provide the much needed face to face interventions.

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