



CARE OPINION Australia
Submission to the National Disability Insurance Agency (NDIA)
in response to the consultation paper
“Proposal for a National Disability Insurance Scheme Quality and
Safeguarding framework”

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Introduction:

Care Opinion Australia appreciates the opportunity to provide feedback on this consultation paper and believes, as outlined, that the platform in its current capacity can support the NDIA's intent to mitigate risk and enhance feedback to services by participants.

The platform (described below) is set up in such a way as to support:

- the participants in providing feedback;
- the services to receive (moderated) feedback along a continuum from positive feedback to complaints (in real-time – effectively and efficiently) and
- the NDIA (or other legislative bodies) in monitoring feedback from participants, carers, family or community visitors and advocates.

Care Opinion Australia (www.careopinion.org.au/) is a not-for-profit web based platform that is focused on service improvement. It is a site where NDIS participants can tell their stories about their experience of the services online. The site is safe for both participants and providers because all stories are moderated and the identities of both the storyteller and individual staff members remain anonymous. Service providers (organisations) are identified. Such transparency and the public nature of the site motivate service providers to act on the story through one or all of the following ways:

1. Demonstrating that they have read the story
2. Providing a personal response to the storyteller (in near real-time)
3. Planning or implementing a change that brings about a service improvement and documenting that on the site.

The primary focus of Care Opinion Australia is to help service users / NDIS participants *change* the quality of their care (rather than just help them *choose* their care) by working in a safe and constructive way with their service providers. The site does have a section for rating the quality of the service provider (once they have submitted their story) but the primary purpose of the site for people to tell their story, be heard, and make a difference to the quality of their care experience. The ability to “be heard” is enhanced by the ease with which service providers receive the feedback, straight into their inbox as stories are told (see attachment 1 “What is Care Opinion” and Attachment 2 “Benefits of a Care Opinion Subscription”)

By way of precedence, the Scottish government has recently subscribed to Care Opinion for their adult social care services. Here is a recent transcript from their Hansard

Official Report - Parliamentary Business: Scottish Parliament



Christian Allard MSP

Yesterday at 01:41 · 🌐

I am delighted that the Scottish Government has announced £102,000 to provide a pilot Care Opinion website for adult social care, which will complement perfectly the Patient Opinion system that we already have for hospitals and which I have promoted in previous debates.

That is the way to provide a national health service for future generations, with a person-centred approach. That is why the people of Scotland support our NHS and why the SNP Government has public support.

Part 1: Proposed Quality and Safeguarding framework for the NDIS:

General:

In giving participants choice and control over their supports *“There is a risk that people with disability could receive poor quality supports that do not help them achieve their goals. There is also a risk that people with disability could be harmed in some way... The aim of [this] framework is to target those areas where the dangers are greatest and the consequences of harm most severe.”* (page 9) At the same time *“the objectives of the framework are to advance the rights of people with disability and minimise the risk of harm, while maximising the choice and control they have over their lives.”* (p 11)

Care Opinion Australia is about giving participants the opportunity to shape their care experience by writing about their story on an independent, anonymous, transparent, public and accessible site. Through openness and transparency, participants are empowered to help improve the quality of the services they receive. This transparency and the freedom of participants to elect what they emphasise in their experience will help to mitigate the risks of poor quality supports and will enhance the sense of choice and control that participants have over their lives and the services they elect to use. The transparency of the stories (published online) helps to mitigate the risks of harm or poor quality support, as services will know that there is an option for participants to “go public” about any concerns.

Three Broad Structural Areas:

Developmental:

“The NDIS aims to position participants as active consumers with choice and control over the supports they need to live the life they want. This means participants need access to high-quality information that can:

- *Drive quality improvement in the system, including building knowledge of what participants should reasonably expect from the delivery of their supports and enabling participants to influence the design and delivery of their supports through real-time feedback”* (p12)
- *Harness, but not depend on, the internet to build empowered communities* (p13)

One of the key functions identified by the Purple Orange Project was that *participants want the capacity to share their experiences and to draw on the experiences of others who might be in similar circumstances, as well as the ability to interact online with providers and other players in the system* (p13)

Under this approach, there might be a dedicated website that would provide a starting point for those looking for disability-related information (p14).

The ability to share their experiences and draw on the experiences of others in similar circumstances is exactly what Care Opinion Australia provides. Participants can indicate that they have experienced something similar to the stories posted by other participants (this is the only way that they can contribute to the story; otherwise they need to tell their own story). Unlike TripAdvisor, Care Opinion Australia is not designed to enable choices per se, its aim is to enable participants to influence the quality of their care experience in real-time by informing services of their care experience. The bank of stories built over time can empower communities. Care Opinion Australia is dedicated to driving quality improvement in service provision. The search function that is available on Care Opinion will enable participants and services to search particular topics or communities of interest.

If there was to be a dedicated NDIA / disability-related information website, it could integrate with Care Opinion Australia through the use of our widgets which can be placed on the website. This enables the partnering website to utilise the accessibility and stories of the Care Opinion site whilst retaining flow through their own site. In this way, their sites not only become information giving (one-way traffic) but can enable participants to comment on providers (two-way traffic).

Preventative:

Service level safeguards — support for service level capacity building

In the NDIS, the most important relationship will be between participants and providers. The capacity of providers is therefore a critical safeguard.

A quality provider will usually have strong governance, policies and procedures, and a corporate culture that fosters respect and openness. They will respect and value feedback from their clients and others and use this feedback to improve and innovate. (p20)

Service providers who choose to use Care Opinion Australia will strongly demonstrate a culture that is respectful and open (and online). Care Opinion gives service providers the opportunity to demonstrate their commitment to listen to the voice of participants and, via their responses online, show where they are improving or innovating as a result of the client's feedback. The "tone" of responses online can also foster a sense of respect and openness to feedback.

Risk management strategies as well as "...measures that encourage providers of supports to deliver safe, high-quality supports. This can involve support for providers to build their capacity, including training of frontline staff."(p12)

Through its email alert system, Care Opinion Australia provides a unique strategy for frontline staff to be provided with real-time stories. These help them 'see through the eyes

of participants' making it an excellent lever for changing culture within organisations to become more participant-centric.

From a Government perspective, Care Opinion could become the main feedback site for participants about any of their service providers. Care Opinion could set-up a range of services whereby providers could engage with the site in a minimalist way (registered only) through to a full subscription with all the reporting, education, coaching and support to use the site to its full capacity Oversight bodies can become "watchers" of the site, meaning they receive email alerts to relevant stories ("watchers" are unable to provide responses). A similar system to this is what has been implemented in England and Scotland.

Corrective:

A key issue for the quality and safeguarding framework is how to handle complaints about supports that are paid for under the NDIS. (p23)

Used as described above, Care Opinion could provide a "birds eye view" of services eliciting positive stories or trends in themes of complaints. Further investigation would be required due to the qualitative and very personal nature of stories; however, it may be possible to be alerted early to developing situations before they become critical.

In Summary:

What kind of support would providers need to deliver high-quality supports?

Access to easy, time efficient and effective feedback mechanisms will be a key support required by providers.

Care Opinion Australia could be part of the Quality and Safeguarding framework by providing:

1. In the Developmental Structural Area:
 - a. Providing information for participants in the form of stories and experiences of other participants
 - b. Building natural safeguards by supporting individuals to have a voice about their services and by providing an anonymous community support network

2. In the Preventative Structural Area:
 - a. The use of a transparent, open platform on which participants can write their experiences may go some way to providing individual safeguards and reducing unseen / unreported risks.
 - b. Service level safeguards can be built through the use of Care Opinion to build capacity of both the organisation and their staff, through the use of real-time stories to bring about innovation, improvement and reward for work well done.

- c. System level safeguards can be implemented by having high level “watchers” in the system (government bodies, NDIA, consumer groups) who are able to read stories and make enquiries in near real-time about incidents or themes seen to be emerging on the site.
3. In the Corrective Structural Area:
 - a. Care Opinion can provide a preliminary avenue for handling “entry level” complaints and, as emerging evidence is showing, reduce the likelihood of escalation if the organisation responds in a caring and individualised manner
 - b. Care Opinion can enable the oversight functions to monitor quality and safety as outlined in 2c above.

Part 2: Detail of key elements of the Quality and Safeguarding framework

This portion of the Consultation Paper considers further options that could strengthen protections for self-management while ensuring choice and control for participants. In particular, Care Opinion Australia believes it could provide important services in the “Systems for handling complaints”

Systems for handling complaints:

The Nature and Usefulness of Feedback / Complaints:

Under the NDIS the disability sector will transition to a more market-based model, in this model feedback (along the spectrum from positive to “negative”) and complaints can provide invaluable information to the organisations about areas for improvement, innovation or consolidation. From the perspective of “umbrella” or supervisory organisations, feedback and complaints can provide alerts to potential risks in the system. For this to work, participants or consumers of services need to have the confidence and means to voice a complaint (or provide feedback). The nature of disability services raises specific challenges in this regard in that participants may have limited cognitive, verbal or physical capacity or they may be fearful that a complaint will negatively impact on their care (or that of their loved one).

The anonymous and moderated nature of Care Opinion Australia goes a long way to addressing these concerns. Feedback and complaints can be provided anonymously in the first instance. Subscribed organisations can reply online and indicate they have addressed the situation or they can invite the participant to hold further dialogue. This can continue in person, if the participant feels safe, or online and anonymous if preferred. Organisations have a significant opportunity to demonstrate authentic care and compassion and willingness to improve in an open forum. This in turn helps them to mitigate any “risk to reputation” from the online complaint. The “tone” of the response makes an enormous difference to the ensuing contact from the client and the organisation’s ability to rebuild

trust whilst building quality. Of course this also allows oversight organisations, such as the NDIA, to see the responses and changes taking place in near real time.

In this manner, Care Opinion Australia can also be used by participants to observe responses and responsiveness (changes and innovation resulting) to feedback. This can also prove helpful to services moving to function in a market- based model, even if the feedback has been such that changes are required. The opportunity to demonstrate flexibility and an ability to resolve issues openly will help to improve their services and their reputations.

Three Options for an NDIS Complaints (Feedback) Scheme:

Option 1: Self-Regulation

“Under this option, providers would develop and operate their own complaints management and feedback systems....The NDIA could be expected to take action where there were serious issues that could cause the NDIA to review the provider’s registration status....providers could use their approach to complaints management as a source of competitive advantage.” (p52)

The key risks under this approach are that consumers would not be sufficiently empowered to be able to drive cultural change, and that the lack of independent, low-cost mechanisms to enable consumers to enforce their rights would lead to a loss of confidence in the system.

Care Opinion Australia is able to address this option and redress some of the risks associated with it. As discussed in the section earlier Care Opinion Australia could provide a preliminary feedback mechanism which integrates into a more complex complaints system if required. Early evidence indicates that if the online feedback is done in a personal and helpful manner, the need for further actions and complaints is reduced. At the same time, given its online transparency, the NDIA could watch stories and intervene where necessary. Once comments from NDIS participants are public and transparent, it gives the power back to the participant, given the platform is anonymous, independent, safe, constructive and easily accessible. Care Opinion could provide a low-cost mechanism to support organisations in establishing self- regulation.

Option 2: Internal and external complaints handling requirements

“Under this option, the NDIA registration conditions would prescribe a set of minimum standards for provider level complaints handling. ...The objective would be to ensure that most complaints are resolved by the provider and the complainant themselves, without external aid,...an alternative model could be the contracting by government of a third party to perform these functions....the NDIA would not have a formal role in the individual complaints resolution” (page 53)

Considerations in this option are that it could strengthen credibility of the sector if participants know they have a means of obtaining help to resolve problems at the same time, in weak markets (for example, regional or rural areas) there is no guarantee that feedback will create any incentive for the provider to address deficits. Unless a complaint is serious enough to warrant reporting to the complaints resolution body, systemic problems in the quality of the service may go unresolved.

The public nature of the Care Opinion Australia site would enable providers to manage the feedback locally whilst understanding that external observers (“watchers”) are also watching the story online. This also helps to address the issue of weak markets. In this case, despite small numbers potentially not creating an incentive to change, the knowledge that external observers are watching the progress of the dialogue and change adds impetus and motivation to engage. Again, this adds power to the community of participants, regardless of their size or locality.

Note: Whilst Care Opinion Australia is not primarily a complaints site, about 5% of our stories are of a complaints nature. These stories are handled differently to the other 95% of stories on the site. They are not published immediately, and some work is done behind the scene to ascertain validity from the storyteller, and to seek information from the service provider and to coach and enable a positive response. If conditions are satisfied then the story goes public. For very small practices / service, Care Opinion Australia does operate an advanced moderation strategy to protect reputational risk to providers. It involves a ‘blurred response’ being posted on the site; however, the public is informed that the story has been sent to a reputable body, for example, the NDIA

Option 3: Independent statutory complaints function

“Under this option...providers would be required, as a condition of registration, to demonstrate that they have effective internal complaints handling processes. Government would establish a formal external complaints body which would assist providers to manage complaints effectively and support participants in having their complaints resolved quickly and effectively...There are two possible ways these functions could be implemented: through a complaints office within the NDIA; or through a separate complaints body...(pge 54)

Considerations here are that this option could provide a higher level of scrutiny; however, it is a higher cost option.

Care Opinion Australia does not provide an independent, statutory complaints function. Its role in this option would be by providing “watcher” status to this body. The option of responses from this body (moderated and participant remaining anonymous) could be considered. It is not a complaint resolution system; however, it would act as a preliminary

alert to the statutory body and a reminder of transparency and accountability for the service providers.

Response to Consultation Questions: (p55)

How important is it to have an NDIS complaints system that is independent from providers of supports?

See comments above for Options 1-3. It is important for providers of supports to have a system that can deal with feedback which can integrate into their formal complaint system. It is important that this system is independent; if done in-house, there remains a risk that it becomes organisational-centric, not participant-centric. In conclusion, there appears to be a need for both internal and external systems for feedback and complaints, where feedback is seen as providing valuable information on what providers can do to improve their services, remain innovative and retain their focus on the participant.

Should an NDIS complaints system apply only to disability-related supports funded by the NDIS, to all funded supports, or to all disability services regardless of whether they are funded by the NDIS?

Care Opinion Australia believes that all disability services need a mechanism to receive and respond to feedback. This not only ensures that the public can feel there is an avenue to 'tell their story' but also ensures ongoing improvement, safety and client focus. In particular, in a market-based model, it is important that all participants in the market have opportunity to show case their responses, changes and innovations. This is fair from the providers' point of view and provides an alternative source of information and choice for participants.

Should there be community visitor schemes in the NDIS and, if so, what should their role be?

Care Opinion Australia is unable to comment on the need for a community visitor scheme generally; however, participant stories could be used by community visitors as part of their assessments; community visitors would be ideally placed to write stories on behalf of participants and would certainly be powerful people or bodies to have as local "watchers" in the system.

In conclusion, Care Opinion Australia believes it has a significant role to play in the management of feedback for the NDIS. As described, the platform is set up in such a way as to support:

- the participants in providing feedback;
- the services to receive feedback along a continuum from positive feedback to complaints (in real time - effectively and efficiently) and

- the NDIA (or other legislative bodies) in monitoring feedback from participants, carers, family or community visitors and advocates.

We look forward to having further input into future strategies.

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Care Opinion Australia, like Patient Opinion, is a not-for-profit charitable organisation run for the benefit of users, carers, staff and the public. It was launched in 2014 and is based on the award-winning platform used extensively throughout England and Scotland. Care Opinion Australia is an independent site where anyone can share their stories about their experience of care. The site covers care and support services (as well as health services) in Australia, giving service users, their families and carers the opportunity to publish their personal experiences, good or bad, of the care system. Providers of care services are able to engage with the platform to demonstrate their commitment to listening and responding to the voice of service users and their carers.