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National Disability Insurance Agency. Sent via email: Belinda.Wilson@ndis.gov.au

Cc: Gerry Naughtin
Malitha Perera

Dear Erandathie,

LEA consultation on the Psychosocial Disability Recovery-Oriented Framework.

6th May 20221 via zoom

Thank you for the opportunity of a joint consultation between LEA and NDIA. I have collated the various additional comments that attendees wished to make about some specifics they are keen for the NDIA to consider in the further development and implementation of the *Psychosocial Disability Recovery-Oriented Framework*.

I reiterate the main points that came from the discussion:

- 1) Principle One: LEA strongly request that the word ‘recovery’ be replaced with another more appropriate word such as ‘life’ or delete the work recovery altogether. The ramification of using this word is creating severe anxiety whenever a plan is due for renewal. Instead of promoting a recipient’s gains, the fear of noting their improvements means they are afraid their funding will be reduced or denied. There are perverse incentives in the use of the work recovery that should not be, and LEA suspects the adaption comes from a lot of the discourse currently in the mental health sector more broadly. LEA is happy to retain the title of the Framework.
- 2) Principle Three: there is a concern in the use of the term Shared Responsibility with mainstream services. LEA strongly request the title be amended to ‘Coordination with mainstream services’ as this better reflects what is happening on the ground. Accountability is key to the roll out of the Framework.
- 3) Participants do not have psychosocial disability in isolation. Their disability affects all parts of their lives and relationships. As such, LEA believes there should be a seventh or additional principle that takes into consideration that families, carers, and the broader community are key players in the person’s life and as such, should be recognised separately for their role.

	comments
Principle one Supporting personal recovery	<p>it’s purpose is about living a life in the community...’like any other person’. So it’s underlying goal is about membership and being a part of community as well as the more individual personal meaning and purpose things.</p> <p>So, it’s about life and living one’s life, which goes up and down just like anyone. I can understand the constraints perhaps that the document formulators are working within re the term ‘personal recovery’ which has clear definitional standing such as in the UK CHIME Framework by Leamy and others, Mike Slade, etc.</p> <p>The potentially missing principle is something that captures more of the person in their environment or context in which they live. A lot of the principle are focused</p>

	<p>solely on the individual and runs the risk of becoming like the clinical systems that remove the person from their social context. So my comments about support being in danger of being siloed and therefore exacerbating the very things that it is hoping to address ie. the person is ‘taken out of their box’ and they and support worker have coffee, and then they are put back in the box without meaningful connection to the local community or others in it. In the hands of low skilled workers, this type of contact can very easily become this, because the support becomes a task rather than a process truly facilitating the person to build their community connections, if you get my meaning.</p> <p>Originally, I advocated in the disability arena before my son was diagnosed with a mental illness and, recovery was often discussed, and the definition of recovery was about each individual obtaining their optimal level of functioning. Since being involved within the mental health arena the definition of recovery has taken on a life of its own and this has caused immense confusion for many working within the sector and unfortunately seems to be used to limit consumers achievements/engagement.</p>
<p>Principle two Valuing lived experience</p>	<p>Valuing Lived Experience, hopefully this will also include carers. The best understanding and information is certainly from those with lived experience.</p>
<p>Principle three Shared responsibility with mainstream services</p>	<p>Of course, that ‘collaboration’ or communication between the network of supports and services should always include the person (and family if they are in the picture) as equal members.</p> <p>There is widespread misunderstanding of psychosocial disability and this means that appropriate supports are difficult to find. The first and foremost principle is that people with psychosocial disabilities need to receive support which will keep them SAFE. (We all remember the death last year of the South Australian NDIS participant who died, despite that she allegedly had daily support.) This means that there needs to be assurance that SOMEONE is accountable for overseeing all supports.</p> <p>Principle 3 will not achieve this; we all know that everyone works in silos and no-one actually takes responsibility for the whole of life needs of someone with extensive psychosocial disabilities. And ageing parents, overburdened families, etc, should NOT have to take this on. Also, many, many participants and families are reporting that Support Coordinators do NOT do this.</p> <p>Therefore, I believe very strongly that people at the severe end of psychosocial disabilities, which is how the moderator today described those who will become participants, require the following principles to be in place:</p> <ul style="list-style-type: none"> • Assurance that there is a competent and skilled workforce available, who have adequate knowledge of psychosocial disability. • Ensuring enough funding allocated to ensure that support workers/allied health workers are able to spend enough time with participants to enable the building of trust and development of rapport to ensure active participation, particularly with difficult to engage participants. • Ensuring adequate funding of appropriate role, eg Case Manager, who has accountability to coordinate whole of life needs of individuals. • When Independent Assessments are introduced, it is essential that the assessors have adequate knowledge of psychosocial disability.

	<p>Principle 3 an observation I have relates to several of the NGO's, who appear to still be utilising consumers funding as if the organisation is the one who is to be making the decisions about the support/s the consumer receives. I am aware of several carers whose loved ones have not had services for many months as the provider states they are not able to provide a service at this time. I have advised some carers to seek out other service providers, however their energy is limited, and they are tired of having to find supports on their own.</p> <p>So how do we ensure there is equity in accessing services/supports and carers are not being left yet again carrying the burden.</p>
<p>Principle four Supporting informed decision making</p>	<p>Supporting decision making must always be about assuming capacity which comes from human rights framework, rather than assuming incapacity, as that is paternalism.</p> <p>Supporting informed decision-making would be ok, if it is done properly.</p> <p>As you know, consumers and carers have struggled with the concept of Recovery for many years, due to the misunderstanding of what it actually means, particularly regarding services and supports for people with psychosocial disabilities (previously known as severe and enduring mental illness) and many, if not most, remained marginalised and unsupported, and dependent on the crisis-driven hospital based mental health system. We cannot allow the NDIS to follow the same path.</p> <p>I am unsure how this will occur as from my own experience my son has not been included as an equal partner. I understand he finds it difficult to engage, however I feel with the right support and encouragement he is able to express his views, however unfortunately he has not had the right support to assist him with this.</p>
<p>Principle five Being responsive to fluctuating support needs</p>	<p>Principle 5 and the fear of losing \$\$/support – need to reinforce somehow the importance of the review process understanding that any achievements are because of the support and that it needs to be continued to ‘maintain’ those benefits. It’s not a case of some support was given, tick that box that the issue has been solved, because it’s ongoing and a lived process. Perhaps there is a conflation with goal setting where there is so much focus on goals that people look to goal achievement and endpoint so much that the ‘lived’ aspect gets a bit lost....and some people do need that walking alongside through life’s ups and downs and just generally day to day.</p> <p>You have my example of paternalism which can creep in easily in the hands of poorly trained and unaware staff. It should always be a subject of supervision conversation and reflected on routinely by workers.</p> <p>You have my comments about what the person and/or family could ask when scouting for an agency re asking supervision and training, type of stability of workforce, etc.</p> <p>The episodic nature of psychosocial disability needs to be understood in the context of recovery and the NDIS needs to recognise that whilst consumers may currently be living well and participating and engaging with their communities, however if the</p>

	<p>supports and support workers are withdrawn there is a real chance the consumer will not be able to maintain their level of wellness and their community connections.</p> <p>I would also like to make mention of the role of support coordinators as not all consumers and carers are aware they can have a support coordinator, however unfortunately even when a support coordinator is incorporated into the plan it does not always deliver what was expected. It is concerning there does not appear to be regulation around the support coordinator role and what recourse is available if their reports are less than satisfactory.</p> <p>My own personal experience with the support coordinator was disappointing and the report submitted to the NDIS was written in very basic terms and lacked a real understanding of my son and his needs and I did not think it was worth the money charged. Also how do we ensure there is full accountability for the money taken from consumer's plans.</p> <p>I agree there needs to be someone accountable for overseeing all the supports to ensure our loved ones are given the proper care and support, as too often services handball consumers with devastating results. We need to make sure there is full accountability, however, there needs to be a few checks to ensure proper support is in place and consumers are well supported</p>
<p>Principle six Building recovery-oriented practice competencies</p>	<p>I have a concern that these types of competencies play into psychosocial disability. Care will have to be taken to ensure these are written competently and with the person's disability in mind.</p>
<p>General Comments</p>	<p>I do not like the 6 principles, except Principle 2: Valuing Lived Experience, hopefully this will also include carers.</p> <p>My experiences in obtaining NDIS funding for my son were quite surprising, as the application from the psychiatrist was very basic and the supporting evidence from the NGO consisted of three dot point goals, one my son had been doing since the age of five and yet his application was granted approval.</p> <p>I find the application process confusing and challenging especially when my son's application is compared to other consumer's applications. I am aware of many other carers submitting substantial supporting evidence from numerous disciplines such as occupational therapy and yet not all of these applications were successful, and several had to be resubmitted or challenged.</p> <p>I believe there needs to be consistency in the application process so everyone with comparable psychosocial disability needs have understanding and knowledge of the processes in making an application with the confidence that it will be a worthwhile experience and deliver them the supports they require.</p> <p>It is worth noting the best information I have gained about the application/planning process has been from other carers who have their own experiences and are aware of the process. My experience of the LAC's has not been great and if I had listened to them and not made my own enquiries my son and I would not have participated in some worthwhile education, training and counselling.</p> <p>When employing support workers, I believe utilising values-based interviewing is key to finding workers who are committed to providing and delivering meaningful support with kindness and compassion. Workers who have a good value base are</p>

	more likely to engage with the consumer, deliver meaningful support and hopefully be there for the long term.
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	One amazing support worker who worked with my son had very limited knowledge of psychosocial disability, however he did understand Aspergers which my son also experiences, and he was so kind, patient, caring and eager to learn about psychosocial disability that he was an excellent support to my son. I believe skills can be learned but it is hard to teach a person to be kind and caring.
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It has been a pleasure to be able to assist and support the NDIA in the convening of this consultation.

LEA looks forward to further discussions in due course.

Kind regards



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