

Quality and Safeguarding Framework

Bespoke Lifestyles is presenting this submission regarding the Quality and Safeguarding Framework for the NDIS particularly with regard to people self-managing their plans.

Bespoke Lifestyles is a non-funded Host Provider based in Brisbane, which began in 2010. Bespoke Lifestyles currently mentors and supports its 117 participants to self-direct and manage their funded supports. This model has proven to be very successful and over the past 5 years has had a profound impact on these people's lives by giving people with disability and their representatives the opportunity to gain the knowledge and skill they need to fully embrace a lifestyle of their choice and the opportunity to be actively involved in all decision-making processes for their lives. **We therefore feel strongly that we want to safeguard this model under the NDIS.**

Bespoke Lifestyles understands that the consultation is seeking input into a system design which will have national consistency and relevance. It is important, therefore, to acknowledge that participants who are self-managing will have arrangements with a strong emphasis on involving others in their lives. For people with disability who do not have these connections, they would need to have access to advocates for supported decision-making to be able to self-manage.

What we have learned from our experience:

- Concerns about safety often involve introducing a wide range of systems but it is actually people who keep people safe – not systems. We have found what is important, is for the emphasis to shift from top heavy systems and policies, to getting good people involved in people's lives who know them well and who look out for them.
- People with disability or their allies acting on their behalf have a clear idea of what support is needed and who is best able to provide that support. Individuals and their families have found that they are well able to choose workers who best suit their needs and who they feel compatible with.
- People have found that having staff directly responsible to them rather than to an external body, leads to much greater ease of communication and the tailoring of support to their needs.
- Our participants have found that with the ability to set up individualised arrangements, not only do they have much greater flexibility and control, but they also experience more consistent and reliable support which in turn leads to them feeling more confident about their ongoing safety and security.

- People have found that even if they engage untrained or unqualified workers, this has not compromised quality in any way. What has been found to be most effective in ensuring quality and consistent support has been when workers build a relationship with the person and the family. Their level of commitment and accountability increases when they feel a strong sense of responsibility to the people that they work with.
- Participants need to be clear about their values and goals and being encouraged to see that an inclusive life in their community is not only their right but also possible.

Important elements in ensuring quality of support and to protect people with disability:

- Bespoke Lifestyles believes that quality and safeguards begin with ensuring the person with disability is at the heart of everything we do. We also believe that when people with disability, together with those closest to them who know them the best, are at the centre of decision-making around their lives and the supports they require, then there is less likelihood of neglect and abuse occurring.
- The key to a quality and safeguarding framework, therefore, is to establish ways to defend or protect that which is of value to the individual participant, and it is assumed that they, or their families, are able to make the best judgement of what is needed for them to live a safe and productive life.
- It is a basic human right that people should have personal autonomy and natural authority in their own lives and so the value of self-direction is now well recognised. If there is choice, control and flexibility in the support that people receive, it opens up opportunities for them to take a normal pathway in life rather than the ‘special’ pathway that can lead to congregated, segregated and isolated lives.
- Isolation can leave people vulnerable to abuse and neglect. We believe that people are best safeguarded when they are known in their community, when they are visible and when they have informal supports – family/friends/allies – around them.
- A focus needs to be on developmental strategies so that individuals have the capacity to build good lives which are safeguarded by their own informal networks rather than only by paid support. These people, because they know the person well, have a clear understanding of a participant’s vision, goals and rights, as well as how systems work, and therefore their involvement is more likely to reflect the hopes and wishes of the participant and will hold the vision for the person.
- Strategies for building these natural safeguards are very important and arrangements also need to be considered which provide certainty that support will continue when the caring relationships change. People need to be encouraged and supported to actively seek out supportive allies which may include developing circles of support.
- We believe that policies and regulations at an administrative level are not as important as having staff who are directly working with people having the right attitudes and getting to know the person that they are supporting well.

Ongoing relationships from workers who care about the person they are supporting are more likely to keep a person safe than service rules and regulations.

What would get in the way?

- Risk management resulting in an overly regulated system which reduces flexibility
- Onerous and bureaucratic systems for participants and workers
- Self-managing participants being required to employ workers who have to comply with too many regulations and systems
- Workers being required to have standardised qualifications
- People with challenging behaviours not being given the option to self-manage
- Inflexible awards

What we believe should be requirements for participants who are self-managing.

Participants:

- need to understand and comply with industrial and workplace health and safety legislation within a private and domestic environment
- should have Household WorkCover insurance to ensure that workers are covered in the case of injury. (the Queensland system for this works very well)
- should also ensure that they write up comprehensive and detailed contracts that covers any likely risk to both parties
- should be informed about liability insurances and given information about how to access these insurances
- should have the skills to manage a budget and complete accountability for plan purchases on a quarterly basis

What we believe should be minimum requirements for workers who are engaged by self-managing participants.

Workers need to:

- fully understand their duty of care
- have values based knowledge and understanding of people's rights and how to support people in a way that upholds their dignity
- understand that their focus should be on getting the person a good life and developing and strengthening the person's relationships
- have criminal history screening that can be checked by participants
- come with character references
- sign up to a Code of Conduct

How to achieve this:

- Participants should have funds made available if they wish to send their workers to workshops where they are given tools and strategies to strengthen good practice in this area
- Develop a Code of Conduct for workers who are working with participants who are self-managing

Question: What kind of assistance would be most valuable for people wanting to manage their own supports?

BL believes that for people to successfully direct and manage their own support, it is essential for them to have timely, accessible and accurate information and also to have access to ongoing mentoring and support for their decision-making. Our experience has shown that people can be strengthened in their capacity if they have ready access to this support.

We believe that people require:

- Access to accurate and comprehensive information:
 - HR issues – recruitment, remuneration and managing staff (this would include recognising which workers have the attitudes and values they require)
 - Worker rights and legal requirements
 - Managing the administrative and financial aspects of their plan
 - Conflict resolution
 - Communication skills
 - Developing and increasing natural networks of support
- Access to ongoing mentoring – advice and support and supported decision-making where necessary
- Access to peer support
- Access to advocacy

This support could be provided by a system where people who have experience managing plans and/or managing staff, are available to mentor self-managing participants. This could be done via:

- Plan managers
- Consultants
- Peer support
- Workshops run by providers in the sector with expertise in this area
- Technology

Other requirements:

- It is important that funds for this mentoring are made available in a participant's plan
- Participants also need funds for operating expenses for self-management
- A suitable new award that gives flexibility but protects the needs of both the service user and the worker

Question: Should people who manage their own plans be able to choose unregistered providers of supports on an 'at your own risk' basis or does the NDIS have a duty of care to ensure that all providers are safe and competent?

- Bespoke Lifestyles believes that participants who manage their own plans should have as much flexibility as possible in choosing the support that is the best suited to them. We do not believe that self-managing participants should be required to use registered workers as this would limit their choice and control. Also this could result in people needing to use 'generic' support workers who may not be the best fit for the individual.

- If a system of registration for workers was ever to be instigated, it would be very important to ensure that this process is streamlined as much as possible and does not become overly bureaucratic to respond to a perceived level of risk that may not in fact be present. Any professionalism of the workforce could well undermine the need for an emphasis on workers developing strong and healthy relationships with those they support.
- However we do believe that there should be some protections in place for participants such as a criminal history screening process for workers, such as a *Working with Vulnerable People* checking system. Participants could then ask prospective workers to provide them with individual clearances. Participants also need a way of checking ongoing validity - similar to the current system that registered services have in Queensland for checking workers with Blue cards issued by The Commission for Children and Young People and Child Guardian.
- We also believe that people who are choosing and managing their own workers need to develop the information, skills and capacity to do this effectively.

Restrictive Practices Legislation in relation to participants who are self-managing their plans

- BL strongly agrees that the use of restrictive practices is an infringement of human rights and is not an acceptable way of responding to challenging behaviours.
- Evidence has shown that when people are supported in a way that respects their individual needs and provides good quality experiences of their choice, 'challenging behaviour' often is reduced significantly or eliminated altogether.
- A major concern that we have is that there has been talk at a policy level here in Queensland that if a person with disability requires some restrictive practice to be in place, that they must receive their support through a service provider and that their families/advocates would not be allowed to self-direct/self-manage their supports. We are very worried about this possibility. Our experience has shown that when those closest to the person manage the supports and have a close relationship with workers who get to know the person well, challenging behaviours often diminish significantly, especially when there is less outside restriction and control over their life. It would be a retrograde step for these people to have services managing their supports again as this was often the cause of the challenging behaviour in the first place as they were in arrangements and situations that did not meet their needs. The person with the disability needs to be living in a situation where they have choice and control in their life to minimize frustration; otherwise they often use behaviour as their only means of communication.
- Although the current Restrictive Practice legislation in Queensland has increased the level of awareness and understanding of restrictive practices, and has contributed to a reduction in their use, the current methodology around the creation of behaviour support plans has proven to be a costly and arduous process for families and for service providers and has no guarantee of producing the required outcomes.

Who should decide when restrictive practices can be used?

- A major concern is when restrictive practice is authorized by guardians not of a person's choice and who do not know the person well. If some restrictive practice is required as a last resort to keep a person safe, these decisions should involve the person with the disability, family, advocates, and support staff. They are the experts about the participant and the challenging behaviour that needs to be addressed when developing any type of behavioural support plan. Such a plan could be devised collaboratively and quite simply and without a great deal of cost as long as it addresses the main issues involved in giving appropriate and well-managed support.
- A safeguard around this would be that this plan could then be approved by an external independent body but this could be an authorized person rather than an administrative tribunal. There could be a register of people who are authorized to approve behavioural support plans. People with experience in behaviour management, such as occupational therapists or psychologists, could undertake this role but a consultative process is essential.
- The current system of unwieldy and cumbersome processes that are often not commensurate with the risk, certainly need to be reviewed with an emphasis on the least paperwork in place as necessary

What processes or systems might be needed to ensure decisions to use restrictive practices in a behavior support plan are right for the person concerned?

- All supports for people with disability should be tailored to their own individual needs and this includes any practices that are used to keep the person safe. If those who are closest to the person are involved in developing a suitable behaviour support plan, it seems more likely that it will be best suited to the person's needs. If standardized systems and rules are introduced, these are likely to curtail people's rights of self-determination and also limit flexibility of support to respond to the person's needs. The most appropriate model of support really should be looked at on a case by case basis and have full agreement between all parties involved.
- Monitoring outcomes for the person in the least bureaucratic way possible would be the best way of determining if the plan is working well. This could again be done as a collaborative process with the person with the disability, family, advocates, and support staff on a yearly basis or more often if changes are seen to be needed. The independent body that approved the plan would be the best mechanism for this review.

Are there safeguards that we should consider that have not been proposed in these options?

- Bespoke Lifestyles also believes that an effective strategy is the appropriate education and training of workers to make them aware of their responsibilities and vulnerability as well as improving their ability to manage challenging behaviour for each particular person.

- This training and its effectiveness needs to be monitored by the people who are closest to the person to ensure it fits with what the person requires. Worker qualifications do not necessarily equate to workers having the skills and empathy that is needed. Getting to know the person well as a unique individual is usually much more effective.

**Would you support mandatory reporting on the use of restrictive practices? Why?/Why not?
If you support mandatory reporting on the use of restrictive practices, what level of reporting do you believe should occur?**

- We believe that mandatory reporting should be for emergency use only. Reporting and monitoring is costly and time consuming, and rarely results in better management of challenging behaviour. The cost and time involved in these activities have, in the past, even made some providers reluctant to provide services for participants who require behaviour support plans for restrictive practice.
- If any restrictive practice is being used by people who are self-managing and a behaviour support plan has not been put in place, there could be an independent body to which workers or others who see this occurring can report to in emergency situations so that an appropriate plan can be instigated.
- The purpose of the independent body would be to provide professional assistance, support and guidance, so that any participant, family, worker or community member who reports to it will find it useful and helpful to improve the situation rather than be obstructive and intrusive.

Conclusion

Our experience has shown that when people are managing their own supports, they experience a greater sense of safety and less vulnerability. Much of this is because of the connections and relationships that they are able to forge and so an emphasis on building networks and creating opportunities for people to really belong in their communities is essential for not only their wellbeing but also their safety.

Relationships rather than systems are the key to people having good typical lives in their communities. However for self-direction and management to be successful, people need ongoing mentoring, practical and financial support and they need to be listened to and trusted.