Villamanta Disability Rights Legal Service Inc. Response to Public Consultation Draft – Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard (April 2023)

About Villamanta Disability Rights Legal Service Inc.

Villamanta Disability Rights Legal Service Inc. (**Villamanta**) has been providing advocacy and legal services to people with disability since 1990. Villamanta's mission is to protect and advance the rights of Victorians with a disability by advising, informing and representing them and acting as an advocate on disability related legal and justice issues, with a focus on issues affecting people with intellectual disability. We are funded to provide advocacy under the National Disability Advocacy Program; NDIS Appeals and the National Legal Assistance Partnership Agreement.

Broadly, we provide legal advice and representation for matters where a person with disability has their rights restricted, or where a particular law applies to people with disability and not to other people. This includes the Disability Act 2006 (Vic), Guardianship and Administration Act 2019 (Vic) and National Disability Insurance Scheme Act 2013 (Cth).

The types of legal issues involved include:

- Issues with disability specific accommodation (group homes, SRS, Specialist Disability Accommodation etc) including quality, safety, and notices to vacate.
- Supervised Treatment Orders.
- Guardianship or administration applications.
- Issues with disability service providers, especially where they are restricting the rights of the person with disability.
- Financial abuse.

Our Experience with Restrictive Practices

Due to the nature of Villamanta's work, we have witnessed restrictive practises (RPs) as described in this clinical care standard. We do not see these types of RPs with all of our clients, or even a majority of them, but for those clients who are subjected to them the impact is significant. In the majority of cases in which Villamanta have assisted a client with an RP, assistance was requested for a different matter. As we worked with the client, it became apparent that the underlying issue was the RP.

Our Recommendations about Restrictive Practices in Clinical Care

Villamanta see that to support the rights, dignity, health and quality of life of people with cognitive disability or impairment in all healthcare settings that there is a need to:

- Explain restrictive practises to those who are subjected to them prior to the restrictions being signed off and implemented.
- Explain to the person the subject of the proposed RP their right to challenge the RPs if they are unfair.
- Increase public knowledge about the rights of those subjected to restrictive practices.

Quality Statement 2 – Informed consent for Psychotropic medicines

'To ensure that decisions about using psychotropic medicines involve the person with cognitive disability or impairment to the greatest extent possible, as well as their families, and to safeguard use in people with impaired capacity.'

Considerations from Villamanta

'When a psychotropic medicine is being considered, provide information and discuss the risks and benefits of different treatment options with the person, their family and carers, support or substitute decision-makers as relevant.
Provide information in a way that meets the person's communication needs and make reasonable adjustments where necessary to support their understanding and facilitate their involvement in decision making.
In circumstances where the person lacks capacity to consent to psychotropic medicines, there are legislative and policy frameworks to assist healthcare providers identify a person who can make decisions on behalf of the person.'

- We confirm the above and submit that any increase in medicine or deprescription should require informed consent.
- Whilst we confirm the benefit in involving family, carers and support there should be a distinction drawn that informed consent can only be provided by the person with a disability or a substitute decision-maker.

'Informed consent is a person's voluntary and informed decision about a health care treatment, procedure or intervention that is made with adequate knowledge and

understanding of the benefits and risks to them, and the alternative options available.'

- We confirm the above and that these principles should be applied to substitute decision makers. This means that any substitute decision makers should have all information available to them to provide this informed consent, which includes a BSP that highlights why non-drug strategies have been unsuccessful.

Quality Statement 4 – Non-drug strategies

'To ensure that people are supported primarily with behavioral, environmental and other non-drug strategies which are not restrictive and are suitable to their individual preferences and needs.'

Considerations from Villamanta

'Choose non-drug strategies based on precipitating and modifiable causes for the person's behaviour (...)For people receiving Aged Care or NDIS services, these strategies should be documented in a behaviour support plan.'

- The existence of a BSP must be explored by clinicians in any prescription or deprescription, this provides the context to the current behaviours and the impact of any current strategies.
- Seek consent to speak with the behaviour support practitioner.
- Without complete information from a current BSP the clinician cannot be sure that non-drug strategies have been sought.
- Should always ask for the most recent BSP.

Quality Statement 5 – Behavior support plans

'To ensure consistency in the care provided to a person with behavior support needs, in all healthcare settings where the person receives care, that is based on a comprehensive individual assessment of the person and focuses on improving their quality of life and reducing the need for psychotropic medicines.'

Considerations from Villamanta

'A behaviour support plan can reduce and potentially eliminate the use of, or the need for restrictive practices if it is appropriate for the person and is followed by all those involved in the person's daily life and care, including healthcare services.'

- There needs to be practice of seeking a copy of a BSP and seek to speak with the behavior support practitioner.

Quality Statement 7 – Monitoring, review and deprescribing psychotropic medicine

'To avoid circumstances of unnecessary initiation and inappropriate prolonged use of psychotropic medicines and to reduce the risk of potential psychotropic medicine-related problems.'

Considerations from Villamanta

Ensure that monitoring of the person's response to psychotropic medicines is an ongoing process of review and documentation (…) At each review, establish that there is an appropriate rationale for continued prescribing. Monitor effectiveness of the prescribed medicine on target symptoms as well adverse effects, and identify, resolve and prevent medicine-related problems.

- We confirm the need for regular reviews although in our practice we have seen the client has been subject to RP for a number of years without any meaningful review occurring.
- In others, the person performing the Independent Person function under their BSP to explain the meaning of the RP and the right of the client to challenge the use of such practice is performed by a family member or other person with an interest in the matter, meaning they are not truly independent.
- Those subject to RPs need to be made more aware of their legal right to request a review
- Where there is a review we would seek to prevent policies that act like 'rubber stamp' like nature of Supervised Treatment Orders and other RPs, requiring scrutiny and fresh eyes when reviewing these RPs and not allowing the same restrictions and reports to be treated as gospel for decades after they have been made.

The case study below highlights one of the impact of a failure of a meaningful review their RP.

Case Study ('X')

The case of X was one in which Villamanta assisted a client who was subject to chemical restraint – specifically, via the use of risperidone, a drug used to supress ADHD behaviours and aggression. When Villamanta came into contact with this client, they had already been subject to this RP for several months, and was experiencing great stress and anxiety as they found this drug severely lowered their mood. However despite the time that has passed and the negative effects experienced, nobody had once taken the time to explain this RP to the client. They did not understand the chemical restraint they were under and this let to further distress. The reason this was able to happen is that the independent third person that had been consulted in regards to these practises that had been assigned to explain them was X's grandparent – however, the relationship between the two was tense and thus an explanation was never given. This is indicative that when appointing the 'independent third person' proper checks are not always conducted and their relationship with the subject of the RP is not properly considered. Eventually, the OPA were able to step in as an independent third party and explain these restrictions to X as a part of their pilot program – but this was not before several months had passed. Across this time, there had been two authorised behaviour plans approved through the necessary process – and yet still no

consideration was given to X's lack of understanding and nobody had sought to explain it to them.

This is demonstrated through case study 'X' which highlights how the existence of a BSP, appointment of an independent person and a review process still resulted in the following consequences:

- The person is not informed of their legal right to challenge the practice;
- The person continues to be subject to a RP without any meaningful review of whether the practice continues to be effective or beneficial;
- Discounting of a person's human rights.