



Australian Association of Developmental Disability Medicine Inc.

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Submission to

National Disability Insurance Scheme Quality and Safeguards Framework –

Introduction

The Australian Association of Developmental Disability Medicine (AADDM) is an organisation of medical practitioners who specialise or have an interest in the health and healthcare of the over 300,000 Australian children, adolescents and adults with intellectual disability (ID). The primary aim of AADDM is to improve the health of children, adolescents and adults with intellectual and developmental disability.

We commend the National Disability Insurance Agency (NDIA) for consulting on the proposed Quality and Safeguards Framework in order to establish an accessible and user friendly but high quality service system for people with disabilities. The National Disability Insurance Scheme (NDIS) will introduce new service providers, additional and alternative drivers on services and providers and, potentially, additional risks for people with disabilities to an already complicated disability service system. A carefully articulated framework to ensure high levels of accountability is essential to ensure the safety of people with disabilities and that they get high quality, relevant and effective services.

AADDM encourages the NDIA to embed the relevance and importance of health for people with disabilities and service providers in the NDIS, even though health services will not be directly funded by the NDIS. Health professionals, especially medical practitioners, play important roles in the diagnosis and management of disability and related health conditions and often have long term involvement in the provision of holistic health services for people with disabilities to achieve and maintain optimal health and function. Further, disability services are often directly involved in health related activities such as monitoring health status, giving medication, accommodating health conditions in intervention plans and promoting healthy lifestyles through exercise, diet and social connection. Accountability for health outcomes is therefore the responsibility of the disability sector, as well as the health sector and the person themselves and their informal support network.

The vulnerability of people with disabilities to abuse and neglect by providers of services and carers has long been recognised. The quality and safeguards framework must implement a system that delivers an open and transparent system of accountability that is consistent with existing national and international standards and continues to evolve in line with those standards

Submission

This submission addresses several aspects of this consultation;

1. NDIA provider registration
2. Systems for handling complaints
3. Restrictive practices
4. Specific health related aspects of care

AADDM recommends the following additional principles be applied to NDIS funded services;

1. Where the person's goals are primarily related to functional, developmental or cognitive therapeutic gains then a rigorous evidence base be demonstrated and further developed for the requested or required intervention.
2. Any professional provider of services, e.g. speech pathologist, must be registered to practice in Australia and maintain professional standards in line with relevant professional college or society requirements.
3. If professional standards of care exist for therapeutic interventions these ought to be followed by service providers.
4. An overarching goal for services should reflect the World Health Organisation's definition of health- a complete state of physical, mental and social well-being

AADDM acknowledges the importance of sufficiently detailed, accessible and up to date information to improve access to services. However, it is the experience of AADDM members that carers and people with disability often require professional and skilled assistance to navigate the system and decide on the most appropriate services, especially where the goals are therapeutic.

Communication between involved professionals and organisations is critically important to ensure continuity of care and coordination across agencies and professionals. This must include both the GP as well as medical specialists. Usual standards such as the person's best interests and confidentiality must apply.

NDIA Provider registration

AADDM recommends that

Option 4: Mandated participation in an external quality assurance system for certain providers of supports implemented.

This option requires providers of certain kinds of supports to undertake a more rigorous quality assurance and improvement process, to meet recognised industry governance and management standards and achieve certification with a recognised certification/ accreditation body. This is now standard practice in many organisations such as hospitals and child care centres.

AADDM recommends that this be applied to organisations involved with provision of services to children and young people, residential or respite services, those supporting people with challenging behaviours and those delivering any form of health related activity or intervention. The NDIA could provide supports and guidance to organisations wishing to be registered under this scheme, with an external accreditor determining compliance.

Complaints handling

AADDM recommends that

Option 3: Independent statutory complaints function, be implemented.

Each organisation should have its own policy and procedures regarding complaints management that is publically available and accessible to users of the service and their advocates. There must be a complaints officer or commissioner independent of the NDIA established with powers to investigate and address serious or unresolved cases of complaints. Such a Commissioner would also have an important role in identifying common issues or trends and so inform systemic improvement.

Restrictive Practices

AADDM recommends that

Option 4: Restrictive practices could only be authorised by an independent decision maker be implemented.

Although currently in some states, e.g. NSW, this is managed internally by a specific panel within the government department (ADHC), this occurs in the context of a higher level of expertise of positive behaviour management than currently exists in most non government agencies. The external authorised approver must be an expert in behaviour management and may function like a senior practitioner.

AADDM recommends that;

1. All professionals providing direct care services to people with disability have basic training in positive behaviour practices and effective communication skills and have an awareness of guidelines and legal requirements around the use of restrictive practices
2. All organisations providing therapeutic, direct care, residential or respite care, education or intervention to people with disabilities employ a professional with expertise in positive behaviour support to develop behaviour management programs with an emphasis on positive practices and skill development.
3. The NDIA fund hubs of expertise in complex and challenging behaviour that can provide training and assist in developing positive behaviour plans that may involve restrictive practices
4. The National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Sector be used to develop standards that apply to all agencies and government departments in line with person and rights centred approach
5. Sanctions be brought to bear on agencies or providers who breach national standards
6. Public reporting on use of restrictive practices

Specific health related aspects of NDIS

Disability services providers have long been involved with the delivery of health related interventions, and this can be expected to continue under the NDIS. It is not uncommon that mistakes and errors arise during the course of health related interventions, e.g. administering medications. These can have substantial adverse effects on the person's health and wellbeing and may even lead to death.

The nature of a person's disability may severely impair their own ability and that of their carers to pursue a healthy lifestyle. This may further compromise the wellbeing of the person and their carer, setting in train a cascade of deteriorating circumstances. Carers often look to disability services to assist in ensuring the person has a healthy lifestyle. This may involve increased exercise, a healthy diet, reduction in soft drinks and getting sufficient sunlight to prevent vitamin D deficiency.

Challenging behaviour can arise from a number of complex and interrelated factors, including poor physical or mental health. Disability services play a major role in identifying and intervening in these factors. Support staff may be able to assist through tasks such as data collection that enables a mental health disorder to be diagnosed and treated, engagement in functionally appropriate tasks and activities, e.g. participation in household tasks, provision of suitable toys and games for young children, and implementation of augmented communication systems to reduce communication barriers and therefore optimise choice and control.

AADDM recommends that;

1. Disability services anticipate and plan for their involvement in health related activities.
2. NDIS develop and implement standards and practice guidelines in relation to common health related procedures such as monitoring health status and administering medication in

collaboration with relevant health professional organisations, e.g. medication charts, interventions for people with swallowing difficulties at risk of aspiration.

3. Nationally adopted health standards of care be implemented by disability organisations. These may include annual evidenced based health assessments, handwashing to reduce risk of infection, wound care, resuscitation, emergency management of seizures, provision of healthy diets and recommended daily activity levels.
4. A suitably qualified health professional be responsible for policy development, training of staff and monitoring of health related activities for each organisation.
5. Reporting requirements for disability services to include reporting of health lifestyle and outcome parameters (e.g. exercise levels, weight, adverse health events)

In conclusion

AADDM highlights the importance of achieving and maintaining optimal health and function to the quality of people's lives and their opportunities for choice, control and participation.

AADDM supports the development of national standards and guidelines for NDIA funded services that enable high quality person centred services to be delivered and a high level of accountability and transparency to be achieved across a range of domains, including health. Collaboration with relevant professional organisations would be of benefit for this process.

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