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Mr. Bruce Smith
Branch Manager
NDIS Market Regulation (Quality and Safeguards) Branch
Department of Social Services
Australian Government, Canberra.

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Dear Mr Smith,

Amaze submission to NDIS Code of Conduct Discussion Paper

Amaze welcomes the opportunity to provide a submission to the Commonwealth Government's *NDIS Code of Conduct Discussion Paper*. As the peak body for autistic people and their families in Victoria, we strongly support the development of an NDIS Code of Conduct ("Code") that has the capacity to ensure the safe and ethical delivery of high quality services and supports to people with disability.

Given the vulnerable nature of many autistic people, protecting and safeguarding them from unethical practices, sub-standard support and potential abuse is paramount, especially within the rapidly growing private workforce.

We agree that the draft Code sets out clear expectations and obligations for providers and workers delivering NDIS services and supports. We are also pleased that the Commission will be able to take appropriate action against any providers and workers that engage in unacceptable behaviours. However, with autism accounting for almost 1 in 3 NDIS participants¹, our submission aims to highlight the importance of the Code and complaints process being accessible to autistic people. We also provide feedback on some definition related issues to ensure that the Code provides maximum protection and safeguards from harm.

(1) Accessibility of the code.

To ensure NDIS participants (and their families and carers) are fully informed about their rights under the Code, and the obligations of providers and workers, it is vital that they are aware of the Code and have easy access to it.

The Discussion Paper (page 10) states:

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¹ NDIS 2017, COAG Disability Reform Council Quarterly Report, Q3, March 2017. Available at https://www.ndis.gov.au/medias/root/heb/he8/8801054359582/COAG-DRC-Report-2016-17-Q3.pdf

"Information about the Code of Conduct, and how to comply, will be available to all participants. Self-managing participants will be strongly encouraged to provide information about the Code of Conduct and its obligations to any unregistered providers they engage".

We urge the government to ensure that the Code is not only made 'available' to participants, but is required to be actively promoted to participants during the NDIS planning and post planning stages (i.e. by the NDIA, Local Area Co-ordinators, service co-ordinators, planners etc.). In addition, all service providers, or at the very least registered providers, should also be obliged to inform participants and their families of their rights under the Code and how they may access it. The obligation should be on all service providers (registered and unregistered) to be aware of the Code and inform participants, not vice-versa.

With 28% of NDIS participants identifying autism as their primary disability, it is vital that the Code's contents be delivered in an "autism friendly" way, i.e. plain English without bureaucratic or jargonistic language and possibly utilising pictures and/or symbols where appropriate. We therefore encourage the Commission to work with a trusted, independent and experienced organisation, that works in close collaboration with autistic people, to develop a version of the Code and/or Code related resources for the autism community - utilising a methodology of co-design with autistic people to ensure usability.

To ensure participants' families and carers, unregistered providers and the broader community are aware of the code it should also be actively promoted across all types of Agency communications.

(2) Accessibility of the complaints process.

The complaints process must be accessible to all participants (and their families, carers and the broader community) to enable complaints to be made and appropriate action taken against providers and workers that engage in unacceptable behaviours.

The Discussion Paper (page 12) states:

"Anyone will be able to make a complaint about NDIS funded supports, including breaches of the Code of Conduct. This includes participants, family members, friends, providers, workers and advocates. In the first instance, people should contact the relevant service provider to make complaints...... In cases where the problem is not resolved by the relevant provider, or when the person does not feel comfortable talking to the provider about the problem, complaints should be directed to the commissions".

We support this two-step process, however a variety of methods for lodging complaints with providers and the Commission must be available (i.e. in person, by telephone, online etc.) to ensure all participants can comfortably, reliably and comprehensively complain about any potential breach of the Code.

Some autistic participants may not feel confident or able to complain in person, may have difficulty comprehending long verbal instructions over the telephone, may not feel confident or able to express their complaint over the telephone or in person and/or may have difficulty

understanding or filling out complex forms. As above, we would therefore encourage the Commission to work with a trusted, independent and experienced organisation, that works in close collaboration with autistic people, to ensure that the complaints process is fully accessible to autistic people. The Commission should then support providers to develop accessible complaints methods and procedures.

The Commission should also be required to ensure that participants, their families, providers, workers and the broader community are aware of the complaints process and how they can lodge a complaint. As above, the right to lodge a complaint under the Code should be clearly explained during the planning and post planning stages and widely promoted across a range of communication mediums. All service providers, or at the very least registered providers, should also be obliged to inform participants and their families about their rights to complain and how to lodge to lodge a complaint under the Code.

(3) Defining violence, exploitation, neglect, abuse and sexual misconduct

We welcome the Code's obligations on providers and workers to actively prevent all forms of violence, exploitation, neglect, abuse and sexual misconduct.

There is evidence that people with communication impairments, behaviour difficulties, intellectual disability and sensory disabilities experience considerably higher rates of abuse and neglect than their peers who do not have disability (and it is likely that this abuse is under-reported).²

There is also evidence that the risk of harm is increased in environments that have a closed culture, cover up reports of abuse and/or fail to protect people who report. They justify and rename abusive practices (e.g. behaviour management), readily accept excuses for abuse, and have low accountability and little outside scrutiny. Finally, these environments have a strong power imbalance between workers and people using the service (i.e. children and their families).³

We therefore agree that harm prevention must be a core focus of the Code, ensuring providers are committed to the elimination of harm and appropriate systems for reporting incidents are in place.

However, we are concerned by the suggestion on page 16 of the Discussion Paper that:

"Providers should have policies that define violence, exploitation, abuse and neglect...."

² Maclean MJ, Sims S, Bower C, et al 2017, Maltreatment Risk Among Children With Disabilities. Pediatrics, 139(4):e20161817; Robinson S 2012, Enabling and Protecting: http://www.cyda.org.au/royal-commission-resources Hughes K et al 2012 Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies, The Lancet, Volume 379, Issue 9826, 1621 – 1629.

³ Report on the Inquiry into Abuse and Neglect against People with Disability in Institutional and Residential Settings..", Senate Community Affairs References Committee, 2015; Robinson S 2012, Enabling and Protecting

We do not agree that it should be left to providers to define these crucial terms as this could lead to considerable inconsistency across service providers and inadequately or inappropriately defined terms. Instead, we urge the government to prescribe the definitions of violence, exploitation, abuse and neglect in the Code or legislation and require providers to incorporate these prescribed terms and definitions into their policies.

The guidance to be provided by the Commission on how to comply with the Code should also be very specific about the policies, systems and procedures that need to be in place to prevent violence, exploitation, neglect and abuse, as well as the type and level of staff supervision and training workers must have. This will be essential to support a thorough, consistent and robust approach to harm prevention across all service providers.

We also agree that all forms of sexual misconduct should constitute a breach of the Code and urge the government to define "Sexual misconduct" in the Code or legislation.

In the discussion paper, at page 30, it is stated that:

"Sexual misconduct is a broad term encompassing any unwelcome behaviour of a sexual nature".

Given the vulnerabilities of many people with disabilities, particularly with intellectual disabilities and neurological conditions such as autism, we would urge the government to ensure the term "sexual misconduct" is defined to encompass <u>any</u> sexual behaviour between a worker and participant, not only supposed "unwelcome" behaviour.

If you have any questions or would like further information on the matters raised in this submission, please contact Braedan Hogan, Policy Manager at Amaze on (03) 9657 1650 or at braedan.hogan@amaze.org.au.

Yours sincerely,

Fiona Sharkie

Chief Executive Officer

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