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**National Disability Insurance Scheme (NDIS) – Code of Conduct**

**A submission in response to the Code of Conduct discussion paper distributed by the Department of Social Services.**

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# **About YDAS**

Youth Disability Advocacy Service (YDAS) is a state-wide advocacy service for young people with disabilities in Victoria, offering a free individual advocacy service to young people aged 12-25 who have a disability.

YDAS is a core agency of the Youth Affairs Council Victoria, the state’s youth peak body. YDAS is guided by a Steering Committee who are predominantly young people with disabilities aged 12 to 25.

# **About YACVic**

The Youth Affairs Council Victoria (YACVic) is the peak body and leading policy advocate on young people’s issues in Victoria. YACVic’s vision is that young Victorians have their rights upheld and are valued as active participants in their communities.

YACVic is an independent, not-for-profit, member-driven organisation that represents young people (aged 12-25 years) and the sector that works with them. Through our research, advocacy and services, we:

* lead policy responses on issues affecting young people
* represent the youth sector and elevate young people’s voices to government
* resource high-quality youth work practice.

We are driven by our members and prioritise their needs and concerns.

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# **Glossary**

**ABS -** Australian Bureau of Statistics

**DSC -** Disability Services Commissioner

**NDIA -** National Disability Insurance Agency

**NDIS -** National Disability Insurance Scheme

**YDAS -** Youth Disability Advocacy Service

**OHCHR –** United Nations Office of the High Commissioner for Human Rights

**‘The framework’** refers to the National quality and safeguarding framework for the NDIS to be implemented in 2019.

**‘Code of Conduct’** refers to the national code of conduct for the NDIS.

**Victorian framework** refers to the proposed state code of conduct and expansion of commission powers enacted by under the ‘zero tolerance’ policy platform by the Victorian Government.

# **1. Introductory Comments**

Youth Disability Advocacy Service (YDAS) is committed to upholding and promoting the rights articulated in international human rights instruments ratified by Australia. Because YDAS works with young people aged 12 – 25, this includes both the United Nations Convention on the Rights of People with Disabilities (CPRD) (OHCHR 2006) and the Convention on the Rights of the Child (CROC) (OHCHR 2002).

Article 7 of the CRPD especially acknowledges the rights of children with disabilities. It says that:

1. *Governments will take all necessary steps to make sure the human rights of children with disabilities are considered on an equal basis with other children.*
2. *In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.*
3. *Governments will make sure that children with disabilities have the right to express their views freely on all matters affecting them, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise that right. (OHCHR 2006).*

Further protection for the rights of children in state welfare systems is outlined in CROC:

**Article 3**

1. *In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.*
2. *2. States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.*
3. *3. States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.*

And:

Article 5

*States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention. (OHCHR 2002).*

YDAS recognises that the National Disability Insurance Scheme (NDIS) was designed around these same principles; with a focus on choice and control, allowing individuals with disability to exercise agency over their own lives, including acknowledgement of the evolving capacity of children to make decisions and complaints. We hope that the Code of Conduct will accurately reflect these rights in full.

YDAS takes our direction from young people with a disability directly and represents their interests throughout this submission. YDAS maintains a steering committee comprised of young people with varied lived experience of disability. In order to accurately represent these interests YDAS has conducted consultations with young people. The feedback received throughout this period of consultation has been used to inform the direction of our submission. Our response is also informed by our work with young people who come to us for individual advocacy support, including making complaints about disability services and the NDIS. YDAS maintains that any code of conduct should function in a fashion that promotes the rights of people with a disability (particularly young people) who are least empowered to exercise those rights.

The Australian Bureau of Statistics (ABS) indicate (as of their October 2016 report) that 12.5% of people with disabilities are aged between 12 and 25; estimating that there are roughly 600,000 young people living with a disability in Australia. However, the NDIA Quarterly Report (as of March 2017,) indicate that the current percentage of NDIS participants within this age group could be as high as 25% (NDIA 2017). This figure displays a clear need to consider the unique communication and education needs of young people with disabilities; particularly in relation to the commencement of the National Quality and Safeguarding Framework.

Young people with or without a disability are at a greater risk of violence, abuse or neglect. They generally have less confidence or agency to speak up when something is wrong. This inability to speak up is often compounded for young people with a disability. This is in part due to rampant social exclusion; which can leave people with disabilities hidden away in institutional settings and family homes. Social exclusion is an acute issue for youth living with disabilities. This has been shown to hinder development and limit the ability to speak up (Gaskin 2012 & Lindsay 2012).Minors under the age of 18 have fewer rights and are subject to greater legislative protections than adults due to their unique needs. Consideration of these vulnerabilities needs to be balanced with the principles of capacity building found within the CRPD and CROC, which allow young people with disabilities to learn to speak up.

According to a report conducted by the Disability Services Commissioner based on complaints data gathered between 2007 and 2015 only 23% of complaints are made by the person with a disability (DSC 2017). This is reflective of people with disabilities being left out of discussions around violence, abuse and neglect. This can reinforce a continued reliance on families, carers and service providers to report incidents. A common theme reflected in our consultation feedback is a desire of people with disabilities to not be spoken for.

*“We need communication and to feel heard.”* (YDAS 2017)

In consulting with our steering committee we learnt that young people with disabilities are likely to wait until an issue becomes urgent before speaking up. This means that the first important step for young people making complaints needs to be confidence building. But young people also talked about not being taken seriously when they do speak up:

*“Sometimes when I make a complaint and I get upset people just assume it’s because of my psychological issues. It’s harder because they won’t understand that I’m just upset about the problem and the fact that I have to make a complaint.”* (YDAS 2017).

There are a number of barriers to young people with disabilities speaking up themselves instead of having others speak on their behalf. In particular, YDAS places great importance on the role of capacity building measures. It is our belief that young people should be empowered to grow and exercise greater agency over their own lives, which will in turn create a more robust and safer disability support system.

As part of our consultation process YDAS distributed a short survey through our networks which asked participants to review the Easy English Code of Conduct and leave feedback on their level of understanding. This consultation as well as our individual advocacy work has revealed a number of areas of concern. -These include:

* The accessibility of the code (rights and procedures)
* Self-management and complaint mechanisms
* Education, privacy and consent (understanding of mandatory reporting and duty of care)
* Capacity of the commission (proactive measures and systemic advocacy)
* Alternate safety measures (communication, choice of service provider.)

Throughout this submission YDAS will make comments and recommendations as they relate to each of these areas.

These barriers contribute in large part to the percentage of complaints made by people with disability directly being as low as it is. In order to ensure young people with disabilities feel comfortable and confident in voicing their concerns we must make sure that any proposed Code of Conduct and associated materials and mechanisms for conflict resolutions are completely accessible to young people.

The advocacy sector has already illustrated throughout the NDIS trials that individual participants will require time and education to build confidence in order to get the maximum benefit from their plan (Warr et al, 2017). This confidence building facilitated by both independent advocacy and various NDIS readiness programs needs to be extended to both conflict resolution and education around the proposed Code of Conduct.

The renewed push for the establishment of a Royal Commission into Violence, Abuse and Neglect in Disability Services speaks volumes for the need of both a quality and safeguarding framework as well as this proposed code of conduct. YDAS believes that accessible complaints mechanisms are one of the many steps needed to confront the systemic abuse and neglect revealed by both the Victorian government’s inquiry into abuse in disability services as well the similar inquiry made by the Commonwealth Senate. YDAS continues to support the efforts of the broader advocacy community to establish a national royal commission into abuse of persons with a disability.

With the Victorian Disability Services Commissioner set to cease operation in 2019; to be entirely replaced by the National Quality and Safeguarding framework. it is the position of YDAS that the both the Department of Social Services along with the National Disability Insurance Agency consider the inadequacies of the Victorian framework (having been in operation since 2006) when putting in place an oversight body like the proposed national commission.

# **2. Issues and Recommendations**

## **2.1. The accessibility of the code**

The accessibility of information is crucial to making the National Disability Insurance Scheme and all related frameworks as inclusive as possible. This must involve going beyond providing an Easy English format and in turn making use of varied forms of communication. YDAS has observed through the distribution of our survey that young people are unlikely in many cases to read a 20 to 30-page document. The Victorian Advocacy League for Individuals (VALID), an organisation working primarily with people with intellectual disabilities and their families, has developed multimedia materials for explaining a number of the behaviours covered by the code of conduct. This method is useful when explaining complex concepts to individuals with limited capacity but may also be effective in engaging young people who often prefer highly visual short form communication. We have feedback from young people that shows a strong preference for online, video engagement.

**RECOMMENDATION:** That the language of the Code of Conduct be co-designed with people with disability, so that it presents as few accessibility challenges as possible in its natural form

**RECOMMENDATION:** There should be a strong investment in a communications strategy to effectively promote the Code of Conduct. As part of this strategy, the government should:

* Engage in co-design of the strategy and resulting materials with people with disability;
* Engage in local face to face discussions with young people, and where relevant, their families about the Code;
* Produce short form communications in various media formats (such as narrative driven YouTube clips) to engage young people with the key elements of the Code.; and produce concise materials that clearly illustrate and explain the procedural elements of the Code of Conduct.

Responses received by YDAS indicated that young people are unlikely to look for a formal complaints handling mechanism like a code of conduct. This illustrates a clear need for education surrounding dispute resolution. The mandatory reporting instituted by the Victorian Disability Services Commissioner in 2010 has led to a greater reporting culture within some disability services; with the ”It’s OK to Complain” campaign encouraging service providers to promote open communication with their client base. This has led to some service providers running information sessions for new clients on the organisations individual complaints procedures. However, as indicated earlier in this submission; of these complaints only 23% were made by the person with disability directly.

**RECOMMENDATION:** YDAS recommends that the government compel the National Disability Insurance Agency to include information about the National Code of Conduct (inclusive of the procedures and mechanisms) within Agency led or funded NDIS information sessions and early planning meetings.

**RECOMMENDATION:** YDAS recommends that the use of the Code of Conduct is monitored in a way that captures the number of people with disability directly making complaints, and which disaggregates data by age as well as disability type, gender identity and cultural background, so that potential gaps in the exercise of choice and control can be addressed effectively. Monitoring data should be made publicly available on an annual basis.

## **2.2. Self-management and complaint mechanisms**

The consultation and advocacy work done by YDAS has revealed that young people are likely to utilise ‘self-management’ in the future. Many of our clients do not want their families involved when accessing our services, which means that building their capacity to understand both self-management and its interaction with the Code of Conduct will be crucial.

Self-management and adherence to the Code of Conduct places significant responsibility on the individual and in the case of a young person may be just another complicated new responsibility in the transition period to full independence. Self-management aims to provide greater choice to NDIS participants by allowing them to engage unregistered providers for their support needs. However Self-management requires the individual to provide these providers with information regarding the requirements of the code of conduct. In order to ensure that participants (particularly young people) are prepared for this increase in administrative responsibility YDAS makes several recommendations.

**RECOMMENDATION:** YDAS recommends that the NDIA train planners to include funding for education around the code of conduct in the plans of newly self-managing young people.. This training should be available in a range of accessible forms – such as workshops – for young people.

While YDAS advocates for young people to build capacity, and assume a degree of responsibility. However, we do not feel that young people should be responsible for the consistent distribution of information in relation to the code of conduct. Controlled and consistent distribution of information to both registered and unregistered providers would alleviate an unnecessary barrier to self-management for young people.

**RECOMMENDATION:** YDAS recommends that the NDIA and/or the proposed Commission work together to make sure that people who self-manage for the first time have access to standardised information and advice about their obligations under the Code.

## **2.3. Education, Privacy and consent (understanding of mandatory reporting and duty of care)**

YDAS recognises that understanding complex ethical issues can at times be difficult for young people. The proposed code of conduct covers the disclosure of information as well as enforcement of mandatory reporting for service providers. YDAS understands the importance of ensuring that young people with a disability understand their rights. It is the experience of YDAS that young people may be unaware of their limited understanding of complex ethical issues such as privacy and consent. It is extremely important that young people engage with these concepts in order to build capacity to exercise their rights. YDAS maintains a consistent practice of explaining privacy and consent to young people with disability when engaging with them. This engagement includes individual advocacy, online correspondence (surveys), group events and steering committee meetings.

Young people with disability may also have a limited understanding of the scope of the duty of care imposed on advocates and service providers. YDAS recognises that it is crucial for young people to be educated around legal requirements associated with their care; particularly as those individuals under 18 are subject to a higher duty of care in order to prevent abuse and neglect.

**RECOMMENDATION:** YDAS recommends that young people have greater involvement in planning meetings and information sessions alongside their parents to ensure they are equipped to exercise choice and control over their own supports.

## **2.4. Capacity of the commission**

YDAS supports a dispute resolution body with the power to empower individuals with a disability and respond appropriately to complex issues. It is the position of YDAS that any successful oversight body should play a large role in driving systemic advocacy and change within the disability sector. A proactive commission has the potential to change the attitude of service providers; moving away from the prevention of complaints and towards providing a consistently higher standard of support. YDAS broadly supports the recent Disability Amendment Act within Victoria as a model for the powers given to the national commission.

The proposed code of conduct is only one piece of a larger policy framework (the National Quality and Safeguarding Framework.) At this time, it is unclear how it will interact both with the national framework as well as with existing state frameworks. YDAS broadly recommends clarification be made in the preceding two years until the Framework’s implementation.

**RECOMMENDATION:** That more detailed consultation on the Code of Conduct is not undertaken until after the Quality and Safeguarding Framework Bill has passed both houses of Parliament to ensure the clearest possible context for further comment.

## **2.5. Alternate safety measures (communication, choice of service provider)**

YDAS maintains that formal safety measures (Framework, Code of Conduct etc.) cannot be completely effective in isolation. This is consistent with feedback received from both the steering committee as well as survey responses. It has been the experience of our clients that they feel most comfortable when they can communicate openly with a support worker; often when they have an existing rapport with the support worker in question. Keeping the barrier to entry reasonable for support workers will allow people with disabilities to work with support workers that suit their needs. When asked what led to greater communication with a support worker; one respondent noted:

*“I use Hireup as my NDIS funding is self-managed. Therefore, my support worker is my friend rather than a random stranger.”* (YDAS 2017)

Good communication within service providers themselves can prevent young people with disabilities from needing to explain every aspect of their care whenever they are engaged by a new support worker. Feedback received by YDAS indicated that young people can feel fatigued if the burden to educate rests solely on the individual.

*“I am more likely to communicate with a support worker if they already have a basic knowledge of my needs.”* (YDAS 2017)

**RECOMMENDATION:** That the proposed code be reviewed and updated to account for successes of state frameworks (such as *ZERO TOLERANCE;* the Victorian policy platform*)*

**RECOMMENDATION:** That the Australian government and the NDIA work together to ensure that other safety measures are developed and enforced in the broader context of workforce development and the implementation of the National Disability Strategy.

# **Appendix**

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