



National Organisation for Fetal Alcohol  
Syndrome and Related Disorders

## **Submission to the Senate Standing Committee on Community Affairs Inquiry into the National Disability Insurance Scheme Bill 2012**

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### **About NOFASARD:**

The National Organisation for Fetal Alcohol Spectrum and Related Disorders (NOFASARD) is an independent not-for-profit charitable organisation representing the interests of individuals and families who are living with Fetal Alcohol Spectrum Disorders (FASD). NOFASARD was established in 1999, is registered as an incorporated association in South Australia under the *Associations Incorporation Act 1985* and has held Health Promotion Charity status since 2007.

The Organisation has a small formal membership base with emphasis placed on the development of a large network of individuals and organisations interested and concerned with FASD and related issues. In July 2012 NOFASARD received a three year grant under the Australian Government Health System Capacity Development Fund which has enabled the expansion of activities to ensure FASD receives due recognition in both national public policy and in practice at a population-wide level.

NOFASARD is working towards ensuring FASD is recognised as a disability in Australia, promoting social inclusion by advancing the rights and interests of people living with FASD, and providing the necessary supports to individuals and families at a grassroots level. This work is fundamentally important in preventing the social, health, economic and justice consequences of this condition for all Australians.



## **LIST OF RECOMMENDATIONS**

1. Section 3(3): A sub-section needs to be included that states that in order to give effect to the objects of the Act, regard is to be had to the current role of mainstream services in delivering disability support.
2. Section 13: The provision of coordination, strategic and referral services must take into consideration the level of understanding, or lack thereof, of a given disability. In regards to FASD, community education and training to raise awareness and build the capacities of the service delivery sector is crucial if referral to mainstream and specialist services is to be effective.
3. Section 15: Devise a plan to ensure equal access to information regardless of disability, geographical location and current life circumstances. The plan should also acknowledge that the person may not have a support network that understands the NDIS and the supports that the Scheme can provide.
4. Section 18: This section needs to be amended to include provision for an informal carer or other nominee to make an access request on behalf of the participant.
5. Section 24(2): This subsection should be reworded to take account of the fact that the intensity of the impairment will not change but may be ameliorated by the intensity of support need.
6. Section 25(c): Include a sub-section that acknowledges the importance of early intervention in reducing the likelihood of secondary disabilities that tend to exacerbate a person's support needs.
7. Section 26(1)(a): A formal disability diagnosis should not be considered as 'information that is reasonably necessary' or a prerequisite for eligibility to become a participant under the NDIS.
8. Section 27: The NDIS rules regarding assessment must include effective assessments for executive functioning that identify the specific needs of an individual in multiple domains.
9. Section 27: The importance of re-assessment in identifying a person's changing needs must be integrated into the NDIS assessment framework.
10. Section 31: A sub-section should be added to reflect the importance of people with a disability having access to an advocate, or other form of support, to build their capacity to make choices and decisions.
11. Section 33(2): Requirements concerning the contents of participant plans and review processes must take into account the often changing nature of goals, objectives and aspirations of people living with FASD.
12. Section 34(c): The NDIS rules should define how 'value for money' will be measured, particularly given that it is often difficult to determine how effective an alternative support may be.



13. Section 34(d): This sub-section should acknowledge that there is not established best practice regarding support services for some disabilities, such as FASD.
14. Section 34(e): People with a disability should have the ability to choose whether or not they want to accept the support of their informal support network (if they have one). The legislation should not make the presumption that people with disabilities have an informal support network or are engaged in the community. In addition, people with a disability may prefer not to rely on the support of their informal support network, such as parents.
15. Section 34(f): Mainstream support services should be required to work with disability support workers in the event that it will clearly benefit the person with a disability in accessing services and engaging with mainstream service workers.
16. Section 43: Include a subsection that gives the participant the right to an independent advocate to support them in determining what elements of the plan they are able to manage.
17. Section 44(2)(a): The NDIS rules must clearly define how 'unreasonable risk to the participant' will be measured.
18. Section 44(3): A criteria for assessing an 'unreasonable risk to the participant' must include protection for people with a disability who have demonstrated that they are unable to balance a budget.
19. Section 86: It is preferable that steps are taken to enable supported decision-making. Where this is not possible, a high threshold should be applied to determinations regarding whether an advocate or other form of support cannot provide an appropriate level of assistance in decision-making processes so as to justify the appointment of a plan nominee.
20. Section 86: Where a decision is made to appoint a plan nominee, if the person already has a legal guardian, the guardian should automatically take on the role of plan nominee.
21. Section 91: Delete the word 'severe' because the onus of proof is too high, particularly for individuals that are already vulnerable.
22. Section 91: Include sexual abuse in this section.
23. Chapter 4, Part 6: Include a subsection that gives the right of the 'person directly affected by the reviewable decision' and their plan nominee (where relevant) to access an independent advocate to help them through the review process.



## **INTRODUCTION**

Thank you for the opportunity to make a submission to the Senate Standing Committee on Community Affairs regarding the National Disability Insurance Scheme Bill 2012.

We welcome the acknowledgement in the Bill of the breadth of disabilities that exist in the Australian community and the range of support needs covered by the Scheme. In particular, NOFASARD endorses the inclusion of both intellectual and cognitive disabilities. NOFASARD begins this submission with a brief insight into Fetal Alcohol Spectrum Disorders (FASD), how the impairments within the FASD spectrum impact upon the lives of people living with FASD, and how FASD will fit into the Scheme.

The commentary provided in this submission is particularly relevant to the development of the NDIS rules to ensure that the Scheme operates effectively for people with FASD. For example, in this submission NOFASARD draws attention to issues relating to assessment frameworks and the importance of a Scheme participant having access to an advocate independent of the National Disability Insurance Agency to support them through all relevant processes, including applications, decisions and reviews.

The role of the plan nominee and respective powers contained within the legislation is a particular concern for NOFASARD given the fundamental importance of ensuring that people with a disability are engaged in all decision making processes that relate to their life.

NOFASARD also highlights the need to improve knowledge and understanding about FASD within mainstream services if the referral and information services proposed in the draft legislation are to be effective.

Within this submission NOFASARD makes recommendations on the following parts of the Bill:

1. Chapter 1 – Part 2: Objects and principles
2. Chapter 2 – Assistance for people with disability and others
3. Chapter 3 – Participants and their plans
4. Chapter 4 – Administration



## **WHAT IS FASD?**

Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term used to describe a spectrum of conditions which are physical and neurodevelopmental that can result from prenatal alcohol exposure. These disorders are not always apparent at birth and may not be noticed until the child reaches school age. Due to the current lack of a comprehensive understanding of FASD among many health professionals and service providers, FASD is referred to as the 'invisible disability'. As a result, a child's condition is often ignored, attributed to a different diagnosis or cast as parental inadequacy.

The medical diagnoses recognised in Australia within the FASD spectrum include: Fetal Alcohol Syndrome (FAS), partial Fetal Alcohol Syndrome (pFAS) and Neurodevelopmental Disorders Alcohol Exposed (ND-AE). The Australian FASD Collaboration has developed a national diagnostic instrument for FASD and is awaiting government approval for its use.<sup>1</sup> Further funding will be required to develop clinical guidelines on its use and to trial the instrument. Due to the status quo, FASD is chronically underdiagnosed in Australia.

The primary disabilities common to FASD last a lifetime and can lead to difficulties in learning, impulsivity, consequential thinking (linking cause and effect), social interaction and making and sustaining relationships with others, and hyperactivity. Typically, unrecognized primary disabilities result in misunderstanding by those with authority. In an effort to meet unrealistic expectations, the individual develops defensive behaviours which are paradoxically used to stereotype and label the individual according to the observed behaviour. This unfairness reinforces the invisibility of the disability and perpetuates the individual's sense of failure leading to an increased risk of secondary disability. These conditions, or secondary disabilities, can include: incomplete education; crime; family and economic dependence; poverty and homelessness; early parenthood and subsequent risk for children.

For adults with FASD, the ability of an individual to live independently often requires appropriate supports to build the capacity of the individual to engage in social and economic life. Therefore, 'interdependence' is a more realistic and supportive goal.<sup>2</sup> It is crucial that accommodations are developed in full consultation with the person living with FASD as the needs of every person are different. With a correct diagnosis and early intervention, coupled with appropriate support for parents and carers during childhood, learning and life outcomes for people with FASD can be vastly improved.

## **SUPPORTS REQUIRED BY PEOPLE LIVING WITH FASD**

FASD is a physical brain-based condition<sup>3</sup> that requires appropriate accommodations (or supports) specific to the needs of a given individual, as is the case with other physical brain based conditions.

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<sup>1</sup> Information about the Australian FASD Collaboration and the project to develop a national diagnostic instrument can be accessed at: <http://alcoholpregnancy.childhealthresearch.org.au/projects/current-projects/development-of-a-diagnostic-instrument-for-fasd-in-australia-2010-2011.aspx>

<sup>2</sup> Community Living British Columbia, *Supporting Success: for Adults with FASD*, Accessed at: <http://www.communitylivingbc.ca/wp-content/uploads/Supporting-Success-for-Adults-with-FASD.pdf>

<sup>3</sup> Malbin, D (2005) *Trying Differently, Not Harder*. Accessed at: FASCETS [www.fascets.org](http://www.fascets.org)



Individuals with FASD and their parents and carers face significant barriers in accessing support services at present. This is largely because FASD is not recognised on the Australian List of Recognised Disabilities.

People living with FASD need life time support which can include the following:

- In some cases, 24/7 supervision and support is necessary. This does not abate across the lifespan and has implications as parents' age and human resources within organisations must account for this high cost of individual need.
- Non-traditional education approaches – this accommodation recognises individuals living with FASD do not learn from mainstream approaches which implicitly rely on functioning memory, cause and effect reasoning, filtering of external stimuli, planning, sequencing and the acceptance of unexpected environmental change.
- Case management
  - Short term goal setting with realistic expectations, intensive support and follow-through
  - Memory prompts for making and keeping appointments
  - Simple visual tools used for planning and listing expectations within timelines
  - Structure and routine
  - The use of the public trustee for financial management

#### **NDIS ELIGIBILITY FOR INDIVIDUALS WITH FASD**

In accordance with section 24(1), individuals with FASD will satisfy the 'disability requirements', enabling them to make an 'access request' to the agency. FASD is a permanent disability, as required by section 24(1)(b), and the needs of an individual living with FASD may change across time.

Under section 24(1)(a), individuals with FASD may have any or all of the following impairments: intellectual; cognitive; sensory and/ or physical. As required by section 24(1)(c), these impairments impact upon the individual's functional capacity, including communication, social interaction, learning, mobility, self-care and self-management.

As required by section 24(1)(d), the impairments experienced by people with FASD do affect their ability to participate in society and seek employment.

The invisibility of FASD, unrealistic expectations placed upon the individual and the subsequent lack of appropriate support services leads to a misguided assumption that those living with FASD are empowered and self-determining. There is often a misconception that the capacity to articulate equates with the capacity to understand decisions being made.<sup>4</sup> This is not to say that individuals living with FASD are unable to make choices but that they often need appropriate advocacy to do so. For example, in respect to seeking employment, those living with FASD need memory prompts,

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<sup>4</sup> Ory, N. (2004) *Why some people can "say" or "talk" more than they can understand and remember*, Accessed at [http://www.fasdconnections.ca/HTMLobj-314/why\\_some\\_people\\_can\\_say\\_or\\_talk\\_more\\_than\\_they\\_can\\_understand\\_and\\_remember\\_by\\_nathan\\_ory.pdf](http://www.fasdconnections.ca/HTMLobj-314/why_some_people_can_say_or_talk_more_than_they_can_understand_and_remember_by_nathan_ory.pdf)



structure and concrete language. A simple change in routine can have devastating consequences. It is not that those living with FASD cannot work, nor that they are unemployable, but rather that sustaining employment without the necessary environmental accommodations is difficult.





## **RECOMMENDATIONS AND COMMENTARY**

### ***Section 3 Objects of Act***

Section 3(3):

A sub-section needs to be included that states that in order to give effect to the objects of the Act, regard is to be had to the current role of mainstream services in delivering disability support.

#### **Recommendation 1:**

Section 3(3): A sub-section needs to be included that states that in order to give effect to the objects of the Act, regard is to be had to the current role of mainstream services in delivering disability support.

### ***Section 13 Agency may provide coordination, strategic and referral services etc. to people with disability***

As noted in the Productivity Commission Inquiry Report, *Disability Care and Support*, and the explanatory memorandum accompanying the Bill, one of the functions of the legislation is to raise awareness about disability. At present, one of the biggest barriers to people with FASD receiving disability support is a lack of understanding about FASD in the service sector.

Community education and training to raise awareness and build the capacities of the service delivery sector is crucial if the provision of 'general supports' through referral to mainstream and specialist services is to be effective.

In terms of appropriate referral services, a multidisciplinary team approach is proposed as best practice. This approach recognises that fetal alcohol exposure can variously and adversely impact across multiple domains and as such a range of expertise should be involved in the assessment process. Through collaboration, the overall assessment feeds into planning for appropriate supports and accommodations.

#### **Recommendation 2:**

Section 13: The provision of coordination, strategic and referral services must take into consideration the level of understanding, or lack thereof, of a given disability. In regards to FASD, community education and training to raise awareness and build the capacities of the service delivery sector is crucial if referral to mainstream and specialist services is to be effective.

### ***Section 15 Agency may provide information***

It is of paramount importance that information about the Scheme is easily accessible to all Australians regardless of disability, geographical location and the support needs of the individual.



There is a very real concern that some individuals will not have equal access to information about the NDIS and how to make an access request to become a participant in the Scheme.

Consideration must also be given to the variety of life circumstances experienced by people living with FASD. Some may have a higher level of independence than others, in contact with the juvenile or criminal justice system, experiencing mental health difficulties, and/or parenting children. For the Scheme to be effective in providing both general and funded support, it is crucial that people living in these settings are included in the dissemination of information and are supported in gaining an understanding of the NDIS and how the Scheme can work for them.

**Recommendation 3:**

Section 15: Devise a plan to ensure equal access to information regardless of disability, geographical location and current life circumstances. The plan should also acknowledge that the person may not have a support network that understands the NDIS and the supports that the Scheme can provide.

***Section 18 Person may make a request to become a participant***

This section needs to be amended to include provision for an informal carer or other nominee to make an access request on behalf of the participant.

**Recommendation 4:**

Section 18: This section needs to be amended to include provision for an informal carer or other nominee to make an access request on behalf of the participant.

***Section 24 Disability requirements***

Section (24)(2):

NOFASARD requests further clarification on how variations in support needs throughout a person's lifetime will be addressed in practice. For example, whilst some people with FASD may be able to function with the support of mainstream support services the majority of the time, they may also require the support of specific disability support services at particular times in their life also. This may include times of personal crisis such as loss of a loved one or relationship breakdown, coping with specific health needs, or trouble with the law.

The level of impairment for a person with FASD does not fluctuate in intensity as the disabilities in the FASD spectrum are caused by damage to the brain due to prenatal alcohol exposure. Instead it is a range of environmental factors that influence the level of support required by an individual at any one time.

This subsection should address changes in support needs for people with a permanent disability, as opposed to changes in intensity of impairment.



**Recommendation 5:**

Section 24(2): This subsection should be reworded to take account of the fact that the intensity of the impairment will not change but may be ameliorated by the intensity of support need.

***Section 25 Early intervention requirements***

Section 25(c):

Early intervention may not always 'mitigate, alleviate or prevent the deterioration of the functional capacity of the person' and their requirements for disability support in the future. However, there are still many benefits to providing early intervention techniques, particularly in reducing the likelihood of a person with FASD developing a secondary disability. This includes the development of mental health problems, trouble with the law, incarceration, alcohol and other drugs issues, inappropriate sexual behaviour and suspension or expulsion from school.<sup>5</sup>

Some examples of early intervention techniques that have been found to be effective for individuals with FASD include: structure and routine, use of concrete language as opposed to abstract language, use of memory prompts to help with organisation of time and transitions between tasks, low stimulus environments, support for parents and constant supervision.

NOFASARD also notes the importance of improving the capacity of the education system to identify children that require early intervention supports and improving knowledge and understanding of early intervention techniques.

**Recommendation 6:**

Section 25(c): Include a sub-section that acknowledges the importance of early intervention in reducing the likelihood of secondary disabilities that tend to exacerbate a person's support needs.

***Section 26 Requests that the CEO may make***

26(1)(a):

NOFASARD requests clarification about what may constitute 'information that is reasonably necessary'. In particular, it is not clear in the legislation whether a disability diagnosis is necessary or assumed as a prerequisite for eligibility to receive funding under the NDIS.

This is a particular concern for people with FASD due to the current lack of diagnosis in Australia and will remain a concern until the national diagnostic tool and clinical guidelines are formally implemented by the Commonwealth Government and health professionals are trained in its use.

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<sup>5</sup> Streissguth, A.P., Barr, H.M., Kogan, J. & Bookstein, F. L., "Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)," Final Report to the Centers for Disease Control and Prevention (CDC), August, 1996, Seattle: University of Washington, Fetal Alcohol & Drug Unit, Tech. Rep. No. 96-06, (1996), accessed at: <http://www.come-over.to/FAS/fasconf.htm>



Given that assessment for a FASD diagnosis is a multi-disciplinary process, further funding will also need to be directed to health facilities designed for this purpose.

**Recommendation 7:**

Section 26(1)(a): A formal disability diagnosis should not be considered as ‘information that is reasonably necessary’ or a prerequisite for eligibility to become a participant under the NDIS.

***Section 27 National Disability Insurance Scheme rules relating to disability requirements and early intervention requirements***

Section 27(1) and (2)(b):

NOFASARD has a number of concerns regarding the development of rules about the assessment process.

NOFASARD supports the use of multi-disciplinary assessment frameworks that accurately assess executive functioning. The inclusion of adaptive behaviour assessment together with IQ assessment is important because many people with FASD have an IQ within the normal range whilst having severely impeded executive functioning.

NOFASARD shares the same concerns as other organisations that deal with cognitive and intellectual disability. For example, NOFASARD identifies closely with the quote from the Autism Association of Western Australia, contained within the Productivity Commission Inquiry Report:

*Many in the Autism population frequently experience problems with assessment instruments that overestimate their abilities and underestimate their need for assistance[...]They remain very vulnerable individuals in need of continuing support to function in daily life.<sup>6</sup>*

NOFASARD also notes that the assessment framework must also identify that support needs change as an individual ages and, therefore, re-assessment must form part of the support plan.

**Recommendation 8:**

Section 27: The NDIS rules regarding assessment must include effective assessments for executive functioning that identify the specific needs of an individual in multiple domains.

**Recommendation 9:**

Section 27: The importance of re-assessment in identifying a person’s changing needs must be integrated into the NDIS assessment framework.

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<sup>6</sup> Productivity Commission 2011, *Disability Care and Support*, Report no. 54, Canberra, p. 311.



### ***Section 31 Principles relating to plans***

Section 31(i):

The majority of people with FASD are unable to make some decisions that impact upon their life and require adequate and appropriate advocacy to support them in making choices that are in their best interests.

It should be considered an ongoing learning process to determine what decisions the person with a disability is able to make and the decisions in which they need support to increase their capacity to make choices. As reflected in the principles under section 31, it is crucial to engage with and consult directly with each individual as no one individual will have exactly the same needs or opinions on how they want to be supported.

Therefore, appropriate frameworks need to be in place to determine how people with a disability can be best supported. Implicit is the right to exercise choice and control and maintain their human right to self-determination. On a practical level assurances must be in place to mitigate against overlooking their basic daily needs, such as health, nutrition, personal care and shelter or accommodation.

For some individuals with FASD, it may be that all choices and decision making processes need to be made with the support of a care giver. Alternatively, a person with a disability may choose to have a representative other than their carer, or may be in a position where they do not have the informal support of a parent or carer and require an advocate independent of the National Disability Insurance Agency.

NOFASARD is fully supportive of enabling people with FASD to experience social and economic participation to their fullest potential. However, it is important that people with FASD are supported to make choices that do not put them at high risk or set them up for failure with damaging consequences such as frustration and low self-esteem.

#### **Recommendation 10:**

Section 31: A sub-section should be added to reflect the importance of people with a disability having access to an advocate, or other form of support, to build their capacity to make choices and decisions.

### ***Section 33 Matters that must be included in a participant's plan***

Section 33(2):

The Scheme needs to take into account that the goals, objectives and aspirations of the participant may change frequently and with little notice. Various environmental factors may affect this, such as a new relationship or relationship breakdown, employment issues, health issues, trouble with the law, and alcohol and other drugs use.



For people with FASD, impulsivity is a common thread, along with an inability to learn from mistakes or to understand the link between cause and effect (the consequences of their actions or decisions), or to apply their learning in one situation to another situation. This makes it very difficult for a person with FASD to stick to one set of goals, objectives and aspirations. Therefore, the structure of participant plans and processes for review need to factor in these issues.

**Recommendation 11:**

Section 33(2): Requirements concerning the contents of participant plans and review processes must take into account the often changing nature of goals, objectives and aspirations of people living with FASD.

***Section 34 Reasonable and necessary supports***

Section 34(c):

The NDIS rules need to define how ‘value for money’ will be measured in practice. For people with FASD, it will not always be clear whether an alternative support will be effective due to the lack of awareness and understanding about FASD amongst the service sector in Australia.

Section 34(d):

There is no ‘current good practice’ in relation to FASD support in Australia. Currently support services are delivered on an ad hoc basis.

Section 34(e):

Not all people with a disability have a close support network or connections with the community that they can rely upon. In addition, people with a disability don’t always want the support of particular individuals, such as parents.

Section 34(f):

This subsection needs to take into consideration the current lack of appropriate support services for some disabilities, including FASD.

It may also be the case that if mainstream services are to provide effective support to an individual, the service needs to work together with a disability support worker. The role of the disability support worker may include assisting the person with a disability in accessing the service and communicating their needs to the mainstream service worker, and helping the person to understand information that has been given to them.

**Recommendation 12:**

Section 34(c): The NDIS rules should define how ‘value for money’ will be measured, particularly given that it is often difficult to determine how effective an alternative support may be.



**Recommendation 13:**

Section 34(d): This sub-section should acknowledge that there is not established best practice regarding support services for some disabilities, such as FASD.

**Recommendation 14:**

Section 34(e): People with a disability should have the ability to choose whether or not they want to accept the support of their informal support network (if they have one). The legislation should not make the presumption that people with disabilities have an informal support network or are engaged in the community. In addition, people with a disability may prefer not to rely on the support of their informal support network, such as parents.

**Recommendation 15:**

Section 34(f): Mainstream support services should be required to work with disability support workers in the event that it will clearly benefit the person with a disability in accessing services and engaging with mainstream service workers.

***Section 43 Choice for the participant in relation to plan management***

NOFASARD supports a person with a disability having a choice in the registered plan management provider and also their ability to change the organisation or person managing their funds if need be.

However, it is not reasonable to expect all people with FASD to make choices that are realistic and match their functional capacity, including their level of ability to manage their own funds effectively.

All people with a disability should have access to an advocate to support them in determining what elements of the plan they are able to manage.

**Recommendation 16:**

Section 43: Include a subsection that gives the participant the right to an independent advocate to support them in determining what elements of the plan they are able to manage.

***Section 44 Circumstances in which participant must not manage plan to specified extent***

Section 44(2)(a) and (3)

In regards to section 44(2)(a), NOFASARD requests that the NDIS rules clearly define how 'unreasonable risk to the participant' will be measured.



The rules should include protection for people with a disability who have demonstrated that they are unable to balance a budget. This must be balanced against the need to protect individuals with a disability from infringements upon their human right to self-determination.

**Recommendation 17:**

Section 44(2)(a): The NDIS rules must clearly define how 'unreasonable risk to the participant' will be measured.

**Recommendation 18:**

Section 44(3): A criteria for assessing an 'unreasonable risk to the participant' must include protection for people with a disability who have demonstrated that they are unable to balance a budget.

***Section 86 Appointment of plan nominee***

This section gives the National Disability Insurance Agency very strong powers to make decisions on behalf of people with disability, posing a high risk of infringing upon their human right to exercise control over their own life. The duties of the nominee set out in section 80 are not an adequate safeguard.

NOFASARD's strong preference is that individuals with a disability are able to access advocacy and support to enable their participation in decision-making processes and to increase their capacity to make realistic choices relevant to their abilities, as opposed to the appointment of a plan nominee.

With this in mind, there should be a framework in place to adequately assess an individual's capacity to make decisions. Furthermore, a high threshold should be applied to determinations regarding whether an advocate or other form of support cannot provide an appropriate level of assistance in decision-making processes so as to justify the appointment of a plan nominee.

Where a decision is made to appoint a plan nominee, if the person with a disability has a legal guardian, the legal guardian should be appointed as the nominee. This will ensure that the powers of the National Disability Insurance Agency do not impinge upon the rigorous process of guardianship orders.

**Recommendation 19:**

Section 86: It is preferable that steps are taken to enable supported decision-making. Where this is not possible, a high threshold should be applied to determinations regarding whether an advocate or other form of support cannot provide an appropriate level of assistance in decision-making processes so as to justify the appointment of a plan nominee.

**Recommendation 20:**

Section 86: Where a decision is made to appoint a plan nominee, if the person already has a legal





guardian, the guardian should automatically take on the role of plan nominee.

***Section 91 Suspension etc. of appointment of nominees in cases of severe physical, mental or financial harm***

The term 'severe' presents a very high onus of proof. Many people with disability are very vulnerable to some form of abuse and may find it difficult to make a complaint. As a consequence, the word 'severe' should be deleted. Any type of abuse is unacceptable and this section should include sexual abuse.

**Recommendation 21:**

Section 91: Delete the word 'severe' because the onus of proof is too high, particularly for individuals that are already vulnerable.

**Recommendation 22:**

Section 91: Include sexual abuse in this section.

***Part 6 Review of decisions***

These provisions assume a high level of knowledge on the part of the person with a disability and their carer or plan nominee. A section should be added to include the right of the 'person directly affected by the reviewable decision' and their plan nominee (where relevant) to access an independent advocate to help them through the review process.

**Recommendation 23:**

Chapter 4, Part 6: Include a subsection that gives the right of the 'person directly affected by the reviewable decision' and their plan nominee (where relevant) to access an independent advocate to help them through the review process.

