



Inclusion Australia

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**Submission to the inquiry into the
purpose, intent and adequacy of the
Disability Support Pension**

July 2021



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Acknowledgments

Inclusion Australia acknowledges the traditional owners of the land on which this publication was produced. We acknowledge the deep spiritual connection to this land of Aboriginal and Torres Strait Islander peoples. We extend our respects to community members and Elders past and present.

Inclusion Australia recognises the efforts of self-advocates who have courageously told their stories and worked tirelessly over the years for equality and human rights for all.

This submission was prepared by Inclusion Australia. To write this submission, we listened to the voices and concerns of people with intellectual disability and their families and advocates and we thank them for sharing their lived experiences.

Contact

Inclusion Australia (NCID) Limited
ABN: 60 084 254 809

Catherine McAlpine
Chief Executive Officer
PO BOX 336
Nunawading, Victoria, 3131 Australia

P: 1300 312 343

M: 0419 530 524

E: catherine.mcalpine@inclusionaustralia.org.au

E: admin@inclusionaustralia.org.au

W: www.inclusionaustralia.org.au

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About Inclusion Australia

Inclusion Australia (IA) is the national peak body for intellectual disability. Previously known as the National Council on Intellectual Disability (NCID), IA was founded in 1954. IA's mission is to work to ensure people with intellectual disability have the same opportunities as people without disability.

IA is a federated body with state agencies in New South Wales, Queensland, South Australia, Tasmania, Victoria and Western Australia. Those agencies are: Council for Intellectual Disability (NSW), Parent 2 Parent (Qld), the South Australian Council on Intellectual Disability (SA), the Speak Out Association of Tasmania (Tas), the Victorian Advocacy League for Individuals with Disability (Vic), and Developmental Disability Western Australia (WA).

IA has a long history of expertise in the employment sector and has advocated for people with intellectual disability and the Disability Support Pension for many years. IA was closely involved in the 2011 review of the DSP Impairment Tables and contributed to the McClure Review of Australia's Welfare System in 2014. The present submission is based on its experience and is informed by people with intellectual disability and their supporters. Direct quotes from the intellectual disability community are included throughout.

Executive Summary

In May 2021, the Senate referred an inquiry into the purpose, intent and adequacy of the Disability Support Pension to the Senate Community Affairs References Committee.

The submission is Inclusion Australia's response to that inquiry.

Inclusion Australia, as the national peak body for people with intellectual disability, has a deep understanding of the challenges experienced when seeking jobs, earning a living and seeking the Disability Support Pension (DSP) and other entitlements. We welcome this opportunity to speak out on these issues in this submission.

To write the submission, we listened to people with intellectual disability, their families, carers and supporters. This included listening to Inclusion Australia's Our Voice sub-committee of people with intellectual disability, and surveys where we asked people about their experiences of the DSP and related employment issues. People with intellectual disability, parents and other family members, advocates, and other supporters responded to the surveys. We thank them all for sharing their experiences and allowing us to use their comments in this submission.

What people told us revealed not only big problems with the DSP system itself, but also the enormous impact the DSP and other related systems can have on people's lives.

Our submission addresses the Terms of Reference of the Senate Inquiry. However, people's experiences and the problems with the DSP and related systems don't sit neatly within one or another and there is overlap.

People with intellectual disability, their families, carers and supporters told us they face many issues relating to the DSP, employment supports and related systems, including that:

- The DSP system is complex and difficult and emotionally stressful to navigate for people with intellectual disability. Most depend on families and carers to help them.
- Information is complex and language is inaccessible.
- Eligibility requirements for people with intellectual disability, a lifelong permanent condition, to get DSP are unnecessarily repetitive, difficult and costly.
- People with 'borderline' intellectual disability are further disadvantaged by DSP rules and processes.
- Eligibility tools and assessment processes are not fit-for-purpose for many people, including people with intellectual disability.
- Systems that are meant to be supporting people with disability are fragmented and don't work together.
- DSP payment rates don't provide enough money to meet people's basic needs. This affects people's health, mental health and creates isolation. Families often need to provide financial support.
- People on DSP (and their carers) did not receive equitable support in 2020, despite having at least the same financial pressures as people on other allowances.

- People are disadvantaged and deterred from working by reductions in payments and the fear of losing the DSP if they work. Reporting requirements are difficult and inaccessible for people with intellectual disability.
- Employment support services are not helping people with intellectual disability to get real jobs.
- People regularly experience discrimination in employment and employment-related situations.

There are clearly many important specific issues that need to be addressed to improve how the DSP works, and we have detailed these in the submission. However, Inclusion Australia believes it is critically important at this point in time for government to do more than just try to address specific individual problems. It is time for government to look more holistically at the fundamental problems of the DSP and inter-related government systems, and their impact on the lives of Australians with disability.

Fundamental problems

DSP systems, processes and rules are based on incorrect beliefs and outdated attitudes about people with intellectual disability.

This creates barriers for people with intellectual disability to open employment and inclusion in the community. The system sets and reinforces the pathway to segregation, welfare dependence, poverty and isolation. Government needs to turn this around so that the DSP and related systems support people's rights to social and economic participation. They need to be focused on making sure people get the support they need when they need it to exercise those rights.

Government must work in co-design with people with disability, their families, carers and representative organisations to review and re-design the DSP and other related systems to ensure they benefit people with disability.

The DSP system doesn't understand intellectual disability and doesn't know how to engage with and communicate with people with intellectual disability.

Government needs to acknowledge the lifelong nature of intellectual disability and re-design the DSP, and other systems, so they work in ways that reduce the need for unnecessary reviews and new supporting evidence of disability.

Centrelink, and government systems generally, need to improve their understanding of people with intellectual disability, and how to engage and communicate with this community. They should do this through co-design with people with intellectual disability and representative organisations.

The systems supporting people with intellectual disability to find and keep employment are fragmented, complex and don't work together.

Government needs to review and re-design how the DSP, NDIS, education and other systems work together to improve jobs and finances for people with intellectual disability, including as part of the new National Disability Employment Strategy.

DSP and other related systems are not designed for the current and future labour market.

Government must look specifically at how these systems need to work in today's changing labour market. People with disability, especially intellectual disability, generally don't work in long-term, permanent jobs with secure incomes. Increased casualisation of the workforce and the growing gig economy means there will be more people with occasional employment and income. The current DSP (and other income support) systems are not designed or resourced to deal with these, especially on a large scale.

This broader perspective is critically important in this time of COVID-19, and into the future. The pandemic is disrupting and reshaping the labour market. Already, we have seen jobs for people with intellectual disability, such as administrative support, disappearing as offices close and more people work from home. As well as the existing one in five Australians with disability, studies show that a percentage of people who survive COVID-19 have significant risk of experiencing physical, neurological and psychological effects for many years.

The UN Secretary General has described the pandemic as "a defining moment for modern society" and calls on countries to build "inclusive and sustainable economies that are more resilient in facing pandemics, climate change, and the many other global challenges"¹.

Australians with disability are already socially and financially disadvantaged, and the pandemic has increased the disadvantage. For example, people on DSP and Carer Payment did not receive the Coronavirus Supplement in 2020, despite experiencing the same increased costs as everyone else and losing the few hours of casual employment that kept their heads above water financially. Government must move quickly to manage this challenge to make sure even more people are not marginalised, at great cost to individuals, our society and the economy.

Evidence shows that when people with disability are employed it benefits both individuals with disability and the broader community^{2 3}. Increased employment of people with disability and carers eases pressure on government systems and supports the sustainability of the NDIS. Inclusion Australia believes that government needs to overhaul, redesign and invest in the DSP and employment support systems (including the NDIS). The objectives must be to uphold the rights of people with disability, harness the skills and potential of **all** people to reduce the social and economic impact of the pandemic, and provide the support people need, when they need it.

Inclusion Australia encourages government to lead the way for change and create an Office for Disability to research, advise, implement and oversee all aspects of government, policy and programs related to people with disability, including employment and income support. Establishment of the Office would show the community that people with disability have rights, are important and that the government is working to create positive change. The Office should work on ways to promote and support engagement and opportunity for people with intellectual and other disability. This would include making sure that government and other programs, such as the NDIS, health and education, work together to bring about the positive changes and the supports that people with disability need in all aspects of life. The work of the Office for Disability must be rights-

¹ <https://news.un.org/en/story/2020/03/1060702>

² https://www.and.org.au/data/Conference/DAE_Report_8May.pdf Deloitte: The economic benefits of employing people with disability 2011

³ <https://www.pwc.com.au/industry/government/assets/disability-in-australia.pdf> PWC: Disability expectations – Investing in a better life, a stronger Australia 2011

based and developed, managed and governed in true co-design with disabled people, including people with intellectual disability.

Importantly, the Office for Disability would be a vital part of government's approach to ensuring people with disability can play their part in contributing to society and the economy at this difficult time, instead of being seen as a burden and a drain on the national coffers.

Responses to the Senate Inquiry Terms of Reference

The purpose of the DSP

The Federal Government says that the purpose of the DSP is to provide financial help for daily living costs to people who can't work due to a permanent condition. The DSP is supposed to encourage employment participation. Most people with intellectual disability could work with the right supports, but the way eligibility is assessed for the DSP and the rules for people who get it create barriers to employment. The systems, processes and rules are based on incorrect beliefs and outdated attitudes about people with intellectual disability. Assumptions that people with intellectual disability can't work or can only work in menial jobs in certain industries, are a legacy of the past. However, they are still the foundation on which the DSP and related government systems have been designed.

As a result, most Australian adults with intellectual disability receive the DSP. With the right support, many of these people could be working.

DSP eligibility criteria, assessment and determination, including the need for health assessments and medical evidence, and the right to review and appeal.

Intellectual disability is a permanent lifelong condition. People with intellectual disability are usually diagnosed in early childhood. People with intellectual disability (defined as an IQ of less than 70) are considered to have 'manifest eligibility' for the DSP – automatically eligible without having to meet other requirements for the DSP. Yet government systems, including the DSP, require people with intellectual disability to provide current evidence of their disability from a health practitioner in order to be eligible. This creates great emotional and financial strain on people with intellectual disability and their families and carers. It also creates an unnecessary administrative and cost burden on the health system and on Centrelink itself.

Government needs to acknowledge the lifelong nature of intellectual disability and re-design Centrelink systems, including the DSP, so they work in ways that reduce the need for unnecessary reviews that require proof of disability.

Getting onto the DSP

People with intellectual disability often find it very hard to get the DSP. They and their families, carers and supporters told us about their experiences and the kinds of difficulties they experienced.

Transition to DSP at age 16

When children with intellectual disability turn 16, Centrelink automatically stops the Carer Allowance or Payment for their parent/carers. Parents have already provided evidence of their child's intellectual disability and level of support needs to be eligible for these payments. At 16, parents

must re-apply for their carer payments and also apply for the DSP for their son or daughter. However, Centrelink does not let families know that this will be happening nor that their child will need to go through a new eligibility process to get the DSP. For young people with intellectual disability, as well as new forms to fill in, this involves a psychological assessment to determine their IQ. Centrelink will not accept IQ reports done when a child is aged under 12 years (which would be most people with intellectual disability), and some families would never have received an IQ report. A school psychologist can do the assessment, but families may not realise this, and some schools resist doing a report for a non-educational purpose. So, they need to find a substantial amount of money to pay for an assessment and there is usually a significant wait time. In the meantime, they don't get their carer allowance or payment. This is very distressing, and parents say they don't understand why they again need to provide evidence to 'prove' their child has a disability, especially when their child has a very obvious lifelong disability such as Down syndrome.

"There seems to be a constant need to prove that the disability has not magically disappeared. There is an onus of proof placed upon the recipient of DSP and their family."

Centrelink needs to let families know that they should apply and how to apply for DSP in the lead up to their child turning 16, so they can begin the application and eligibility process and have a smooth transition to DSP. When a child's parent/carer has already been receiving a Carer Allowance or Payment, based on the child's diagnosis of intellectual disability, there should be no need for repeated IQ testing to show eligibility for the DSP.

Manifest eligibility

Some families said that the manifest condition rules were effective and had saved them from having to provide further evidence of their son or daughter's disability in order to get DSP. But others said the rules were challenging and unfair for people whose IQ testing was 'borderline', just a few points over the cut-off point of 70, but who still need as much support. These people said they had to go through long and onerous processes to prove eligibility for DSP.

Borderline intellectual disability

"It (borderline intellectual disability) can be very difficult and hard to prove. Most parents give up with the constant rejections."

"Success seems to vary, depending on who processes the application."

People told Inclusion Australia that there are issues that specifically affect people with mild or borderline intellectual disability when they apply for the DSP. These include that:

- Some people don't realise they may be eligible,
- The forms are hard to understand and fill in (and people may be less likely to have family or other support),
- It is even harder to get the evidence they need,

- People who helped their students to apply for DSP saw varying success that didn't reflect each person's IQ and support needs.

Getting evidence to show you are eligible for DSP

Almost all the people with intellectual disability, their families, carers and supporters we consulted with said people often face problems when trying to provide sufficient evidence to show they are eligible for the DSP. This included getting evidence that Centrelink will accept, such as an up-to-date IQ score for older people with intellectual disability. Most people only have old childhood reports, or no reports, and need to get and pay for a new assessment.

Here is what people had to say about the difficulties they face providing evidence:

"Needing to provide a recent report is costly (\$2000+) and the waitlists are in excess of 6 months."

"It's hard to get an assessment. Psychologists won't do an assessment just for a DSP application. They have to have valid and substantiated reasons to do the assessment."

"Centrelink won't even acknowledge the impairment without an IQ score, despite all the other evidence stating that the intellectual disability is significant enough. It's a huge barrier."

There are specific frustrations around needing to continually prove their lifelong disability:

"IQ doesn't change, so it's frustrating that people have to prove their disability many times."

"Intellectual disability doesn't disappear!"

People said that Centrelink isn't clear about what evidence people need to provide. Applicants provide medical reports and doctors' letters, but these are often knocked back by Centrelink.

"The assessments are called into question by unqualified people. A public servant going over the reports often questions you (the carer) about the report that has been compiled by a qualified person. You then feel you have to prove your loved one is disabled enough and it causes a lot of stress."

People also said that Centrelink staff don't understand intellectual disability and this affects decisions about eligibility.

"They suggested that intellectual disability doesn't impact certain areas of life, such as mobility and personal care."

"For people with intellectual disability and families having to say your story repeatedly to people that often have limited understanding of the people they are assessing is frustrating."

Assessment

Impairment tables

Since 2014, Centrelink has used ‘impairment tables’ as a tool to help them decide if a person, who doesn’t meet the manifest rules, is eligible for the DSP. The tables are used to assess how your condition affects your ability to do things such as walking, lifting or concentrating. Centrelink uses the tables to calculate a score based on how your condition affects your ability to work. To get the DSP, you need to have a score of at least 20 points, which Centrelink says is a ‘severe functional impact’. If a person has more than one condition, these are assessed separately; if they don’t consider one of the conditions to be ‘fully diagnosed, treated and stabilised’ then a person with multiple disabilities requiring significant support may not score highly enough on the scales to get the DSP.

“When a person scores dramatically differently across domains, e.g. high in some areas, but low in others, this skews the results.”

There are other requirements to fulfil, even if you score at least 20 points on the impairment table rating, such as attending a Program of Support (to learn work readiness skills) for 18 months. And, if a person is assessed as being able to work at least 15 hours a week, they just aren’t considered eligible for DSP.

Assessments

People with intellectual disability communicate in many different ways. Many people can only be understood by people who know them well. Real communication with people with intellectual disability takes time, understanding and expertise. The impairment table assessment process (and other Centrelink assessments such as Job Capacity Assessments), don’t take into account people who don’t use speech to communicate (or people from different cultural backgrounds), and there is no opportunity to spend time to get to know the person. People may also be anxious or fearful of the assessments and of ‘failing’ them. Assessors also don’t understand that acquiescence⁴ is common; that is, many people with intellectual disability will tend to go along with what is asked or suggested, or say what they think the person wants to hear.

One parent shared this example:

Assessor: “Do you use public transport?”

Person with intellectual disability: “Yes.”

The assessor ticks the box.

Mum interjects, “Yes they use public transport, fully supported by myself or an Education Assistant... So no, they don’t ‘use’ public transport independently.”

⁴ The Speak Out resource, *Communication – it’s not a spectator sport* describes acquiescence as follows: “Many people with intellectual disability say ‘yes’ to questions or accept and agree with things, regardless of what has been asked, and often without really wanting to. This is called acquiescence. People with intellectual disability often mask their communication difficulties to avoid the stigma of being labelled as having a disability. It is very common for people to adopt a passive communication style, allowing the more powerful person to control the conversation.”

Others questioned the suitability of assessment tools, such as IQ testing that relies on a person using speech, and Job Capacity Assessments that they say use the same tool no matter the person's disability.

Job Capacity Assessments to assess whether they a person is eligible for support from a DES provider are carried out via a series of general questions. Yet a person's capacity to work depends on the kind of job, the supports they have, and whether there are barriers to them doing the job.

All these factors unfairly affect the validity of assessment scores and outcomes, closing off employment pathways for many people.

Impairment tables, Job Capacity Assessments and other Centrelink assessments are not fit-for-purpose for many people, including people with intellectual disability. Centrelink, and government systems generally, need to improve their understanding of people with intellectual disability and how to engage and communicate with this community.

Navigating the system

The DSP system is inaccessible and unnecessarily complex. It places huge stress on people with disability and their families and carers and it discriminates against and disadvantages people who are unable to navigate the system.

Information is very complex and largely inaccessible to people with intellectual disability - and many families and carers.

People with intellectual disability told us:

"My sister did it for me a long time ago."

"It was too much paperwork."

"Mum helped me."

"I took many hours and I had to do a long test about my ability to work and my IQ. I needed my Mum to help and she had to take time off work to do that."

Rules, processes and requirements are complex and convoluted – for anyone.

Supporters of people with intellectual disability told us:

"It's difficult breaking that information down...it's medico-language that even I, as an advocate, am not always able to interpret."

"Centrelink staff give inconsistent or differing information regarding what supporting evidence is required."

Emotional impact

Many people commented on the emotional impact of trying to get DSP and dealing with Centrelink.

“It felt bad because it was showing up my disability which I hate talking about.”

“Trying to prove disabilities for DSP is soul-destroying. The hoops you have to jump through to prove incapacity is awful.”

“The staff don’t like me because we tried to fight them (to get DSP). I still hate going to my local Centrelink office because there still people there that I know.”

“...we don’t even acknowledge the emotional hurt people experience going through the assessments. To know they’ve tried their hardest, exhausted themselves in the process...the feelings of shame are overwhelming.”

The impact of geography, age and other characteristics on the number of people receiving the DSP

Families living in regional and remote areas told us about their experiences applying for the DSP. It is difficult and costly to get reports; there just aren’t the specialists available.

Parents said that assessments done over the phone meant that assessors don’t get the full scope of a person’s disabilities.

“I am extremely opposed to Job Capacity Assessments done over the phone. I feel it disadvantages the client as the interviewer cannot see the body language and anxiety of the person they are interviewing, and will miss visual indicators of the client struggling to answer.”

While phone assessments were previously used mainly due to location, since Covid-19, they are more common and look likely to be used more for the foreseeable future.

The impact of the DSP on a disabled person’s ability to find long term, sustainable, and appropriate employment within the open labour market; and

The capacity of the DSP to support persons with disabilities, chronic conditions and ill health, including its capacity to facilitate and support labour market participation where appropriate.

Inclusion Australia supports meaningful work in real jobs. These are jobs with award wages and entitlements. Real jobs support workers to develop their skills to benefit them and their workplace.

In meaningful employment, the person with disability:

- Works alongside other staff members as colleagues.

- Is valued in their role after government wages subsidies run out, and
- Gets the same financial benefit from their work as other staff in similar roles.

The government has created different kinds of employment supports:

- Disability Employment Services (DES)
- Australian Disability Enterprises (ADE), and
- School Leavers Employment Services (SLES)

But even with these support services, the number of people with intellectual disability working in open employment is very low. In fact, there are more people with intellectual disability now working in ADEs than there used to be. Around 20,000 people work in ADEs; most are people with intellectual disability.

It is hard for people with intellectual disability to get into the DES program, and DES doesn't provide the ongoing support that many people need in the workplace. NDIS Employment Supports were changed in 2020 to give more flexibility to assist people who need high levels of support to find and keep a job. However, many people don't know about the changes, and others are finding it difficult to get the funds in their NDIS plans. The system is simply not helping people with intellectual disability to get jobs.

Discrimination within the labour market and its impact on employment, unemployment and underemployment of persons with disabilities and their support networks.

A major cause of failure is that the DSP and Australia's employment support system are based on incorrect beliefs and outdated assumptions about people with intellectual disability. The systems and processes, beginning with segregated education systems, indirectly discriminate against people with intellectual disability because of these assumptions. For example, the Services Australia fact sheets say that Centrelink will accept a report from a 'special school' including a psychologist's report with an IQ score or ability to undergo IQ testing as part of applying for DSP. The department clearly assumes all children with intellectual disability go to 'special schools'. Many do, and that is despite all the evidence showing that inclusive education is one of the most important factors influencing whether a person with intellectual disability will work in open employment. One reason for this is that segregated schools prepare students to work in ADEs by setting expectations and organising work experience in ADEs.

Also, while manifest eligibility may remove some hurdles in getting the DSP, it is based on the assumption that a person can't work, so it simultaneously creates barriers to employment.

The result: segregated employment (ADEs) or alternative day programs, perpetuate societal beliefs about people with intellectual disability. The systems, not the actual capability of people with intellectual disability, prevent people from earning a real wage, contributing to the economy and condemn them to a life of welfare dependence. Instead, the systems need to start with the assumption that many people with intellectual disability could be gainfully employed with the right support. Employment supports need to be centred around the individual. While recognising the

challenges people with intellectual disability face, they need to focus on the skills and capabilities of individuals.

When government systems and processes themselves discriminate, it is no surprise that this results in low employment figures for people with disabilities. In 2018, 48% of people with disability are employed, compared with 80% of non-disabled people⁵. Unfortunately, the 2018 data does not distinguish between intellectual and other disabilities. Looking specifically at people with intellectual disability in 2012, only 39% were in the labour force (a mix of seeking employment, employment in ADEs and open employment). Only 12% of people with intellectual disability were employed full-time, compared to 32% of people with other disabilities⁶.

In 2018, over 45% of people with disability said they had experienced unfair treatment or discrimination from their employer in the previous 12 months, and 2 in 5 said they had experienced unfair treatment or discrimination from work colleagues⁷.

People with intellectual disability told us about their own experiences of discrimination:

"I have had difficulties while doing work experience, both customers and the people I was working with."

"I got moved around, no choice. Didn't get paid. I had a mental breakdown."

Families said:

"People in a supported employment group were only paid \$2.20 an hour to do dirty, menial jobs such as a council contract to pick up rubbish – dirty nappies and faeces, in parks. Absolutely disgusting because they thought that was all our son was good for."

"Employers think the situation is a burden on them, instead of making the workplace accessible and welcome... Like as if someone with ID doesn't have human rights."

"The view that 'they have an income already'. Unwillingness to make adjustments. Perception that people can't work, rather than looking at skills on offer."

⁵ Australian Bureau of statistics, Disability, ageing and Carers, Australia: Summary of Findings, 2018, 24 October 2019 <https://www.abs.gov.au/statistics/health/disability/disability-ageing-andcarers-australia-summary-findings/latest-release>

⁶ Australian Bureau of Statistics. (2012). Intellectual Disability, Australia, 2012 (Cat.no.4433.0.55.003), 30 June 2014

⁷ Australian Bureau of Statistics, Disability and the Labour Force, 24/7/2020. <https://www.abs.gov.au/articles/disability-and-labour-force>

A major problem that creates difficulties and disadvantages people is that the systems supporting people with intellectual disability to find and keep employment are fragmented, complex and not good at communicating with people with disability, or with each other. DES, ADEs and NDIS are not delivering good employment results for people with intellectual disability. They need to be simplified and aligned.

People told Inclusion Australia they didn't know there was a link between the DSP and employment support:

"I didn't know people with intellectual disability could get job supports."

"We had no idea – we just had to do it all ourselves."

People said they had no idea how NDIS could help with employment, or had little success getting their help.

"Our son had a Job Capacity Assessment when he applied for DSP. He could only work a couple of hours a day, and he wasn't even offered work at an ADE. So, we asked NDIS for employment support, but got hardly anything. He wants to work but the whole system is failing him."

Changes to the DSP, DES, NDIS employment supports and ADEs would provide better support for people with intellectual disability. Over time, this would change community beliefs and expectations because people with intellectual disability will be able to show they can do real jobs and be part of the success of business and other workplaces.

Government needs to review, re-design and streamline how the DSP, employment supports, NDIS and education systems work together to provide meaningful jobs and improve finances for people with intellectual disability. This needs to be part of the new National Disability Employment Strategy.

The adequacy of the DSP and whether it allows people to maintain an acceptable standard of living in line with community expectations

Government says that the purpose of the DSP is to provide financial help to people who can't work due to a permanent condition. The DSP is meant to cover basic daily living costs, but even with the various allowances that people on DSP can get, people who rely solely on the DSP are barely above the poverty line.

People said that the DSP often doesn't cover the basics such as a place to live and food on the table, let alone other expenses. People with intellectual disability experience chronic illness at a much higher rate and have support needs that are not covered by the NDIS. People who filled in our surveys told us about the impact of not having enough money on wellbeing, health, mental health, community participation and isolation.

"People with intellectual disability have at times more expenses than other people."

“People can only afford to buy frozen vegetables and crackers and cheese combos. They don’t have support to go into the community either. It’s an incredibly isolating life.”

“It doesn’t cover the cost of living. You can never really own anything or have security of life. There are huge implications for health (can’t pay for decent health insurance) and ability to develop natural relationships in the community due to factors like cost of access and participation. It’s a hard life, just above the poverty line.”

Many people with intellectual disability live at home with their families because they can’t afford not to. Those who live more independently often depend on their families supported to get by financially.

“We supplement our son to live, otherwise he wouldn’t be able to afford to live in his own home like any other person his age.”

Almost everyone told us that the DSP is not adequate and needs to be increased. Some said it is getting harder to live on the DSP.

“It is a basic human right to be able to afford shelter and food. People on the DSP as their only income stream can’t even do that. DSP is not meant to be a gap-filler like other allowances. It should be enough to support someone long-term.”

“The cost of living and housing continually increases. There was a time when someone on DSP could purchase shared equity accommodation with the state government. This offered secure housing and was a source of pride, but it’s no longer achievable. People with intellectual disabilities should not be made to live in poverty.”

Other supports that people said were a necessity for people with intellectual disability to live a comfortable life included subsidised housing or better rental assistance, and help with medical/health expenses, household bills and utilities. Some people also said that they need help with transport. They said they lost Mobility Allowance when they joined the NDIS, and now their NDIS transport allowance had been withdrawn, making it much harder to get to medical and other important appointments, grocery shopping and work.

The appropriateness of current arrangements for supporting disabled people experiencing insecure employment, inconsistent employment, precarious hours in the workforce; and inequitable work practices.

If people with disability do get work to supplement the DSP, they are often subject to inequitable work practices and penalised by the very systems meant to support them.

For example:

ADEs generally pay supported employees at a very low hourly rate that won't affect their DSP, using wage assessment tools that could be considered discriminatory for non-disabled people.

People with disability who work and earn over the threshold (\$178 per fortnight in 2020) lose 50c in the dollar of their pension. This is a disincentive to work, and many people fear losing their DSP if they work.

When people on the DSP are earning wages that are not consistent, they must report fortnightly to Centrelink, and they also receive letters. People with intellectual disabilities find the reporting processes very difficult. Parents and supporters told us:

"There are often online system technical issues and long wait times on the phone reporting line."

"For many, literacy and numeracy levels are low. Centrelink is seen as an authority figure and it is frightening and intimidating receiving correspondence from them. Correspondence is not written in Easy English and it is not easy for people to access support to have these letters explained in a manner that they understand."

"Reporting any hours worked is a nightmare. Keep in mind it's the primary carer of the person with an intellectual disability who usually has to report on their behalf, and there is ALWAYS an issue."

"People with ID require support to submit this information and are reliant on their family or carers to do this and navigate the Centrelink system that is difficult for anyone, let alone people with a disability."

Centrelink's onerous rules and processes discourage people on the DSP from working and keep them from earning a wage that would improve their standard of living. As the labour market becomes increasingly casualised, focussed on gig employment, and with the effects of the pandemic on employment and the economy likely to be with us for years, sporadic work is becoming much more prevalent. This is even more so for disabled people, including people with intellectual disability. So, it is important that reporting obligations are fairer, more accessible, easier and encourage rather than discourage people to work.

Inclusion Australia suggests the Government ask the Productivity Commission to review the DSP and recommend ways to ensure that DSP payments meet people's needs, and enable people to work without unfair financial penalties and unnecessary levels of administration and reporting.

The economic benefits of improved income support payments and support for persons with disabilities, their immediate households and broader support services and networks.

We have already described the significant disadvantages people with intellectual disability and their families face due to the current level of DSP funding. Raising income support to an adequate level would improve people's physical and mental health, reduce isolation and enable people to have a decent standard of living. It would enable people to be included in and contribute to the community. It would reduce the amount of support – practical, emotional and financial – that families, carers and other informal supports need to provide. The benefits are potentially huge for so many people, and for the community.

Yet in 2020, Parliament decided not to include people on the DSP and Carer Payment in the Coronavirus Supplements of \$550 per fortnight that were paid to most other recipients of income support. This was despite people with disability also experiencing greater costs and loss of part-time work, pushing people even further into debt and poverty. As we write this submission, we may be on the brink of a national pandemic disaster. Older people and people with disability will be the most vulnerable yet again. It is critical that the government recognises that just as everyone can contribute, then everyone should be treated fairly when it comes to income support.

People on the DSP and Carer Payment should always be included in future payments like the Coronavirus Supplement.

The relative merits of alternative investments in other programs to improve the standard of living of persons with disabilities.

Australians with intellectual disability need both specialised and mainstream services to work together to uphold and support their rights to social and economic participation in the community. Government must invest in Tier 2 of the NDIS, to benefit all Australians with disability and the wider community.

The NDIS was intended to enable participants, and their family carers, to be able to participate socially and economically in the community. This participation and investment in Tier 2 were important factors in how the NDIS would benefit the whole community and be sustainable.

The NDIS made some important policy changes to its employment supports in 2020, which would enable many more people with high support needs (and consequently more family carers) to work. However, this does not yet appear to be translating into practical change for participants. The NDIS is also taking away people's transport allowances that help them find jobs and go to work.

Education systems are a critical part of the equation. Across states and territories, governments persist with segregated education for students with intellectual disability despite no evidence to support it. This perpetuates outdated beliefs and sets young people on the well-worn pathway to a segregated life of welfare dependence. Governments must work together to stop this discrimination.

We have mentioned the role of families and other supporters many times in this submission. The DSP and other systems, including NDIS, education, housing and more, need to understand how much people rely on this informal care. They need to understand that providing this support takes people away from their own lives, and the impact is enormous, individually, within each family, and

collectively on the community. Yet recognition of the issues and appropriate support is scarce. Government needs to look at how to address this, not simply by throwing money at carer organisations and programs, but by fixing the systemic problems so that informal supports are not under this ongoing pressure and can pick up their own lives – including going to work.

Inclusion Australia encourages government to create an Office for Disability to research, advise, implement and oversee all aspects of government, policy and programs related to people with disability. Establishment of the Office would show the community that people with disability have rights, are important and that the government is working to create positive change. The Office should work on ways to promote and support engagement and opportunity for people with intellectual and other disability. This would include making sure that government and other programs, such as the NDIS, health and education, work together to bring about the positive changes and the supports that people with disability need in all aspects of life. The work of the Office must be rights-based, and developed, managed and governed in true co-design with disabled people, including people with intellectual disability, and their representative organisations.

Importantly, the Office for Disability would be a vital part of government's approach to ensuring people with disability can play their part in contributing to society and the economy at this difficult time, instead of being seen as a burden and a drain on the national coffers.