



## **Submission to Joint Standing Committee re inquiry into the use of Independent Assessments in the NDIS.**

### **1. Background:**

This submission is provided by the Committee of Management for Waverley Helpmates Inc (WHM), based upon concerns evinced by parents and advocates for the Participants at WHM regarding the proposed NDIS “Independent Assessments”.

WHM has been operating for over 35 years and is a supported employment and training program providing gardening, cleaning and ironing work in the local community for thirty-three (33) people with a disability. It was initially founded with the support of & active participation from Rotary, a local MP (Geoff Coleman, Liberal, Syndal) , a Special School Principal and families who were seeking practical employment and support for their sons and daughters after leaving school.

Most Participants (also referred to as Helpmates) at WHM live with an evident intellectual disability, and many have other co-morbidities intellectual or psychosocial disability of some type (PWID).

WHM is an approved Australian Disability Enterprise, is audited annually for compliance with the National Disability Standards and receives funding principally from the NDIS and other relevant government sources. Prior to the formation of the NDIS, WHM received funding & support from both the Victorian Government (DSS) and Centrelink/ Services Australia.

Most of the participants at WHM are over 25 years old, so the parents and advocates have already spent many years grappling with the administration of support services for people with a disability (PWD).

At the risk of stating the obvious, none of the WHM Participants will ever cease having their intellectual disability.

Our families’ long interactions with the administration of those support services, navigating Centrelink, the Department of Education, the medical and Medicare systems, specialist Dental services, the Mental Health system, and now the NDIS, mean that the participants and their families and advocates have far more experience in the disability ‘system’ than those who operate the disability system – in some cases, WHM families have been negotiating these systems for almost 50 years!

We note that the NDIS caters for many more PWD (physical disability only) than PWID. The proportions are understood to be of the order of 90% to 10%.

The NDIS’ understanding of the needs of PWID is at the core of the concerns for our WHM Participants, who lack the ability to understand and communicate at the complex level necessary to deal by themselves with the bureaucracy of the NDIS.

For further details about Waverley Helpmates and its role as an NDIS provider to its community of PWID, please refer to Section 4.



## 2. Assessments

Waverley Helpmates raises the following concerns regarding the change of annually assessing persons with a disability via the proposed method of “Independent Assessments”.

WHM ask:

1. why the results of previous trials not been made public?
2. why the trial was reduced to 90 participants instead of 3000?
3. When will the results be made public?
4. What assessment tools will be used (as distinct from the Appendix outlining the tools that won't be used)?

All Participants at WHM, have, at various times prior, during and after completing schooling (when most of them were assessed as being eligible for Specialist Education, rather than Mainstream Education), undertaken a variety of assessments to establish that they were, and still are, eligible for the Disability Support Pension, and subsequently for most Helpmates, for the NDIS.

Previously, DSS used to complete an independent review of all participants using DMI (Disability Measurement Instrument) every two years. All Participants at WHM were included in this process and it had been agreed that their disability was permanent and long term.

As is well known in the Disability Support community, people with an intellectual disability often suffer from anxiety plus a range of other challenges. The completion of an Annual Assessment can cause emotional trauma and anxiety.

In their current work, participants at Waverley Helpmates are continually assessed for allocation of work. This assessment is not noticed by the participants and causes no distress as it is completed via observation by the Manager and the various Supervisors.

Previously, under DSS processes, the WHM Manager completed formal assessments with all participants and provided evidence to DSS for each person. This was completed over a 13 week period. This assessment allowed for the Manager to understand the capacity of each participant and had the advantage that the participants were not aware that they were being observed, as the observations were completed in consultation with the Supervisors and formed part of the day to day routine.

The Helpmates were therefore relaxed, and not reacting to a strange or stressful environment during those assessments.

DSS then would come and verify the assessment completed by the Manager and the DSS assessor would then modify the funding if appropriate if found to be different from the last assessment or from the Manager's assessment.

If the Assessments are conducted by NDIS, it is very important that previously completed assessments, reports and associated documents are **actively sought out and reviewed prior** to the assessment so the Assessor has complete information available.

This is important because at various NDIS meetings, Participants or their Advocates have been advised that the Reviewer has “not had time to review documents submitted prior to the face-to-face meeting”. This raises concerns of the adequacy and relevance of both previous and the future Assessment(s) and casts doubt on the appropriateness of outcomes.



Given the nature of the intellectual and psychosocial disabilities (eg diagnosed ASD, ADHD, Anxiety or other conditions not immediately discernible (when compared with being in a wheelchair) of many of the Helpmates, consideration must be made of their intellectual disability. It is well established that the WHM participants will almost always agree with what an outside Assessor suggests – i.e. “can you dress yourself?” – the participant will usually say ‘yes’ even though they need assistance and direction.

This feature of PWID was shown most strikingly in ***The Royal Commission into Misconduct in the Banking, Superannuation and Financial Services Industry (2019)*** which recorded a financial adviser asking a young man with Down Syndrome to agree to contract terms and conditions about which he clearly had little understanding. The Royal Commissioner was particularly scathing of this unconscionable conduct by the financial advisor and his employer.

Similar outcomes could readily be expected if a PWID is asked the questions included in the CHIEF questionnaire. These are very open questions, and in the immortal words of Donald Rumsfeld, the PWID is dealing with “unknown unknowns”. Many have no concept of what ‘normal’ is. Without an Advocate, to assist and mediate to the necessary standard of proof, most PWID would simply give an answer that would make the questioner cease asking them questions.

WHM is particularly concerned that the assumption of PWID being capable of responding in a fashion which an independent ‘reasonable person’ would deem to be ‘informed’ is highly unlikely. Most just want the process to stop and will do anything that they think will make the questioner go away.

This is why prior to the introduction of the NDIS, DSS always insisted that all assessments were completed by a highly qualified person (psychologist, OT, psychiatrist in conjunction with the participant’s own GP and other associated supports such as the parent, advocate, or counsellor who were all known to the Participant / Helpmate.

According to the NDIS Appendix which details the criteria for the use of the various Independent Assessment tools, a major consideration noted therein is that *tools utilised should NOT require specialised training*. Indeed, the highly relevant diagnostic descriptions in DSM5 are noted as not being suitable for the new NDIS Assessment process precisely because DSM5 requires professional training to use it!

In the current NDIS review process, ongoing written support statements are sought and submitted from a Participant’s support worker or Advocate plus other formal supports. This valuable and person-centric approach appears to be lost in the proposed new Assessment process.

If Participants are forced to appear before a panel of people they have never met before in a situation which is already uncertain, they are likely to become very anxious, upset and confused. EXTRA time will be required to reduce those ‘flight or fight’ reactions and to ensure that accurate information is actually achieved. For example, the average appointment time in a dental surgery for check-ups is approximately 30 minutes. At the Royal Dental Hospital Specialist Clinic it is over 1 hour. The process of using an unknown panel will be very confronting to the Participant and also will be time consuming if it is to be completed correctly.



Can you please advise what is the role of parents, advocates and carers are in these Assessments? Their relationships with each participant are vital to the outcome. How are these informed and experienced people going to be asked for their input?

It has been the experience of a majority of the Waverley Helpmates Participants who are funded by the NDIS, that for each review with the NDIS, the NDIS Assessor/Reviewer has been different from the previous Reviewer and therefore has limited knowledge of the Participant and has no rapport, experience with, or understanding of the Participant.

As outlined above, often the new NDIS Reviewer has not had time to review information and documents submitted prior to the meeting to assist with the review, and in a disturbing number of cases, evidently has not reviewed the file at all!

How is this going to be rectified with this new Assessment process?

Given the lack of familiarity of Reviewers/Assessors with the Participants, how do they assess whether the Participant is having a 'good' day vs a 'bad' day? How do they assess whether the Participant is reacting to their unfamiliarity with the Assessor.

What is in the Independent Assessment questionnaire that accommodates for a person to be assessed overall, and not "a person's moment in time function".

### **3. Terms of Reference**

The terms of reference for the Joint Standing Committee note:

*"As part of the Joint Standing Committee's role to inquire into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS), the Committee will inquire into and report on independent assessments, with particular reference to:*

- a. the development, modelling, reasons and justifications for the introduction of independent assessments into the NDIS;"*

WHM is unable to establish a logical, business, health or personal reason for the implementation of the proposed Independent Assessments, especially on an annual basis, as it appears that the deficiencies of the present system will be retained and a dumbed down Assessment process will reduce the relevance of the Assessment.

- b. "the impact of similar policies in other jurisdictions and in the provision of other government services;"*

WHM has no knowledge of these types of assessments being completed in a similar environment in Australia. Even in the Aged Care system, the resident's own GP and clinical specialists participate in the transition to Aged Care and continue to be involved. To do otherwise is to deny the resident's personal choice (which may be mediated in consultation with the ACF or the family – but nonetheless, the choice remains with the resident).



c. *“the human and financial resources needed to effectively implement independent assessments;”*

1. *Need assessors to be formally trained*

WHM questions the additional cost involved with training people who are not experienced clinical psychologists, OT's, etc

WHM also questions why it is proposed to **remove** the known areas of expertise for these assessments (not using clinicians, OT's, psychologists, etc)

WHM asks why extra cost will be incurred to NDIS to undertake these assessments which have already been completed and results established that will not change in the short or long term.

The whole point of the NDIS was that Participants or their family would not have to continue repeating their story, year after year, to demonstrate that their diagnosis of say, Down Syndrome, or Cerebral Palsy had not been miraculously cured!

For known conditions (e.g. ABI, ASD, ID, CP, Down Syndrome, Prader Willi Syndrome, Fragile X, etc ) the short and long term impacts do not change.

WHM asks why would the NDIS actively seek to incur **extra** costs annually for Participants when nothing is going to change?

d. *the independence, qualifications, training, expertise and quality assurance of assessors;*

From the information provided to date, the training and qualifications of Assessors has not been fully established and a trial has not been successfully completed.

From personal discussions with a highly qualified scientist who has been contacted by NDIS re undertaking assessments, the qualifications of Assessors are not defined and therefore will inevitably vary across Providers.

No formal training program has been published, and therefore cannot be reviewed and assessed by relevant clinicians and disability professionals.

The absence of clarity on the qualifications and experience requirements for Assessors is profoundly disturbing and can only suggest that the NDIS is seeking to avoid properly catering for Participants by “dumbing down” the Assessment process.

WHM supports that Assessors should be neutral and the person/assessor consistent and a relationship established so validity can be established by the



assessor. This is not possible in a one hour, one off assessment by an Assessor that the Participant has never met prior to the assessment.

It is also questionable how multiple privatised providers can meet the requirements of ISO9001 (quality assurance) without consistent criteria which Auditors need to assess against. How can an auditable process (as is required by ISO9001) be demonstrated?

*e. the appropriateness of the assessment tools selected for use in independent assessments to determine plan funding;*

WHM has identified that one single tool would not meet all criteria necessary for a holistic assessment of a person's support requirements under the NDIS. The Toolkit lists six assessment tools with align with the World Health Organisation's International Classification of Functioning, Disability and Health (WHO ICF).

The tools assess how a person functions in their daily life and considers support requirements relevant to capacity, performance and environment factors. Each participant may undertake more than one assessment utilising different tools as part of their independent assessment.

The Vineland assessment will have been completed by majority of participants who have qualified for NDIS support in the past, therefore why do they have to complete it again? A person's IQ does not fundamentally change, and nor does their degree of engagement (or lack thereof for Autism). What does happen, as for the rest of the community, is that physical ageing may in fact exacerbate depression in Autistic Participants, or other similar changes.

The WHODAS 2.0 assessment is vague and requires the input of other parties (e.g. parent/carer)

Example – D5.1 Taking care of household responsibilities (very vague – these differ across every situation).

A participant may answer "None" (however the parent/carer can then find dirty dishes in the sink daily, food scattered across rooms, etc). The Participant's answer is very different to reality! This is exactly why they need support and care.

*f. the implications of independent assessments for access to and eligibility for the NDIS;*

WHM agrees that assessment for all participants is necessary and should be uniform and derived longitudinally from initial assessments (with the use of properly qualified and trained specialists in the clinical fields pertinent to the disability).

Assessments should then be based on some form of matrix, standard assessments should be completed based on initial diagnosis This can also be





reviewed, and importantly for audit reasons, tracked if degeneration occurs as part of the clinical diagnosis.

- g. the implications of independent assessments for NDIS planning, including decisions related to funding reasonable and necessary supports;*

For current Participants who are already on NDIS and have already been diagnosed with a condition **that will not change** irrespective of time, training, such as. ABI, ASD, ID, Down Syndrome, etc, annual Assessments are a waste of time and taxpayers' money.

- h. the circumstances in which a person may not be required to complete an independent assessment;*

As mentioned previously, people who are already on NDIS and have already been diagnosed with a condition that will not change irrespective of time, training, etc (i.e. ABI, ASD, ID, Down Syndrome, etc) will not change and therefore annual assessments are a waste of time and money.

- i. opportunities to review or challenge the outcomes of independent assessments;*

There need to be clear guidelines so everybody understands the steps. This is a major cause of anxiety for both participants and families and needs to be streamlined and transparently communicated to all.

- j. the appropriateness of independent assessments for particular cohorts of people with disability, including Aboriginal and Torres Strait Islander peoples, people from regional, rural and remote areas, and people from culturally and linguistically diverse backgrounds;*

From our experience, culturally diverse backgrounds provide even more challenges because of lack of understanding, and cultural belief and actions. A 'one size fits all' approach by non-clinicians is likely to exacerbate those challenges.

- k. the appropriateness of independent assessments for people with particular disability types, including psychosocial disability; and any other related matters*

As mentioned previously, people who are already on NDIS and have already been diagnosed with a condition that will not change irrespective of time, training, etc (i.e. ABI, ASD, ID, Downs Syndrome, etc) will not change and therefore annual Assessments are a waste of time and money.

Please also refer to our response earlier describing the apprehension of Participants and the unreliability of the answers when Participants have psychosocial disabilities. This is particularly relevant for PWID, with comorbidities such as ABI, Autism, Down Syndrome etc.



## 4. Waverley Helpmates Inc

At Waverley Helpmates Inc. we value and respect the people we work with and act as advocates for people with disabilities. WHM seeks to enable the transition of Helpmates into open employment where practicable.

### a. Mission Statement

Waverley Helpmates, a supported employment and training program, seeks to enable participants to realise their vocational potential and develop their independence through meaningful work. The program provides a quality lawn mowing, ironing and cleaning service to the local community, whilst developing Participants' work skills and ethics.

### b. History

The concept behind the Helpmates commenced in 1982 from a number of interested families, a Special School principal, and members of the wider community.

- 1982 – Moorabbin Helpmates was established which grew from a voluntary community group.
- March 1986 – Demonstration funding (Commonwealth) was provided to develop a similar group in a different location. Staff were appointed and worked out of the Moorabbin office until an area was located.
- July 1986 – a public meeting was held in Ashwood identifying two previously disadvantaged groups. (The aged who require a reliable and affordable garden service and those who wanted to work but required ongoing support and training).
- December 1986 – permanent premises were located at 14 Mavron Street Ashwood after Waverley Council had provided a temporary location in Montclair Avenue.
- October 1987 – the program was evaluated. There were three staff, ten participants, 190 customers and an elected Committee of Management. The process of establishing an autonomous identity had begun.
- April 1989 – Waverley Helpmates became an Incorporated Body.
- June 1990 – State Government funded a further ten positions for Helpmates and an additional two staff members.
- September 1991 – Waverley Helpmates auspice a twelve-month project; Waverley Skills Development Program.
- July 1992 – all Employment programs were transferred to Commonwealth funding.
- January 1993 – the cleaning team was developed with four participants and one staff person.
- 1997 – two people accepted under Futures for Young Adults funding
- March 2003 – first Australians Working Together (AWT) case-based funding participant accepted.
- August 2004 – first group of Helpmates moved from Block Funding to Case Based Funding.
- 2005 – 2006 Renovations were completed and the office expanded to 3 offices with addition of toilets, showers and kitchen.
- January 2006 – all remaining Helpmates moved from Block Funding to Case Based Funding. Capacity had increased to 30 Helpmates.
- October 2007 Waverley Helpmates celebrated its 21st year of operation.





- January 2008 - Commonwealth Government provided funding for three additional Helpmate places, bringing the total to 33.
- March 2009 – beginning of a small ironing program based in the Mavron Street office.
- November 2011 – loss of the cleaning team school contract and development of new cleaning directions.
- 2016 Celebrate 30 years of operation of Waverley Helpmates Inc
- 2017 commence transition to the National Disability Insurance Scheme
- 2018 EBA for Helpmates successfully negotiated with Fair Work Commission
- 2018 Manager commenced Long Service Leave after 30 years as Manager
- 2019 appointed as the new Manager, and most Helpmates transferred to NDIS funding.

The gardeners work on private gardens or contracts and the cleaners work at churches, halls, private houses and local businesses. The ironers iron baskets of clothes at the Helpmates office. All the Helpmates have their own jobs for which they are responsible and paid. Note – WHM participants are all over 18 years+.

Waverley Helpmates is managed by a Manager and supported by a voluntary Committee of Management who review all major decision regarding the operating process and procedures, costs, investments, machinery and equipment, programs and services. WHM is an approved Service Provider to the NDIS and receives Commonwealth funding via each Helpmate's NDIS plan.

Waverley Helpmates employs Supervisors who are qualified at a minimum of Cert. IV Disability Services, First Aid, have completed a Defensive Driving Course and have experience and training in working with people with a disability. Continual professional and personal development is undertaken annually by all managers and supervisors.

Everyone works together at Waverley Helpmates as a team to make it an enjoyable place to work.

**c. Why Do People Choose to Work at Waverley Helpmates?**

- The small size of Waverley Helpmates means that the Supervisors really get to know Helpmates.
- Waverley Helpmates is an independent organisation and not under the umbrella of a larger organisation.
- Helpmates are placed on individual worksites and work independently of each other or in a collaborative team environment for large customers such as Aged Care facilities where they work on a regular once-a-fortnight basis ("Backyard Blitz" style to complete all work in 1 day).
- Each Helpmate is provided with a roster of regular customers and is supported to develop good working relationships with these customers and to provide quality service to customers. Often, the Helpmates develop strong associations with their customers.
- Support provided to the Helpmates is consistent and ongoing for the duration of employment.
- There is no end date for a Helpmate's employment, they can work at Waverley Helpmates for an extended period of time.
- Helpmates can work full time or part time.



- Waverley Helpmates has a social and training aspect as well as the work roles. Some activities regularly organised at Waverley Helpmates are: planned supported holidays, cooking courses, basketball, Melbourne Show visit, working bees for charities, cultural events reflecting the wider or Helpmates community (eg Chinese New Year, Diwali etc), Christmas parties and excursions.
- Waverley Helpmates is committed to developing a social conscience in its participants and enables and encourages fundraising and volunteering activities for other charities. (For example, Clean-up at Reefton Country Fire Association buildings, helping Avalon support the homeless, fundraising at Bunnings Chadstone sausage sizzles etc).
- Waverley Helpmates embraces cultural diversity and celebrates individual differences through events, such as cultural awareness days.
- Helpmates work on individual goals which can be solely related to their employment, or more holistically related to other aspects of their lives. These goals are based on their interests and wishes.
- Staff at Waverley Helpmates are experienced and well trained and stay for many years because they love the job.
- All Supervisors are accessible to the Helpmates on a daily basis and establish good working relationships.
- Staff members all work together as a team to support participants/Helpmates in the best way possible.
- The Helpmates have elected representatives on the COM and participate in decision making at weekly Friday meetings.
- Waverley Helpmates uses innovative methods to achieve goals, such as the “Green Card” system of individual aims and rewards, aligned with their work and NDIS goals.
- Family, friends, carers and advocates are invited to become involved in many ways and their support is encouraged and valued.



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