

Greater Brisbane Hoarding and Squalor Strategies Group (GBHSSG)

National Disability Insurance Scheme (NDIS)

Hints and Tips to Improve Outcomes for those Experiencing Symptoms of Hoarding Disorder

Members of the GBHSSG continue to report that their clients who experience symptoms of hoarding disorder are failing to be assessed as NDIS eligible, and those who are found eligible are failing to receive adequate care packages.

The following hints and tips provided by members of GBHSSG, may support improved outcomes for clients.

To Help Achieve Eligibility -

- It is too challenging for clients to self-apply – they need to be supported by pro-active, experienced service providers/support services who understand their condition (and how hoarding disorder is impacting on their lives) and can support them to write their application, get support for their application (e.g. by enlisting support of LACs at Carers Qld) and advocate for them during the process of applying to the NDIS
- It is really important that the right questions be asked during assessment and that the right answers are provided – Support Services can help with this e.g. not asking the client whether they have a mental health condition but instead if they have trouble sleeping, experience low moods, have lost loved ones etc.
- Go straight to the top – get the Local Area Coordinator (LAC) North and South with Carers QLD to support the application process
- Focus on the **IMPACT** of hoarding on lifestyle, quality of life and ability to live safely in the home – e.g. barrier to ability to shower, to prepare meals, the ability to move safely around the home etc.
- Support letters from doctors can be a big help, especially if it focuses on the **IMPACTS** – but GPs are often not aware of/understand hoarding or have the right language to write a strong letter of support for someone experiencing issues with hoarding to the NDIS

People with hoarding issues may also lack insight into the level of hoarding they experience or are too ashamed to reveal reality – it is really helpful if the support worker goes with them to see the Doctor and advocates on their behalf

The Support Service can draft effective words that can be used by Doctors and other health professionals, e.g. OTs, to be used in letters of support for their NDIS applications

- Assessments and reports by OTs in the home are very helpful to assess the level and impacts of hoarding – brokerage fees are needed to pay for the assessment that are used to support NDIS applications
- NDIS support letter – include following sections:
 - Introduction – your role, how client came to your attention, assistance you have been providing
 - Disability attributable to psychiatric condition – outline how client demonstrates symptoms of hoarding disorder e.g. difficulty discarding items, how possessions clutter lounge, kitchen etc.
 - How impairment results in reduced functional capacity in following areas:
 - Communication
 - Social interaction
 - Learning
 - Mobility
 - Self-care
 - Self-management
 - Support client currently receives
 - Reasonable and necessary supports client requires to live an ordinary life e.g:
 - De-cluttering assistance and rubbish removal
 - In-home domestic assistance
 - Activities of Daily Living skills training
 - Psychological support
 - Physical health
 - Social support
 - Transport
 - Home maintenance
 - **SUPPORT COORDINATION**
- Complete WHODAS 2.0 – 12-item version, which asks about difficulties experienced by client due to their health condition AND Life Skills Profile (LSP-20), which assesses client’s general functioning. Include results of these surveys as part of NDIS support letter

Once Eligibility is Achieved, How to Get an Adequate Care Package -

- The NDIS can pay for OT assessments made after the client has been assessed as eligible, to support package planning – ensure the assessment is made in the home
- Therapeutic, one on one specialist cleaning is mostly being funded under Core Supports – this pay scale is too low – it needs to be funded under Capacity Building – this will change in July 2020 when funding can be used more flexibly
- All service time needs to be captured as a **‘WHOLE OF SERVICE’** – e.g. packing up, dropping off rubbish at the tip, dropping off donations etc.

Ensure when NDIS package is renewed (occurs at least annually) that the same services are included. For example, de-cluttering assistance may be omitted in client's renewed package due to lack of understanding that de-cluttering can be a long process, depending on the severity of client's hoarding issue.

Please See Attached - a de-identified support letter written by Nicola Marshall Brisbane City Council's Resident Liaison Office, to be submitted as part of a resident's application to access the NDIS. This letter includes examples relevant to this particular resident; however, it can be tailored accordingly depending on the individual's specific hoarding symptoms, mental and physical health issues etc.

Lifestyle & Community Services / Inclusive Communities
Connected Communities
Level 11, 266 George Street, Brisbane, QLD 4001
GPO Box 1434 Brisbane Qld 4001
T 07 3403 8888
www.brisbane.qld.gov.au

Day, XX Month Year

National Disability Insurance Agency
GP Box 700
Canberra
ACT 2061

Dear National Disability Insurance Agency

RE: Resident's Name	DOB:	Reference #:
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I am writing this letter to support the application of **Name** to receive funded supports and an individual plan through the NDIS.

How have you or your organisation been supporting the individual

I have been supporting **Name** in my role as the Resident Liaison Officer at Brisbane City Council. This role involves coordinating the Hoarding and Squalor Reduction Initiative, which supports residents affected by hoarding and / or living in squalor and whose properties pose potential public health risks.

Qualifications / experience of author of the support letter

For more than three years I have supported residents like **Name** who are impacted by hoarding and squalor and I possess a Psychology degree (with Honours), a Graduate Diploma of Psychological Science and Masters of Counselling and Psychotherapy.

How the individual came to the attention of your organisation

Name came to the attention of Brisbane City Council in **date – month and year** through contact from **referral organisation**. [State issues identified by referral organisation]

How have you / your organisation been assisting the individual

I have been assisting **Name** to de-clutter their property since **date – month and year** and progress has been slow. **Name** is unwilling to dispose of many items and regularly accumulates new and used items. **Name** is unable to assist workers due to [physical health issues – if applicable]

Please see below for evidence of **Name's** eligibility to access the NDIS and fulfilling the disability requirements, and of **Name's** reduced functional capacity as a result of their disabilities. I have also outlined the services that **Name** currently receives and the reasonable and necessary supports **Name** requires to live an ordinary life.

Part 1: Main Eligibility Requirements for accessing the NDIS

- **Permanent impairment** – **Name** has a severe and persistent mental illness in the form of Hoarding Disorder and has also experienced symptoms of [insert other physical or mental health issues here]
- **Age** – **Name** is currently aged **XX**
- **Lives in Australia in an NDIS area** – **Name** lives in **name of suburb**, a suburb in [insert region e.g. North, South, East, West or Central] Brisbane, Queensland
- **Australian citizenship** – **Name** was born in Australia and is therefore an Australian citizen [or state if individual obtained citizenship through another method]

Disability Requirements

a) **Disability attributable to a psychiatric condition** – **Name** demonstrates symptoms of Hoarding Disorder, a recognised psychiatric condition as per the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders published in May 2013. See below for examples:

1. **Difficulty discarding items** – during de-cluttering sessions with **Name**, they have shown difficulty in allowing items of little monetary value to be removed from the property including old correspondence, newspapers, damaged clothing, cardboard and polystyrene boxes etc.
2. **Perceived need to save items** – **Name** gathers items from skip bins, garbage and recycling bins and brings these back to their property. Items are sometimes in poor condition; however, **Name** feels the items will be useful to them in the future, or they can be repaired or given to other people.
3. **Accumulation of possessions that clutter living areas and compromises their intended use** – there is a high level of accumulated items in all rooms of **Name**'s home with items reaching to at least waist height. Furniture and surfaces are covered with items. There is no clear food preparation area in the kitchen, **Name** is unable to access the bath / shower due to items stored in the bathroom, and items are stacked on **Name**'s bed reducing space available for them to sleep. **Name** also regularly purchases [states type of items individual acquires - if applicable]. **Name** also overbuys food and stores food items throughout the property.
4. **Hoarding causes impairment in social, occupational functional areas** – see below

Hoarding Disorder specifiers – **Name**'s difficulty discarding possessions is accompanied by excessive acquisition of items that are not needed and for which there is no available space. **Name** also has poor insight into their disorder, as is mostly convinced that their hoarding-related beliefs and behaviours are not problematic despite evidence to the contrary.

b) **Impairment is likely to be permanent** – **Name** has been affected by hoarding and / or living in squalor for several years (exact length of time unknown). **Name**'s hoarding behaviours are deeply entrenched and are unlikely to change without psychological intervention. **Name** is reluctant to engage with psychological support services as does not recognise their behaviours are problematic for their own health and safety.

c) **Impairment results in reduced functional capacity**



Activities	Functional impact
Communication	Name speaks clearly and can be understood; however, their ability to concentrate for long periods of time is limited as they become weary and need to rest. Name 's memory is limited; they repeat information they have already told me. Name also becomes confused by what services are being provided by the different organisations assisting them
Social interaction	Name does not leave their house except [state reasons - if applicable]. Name has a few neighbours who assist them by purchasing additional shopping items and a friend who calls them daily to check on their welfare. Name is no longer a member of any social, community or church groups and their only visitors are their friend and support services. Name has not been to visit their GP for at least two years
Learning	Name does not undertake any educational activities. Name 's ability to retain learned information is limited due to their poor memory
Mobility	Name is unable to walk far due to the impact of their [physical health issue – if applicable]. Name is also unable to stand up for long periods of time as becomes light-headed and unsteady. Name 's home presents risks of falls, slips and trips due to the accumulation of items. Access is blocked to bedroom where Name stores food items and there is a narrow pathway from the front to rear door. Access is particularly difficult from the kitchen to the lounge room
Self-care	Name does not take care of their physical health as has not been to see their GP for at least 2 years. Name has not had a shower or bath for several months due to the accumulation of items in their bathroom and also the effects of their [physical health issues – if applicable]. Name lacks the daily living skills to maintain the cleanliness of their home. Name suffers with insomnia, possibly exacerbated due to poor sleep hygiene as a result of the volume of items in their bedroom. Name also has poor nutritional intake as has limited cooking facilities in their home. Name 's property is a potential fire risk as several electrical cables have been chewed by rodents and some power outlets are not functioning. Name therefore uses extension leads throughout the property, which increases risk of fire and falls, slips and trips
Self-management	Name is able to manage their own finances but has reported not paying bills on time due to misplacing paperwork amongst the accumulated items and not having a set place to store important documents.

Supports that **Name** currently receives

Name is supported by the following organisations:

- Organisation A - minor home and repairs and maintenance
- Organisation B - online shopping services
- Organisation C - de-cluttering assistance and rubbish removal

Reasonable and necessary supports **Name** requires to live an ordinary life

- **De-cluttering assistance and rubbish removal** – this will improve **Name's** access to all areas of their home and allow them to use all rooms for their intended purpose, for example: kitchen for cooking, bathroom for washing and bedroom for sleeping. This will also create a safer living environment for **Name** by reducing the risk of fire, falls, slips and trips ~~and also~~ infection due to elimination of rodents. Ideally support workers should have a social work / psychological qualification enabling them to discuss reasons for **Name's** hoarding behaviours and attempt to address them
- **In-home domestic assistance** – following de-cluttering **Name** will require domestic assistance to maintain the cleanliness of their home
- **Activities of Daily Living skills training** – **Name** requires education about basic housework tasks to assist with maintaining the cleanliness of their home
- **Psychological support** – **Name** to receive grief counselling due to loss of their mother and father which it is my opinion they have not truly addressed and which may be one of the causes of their hoarding behaviours
- **Physical health** – regular appointments with GP to monitor **Name's** overall health and wellbeing and investigate treatments to manage their [physical health conditions – if applicable]
- **Social support** – to help integrate **Name** back into the community
- **Transport** – to and from medical appointments and social support groups and activities
- **Home maintenance** – minor home repairs, plumbing and electrical work
- **Support coordination**

The following functional assessments have also been completed, and their scores are provided below:

- WHODAS 2.0: An overall score of (insert %) - indicating significant functional impairment [depends on score]
- LSP 20: X items out of a possible 20 (X%, X questions not applicable) reflect a lower level of functioning [depends on score]. The domains of self-care (X%) and withdrawal (X%) were particularly low [depends on scores]

If you require further information or have any queries please contact me on **07 3178 5080** or via nicola.marshall@brisbane.qld.gov.au. I work from 8:30 AM to 4:30 PM Monday to Friday.

Kind Regards

Nicky Marshall
Community Development Team
Inclusive Communities | Lifestyle & Community Services
Brisbane City Council