

Participant Information Sheet – Research Study for Higher Levels of In-Home Aged Care Funding for people with disability

Study title: Research Study for Higher Levels of In-Home Aged Care Funding

Researchers: Applied Aged Care Solutions and Deloitte.

What is the purpose of this document?

You are being invited to take part in an assessment of your current care needs. This is to inform research being conducted by Deloitte and Applied Aged Care Solutions (the research team) for the Department of Health and Aged Care to inform potential in-home aged care programs can better support people with disability.

This information sheet has details on the purpose of the research, the benefits of participation, what your involvement includes, and how we will use your information. Please read this sheet and ask any questions you might have.

What is the purpose of this research study?

People who acquire significant disability later in life (post 65 years) face challenges in receiving appropriate support for their needs. They are ineligible for NDIS support due to their age, and the aged care support is not designed to adequately support their needs.

The Department of Health and Aged Care (the Department) has commissioned Deloitte and Applied Aged Care Solutions to conduct a research study into in-home aged care for people living with disability, to understand how to better support people with disability in the home.

To do this, we are looking to assess the needs of 50 older Australians with disability across Greater Sydney and Greater Brisbane to understand the appropriate supports required, and cost of these supports, to support their needs. This information will help the Government to understand how future in-home aged care programs can better support people with disability.

This research will survey 50 older Australians with disability across Greater Sydney and Greater Brisbane over the period November 2023 to January 2024.

Do I qualify to participate in the study?

If you, or a family member, have one of the conditions listed below, acquired the condition after 65 years, and do not currently receive support via the NDIS or the DSOA program, you qualify to participate in this research project.

List of conditions that are included in this study:

- Acquired brain trauma
- Stroke causing severe disability
- Blindness in both eyes
- Parkinson's disease
- Motor Neuron Disease
- Muscular dystrophy

What are the benefits of this research?

This research may inform the design of in-home care provided by the Australian Government. The Royal Commission into Aged Care Quality and Safety found that the aged care system is not designed to support the needs of people with disability. The Royal Commission identified that people with disability cannot access the supports they need through the aged care system. Further, there is an equity in the supports available for older people with disability under the NDIS in comparison to those receiving support through the aged care system.

The findings from this research study could help the Government to understand how future in-home aged care programs can better support people with disability. This could improve the lives of many Australians, allowing them to receive the care and supports that they need.

What will you ask of me?

A professional aged care assessor will visit you to undertake a comprehensive needs assessment. This assessor will use a needs assessment tool, and will be a similar experience to needs assessments that you may have received in the past. The needs assessment will occur in-person with the assessor over a 60 minute period.

The assessment will aim to observe your needs across a range of areas, including:

- Your social activity
- Your mobility needs
- Your physical and personal health
- Your medical and medication needs
- Your cognitive needs
- Your psychological needs

Using this information, the research team will be able to understand what supports you (and people like you) require to be adequately supported in the home.

How do I participate or find out more?

If you wish to participate in this research, or simply want to find out more, please contact the research team via one of the following channels:

- Phone: +61 7 3308 1336
- Email: hlcresearchteam@deloitte.com.au

Do I have to participate?

If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you can change your mind at any time. Your choice will not impact any relationships you have within your aged care provider.

If you choose to take part, you do not need to answer any questions you do not want to.

If you seek advice on whether to participate in this research, please speak with a family, a trusted person or your GP.

What if I choose to participate and then later decide to withdraw?

If you choose to take part and later change your mind you can pull out at any stage. Please notify Michael Stoneham from the Deloitte team at hlcresearchteam@deloitte.com.au or on +61 7 3308 1336. If you choose to withdraw your participation from the study, your data will be deleted by the researchers. Your data will not be used in the research study.

What possible benefits might I get by taking part?

Your contribution could help the Department of Health and Aged Care understand how they can improve aged care to better meet the needs of all Australians. Your participation may support the improvement of in-home aged care in the future.

What are the risks for taking part?

From an ethics standpoint, this is considered a low-risk evaluation. The only foreseeable risk for you is one of discomfort, including physical discomfort when undertaking mobility tasks. You may also feel inconvenienced from giving up your time to participate in the needs assessment.

If you wish, you can have a trusted support person present while the assessment is conducted. If you need support contacted this person to attend the assessment, please let the assessors know and they will provide you with the appropriate support.

If any such type of distress or dissatisfaction is highlighted through the assessment, assessors will ask if you would like to stop or continue with the assessment. If the assessment is stopped, the assessor will ask if you would like your data (provided up to the point) included in the research.

After the completion of your assessment, you also have the following complaints, advocacy, and therapeutic support pathways available to you. Please let the assessor know if you would like support in contacting this support.

- You can submit a complaint directly to the Deloitte team by sending an email to hlcresearchteam@deloitte.com.au or calling +61 7 3308 1336.
- Formal complaints regarding experiences with aged care and aged care assessments can be made by contacting the Aged Care Quality and Safety Commission, a free service. To make a complaint, contact 1800 951 822 (free call from landlines) or TTY 1800 555 677. Interpreters can be arranged.
- For counselling and emotional and psychological support services, contact the National Counselling and Referral Service on 1800 421 468 for counselling support, or ask to be connected to a counsellor or advocate. Support is free, independent, and confidential.

How will the data collected from me be stored, analysed and reported?

Assessors will take notes on laptops, tablets or on paper during the assessments. The assessment will be stored and not connected to you at any stage. No one will be able to know your health information in any report.

Your data will be analysed by the research team (Deloitte and Applied Aged Care Solutions). The findings of the analysis will be reported in a report, delivered to the Department of Health and Aged Care. You can request your own personal information collected as part of this research at any time.

Data will be held on a protected server that only the assessment team can view. Your data will be private and only used for this research. In 5 years, all information will be deleted.

Please note that the needs assessment undertaken for the purposes of this research is not related to any needs assessments you have done in the past. Further, any information gathered as part of this research will not impact or effect your current care plan, or your medical record.

Will the results of the study be shared and published?

The results from the assessments and other activities will be captured in a Report. It will be completed by February 2024. The Government will select who will receive a copy of the report and when. If you want to know how the report will be shared, please contact Michael Stoneham at hcresearchteam@deloitte.com.au or on +61 7 3308 1336.

Who is completing and paying for this research?

The Department of Health and Aged Care has paid Deloitte to do the review.

Does the research study have Human Research Ethics Committee approval?

The Bellberry Human Research Ethics Committee has reviewed and approved this study in accordance with the National Statement on Ethical Conduct in Human Research (2007).

Who can I contact if I have a question or a complaint?

If you have any issues or questions about the assessment or study please contact Michael Stoneham at hcresearchteam@deloitte.com.au or on +61 7 3308 1336.

The Bellberry Human Research Ethics Committee has reviewed and approved this study in accordance with the National Statement on Ethical Conduct in Human Research (2007) – incorporating all updates. This Statement has been developed to protect the interests of people who agree to participate in human research studies. Should you wish to discuss the study or view a copy of the Complaint procedure with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the Operations Manager, Bellberry Limited on 08 8361 3222.

Use the information to learn more about the services available to you if you think you have been affected by the study.