



My Health My Communication

In partnership with Nepean Blue Mountains Health and DARE



My Health My Communication Final Evaluation Report

November 2023

The My Health My Communication Project was funded by the Department of Social Services as part of a NDIS Information, Linkages and Capacity-Building (ILC) Program. This project was delivered as a partnership between Dare Disability Support (DARE) and Nepean Blue Mountains Local Health District (NBMLHD).



Health
Nepean Blue Mountains
Local Health District

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Message from Project Sponsors

I would like to commend this final report of the My Health, My Communication Project and take a moment to reflect on the ongoing legacy of the project to the Nepean and Blue Mountains community. In a time where there has been an increased focus on life outcomes for people living with a disability, health remains a domain of life where people continue to experience poor outcomes in comparison to the general population.

People living with disability can experience complex health needs due to their disability, which can place them in a vulnerable position. In the case of people with cognitive disability and communication limitations, the gap between a positive and poor health outcome can be the difference of having access to the right information at the right time. Sometimes the solution is simple and elegant.

My Health, My Communication went to the heart of the problem and designed a simple and consistent resource for people with disability to use in health care situations to clearly articulate their specific health needs. The project also recognised that it needed the expertise and good will of health professionals, disability providers and the community and most importantly people with disability themselves and their families. With this in mind, DARE Disability Support partnered with Nepean Blue Mountains Local Health District, and extensively consulted with people with disability and the community to create a powerful communication tool.

The *Getting My Health Information Ready for Hospital Toolkit* was then distributed extensively across the district and has proven to improve the experience for people with disability in hospital and to rely less on specialist services for support in these situations.

We have had the great fortune to work with the dedicated team at the Nepean Blue Mountains Local Health District and a core group of people with disability who have shown commitment to complete this project. As a team, we all understood the potential of the tool, and were motivated to realise this potential.

I would like to acknowledge the support of Governor of NSW, Her Excellency the Honorable Margaret Beazley AC KC, the Hon Marise Payne MP, the former NSW Premier The Hon Dominic Perrottet MP, our local Federal Member for Macquarie, Ms Susan Templeman MP, and our local State Member for the Blue Mountains, Ms Trish Doyle MP. I would also like to thank from NBMLHD, our sponsor Karen Arblaster, the project team members Karen Alexander, Dawn Hutley and Linda Mortimer for their work and partnership on this project, and Kathryn Woods and Mandy Brown from DARE. Finally, a special thanks to Graham Finch, ambassador and person living with a disability for his time and expertise.

Ben Droll, CEO
DARE Disability Support

Nepean Blue Mountains Local Health District has been involved in the My Health My Communication Project as a collaborating partner since the grant submission in 2020. We have been proud to be involved with Dare Disability in looking at communication in health care within our district.

Communication is the cornerstone for good healthcare, ensuring that the person's needs, values and preferences are clearly heard and understood, whatever the communication strategy. My Health My Communication enabled engagement with consumers during a time when this was difficult for people with disability.

Use of the Agency for Clinical Innovation [ACI] Redesign methodology enabled both health care staff and consumers to talk about the issues and collectively work on solutions that meet the needs of the consumer and health staff.

The solutions developed in collaboration between Health and Dare Disability participants will be used to ensure effective transfer of care, maximising the opportunities for the person with disability to be supported in the most appropriate way both in hospital and in the community where they live.

Thanks to our partners at Dare Disability for their engagement with our team on the project.

**Dr Karen Arblaster, Director Allied Health, Research and Strategic Partnerships
Nepean Blue Mountains Local Health District**

Project Background

What is the project and how did it come about?

DARE and NBMLHD created the My Health My Communication project, which launched in October 2020, to create solutions to improve communication in hospitals for people with intellectual and developmental disabilities.

The project's aim was to co-design communication strategies with people with intellectual and developmental disabilities for improved sharing of key information and positive interactions and experiences of communication with health staff enabling people with disabilities to be more involved in decisions about their care.

Working in collaboration with health staff, people with disability, carers and support workers, the project has developed some wonderful communication tools that will support better health outcomes.

Funded by the Australian Government Department of Social Services, the project targeted the local health district including Lithgow, Blue Mountains, Hawkesbury and Nepean.

The opportunity for NBMLHD to work collaboratively with DARE came from discussions regarding support for people with disability in hospitals. All agreed that having good communication with patients, families and carers in how to best support people with disabilities can and should, be provided. A significant area of concern and advocacy was around the issues of paid supports to facilitate communication in hospital.

This project has been supported by a NDIS Information, Linkages and Capacity Building Grant Funding for Mainstream Health.

Of the 8 Grant Priorities, communication was identified as the key issue for action, based on the feedback from people with disability, anecdotal patient stories and results of the Bureau of Health Information¹.

The project also aligned with NBMLHD Strategic Plan Direction 2 - Better Patient and Consumer Experiences – providing person-centred care and delivering high quality, safe and culturally appropriate health services to residents of the Local Health District.

¹ Exploring experiences of hospital care for people with disability retrieved from: https://www.bhi.nsw.gov.au/BHI_reports/Insights_Series/Exploring-experiences-of-hospital-care-for-people-with-disability

Case for change

Approximately 1.86% of the Australian population has intellectual disability (ID), either as the primary disabling condition or an associated condition. This equates to 328,000 people.

Compared to the general population, people with ID and their carers have a less favourable experience with a healthcare system with poorer health outcomes, shorter life expectancy and higher mortality rates.²

People with cognitive disability may not understand the admission, treatment or discharge process when requiring health treatment.

60% of people with ID have severe communication limitations³ and there is a high prevalence of challenging behaviour in adults with ID (about 1 in every 5-6 adults). Communication impairments and having a severe-profound ID were consistently associated with self-injurious, aggressive, destructive and stereotyped behaviour.

The interaction of different combinations of comorbidities (and each person's individual character) also means that a person with disability often requires very personalised and specialised supports, particularly around communication.

In a survey of people with disability and their carers' in 2016, the Bureau of Health information report [Bureau of Health Information. *Patient Perspectives – Exploring experiences of hospital care for people with disability, Adult Admitted Patient Survey 2015*. Sydney (NSW); BHI; 2017] noted that people with disability and their carers rated their experience at less than the NSW state average in the following:

- Health professionals completely discussing their worries and fears [19% NBM, 37% NSW]
- Staff knowing enough about their medical history and care/treatment [56% NBM, 67% NSW]
- Being involved in decisions about their care [40% NBM, 57% NSW]
- Being involved in decisions re discharge [56% NBM, 62% NSW]
- Staff answering questions in an understandable way [57% NBM, 72% NSW]

For these reasons, the case for change is strong – people with disabilities need better communication in hospitals.

² ACI Building capability in NSW health services for people with intellectual disability: the Essentials https://aci.health.nsw.gov.au/data/assets/pdf_file/0005/372524/ACI-Building-capability-NSW-health-services-people-intellectual-disability-essentials.pdf

³ AIHW 2018 Disability in Australia: intellectual disability: <https://www.aihw.gov.au/reports/disability/disability-in-australia-intellectual-disability/contents/summary>

Goals and objectives

Problem Statement:

To develop clear processes or comprehensive resources to ensure appropriate communication among patients with intellectual and developmental disabilities and their family/support personnel and health staff.

Goal:

The My Health My Communication project will improve communication in health with people with intellectual disability, acquired brain injury, autism or Down syndrome through redesign of current systems and resources, training and advocacy.

Objectives:

- Establish a scalable model of support with easy-to-use communication resources to mitigate risk and optimise health outcomes for patients with 'invisible' disabilities like Intellectual Disability, Autism and Acquired Brain Injury.
- Improve communication among patients, family, disability staff and health professionals.
- Create resources that will provide a streamlined process that can be accessed by health staff with a kit of consolidated resources that can be used accurately, timely and efficiently.

Delivery

The funding targeted people with disability living in the Nepean and Blue Mountains local health district [NBMLHD], covering the local government areas of Lithgow, Blue Mountains, Hawkesbury, and Nepean.

These areas service a substantial and growing population of people with disability who were identified as the target group that would gain the highest benefit of this vital support.

To best support NSW Health making the changes necessary to facilitate the project, a key representative, Dawn Hutley, provided guidance from the Agency for Clinical Innovation applying clinical redesign methodology throughout the project in collaboration with people with disability, health staff, carers and support workers.

A formal application for ethics oversight was approved for the projects activities and was provided by NBMLHD ensuring the rigour of the project in meeting its objectives.

Mixed methods of research have been applied to inform the project throughout all stages through, surveys, interviews and focus groups that have enabled the project to gather essential data to identify key issues with communication and develop solutions to support improved outcomes for the target group.

Launch of the Project

Following the initiation stage, the project officially launched online in October 2020, with support from some high-profile people including - Her Excellency the Honourable Margaret Beazley AC KC, The Hon Marise Payne, Mr Gareth Ward MP, and Ms Susan Templeman MP.

This was led by people with disability who introduced the project and guest speakers in a suite of short videos on the project website.

<https://www.myhealthmycommunication.com.au/launch/>



Highlights of the Project

Engagement with over 160 participants via surveys, focus groups and interviews - health staff, people with disability, carers and support workers

Co-designed project

300 launch packs!

Support from Government representatives including Her Excellency the Honourable Margaret Beazley AC KC

1500 physical toolkits produced

43 online toolkit registrations

Communication tools that are now being used by the local community - Lithgow, Blue Mountains, Hawkesbury and Nepean

833 toolkits distributed

Winner of Innovate Together Quality Awards - Partnering in Providing Care

Roadshow around Lithgow and Blue Mountains hospitals to promote toolkit

I think it's a great help for people who can't talk or have anxiety when they go to hospital

~ Josh, DARE

Research and Consultation

The following research and consultation activities were conducted during the initiation and diagnostics stages of the project:

- A comprehensive literature review was undertaken to inform the project. Of these included; current legislations, human rights, current statistics regarding the prevalence of people with communication disabilities and known barriers to healthcare and grey literature offering insights into the key issues.
- Consultation with participants consisting of people with disability and their carers, health staff, and supporters, through surveys, interviews and focus groups.
- Root cause analysis which identified common themes on which to focus solutions.

Data from initial surveys, interviews and working groups told us:

- People with intellectual and developmental disabilities appreciate healthcare workers when they talk directly to them and adapt their communication so that they can better understand things being discussed.
- Carers and support workers want to assist healthcare workers to communicate and understand people with intellectual and developmental disabilities through accurate handover of information.
- Hospital staff agreed that a good handover knowledge about the person’s preferred communication methods and taking time to listen are all very important, and training is needed.

Working group participants shared their ideas on solutions to improve communication in hospitals. These ideas were rated and prioritised for clinical redesign of solutions that would be co-designed by people with disability towards meeting the projects objectives.

| Use pictures and communication tools | Handover of information | Six-minute intensive training (SMIT) |
|--------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------|
| Easy read resources and tools to assist with communication and to explain procedures and things that are going to happen | Essential information that a hospital needs from a patient, in an easily accessible and streamlined format | Concise training for hospital staff on topics such as ways to communicate and disability awareness |

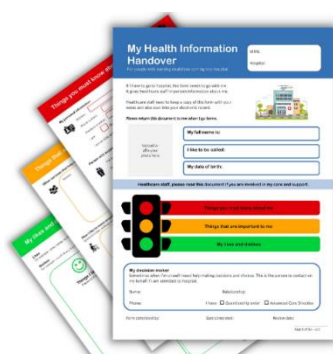
Our Solutions to Improve Communication

Getting My Health Information Ready for Hospital Toolkit

Following comprehensive consultations where both people with disability and healthcare workers collaborated in providing advice and input as key contributors, the project launched the toolkit '[Getting My Health Information Ready for Hospital](#)' in December 2022. See page 22 for further details about the launch on International Day of People with Disability 2022.

This free toolkit was developed by and for people with disability to share their important healthcare information when going to hospital or other health services.

The toolkit features:



My Health Information Handover Form

This form was developed based on a UK version called a hospital passport. The fillable PDF form is divided into sections and set out using a traffic light system, with the first section in red, covering the most important information to know about a person before providing care and treatment.

My Health Information for Emergency Services Wallet Card

This folded Wallet Card can be used alongside the My Health Information Handover Form. It is designed to provide emergency services with some of the most vital information needed to provide care right away.



Guidance notes for completion

The guide has instructions and prompts to help people think about things the hospital will need to know about them. It also includes a 'Ready to Go Checklist' to help prepare everything that may be needed in case of an emergency visit to hospital.



The toolkit comes in a sturdy document wallet that a person can take with them to hospital. It's clearly labelled and big enough to fit other important documents and items such as communication aids and medication packs.

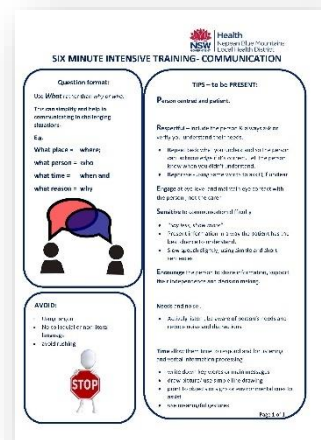
The project produced a total of 1500 physical toolkits available for distribution plus additional wallet cards. All of the tools (aside from wallet cards) are available to download for free from the project website and people have the option to build their own toolkits.

This toolkit aligns with the identified solutions: Handover of Information and Use of Communication Tools.

Communication Training for Health Staff

This training was developed to provide staff with quick tips and things to avoid when communicating with people with disability. The training is provided in the Six Minute Intensive Training (SMIT) format.

This training aligns with the identified solution: Six Minute Intensive Training.



Communication Tools

A communication tools page is available on the project website which hosts a range of resources to support people with disability.

As part of DARE's COVID response, a range of guides about COVID-19 were developed to assist and support those with disability to stay safe and informed. The tools were rolled out on the website with some great feedback received from group homes supporting people with disabilities.

The page also includes links to various tools developed by others such as:

- Say Less Show More
- Council for Intellectual Disability (CID)
- Australian Government Dept. of Health and Aged Care

<https://www.myhealthmycommunication.com.au/communication-tools/>



These resources were co designed by people with disabilities to meet the solution: Use Pictures and Communication Tools

Summary of Activities

Here is a summary of the activities that were completed at each stage of the project.

INITIATION

- Establishment of the project team
- Development of project management plan
- Communications and stakeholder management plan
- Risk mitigation plan
- Literature review
- Project launch

DIAGNOSTICS

- Surveys with health staff, people with disability, family, carers and support workers to identify issues with communication.
- Focus groups and consultation to share ideas on ways to improve communication. Conducted face to face and over Zoom and included health staff, people with disability, family, carers and support workers.
- Root cause analysis and prioritisation of key issues

SOLUTIONS

Consultations and workshops:

Face to face and Zoom workshops were conducted during the solutions design phase with health staff, people with disability, carers, family, DARE support workers, disability service managers, and other Disability Service Providers.

This included:

- Solutions Workshops to generate ideas for the key issues identified during Diagnostics
- Analysis of data generated from workshops to identify solutions to be implemented
- Review of existing tools to determine if suitable options already exist
- Presentation and discussion of ideas for handover forms and wallet cards

Development and testing of identified solutions:

- Development of COVID-19 easy read tools, available on the project website
- Handover forms and wallet cards created and distributed for initial review
- Presentation of the tools to NADO and Thorndale inviting them to join the launch and trial
- Project website set up for people to register and download the toolkit
- Toolkit documents finalised and published on the project website

IMPLEMENTATION

- Collation of 1500 physical toolkits for distribution
- Official launch of the toolkit with International Day of People with Disability - events held at DARE with special guests,
- Distribution of 300 launch packages to NADO, Thorndale and DARE, consisting of a promotional kit with information to register and free wallet cards,
- Roadshows at Lithgow and Blue Mountains Hospitals to promote the toolkit,
- Presentations to CEO Roundtable members,
- Email campaigns and social media posts promoting the toolkit,
- Distribution of toolkits – 833 toolkits distributed as at the date of this report,
- Ongoing feedback has resulted in several minor changes to improve the handover form, and
- Promotion of surveys to obtain additional feedback

SUSTAINABILITY

- As at the date of this report, the project still has just over 600 physical toolkits available for distribution, as well as additional wallet cards,
- The downloads page on the project website has been revised so that people can download the tools without having to register and can create their own kit,
- DARE has committed to maintaining the project website to ensure all resources continue to be available to download for free, and
- DARE will continue to promote the toolkit within its regular promotional activities.

Website and Promotion

The project website was created as part of the original launch of the project. The website contains information about the project, launch videos, project updates, news, surveys and communication tools.

<https://www.myhealthmycommunication.com.au/>

Promotional activities were conducted throughout the project which included:

- Regular social media posts
- Email campaigns to subscribers
- Information flyers
- Newsletters
- Project updates

Evaluation

The following evaluation activities were conducted throughout the project.

Data taken from commencement of the project identified key barriers for people with disability in effective communication with hospitals.

In review of the data, evaluation found that the project has met and exceeded the original objectives to support people with disability as it has extended its reach into the aged care sector and proven of value to people with English as a second language.

Surveys, focus groups, interviews, and feedback have all contributed to the excellent outcomes of this project.

ILC program outcomes

The following table lists the outcomes developed for the ILC program that directly applied to this project and how My Health My Communication has met these outcomes.

| | OUTCOMES | HOW WE HAVE MET THESE OUTCOMES |
|----------------------------|---------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| SHORT-TERM OUTCOMES | The person has increased confidence to access or use of mainstream services because of your project. | People with disability told us that they like the toolkit as it's easy to understand and that it does not miss any important information. |
| | The person reports mainstream services respond positively to assisting them because of your project. | The toolkit has been shared with services across the disability and aged care sectors with uptake of aged care providers expressing interest in access and use of the tools. |
| | People with disability have involvement in the improvement of mainstream services and has increased leadership and influencing opportunity. | People with disability and their supporters contributed throughout all stages in the project in the co-design of the project's resources. |
| | The person has a say on what is important to them when in the co-design process. | Feedback from people with disability in focus groups and interviews was documented and fed into the project at each stage to guide and direct the projects activities and solutions. |
| | The person feels their contribution towards your project is valued. | <p>The project has received some wonderful feedback from people with disability as detailed throughout this report informing us that they were proud of the outcomes of this project.</p> <p>In celebration of the project's success, people with disability were recognised for their support in delivering the projects key milestones and achievements at all project celebrations and events.</p> |

| | | |
|-----------------------------|--------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| MEDIUM-TERM OUTCOMES | People with disability engage with mainstream services and staff members. | The relationships built with NBMLHD have presented ongoing value to people with disability in engaging better with their local hospitals. |
| | People with disability report improved experiences in accessing mainstream services. | The toolkit has enabled people with communication disabilities to better communicate their needs in key areas of supports. |
| | People with disability access mainstream services at the same rate as everyone else. | This project provided evidence that people with disability in the target group access mainstream healthcare more frequently than that of the general population, however often experience poor outcomes with a causal link to communication. This project highlighted the importance of great communication for healthcare staff in supporting their patients with disability. |
| LONG-TERM OUTCOMES | People use mainstream services rather than specialist disability services. | The toolkit has offered greater independence and empowerment for people with disability in engaging with hospitals. |
| | Greater choice, independence and autonomy for people with disability. | <p>The toolkit has enabled people with disability to own and author their personal healthcare supports with information that establishes a direct line of communication to each person.</p> <p>Our feedback has indicated that people with disability have felt empowered and have a greater sense of safety as they know what is written in their handover, and that they have felt greater choice and control in relation to communicating their supports and guide key decisions that may not be expressed in their verbal communication with healthcare teams when attending the hospital.</p> <p>This outcome better supports the principles of patient and person centered care.</p> |

What are people saying?

The tool kits have been received well by my clients. In particular my 72-year-old client who had hearing loss, vision impairment and had some behaviors associated with isolation was able to take the toolkit to his recent cataract surgery. We filled out the information sheets together and it made him feel more confident about his surgery in communicating his individual needs. He was also able to take his blister pack with him in the satchel.

~ Wesley Mission

We have implemented the tool kits in SIL and the team have given excellent feedback on them.

~ NADO

The Health Information Toolkit have gone down fantastically here in the office, all my fellow workers seem to love them, and we are down to our last few. My manager has suggested that we add them into the intake process for when we engage with new participants.

~ Alleviate Support

The toolkit had very positive feedback from the client and the support workers. They all thought it was a fantastic idea. It has been filled in ready with the client should they need it. It has not been required to be put into action yet. After the feedback from the initial toolkit, I do think they would be useful to send out to more of our clients, so a few more would be appreciated, thank you!

~ Mypower Foundations

Absolutely love the toolkit!!

However, I must be honest, I utilized it for one of my elderly clients that is isolated. I'd love more if you are happy for me to provide to my senior clients who have no support.

~ Camellia Care Services

The toolkit proved to be very useful to older people with a disability or chronic conditions resulting in decreased functional capacity, especially the Care finder clients that are often older vulnerable people that are at a higher risk to present at hospital.

~ Caseworker, Nepean Hospital

I think it's a great help for people who can't talk or have anxiety when they go to hospital.

~ Josh, DARE

There are sometimes language barriers with different patients, this [the toolkit] simplifies all that.

It's all pretty basic, and not much gobbledy goop and very easy to understand.

~ Graham, DARE

I joined the working groups to hopefully make it a lot easier for people to communicate with hospitals and other people because I've been in the same situation.

I get a little anxious, I get a bit worried, and get tongue tied and scared about what is going to happen.

~ Cathy, DARE

In using this toolkit for a client of mine I was told that it was excellent as it gives paramedics, and nursing staff key information about a person with disability that can be referred to at each point of admission to discharge in a format that is fast to read and easy to understand.

~ Chris, DARE Support Worker

What have we done well?

- Our delivery approach - using the clinical redesign methodology allowed the co-design of the project with health staff and people with disability.
- Communication access – we were able to adapt and use different ways of consultation such as online Zoom meetings. In addition, the project website hosts a range of information for people to access.
- Communication tools – the development of tools that are now being used by many in the local community. 833 toolkits to be exact! With many more handover forms continuing to be accessed and downloaded from the website.
- Ability to engage with other Disability Service Providers to trial the toolkit within their service – NADO and Thorndale distributed over 100 toolkits across their services.

What have been some of the challenges?

COVID-19 certainly created some challenges in the early stages of the project.

Face to face surveys and workshops with people with disability and their supporters was restricted during the diagnostics phase of the project due to lockdowns.

The continued restrictions and lockdowns required the project to adopt different ways of engaging with people using online methods such as Zoom meetings as well as via phone and email. We also continued building our social media and keeping people up to date with newsletters, email updates and updates via the website.

We had a temporary stall in the progress of NBMLHD in supporting the project during this time given the constraints of hospitals being closed to the project and staff being redeployed in seconded roles according to the COVID-19 operational management response. Whilst efforts were made for remote engagement, this was not possible in enabling access to hospital staff and some people with disability to access the consultations during that period.

We successfully applied for an extension of time which allowed the project to catch up on lost time and re-engage with health staff and people with disability and their supporters.

How can we improve?

The project has shown us areas that we can improve in future projects:

- Our aspirations for this project included contribution and involvement of primary and mainstream community health services, unfortunately due to the impacts of the slow down in the project amid the COVID-19 outbreaks. there was no possibility of reaching these services as there was no time or resources that could be spared by these services. The extension enabled the project to meet its primary objectives with success, however without these interruptions, the project may have gained more in facilitating these activities.
- Further collaboration to involve more mainstream services adding value through partnering with universities, was also included as an aspiration of this project in complimenting the project through in kind supports in future. We believe these partnerships can assist projects to better collate and evaluate data and evaluation in partnering with research fellows.
- In future, disaster preparedness will be factored into initial planning stages with clear strategies to maintain key communications and impacts on the project's momentum. In addition to the impacts of COVID-19, DARE also responded to natural disasters in its services whilst undertaking project activities over the funding period in response to fires and floods.

Did the project reach its objectives?

Objective 1:

Establish a scalable model of support with easy-to-use communication resources to mitigate risk and optimise health outcomes for patients with 'invisible' disabilities like Intellectual Disability, Autism and Acquired Brain Injury.

The resources developed are sustainable, the website will continue to be hosted by DARE on a long term basis to provide the resources free of charge to people supported by both the disability and aged care sectors.

Objective 2:

Improve communication among patients, family, disability staff and health professionals.

The toolkit for Getting My Health Information Ready for Hospital, gives ownership of the handover of key information back to people with disability. Their needs are expressed in their words and practical assistance to ensure the support needs are met and is easily identified using the tools.

Objective 3:

Create resources that will provide a streamlined process that can be accessed by health staff with a kit of consolidated resources that can be used accurately, timely and efficiently

The toolkit has consistently met this objective and has been refined and amended to ensure information flow is intuitive and fast to read and understand by key staff supporting the person with disability.

Other highlights of the project

- Winner of Partnering in Providing Care Award as part of the Nepean Blue Mountains Local Health District Innovate Together Quality Awards, November 2023.



- Launch of the toolkit alongside celebrations for International Day of People with Disability 2022. The project was delighted to have some very special guests attend. <https://www.myhealthmycommunication.com.au/news/idpwd-2022/>
- In July 2023, a trial was conducted with the medical records team at Nepean Hospital for uploading a scanned copy of a patient's Health Information Handover Form into their electronic record. The trial was a success! This process will be incorporated into staff procedures and will be accessible as an additional tool to support staff.
- Presentation at the ACI Healthcare Redesign Symposium.
- Feedback identified that the tools are helpful for people beyond those with intellectual disabilities with feedback telling us that the universal design of these tools is also proving effective in supporting people in Aged Care, Mental Health, and Cultural and Linguistically Diverse groups.
- Disability service providers outside of our project's jurisdiction have shown high levels of interest in the toolkit. They were directed to the website where they could download the handover form and guidance notes for them to set up their own toolkits.
- Collaboration and connections between people with disabilities and other mainstream organisations were established.
- A great article published in the Western Weekender.
- Support from political representatives including, Her Excellency the Honorable Margaret Beazley AC KC, The Hon Marise Payne, Ms Susan Templeman MP and former NSW Premier The Hon. Dominic Perrottet MP.

What is the future of the project?

As word of the toolkit starts to spread, interest is coming in from providers and individuals in areas that are outside the jurisdiction of this funding.

With all the hard work of research, consultation and resource development now complete, additional funding would allow the project to produce additional physical toolkits and provide education and promotion of the toolkit within other health districts. DARE is optimistic that future funding can be secured to allow continuation and expansion of the project.

Should further funding not be secured, DARE is committed to maintaining the project website so that the toolkit and other resources will remain available for people to download.

Conclusion

As detailed in this report, the My Health My Communication Project has succeeded in its goals to provide a sustainable solution that better enables people with disability to communicate with their healthcare providers.

Key information that ensures quality in the delivery of healthcare supports is improving the safety of people with disability, by ensuring vital information about health supports, such as risks of choking during mealtimes or supports for high risk behaviors such as absconding and self-harm, can be clearly understood and identified and added to the persons medical record at admission to hospital.

The key achievements of this project are attributed to the contributions of people with disability that have supported the project throughout every stage and the ongoing commitment of our project team of dedicated healthcare staff who have supported our project from Nepean Blue Mountains Local Health District.

The Getting My Health Information Ready for Hospital toolkit:

- Enables people with disability to be more involved in their care,
- Assists people to communicate their needs in an accessible format,
- Improves communication between staff and person,
- Communicates consistent information between multiple staff, and
- Improves a person's hospital experience and outcomes.

Acknowledgements

We acknowledge and thank the National Disability Insurance Scheme (NDIS) Information Linkages and Capacity-Building (ILC) grant for funding the My Health My Communication project.

We acknowledge the support provided by Nepean Blue Mountains Local Health District as partners in the project, as well as our project sponsors.

We acknowledge the support received from Government representatives.

We also acknowledge and thank everyone who participated in using the communication tools that were developed by the project.

Finally, we acknowledge and thank all health staff, people with disability, carers and support workers, who co-designed and participated in the project.