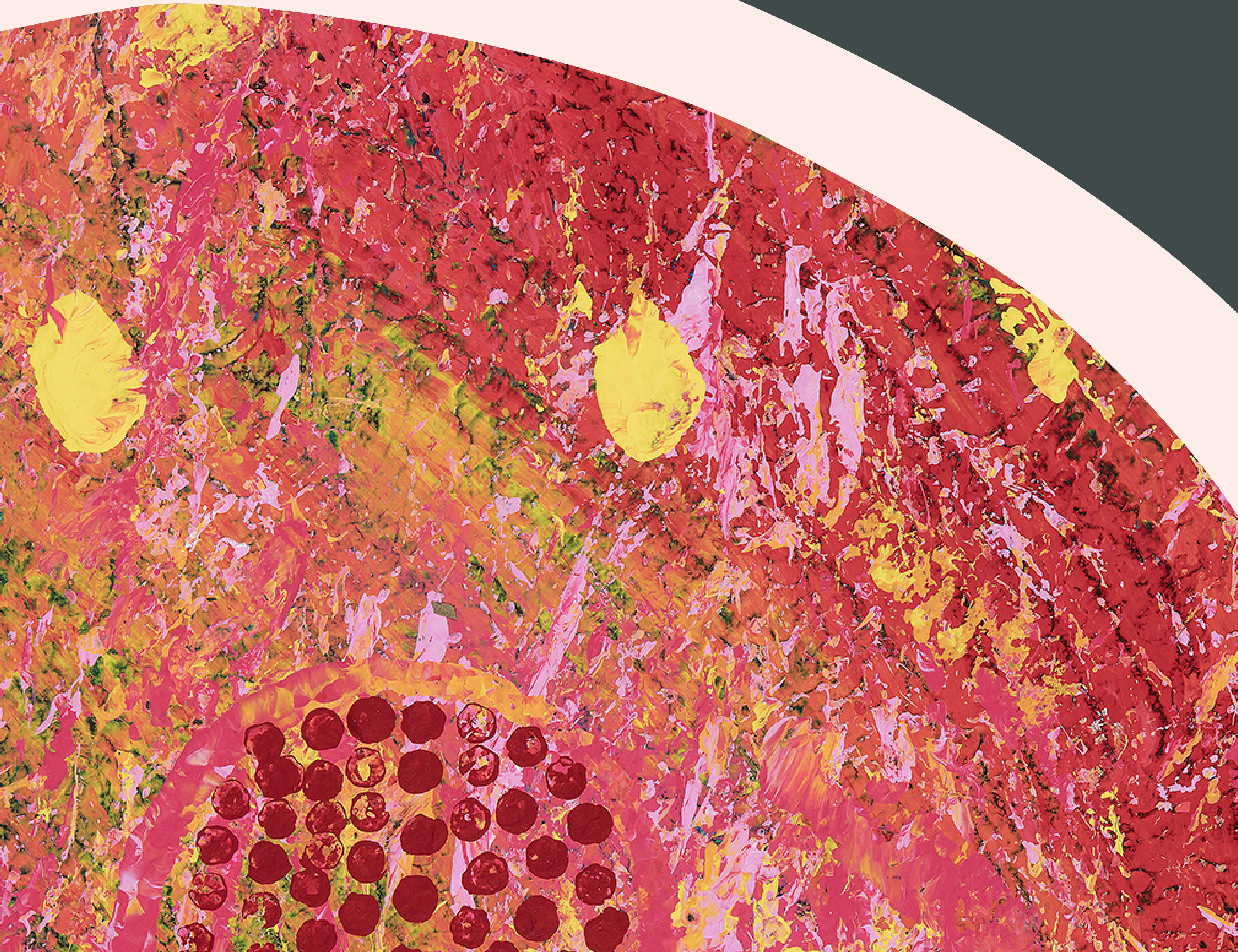
National Centre
of Excellence in
**Intellectual
Disability Health**

A Framework for Translating Health Research into Meaningful Benefits for People with Intellectual Disability



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Acknowledgement of Country

We acknowledge the Traditional Custodians of Country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to them and their cultures, and to elders both past and present. We pay our respects to all First Nations people with intellectual disability and acknowledge the higher prevalence of intellectual disability among First Nations peoples and the distinct challenges they face, along with the contributions they make to society.

Acknowledgement

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Cover Artwork

Pomegranate, Jorja Clements-Grasa, 2025

National Centre of Excellence in Intellectual Disability Health

The establishment of the National Centre of Excellence in Intellectual Disability Health was in response to the significant health disadvantage experienced by people with intellectual disability. The Centre supports the delivery of the Australian government's National Roadmap for Improving the Health of People with Intellectual Disability.

The Centre builds on the work of 3DN and the Centre's nine Consortium organisations – First Peoples Disability Network, Council for Intellectual Disability, Down Syndrome Australia, The Kids Research Institute Australia, Queensland Centre of Excellence in Autism and Intellectual Disability Health, Queenslanders with Disability Network, Centre for Disability Studies and UNSW.

Our vision is that every person with intellectual disability in Australia gets high quality health care.

Our mission is to work together with people with intellectual disability to make their health as good as it can be.

Our values

- We support the leadership of people with intellectual disability in their own lives and in the Centre.
- We are leaders in accessible communication and other inclusive practices.
- We respect family members and other advocates.
- We include people from diverse backgrounds.
- We listen to each other and value all perspectives.
- We are honest and open.
- We are accountable to people with intellectual disability and each other for what we do.

Contents

Executive Summary

Intellectual disability (ID) is characterized by significant limitations in both intellectual functioning and adaptive behaviour, with onset during the developmental period. ID is estimated to affect 1-2% of the Australian population. People with ID often experience poorer physical and mental health, reduced life expectancy, high rates of avoidable death and preventable hospitalisations when compared to the general population. This has been attributed to barriers in accessing healthcare such as poor communication, limited preventive care, and lack of provider training in working with people with ID. Despite these disparities, health research involving people with ID remains limited in Australia, with notable gaps in inclusive research designs and implementation of findings.

Translational research refers to a strategic and systematic process to convert basic research knowledge into practical applications that enhance health and well-being. It is characterised by partnerships, stakeholder engagement and multidisciplinary teams.

Using a multi-stage process we developed a Translational Research Framework to guide health research for and with people with ID. Designed to augment existing knowledge translation frameworks (such as RE-AIM) that were developed for the general population, it presents seven evidence-based principles to ensure impactful study designs and improved health outcomes for people with ID.

The purpose of this document is to: (1) Provide a framework for translational health research for and with people with intellectual disability, (2) highlight some gaps in various research methods and agendas, and (3) increase research capacity for studies for and with people with intellectual disability by providing useful resources.

See next page for an Easy Read Summary of this page

Easy Read Summary

Lots of people in Australia have Intellectual Disability or ID. They often have health problems.

They can get sick from things that we can prevent.

Why does this happen?

Some doctors and nurses don't understand people with ID.

In Australia, there is not enough health research about people with ID.

Research does not always make real changes.

Translational Research turns good ideas into real actions

Working together with people with ID, partners and experts.

Our Framework

Helps make research useful for people with ID.

Researchers can follow the steps.

It has 7 important steps.

This Document

Tells researchers about the steps.

Shows them what work needs to be done.

Help researchers do better studies by sharing useful tools.

Translational Research

New research must be translated into population-level healthcare practice to achieve the greatest benefit. For people with ID, translating evidence specific to their health is essential to ensure that they receive optimal care and experience better health outcomes [1]. To create these real-world benefits, clinical concepts need to be converted into knowledge that is meaningful for stakeholders who will use or benefit from it [2].

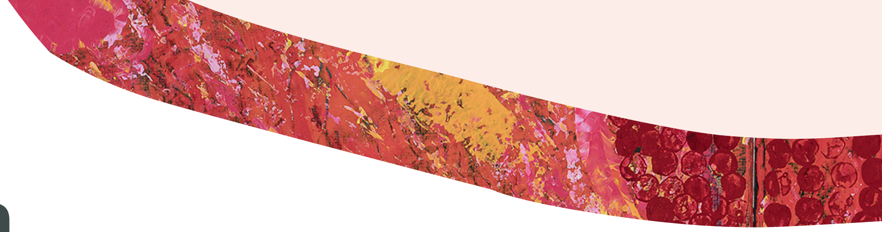
The process of integrating new evidence into practice begins with translation from preclinical studies to human trials, followed by translation into clinical practice and community settings [3]. This second stage is complex and is the focus of implementation science, which examines the contextual factors that influence the adoption of evidence-based practices in routine care [4].

Context plays a critical role in both translational research and implementation science because it shapes how stakeholders' current attitudes, workflows and behaviours adapt to changes required for integrating new knowledge [5]. Several frameworks have been developed to guide and evaluate this process by identifying and managing contextual barriers and facilitators. These factors, such as how an intervention is perceived by supporters of people with ID, or the extra time clinicians need to implement changes [6] can determine whether research is successfully translated and leads to sustained improvements for people with ID.

Further details on knowledge translation and implementation frameworks can be found in Appendix B.

See the next page for an Easy Read version of this page.

Making new ideas work



Introduction

Intellectual disability (ID) is defined by significant deficits in both intellectual functioning (i.e., impairments in reasoning, problem-solving, planning, abstract thinking) and adaptive behaviour (i.e., conceptual, social and practical skills) with an onset during the developmental period (i.e., before 22 years of age).[7] Globally, people with ID represent approximately 1-3% of the population, with prevalence higher among males.[8] In Australia, over half a million people, that is around 3% of the population, have an ID, with around 60% of these individuals having a severe impairment in activities of daily living.[9]

Typically, people with ID have poorer levels of physical and mental health when compared with the general population.[10] They also experience a lower life expectancy and a high rate of avoidable deaths.[1] In Australia, an estimated 38% of deaths of people with an ID are potentially avoidable.[11] In addition, people with ID in Australia are 4.5 times more likely to have potentially preventable hospitalisations.[12] They also face multiple barriers to accessing healthcare services, which prevent them from receiving appropriate care when needed.1 This includes having poor access to primary care and preventive care such as vaccinations, lower healthy lifestyle interventions and health screening measures.[12] The major reasons for these barriers include challenges in communication and information access, as well as lack of education, awareness, and training on staying healthy and following available guidelines.[12] These health disparities highlight an urgent need for change; however, impacts from health research for and with people with ID remains limited.

Translational research refers to a strategic and systematic process to convert basic research knowledge into practical applications that enhance health and well-being. It is characterised by partnerships, stakeholder engagement and multidisciplinary teams,[13] the "translational" aspect referring to all the different points of view and specialist knowledge each bring to the work.[14] See Box 1 for a more detailed explanation of Translational Research.

Barriers to translation in Australia include the limited inclusion of people with ID in research (including their enrolment in clinical trials, and their active role in research design),[15] poorly designed or absent implementation of research outcomes,[16] lack of longitudinal cohorts, limited data linkage, and inconsistent identification of people with ID.[17] Therefore, taking necessary steps to address these research gaps and to implement meaningful outcomes has a potential to make a difference in the lives of people with ID.

Accordingly, this document presents a research translational framework and provides guidance for researchers to conduct high impact research for and with people with ID.

The purpose of this document is to: (1) Provide a framework for translational health research for and with people with intellectual disability, (2) highlight some gaps in various research methods and agendas, and (3) increase research capacity for studies for and with people with intellectual disability by providing useful resources.

Briefly, the methods used to develop the Framework were: (1) Review of existing knowledge translational frameworks. (2) Assessment of their usefulness in guiding research with and for people with ID. (3) A scoping review of peer-reviewed studies that described outcomes of real-world research for people with ID to identify practices associated with impactful research. (4) Distillation of the 12 research practices/strategies found (specific to people with ID) into seven principles. (5) Principles were further researched in the published literature, to flesh out conceptual underpinnings, best practice, specific methods, and to collate useful resources, and organisations and agencies working with and for people with ID.

The full methods used to develop the Framework are outlined in Appendix A.

Translational Framework for ID Research

A research translation framework was developed to guide meaningful translation of health research for people with ID into practice. The Framework is structured around seven principles shown in the literature to facilitate high impact research, generally, and specifically when working with people with ID. Section 2.1 presents this framework by describing the seven principles with the infographic. Section 2.2 provides examples of how previous studies have used each of the principles in the framework so that researchers can better understand how they may inform their own work. An Easy Read version of the Framework is in Appendix G.

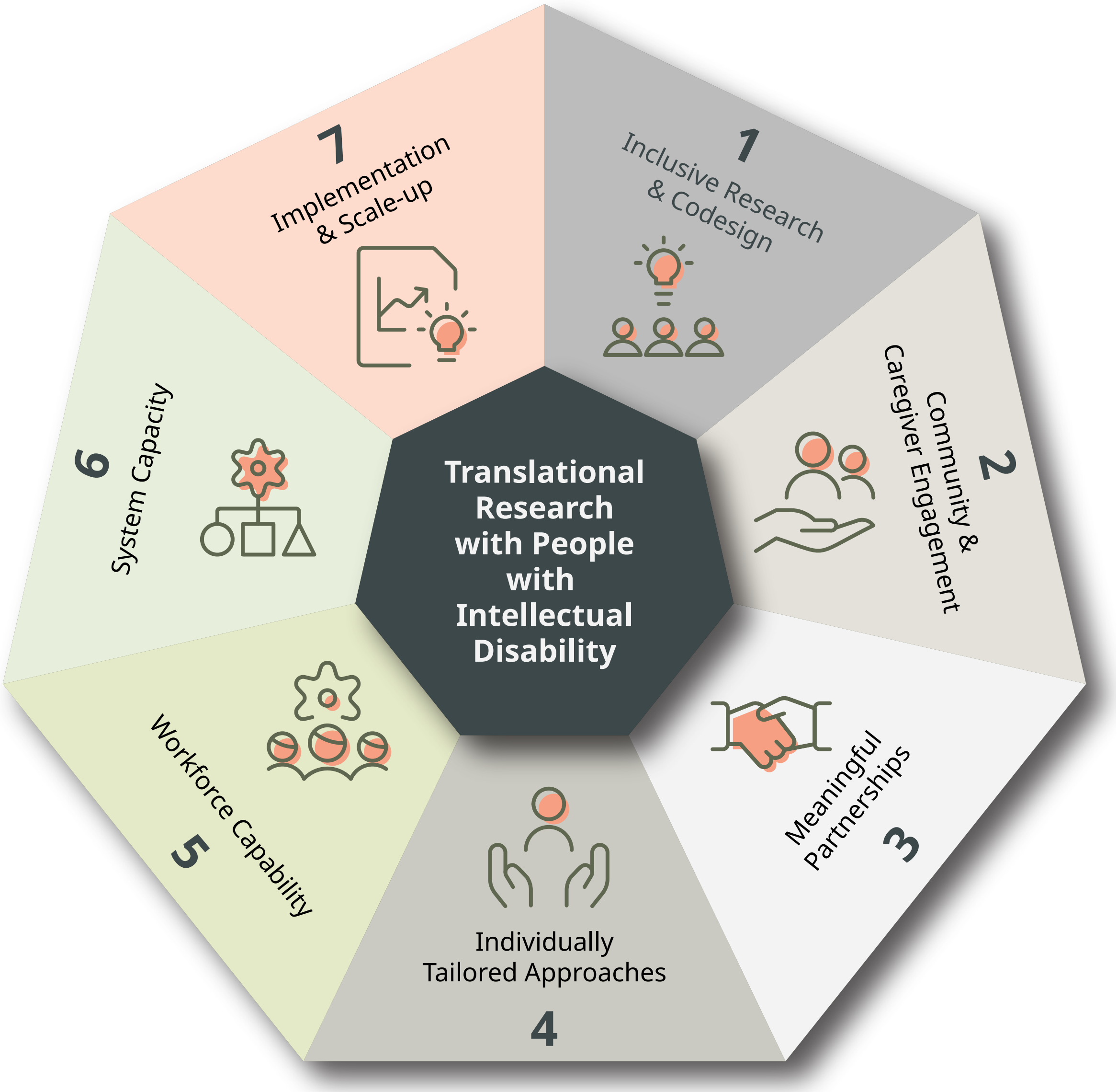


Figure 1: Principles of meaningful translational research for and with people with ID.

Principles in the Framework

Inclusive research and codesign

Involving people with ID, and their supporters in every stage of research – from setting the research agenda, designing the research and the intervention, making decisions about implementation strategies, dissemination and evaluation – is crucial to ensure the outcomes are relevant, appropriate and acceptable.[18–20] Meaningful translational research requires moving beyond inclusivity to providing people with ID with a sense of ownership over the aims, processes, and outcomes of research, and including strategies to guard against the dilution of their voices among others.[21] This includes empowering people with ID to make informed decisions about participation, to be involved in selecting research topics and aims that meet their needs, to build trust, and to improve accessibility and acceptability throughout implementation and research processes.[22,23] While it is important to conduct rigorous empirical data collection that includes objective measurements of health outcomes (e.g., epidemiological studies), the experience and perspective of people with ID and their supporters is also needed to interpret that data meaningfully and appropriately.

Alongside people with ID and their supporters, a variety of additional stakeholders experienced in working with people with ID should be engaged to include multiple relevant perspectives as appropriate to the context of the research (e.g., researchers, facility staff, clinicians).[24] Involving the right stakeholders in all stages of the development and implementation of an intervention may include input into its components and materials, assessing its feasibility and exploring how to address likely barriers and facilitators, reviewing implementation progress, and making adaptations as required.[25] Community-based interventions may enable greater involvement of people with ID, because they are able to participate in a more familiar context and with the support of their peers.[26]

Community and Supporter Engagement

Recognising families and supporters of people with ID is critical in translational health research due to their key roles in influencing health outcomes of people with ID. Researchers should acknowledge that family members and supporters vary in their attitudes, capacities and resources, and interventions should be adjusted accordingly to encourage their involvement. Families and caregivers may also require additional help to build the skills and confidence needed to support people with ID to participate in research.[27] For example, in interventions requiring technology use, supporters' skills and comfort in using technology may impact the degree to which people with ID are able to take part.[27] Healthcare and disability professionals may be included as part of support networks of people with ID, depending on the configuration of care and the level and type of support around each person.

Meaningful Partnerships

For people with ID and their supporters to engage they must trust that researchers will represent them accurately and act in their best interests. Trust also helps to reduce anxiety about participation and improve the accessibility and acceptability of research.[24] Partnerships with organisations that already have the trust of people with ID provide a safe working space for all. Engaging with organisations that support and inform people with ID may be a way to foster participation of people with ID, while providing additional safeguards of their interests.[28] Additionally, partnerships can be strategic, providing access to crucial cross-sectoral collaborations that have already been built, e.g., between health and disability sectors, to address specific health issues alongside broader social determinants of health.[29] Finally, the power of partners to endorse and disseminate knowledge of new research is crucial for scale up and widespread adoption.

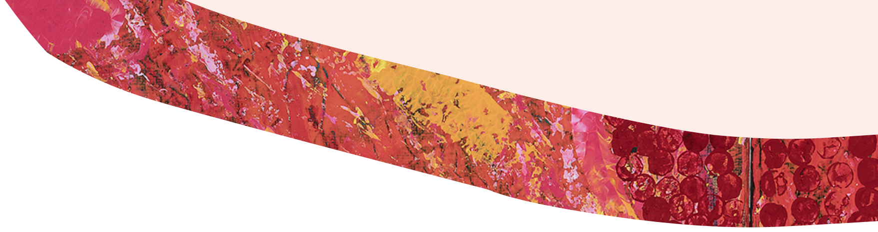
Individually Tailored Approaches

Health interventions involving people with ID need to allow for adaptability within their design, to allow for tailoring according to an individual's needs and characteristics. This helps to ensure relevance and suitability for end users, adoption of interventions, and whether expectations of the impact of an intervention are met.[21,30] It may involve identifying the degree of impairment of individual users and considering individual variations, such as how much support is needed, what ability a participant has to use technologies, or their tolerability of medical devices.[22] Some individuals may have additional complexities due to multiple needs, potentially requiring several accommodations to participate in an intervention.[31]

Workforce Capability

Interventions involving health, social or educational professionals need to be delivered by a workforce that has appropriate knowledge, skills and competencies to work with people with ID. The Intellectual Disability Health Capability Framework and the National Safety and Quality Health Service (NSQHS) Standards User Guide for the Health Care of People with Intellectual Disability have both highlighted inadequacies in the education provided to healthcare professionals about people with ID who access healthcare.[32,33] In Australia, content relating to people with ID may only be available to 10% of nurses and 15% of doctors during their foundational education.[34] Without this education, the capabilities of the majority of Australia's healthcare workforce are insufficient to meet the health needs of people with ID.[35]

Healthcare professionals pay a pivotal role in the delivery of many health interventions. Without the correct training and experience, they may not understand the intervention, or may omit crucial components.[31] Interventions should be designed with an understanding of staff’s existing skills and knowledge, in addition to their time and availability to deliver the intervention.[27,31] Training that is specific to each intervention should be part of the research design, planned and provided as required, by trainers who have experience specific to people with ID.[31,36] Training should include education about the impact and benefits of each intervention, and clearly state the features that are core to its effectiveness and those features that can be tailored to each individual (e.g., the size of the typeface on an app). Training should aim to promote staff commitment and positive attitudes towards the benefits that are possible through the intervention.[37] Finally, staff training should include the skills and understanding required to tailor adaptable features of each intervention to the individual needs of people with ID within the context of their community and support base.[38]



System Capacity

All new interventions need to consider closely the context into which they are being introduced. The capacity of the system – the organisation, facility, or community setting that the focal participants inhabit – in terms of human, infrastructural and financial resources can have a profound impact on outcomes. While this is true for all translational research efforts, it is especially important for research for and with people with ID. For large-scale interventions that involve whole organisations, such as hospitals or large residential facilities, where people with ID are a small subset of patients or clients, thought needs to be given to how people with ID should be identified. Interventions may require supportive infrastructure or adjustments to the environment that need to be carefully scoped out on site and assessed for feasibility with managers (for example, interventions that require a quiet space to sit with participants). The larger the organisation, the more complexity is involved, and this increases the potential for unintended consequences to arise (e.g., changing a process for a patient in one area of the hospital may negatively affect processes in another area). Designing less complex (e.g., single component) and resource intensive interventions may therefore support organisational capacity for change by reducing human and financial resources required.[21,24] Embedding new processes into existing workflows, and aligning with the organisation's values can also aid in adoption of the intervention.[26] The organisational changes required for implementation should be assessed and planned clearly, with the priorities of people with ID at the forefront, to ensure fidelity to intervention design.[39]

Organisational readiness is associated with greater implementation success for interventions based in hospitals and other facilities[40]. Socialising upcoming changes and assessing capability and attitudes (e.g., through the Organisational Readiness for Implementing Change Survey[40]) can increase successful initial adoption and later scale up. Piloting an intervention should always be undertaken before full implementation to test and refine all required processes which may influence its uptake and effectiveness.[21]

In community settings, interventions should be designed using an understanding of existing support networks and services used by people with ID. Values and practices known to be effective in community settings may be adapted to promote the new intervention in organisations, such as using existing behaviour support plans.[41]

Implementation and Scale-up

Interventions that are piloted and shown to work well among one group of people, or at one site, rarely spread passively and "catch on" at other sites without an active implementation and scale up plan.[42] Planning for implementation and scale up shouldbe a part of the research design from the start. Knowledge translation frameworks such as RE-AIM (Reach, Effectiveness, Adoption, Implementation, and Maintenance)[43] or EPIS (Exploration, Preparation, Implementation, Sustainment)[44] can effectively guide implementation and ensure dissemination and scale up of promising interventions. For scale-up, a clear understanding of which components of the intervention can be adapted to suit the context, and which cannot should be made clear to potential new adopters to ensure the intervention works as intended.[5] This should incorporate any changes that may affect successful implementation including policies, associated roles and responsibilities and other context related issues. [27]

Appendix E explores some theoretical and conceptual underpinnings of some of these principles.

Principles in Action: Examples of Best Practice in translational research for and with people with ID.

Inclusive Research and Codesign

Researchers from the UK used an adapted model of Experience Based CoDesign (EBCD) to develop an intervention with people with ID and other stakeholders, including family members, people working with people with ID in support roles, and health and social care providers.[45]

- Evidence-based parameters were developed for the intervention: to be accessible for people with ID (mild-moderate), to focus on symptoms of anxiety, and to use mental imagery components
- Codesign participants were presented with potential materials and intervention features, which could be adapted during the codesign process (e.g. examples of previous mental imagery interventions and possible outcome measures) rather than designing new materials.
- Accessibility was prioritised throughout the codesign process, making adaptions to EBCD based on evidence and the clinical experience of working with people with ID amongst members of the research team.
- Focus groups were facilitated by a clinician with 17 years of experience working with people with ID. When presenting information in the focus groups, facilitators prioritised: communication that supported participants to understand the information thoroughly (e.g. using open-ended questions and examples to confirm understanding), developing rapport to ensure participants felt comfortable to ask questions and seek clarification, and valuing all contributions.

Community & Supporter Engagement

A Swedish study implemented a diet and physical activity intervention for people with ID living in community homes.[26] The multi-component intervention included extensive training for caregivers, who then provided health promotion support for people with ID to improve health literacy and health behaviours.

- Caregivers participated in a study circle, including ten 90-minute sessions to increase their understanding of health. The sessions also enhanced caregivers' skills to refine their work routines based on the health information learned. It also facilitated making changes in the social and physical environment of the community home to support integration of health behaviours.

Meaningful Partnerships

The National Health & Medical Research Council Partnerships for Better Health Project aimed to improve mental health outcomes for people with ID through a cross-sector project.[46]

- Partners included the Council for Intellectual Disability, Inclusion Australia, the Centre for Applied Disability Research, the Department of Developmental Disability Neuropsychiatry (now part of the National Centre of Excellence in Intellectual Disability Health), the NSW Agency for Clinical Innovation, the Mental Health Commission of NSW, the Mental Health Review Tribunal, Ombudsman NSW, the University of NSW and NSW Government departments including: Family & Community services, Education & Communities, Justice – Corrective Services, Office of the Public Guardian, and the NSW Ministry of Health.
- Engaging with a broad range of partners enabled integration of data from a range of sources to develop a profile of mental health and service use in people with ID, comprehensive policy analysis, and engagement with people with ID, clinicians, and staff from disability and education services, to understand how to better recognise mental health disorders in people with ID and to improve access to mental health services.

Individually Tailored Approaches

A Norwegian pilot intervention used mobile health (mHealth) applications to support and encourage physical activity in people with ID.[22]

- The main mHealth application was developed by family members of people with ID to provide individualised physical activity programs for each person. User representatives provided feedback on the application throughout the development process.
- Varied interface options were available for tailoring the application to the communication preferences of each user, including symbols only, easy-to-read or plain text, and read-aloud mode.
- Each participant had a personalised goal-setting meeting, along with their caregivers, to formulate their physical activity goals.

Workforce Capability

An Australian study used an action research framework to increase healthcare staff's understanding, confidence and skills of working with children and young people with ID in a tertiary children's hospital.[47]

- Training was delivered to a multidisciplinary group of clinicians
- Training strategies included: Motivational Interview (increasing understanding of problems), Flipped Classroom (optimising time effectiveness by exposing students to knowledge before each class), and Process Mapping (mapping patient pathways through the hospital system).
- Training focused on reflective discussions, principles of adult learning, peer norming, and ways to transform knowledge into action.
- A simulation coordinator was engaged to mock scenarios and characters presenting challenging behaviours. Participants then practiced de-escalating these situations using a structured approach.

System Capacity

A Dutch study that aimed to increase access to technology for people with moderate to profound ID living in residential care facilities, implemented an intervention to improve the capability of direct support professionals to assist them.[37] The program was implemented across four residential facilities.

- Consultations were held with each facility to check that the aim of the project aligned with the facilities' goals, and to assess their readiness to start.
- Researchers worked closely with staff at each facility to recruit appropriate teams, helping them first to assess if they had capacity as well as enthusiasm.
- Managers at each facility provided time for teams to complete E-learning modules and attend face-to-face sessions.

Implementation and Scale-up

An Australian study examined the feasibility of scaling up an exercise mentorship program for young people with disabilities, highlighting aspects of implementation specific to young people with ID.[48]

Scale-up to accommodate different levels of ability and complexity required adaptations to the initial program. These included additional screening and risk analysis processes, extra support from the exercise mentors and in-person consultation.

- Mentors in the original program were all physiotherapy students. During scale-up, mentors from broader health-related disciplines were able to recruit participants. To accommodate the greater numbers, an online application to monitor exercise progression during the program was also introduced.
- Additional gym sites were added to accommodate participants who were unable to travel to the original locations.

Some Gaps in the ID Research Agenda

In this section, research gaps and key areas for future translational health research involving people with IDs specific to the Australian context are presented. These provide guidance and highlight key activities that research should focus on, supporting researchers, funders and organisations to stay focused on the most important aspects of intellectual disability health research.

Participation in Clinical Trials

People with ID have the right to be meaningfully engaged and involved in research that impacts their lives.[49,50] However, they are often overlooked and excluded from participation in clinical trials due to systemic biases in eligibility criteria and challenges in accurately identifying their needs. Common exclusion factors include having a diagnosis of an ID, limited functional capacity, and difficulties with reading and writing.[1] Evidence indicates that globally around 35.3% of clinical trials have explicit exclusion criteria for people with ID in their research.[2] Exclusion factors are mostly about consent, potential risks of harm, vulnerability or frailty and perceived negative impacts on research outcomes.[1]

This exclusion undermines the evidence base for treating and supporting this population.[51] As a result, treatments targeting the general population may not be tested for people with ID, making it difficult to understand how to best address their needs and generalise results to real-world patients.[52] This may lead to higher rates of chronic illnesses, poorer access to care, and higher rates of preventable deaths for people with ID.[53] Therefore, there is an urgent need for researchers to find ways to include people with ID in research for broader groups.

The NHMRC National Statement on Ethical Conduct in Human Research (2023, updated 2025)[49,50] provides valuable high level guidance but does not give explicit step-by-step advice on how to include people with ID in research or what specific strategies should be adopted. Furthermore, the Statement is general for all human research and not specific to clinical trials where exclusions are most commonly observed. Therefore, there is a clear need for more detailed checklists and guidance to help researchers address the ongoing issues related to exclusions of people with ID.

Codesign Methods for people with ID

Despite growing interest in inclusive research and the use of codesign methods, significant gaps remain in the meaningful involvement of people with ID in Australian health research. Codesign can often be deemed infeasible due to barriers such as institutional constraints, communication difficulties and limited resources.[54,55] People with ID should be included as active partners in the research process from beginning to end.[19,20,56] Robust models showing how to do this are needed to guide researchers. While codesign models for the general population abound,e.g.,[57] few comprehensively outline what best practice looks like for codesign with people with ID.

Embedding Research in Routine Practice

Some healthcare interventions for people with ID which have been found effective, appear to peter out in the real world after the study period ends. Other interventions do not make it past the pilot stage perhaps being deemed unfeasible in everyday practice. Others may be shown to be effective but fail to move into more widespread practice. For example, there is low and inconsistent uptake of healthcare interventions and guidelines for people with ID reported in Australian primary care.[16] Australian hospitals are also reported as lacking a routine practice of making reasonable adjustments for people with ID to optimise their care.[58] This highlights clear gaps between evidence and routine practice. This gap is known as the “Valley of translational death[59]” and is often attributed to a lack of active strategies to support implementation and scale-up. There are rigorously developed and validated implementation determinant and planning frameworks already in existence (e.g., CFIR,[60] TDF,[61] RE-AIM[43]), however, there is limited evidence of their widespread application for healthcare interventions for people with ID. This current work attempts to address this gap.

PREMs and PROMs for People with Intellectual Disability

Patient-Reported Experience Measures (PREMs) and Patient-Reported Outcome Measures (PROMs) are validated tools that collect standardised outcomes from the perspective of patients themselves. They are essential for capturing the perspectives of patients on the quality of healthcare services. However, these tools have rarely been developed or validated for use with people with ID, who are thus often excluded from PREM and PROM data collections due to cognitive and communication barriers, use of complex language, reliance on self-completion, and a lack of supportive tools.[62,63] Assessing patient experience for people with ID requires careful consideration of who is included, how tools are designed, how data are collected and how the findings are applied in real-world contexts, to make an impact. [63] Recent initiatives, such as the "Listen to Me" research project [62] have begun to focus on co-creating PREMs and PROMs that are accessible and meaningful for this group.[62] Therefore, having more validated and standardised set of outcome and experience measures are quite valuable allowing comparison between studies implementing the same intervention.

Large-scale Datasets and Longitudinal Cohorts

Collecting and utilising existing large-scale and longitudinal datasets should be a key priority for researchers in the field of ID research in Australia. Challenging this possibility, ID is not identified consistently across national datasets, making it difficult to track individuals over time. Further, different sources of data are dispersed across multiple sectors (e.g., health, education, social care) highlighting the need for improved communication and linkage of datasets to increase visibility and maximise their use.[17] Although some statewide studies have been conducted, there remains a need for large national cohorts of people with ID.[1] At present there is no consensus on how people with ID are identified by organisations or health services, meaning that data may be inaccurate, inconsistent or conflated with other cohorts. For example, data may include people with conditions that are only associated with ID in some cases (e.g., autism spectrum disorder, cerebral palsy). This reduces the value of research for either group.

Equity in Healthcare Access

Research should focus on maintaining health equity so that everyone has a fair opportunity to be healthy based on their needs. In Australia, people with ID face significant equity issues that impact their access to healthcare. Research shows that people with ID have limited access to preventive care such as vaccinations, cancer screening and lipid checks.[64] Inadequate access to primary healthcare has been attributed to lack of provider training, communication barriers and limited experience of treating people with ID by general practitioners.[65] In addition, people with ID are more likely to be obese, less likely to engage in active physical activity, and have less knowledge about healthy lifestyles and eating habits compared to the general population.[12] Difficulty accessing care manifests in a range of poorer health outcomes for people with intellectual disability including more than twice the rate of avoidable deaths, double the rate of emergency department and hospital admissions, and higher rates of physical and mental health conditions.[18] High-level strategies towards equity are set out in recent documents such as The National Roadmap for Improving the Health of People with Intellectual Disability (2023).[18] Real world interventions, such as Western Victoria Primary Health Network's project – Supporting People with Intellectual Disability to Access Health (SPIDAH) project[66], work locally to support staff and people with ID to make reasonable adjustments that support easier access to care.

Researcher Toolkit

In this section, a researcher toolkit is provided for intended use by health and social care researchers who are working with, or planning to work with people with ID. The toolkit aims to support researchers in planning, designing and conducting health research with people with ID. It includes guidance on these topics: ethical considerations, inclusive research practices, and promoting accessibility for people with ID. Information relevant to common research methods (both qualitative and quantitative), available data sources for researchers, and research partners who are conducting research in the field of ID are also provided. In addition, Appendix B contains links to useful ethical guideline statements and standards from a range of organisations in Australia. Appendix C lists various Australian groups conducting or supporting research for and with people with ID who may be considered in the role of strategic partners.

Ethical Considerations in Research Involving People with Intellectual Disability

People with Intellectual Disability as a Population Requiring Additional Considerations

Working ethically requires balancing the need to protect participants, such as people with ID who generally require additional considerations to appropriately participate, while still ensuring that research goals can be achieved without placing unnecessary restrictions on researchers.[67] A key concern is determining the extent to which people with ID need accommodations to usual practice. One approach is to include people with ID directly in the ethics process and discussions. Their involvement can allow ethically acceptable approaches to be tailored to their specific needs, helping to resolve potential ethical dilemmas.

The nature of the relationship between researchers and participants needs to be considered. Terms of engagement, including roles and clear boundaries, should be established at the outset. Communication and rapport-building may require specific skills and training when working with people with ID. Researchers should also consider the social networks and skills of people with ID, as well as their environments and existing relationships, before commencing research relationships. Where appropriate, they can incorporate available resources to support the research process, such as staff in group residential settings or family members and supporters. [4]

Obtaining Informed Consent

In Australia, obtaining informed consent from people with any disability is guided by the National Statement of Ethical Conduct in Human Research.[67] Researchers must disclose all necessary information for respective participants or authorised third parties to make an informed decision before participating in research. Potential participants should be able to understand the information provided and ask questions or discuss any other concerns they may have with the researchers before giving informed consent. Therefore, obtaining informed consent from people with ID can sometimes be challenging since many individuals may find it difficult to read and understand conventional participant recruitment and consent materials. [6,10]

Some strategies to enhance the understanding and comprehension for people with ID include: using Easy Read format,[68] breaking down information into smaller simpler sections, using bullet points, repeating key messages and adding visuals to support their understanding. Other accessible methods such as videos, graphics, storybooks, or vignettes may also be used to help people engage with the information more effectively.[10]

It is also important to determine the capacity of individuals before obtaining their consent. For example, people with mild to moderate ID often have the capacity to provide their own consent while people with severe ID may not. In these cases, other approaches should be used, such as involving family members or a legal guardian, paid caregivers or staff who know the individuals best to help ensure informed consent is obtained. [6,10]

There are several other guidelines in Australia which provide guidance for researchers when conducting research with people with ID. Appendix B contains links to useful ethical guideline statements and standards from a range of organisations in Australia.

Research Methods for people with ID

A range of research methods, including both qualitative and quantitative approaches, can be used and tailored to meet the diverse communication and support needs of people with ID. For all designs, strategies should be incorporated to enhance the accessibility of methods, ensuring people with ID can participate.

Accessible designs

Accessible research practices need to be incorporated when conducting research with people with ID to enhance their meaningful participation and engagement. Different strategies are used in this context.

Universal designs

Adhering to the universal design concepts is recommended to improve the acceptability. This includes using large texts, dark prints, enabling websites and other online reading resources compatible with screen readers and using plain languages [69].

Easy read documents

Research documents such as participatory information sheets and consent forms should be prepared in easy read format to ensure they are accessible and understandable for people with ID. Easy read is a communication technique that presents the complex information in a simplified and a clear layout often supported by images to make content more meaningful and easier to interpret. This Australian website Easy Read | Style Manual provides guidance on how the Easy Read materials should be created in detail.

AAC – Augmentative and Alternative communication

AAC encompasses a range of methods including unaided systems such as manual signs (e.g., Auslan) and gestures as well as aided systems such as the Picture Exchange Communication Systems (PECS) and speech generating devices (SGD). Aided AAC can be further categorised into high tech options (e.g., SGDDs, tablets and apps) and low tech communication systems (e.g., PECS, eye gaze boards and symbols on a notebook).[70,71] When incorporating AAC into research, it is important to identify the strategies participants typically use and to consider their current communication abilities.[71,72] In addition, communication partners such as family, friends and support workers should be made familiar with the AAC techniques if they are being used, to ensure their effective use.[72]

Visual aids

Visual aids represent one form of AAC used in research with people with ID. In research, visual aids are often used to assist interviews. For example, the use of cue cards with simple symbols to represent key elements such as places, people, feeling, talk and action can be complemented for open ended questions.[71] Some methods are totally dependent on visual aids. A notable example is using photographic research methods to obtain lived experiences of people with ID. Here, participants are encouraged to take photographs themselves of the things they find interesting and relevant to the project. This approach can be quite effective in capturing their thoughts because photographs could communicate perspectives and ideas themselves without necessarily being interpreted. From using photo albums in open-ended interviews to more developed approaches such as photovoice are quite popular in this regard. These methods put people with ID in a position of ownership and give them a chance to reflect their lives through their own voice.[69,71]

Other methods

With the recent technological enhancements and the COVID-19 pandemic, there has been a shift toward conducting research in virtual environments. This shift has enabled more opportunities for using inclusive and accessible technologies for research with people with ID. Tools such as video sharing, video conferencing platforms, telephone interviews, audio recording, slide presentations, online surveys, and innovative methods like photo-sharing applications and digital journalling are increasingly being adopted. These approaches are often tailored to the needs of the participants and enhance the accessibility through the use of tablets, stylus tools, compatible with screen reading, camera equipment and text-chat software.[69]

Qualitative Methods

Qualitative methods can explore unknown factors and have the capacity to empower participants while generating meaningful insights through ongoing, flexible engagement. This approach enables researchers to capture the nuanced lived experiences of people with ID.[2] Normally, it begins with a defined research question, and the chosen method should be appropriate to address that question.[2] Traditional qualitative methods should be adapted to meet the various needs such as communication and cognitive abilities of people with ID. This could mean involving a support person such as a family member, caregiver, or a co-researcher, involving communication aids and facilitating a more supportive environment where they feel more comfortable to express themselves.

Interviews

Interviews are typically conducted one-on-one or with a support person if needed. Interviews use simple conversation in plain language and flexible formats. Conducting interviews with people with ID presents several methodological challenges. To address these, three key principles should be maintained. First is authenticity, ensuring that the expressed views are representative of the true context and are fair. Second is validity or credibility, ensuring that the expressed views are interpreted correctly. Third is reliability or trustworthiness, ensuring that the responses genuinely reflect what the person believes.[3]

If adapted properly, interviews can yield rich insights into the views and perspectives of people with ID. Therefore, communication adaptations are essential when engaging with people with ID. Researchers should use plain language and simple questions, minimizing complexity that many individuals with ID may find difficult to answer.[4] If open ended questions are challenging, researchers may incorporate other visual tools without leading participants.[5] For example, visual aids such as picture cue cards, self-produced photographs, and printed images or symbols can help individuals with limited verbal skills express their views with less pressure.[4] Similarly, if a person relies on communication strategies such as augmentative and alternative communication (AAC) systems, their preferred method or a combination of methods should be incorporated to enhance their ability to respond during interviews. Examples of AAC systems include simple gestures, sign language, or high-tech voice synthesizers.[4]

Interviews should focus on building trust and creating comfortable relationships with the person, which often requires flexibility and patience. For example, using multiple short sessions instead of one long session may help achieve more meaningful outcomes. Researchers may also involve a familiar support person or caregiver in the interview process if it helps the participant feel comfortable or provides assistance with interpretation. However, the role of support persons should be managed carefully so they do not dominate the process. Their role should be to facilitate by focusing on the person with ID, only clarifying or translating when necessary. In addition, training co researchers with ID to conduct or co facilitate interviews can enhance engagement, as participants may feel more comfortable opening up to someone with similar experiences. Therefore, co interviewing with people with ID can be a powerful approach.[4]

Focus Groups

Focus groups encourage open conversations, leveraging group dynamics to build confidence and to elicit ideas within peer support and validating settings. A well-designed focus group may enable sharing more experiences and feelings among people from similar contexts getting peer support in non-threatening environment compared to one-on-one interviews. Participants often encourage and validate each other using both words and non-verbal gestures which enhance their contribution and peer to peer communication. [4]

Having a skilled facilitator is also quite essential in moderating the discussions. The facilitator should use plain language, clear voice, speak slowly and check for understanding frequently. Focus group discussions often use visual aids and easy read materials to guide the discussions.[6] In addition, some focus groups might give permission to have an interpreter or a support person such as family member or a caregiver to assist with the participant's communication. However, similar with the interviews, it is important to define and inform about the role of the support person so that they do not intervene and offer their own opinions instead support delivering the thoughts of people with ID.[4,6]

Ethnography/Observation

Ethnographic studies have been quite common in this field over a long period of time. Ethnography involves deep observations and immersion in participants natural environment to understand their behaviours, routines and cultures. Typically, ethnographic studies in this field includes frequent visits to group homes or living in group homes, or participating in community activities alongside with people with ID. This approach is quite valuable, especially when participants cannot articulate their experiences through interviews. Researchers can closely observe participants and learn by observing and interacting over time and come to meaningful observations.[4] Therefore, ethnography enables researchers to live and experience the way people with ID live rather than operating in experimental situations.[7] However, this might involve several ethical issues including invasion of privacy, overstepping boundaries or revealing poor and harmful practices. Therefore, having a strong ethics protocol considering these ethical aspects is essential when conducting ethnographic studies involving people with ID. [4]

Visual Methods

Visual methods use pictures and other visual tools to involve people with ID in research. These methods are very inclusive for people with ID because they do not rely heavily on verbal communication. One common approach is photovoice, where participants are given cameras to take photos about their lives and after that researchers analyse contents in the photos or have a further discussion with the participant about what they have included. These visual methods such as photovoice, images, or video recording can support people with ID to share their experiences and express themselves in more natural and convenient ways. By using these methods, researchers can adapt to different communication strengths and make sure that people with ID are actively included in the research.[73]

Diaries and Journals

Diaries can be used in research with people with ID by asking participants, or with support from their families, to record their daily experiences in written, visual, or audio formats. They offer valuable insights about their routines, emotions, and day to day behaviours over time. Diaries may be feasible to use and work well with both children and adults who can use simple writing or visual symbols. However, it can be sometimes burdensome when participants have to record daily entries in the diaries. Therefore, this method needs to be used with caution. [74]

Quantitative Methods

Surveys

Surveys and questionnaires with people with ID can be challenging to administer and the type and complexity of the questions may be limited due to communication difficulties with people with ID. Therefore, surveys with people with ID should be adapted, providing appropriate accessible methods. Standard questionnaires often need to be simplified into plain language, with shorter sentences and visual supports like symbols or pictorial Likert scales to aid comprehension. Researchers may need to read questions aloud, use concrete examples, and break sessions into shorter parts to avoid fatigue. Building trust, ensuring respect, and allowing flexible management (e.g., oral responses, breaks) have been shown to enhance participation and data quality. Sometimes support persons are used to gather responses about their views, but this needs to be interpreted cautiously so that it reflects the perspectives of people with ID accurately.[73]

Randomised Controlled Trials (RCTs)

RCTs are considered a ‘gold standard’ in testing interventions as they allow researchers to determine whether an intervention makes a difference and provide rigorous evidence. However, research shows that only about 2% of RCTs have included people with ID while around 90% have automatically excluded them. [75,76] This exclusion is often based on limited consent capacity, challenges in communication and comprehension, recruitment difficulties, and the need to adapt interventions or engage support persons and other stakeholders. If reasonable adjustments are made to accommodate the needs of people with ID, they can be included in RCTs effectively. Some strategies include making resources accessible using easy read documents, visuals, simple language and activities, piloting interventions and field testing to ensure tolerability before the full RCT and involving support persons to assist in decision making and participation. [75,77]

Data Sources Available for Researchers

This section provides an overview of some of the existing data sources available for researchers in the context of intellectual disability in Australia. It also reports on identified strengths and challenges of the data sources as well as future recommendations to address critical research gaps in the field.

National Surveys and Databases

The Survey of Disability, Ageing and Carers (SDAC)

This is a population-based survey conducted by the Australian Bureau of Statistics every five years since 1981. Initially, the survey collects household information, then each person with disability (which includes ID) completes a personal interview. These interviews are conducted by proxy for young people or people unable to answer for themselves due to their disability.[78] The SDAC collects demographic and socio-economic information, measures the prevalence of different types of disability in Australia and the need for support amongst people with disability, and provides information about people who provide informal care for people with disability.[79] Additionally, the SDAC includes questions about experiences of care amongst people with disability, relating to general practitioners, medical specialists, dental practitioners, hospital emergency departments and admissions, and telehealth consultations. These questions explore whether the person has visited these health professionals in the past 12 months, whether they needed to visit a health professional but didn't, reasons for not accessing care when needed, wait times for appointments, whether care was coordinated, and if referrals were provided [80].

The National Health Survey (NHS)

This survey uses the short disability module from the SDAC, identifying people with intellectual disability.[81] It additionally collects information on self-assessed health status, self-reported height and weight, long-term health conditions, risk factors (e.g. smoking or vaping, alcohol consumption, and physical activity), bodily pain, psychological distress, and takes physical measures including blood pressure, height, weight, and waist.[82] Additionally, the NHS is linked with the Pharmaceutical Benefits Scheme (PBS) providing information about medications dispensed to survey participants 6 months before and after they are interviewed for the NHS.[82]

The National Disability Insurance Agency (NDIA)

The NDIA implements the National Disability Insurance Scheme (NDIS). It provides data to identify the demographic profile of people participating in the NDIS, payments made, participant outcomes from baseline (entry in the scheme) and through responses to longitudinal surveys, participant experiences of the scheme (e.g. satisfaction or complaints), and the number of providers supporting participants with their disability.[83]

Linked Datasets

The National Disability Data Asset (NDDA)

This is a new resource to identify health outcomes for people with disability, created through collaboration between the Department of Social Services, the Australian Bureau of Statistics and the Australian Institute of Health and Welfare. Data are included from the SDAC, NDIA, PBS, and the Medicare Benefits Scheme (MBS), which provides on health services accessed. Additionally, hospital admission data are available for some states and territories, and national death registrations. The first data was released from the NDDA in December 2024.[84] Further data releases in 2025 expand the range of data to include housing, education, transport and justice. The NDDA is planned to be fully operational in 2026.[84] Applications for data are open:

https://www.ndda.gov.au/research-projects/apply-data-access

The National Health Data Hub (NHDH)

This resource links data from the NDIA, MBS, and PBS, with national hospital data, the immunisation register, aged care services, the Australian and New Zealand Intensive care society, the National Death Index, and demographic data. There are varied date ranges available for each dataset, but they all provide data up to at least 2022. The NHDH can be accessed here:

https://www.aihw.gov.au/reports-data/nhdh/access

Intellectual Disability Exploring Answers Database (IDEA)

IDEA is a population-based resource for the state of Western Australia (WA), which is specific to people with intellectual disability. It includes all children born in WA and identified as having an intellectual disability, since 1983. Additional data include those from the NDIA, the WA Department of Communities, and the WA Department of Education.[85]

https://www.thekids.org.au/projects/idea-intellectual-disability-exploring-answers/

Strengths and Challenges in Data Availability

Strengths

One of the key strengths in the current data landscape is the availability of health and disability service use data for people with ID. Linked datasets, such as the National Disability Data Asset (NDDA) and the National Health Data Hub (NHDH), which include hospital records and MBS data, provide valuable insights into patterns of service use, which are currently known to include high rates of ED presentations and adverse events amongst people with ID.[29] Additionally, the Survey of Disability, Ageing and Carers (SDAC) includes a patient experience module that provides some understanding of barriers to service access. When linked with other datasets, the SDAC can help build a more comprehensive picture of healthcare interactions and outcomes for people with ID. These datasets are instrumental in monitoring key issues identified by the National Centre of Excellence in Intellectual Disability Health (NCEIDH) in the recent *Intellectual Disability Health Report*, such as poor patient experiences of interacting with the health system, and systemic barriers to care.

Challenges

Despite these strengths, several challenges limit the utility and inclusiveness of existing data sources.

Service-based data limitations

Most datasets capture information only from individuals who are actively accessing services. Despite the patient experience data collected in the SDAC, this still leaves a significant blind spot around unmet healthcare needs and exclusion from services, which are critical issues for people with ID.

Definition and identification of intellectual disability

Accurate identification of people with ID in datasets remains problematic. The SDAC and the short-form module in the National Health Survey define intellectual disability broadly as “learning or understanding difficulties,” which risks conflating intellectual disability with learning disorders such as dyslexia.[86] This issue has previously been highlighted in detail, in Inclusion Australia’s report *Gathering the Evidence: Data on people with intellectual disability in Australia*. This lack of specificity undermines the ability to distinguish between different levels and types of intellectual disability, which is essential for nuanced analysis and targeted interventions.

Survey accessibility and respondent type

Surveys may be completed by people with ID themselves or by supporters, which raises questions about the accessibility of survey instruments, the skill of the persons administering the surveys, and the authenticity of reported experiences. This affects the reliability of data on patient experience and service barriers.

Geographic exclusions

The SDAC is the source of some of the most detailed data about people with ID, yet it omits very remote areas and discrete Aboriginal and Torres Strait Islander communities,[81] limiting the ability to understand and respond to the experiences of First Nations peoples with intellectual disability. This gap was also identified in the NCEIDH Intellectual Disability Health Report as an area for improvement.[29]

Examples of High Impact Research Projects in Australia

National Health & Medical Research Council Partnerships for Better Health Project, Improving Mental Health Outcomes for People with an Intellectual Disability| Department of Developmental Disability Neuropsychiatry (3DN)

This project focuses on improving access to and the quality of mental health services for people with ID. It adopts a data driven approach identifying several linkages and gaps across multiple service sectors such as mental health, disability, justice and education and highlights the benefits of engaging cross- sectors in addressing mental ill health among people with ID. Key strengths of this research include its data driven approach and analysis of cross-sector services to identify gaps, its focus on addressing gaps in policy and policy development in the field, and its commitment to involving people with ID and their supporters in the research process to develop an evidence based approach to mental health service and policy development for people with ID.

Listen to me | CHSSR | AIHI | Macquarie University

This research project focuses on co-creating PREMS with people with ID using web-based platforms and digital tools. A key strength of this research is the co-production of PREMS with people with ID and the use of co-research practices to create user-centric designs that are ready for adoption. In doing so, it aims to improve healthcare quality and outcomes for people with ID, including reducing preventable hospitalisations and prolonged lengths of stay.

A short video describing the project can be found here:Listen to Me - PREMS for people with intellectual disability

Community-based participatory-research through co-design: supporting collaboration from all sides of disability | Research Involvement and Engagement | Full Text

This is a project conducted in Western Australia within a disability organisation. It includes designing of a tele-practice model incorporating a codesign research approach. One of the highlights of this project is the inclusion of an embedded researcher and a peer researcher with lived experience of disability throughout the project. The codesign process also included five workshops and a reflection session with ten people with lived experiences and staff who were involved as co-researchers. Therefore, this project clearly demonstrates and provides valuable insights on the use of a codesign approach within the disability context.

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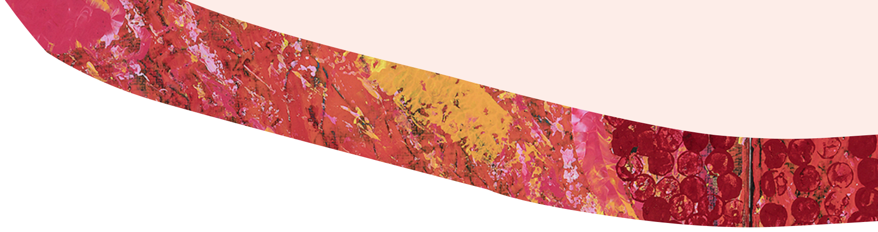
Appendices



Appendix A: Methods for developing the Framework for Translational Research with and for people with ID.

First, a **review of existing knowledge translation and implementation frameworks** was undertaken, searching published grey and peer-reviewed literature. The rationale here was to not “reinvent the wheel” if a good framework already existed, or to identify a framework that could be appropriately adapted. A set of four knowledge translation and two implementation frameworks were chosen based on their record of robust development and validation, and record of usefulness in the literature. Next, the six frameworks were **critically appraised for their appropriateness** as a guide for health research with people with ID.

Knowledge translation frameworks considered:

- I-PARIHS: Promoting Action on Research Implementation in Health Services[87]
- KTA: Knowledge to Action Framework[88]
- ISF: Interactive Systems Framework[89]
- RE-AIM: Reach Effectiveness Adoption Implementation Maintenance, RE-AIM with PRISM: Practical Implementation Sustainability Model[43]

Implementation Science frameworks considered:

CFIR: Consolidated Framework for Implementation Research[60]

TDF: Theoretical Domains Framework, and the Behaviour Change Wheel[61,90,91]

All knowledge translation frameworks were seen to be useful guides to effective translation, but were **lacking in specific principle**s to guide research with and for people with ID. Both implementation frameworks were useful for guiding different types of interventions or change programs but again were lacking in specific advice for this research. For example, most had vague or absent advice around “seeking patient perspectives” or “considering context”.

Rather than adding to an existing framework, a **new framework** was developed to specifically guide research with and for people with ID. The framework provides seven principles to supplement, not replace, existing frameworks and clarify the vague or absent advice around “seeking patient perspectives”43 or considering “external context”.[60]

Second, a **scoping review** [still in preparation] was undertaken with the research question: *What factors are associated with impactful implementation of healthcare interventions from research with and for people with ID being used in real world situations*? The search was restricted to peer-reviewed empirical research and was conducted in MEDLINE (via Ovid), CINAHL (via EBSCOhost), Embase, PsycINFO, Scopus, and Web of Science. Studies had to be carried out in real world settings and must include an evaluation of clearly defined outcomes.

Title-abstract screening was conducted on 804 articles, full text on 134 leaving 18 in the final set. Data extraction on these 18 articles **included identification of key practices and research design features** present; firstly, those that mapped to Expert Recommendations for Implementing Change (ERIC) strategies[92] (cohort agnostic) (n=32), and secondly specific to research for and with people with ID (n=12). These latter 12 features were developed into seven principles for the Translational Framework for Research with and for people with ID.

In the final step, these principles were **further researched** in the published literature, to flesh out conceptual underpinnings, best practice, specific methods, and to collate useful resources and organisations and agencies working with and for people with ID.

Appendix B: Existing Knowledge Translational Frameworks

In this section we give details of several popular existing knowledge translation or implementation frameworks. The purpose and uses of each are outlined and an example of a study that used the framework is provided.

For researchers new to translational research, courses and support offered by Agency of Clinical Innovation (NSW) can be invaluable to learn skills and concepts on actual projects in real time. Redesign and change management courses and help | Agency for Clinical Innovation

Knowledge-to-Action (KTA) Framework

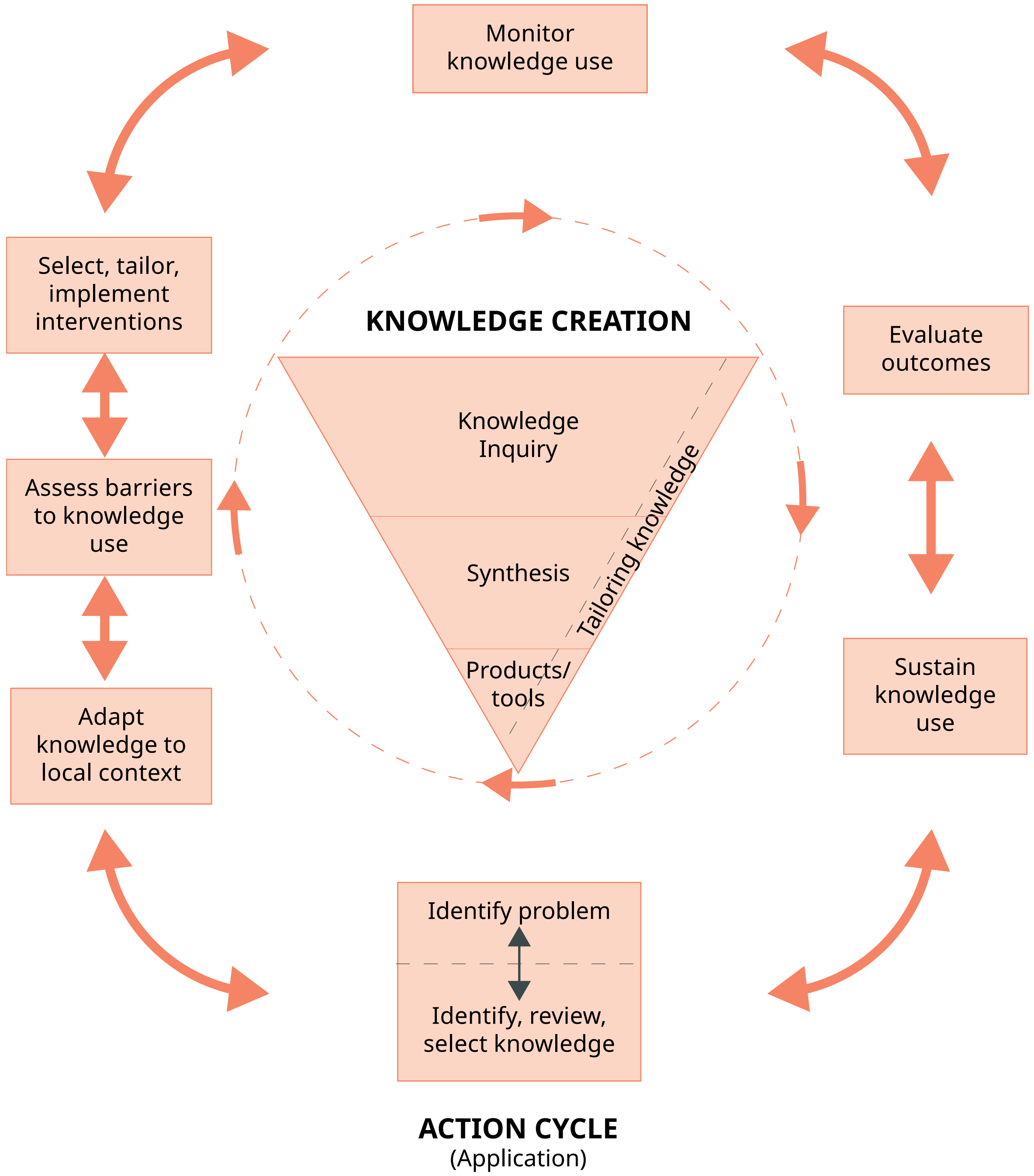


Figure 1: KTA Framework

The Knowledge to Action (KTA) framework focuses on transferring knowledge, resulting in various actions among different stakeholders while maintaining appropriate relationships. KTA has two components: 1) Knowledge creation and 2) Action cycle [93]. The knowledge creation phases may influence the action cycle and the phases of the action cycle may occur sequentially or simultaneously [93].

Knowledge creation is represented by the funnel in the middle (Figure 3) and involves creating and refining knowledge related to health care. As knowledge moves through the funnel, it becomes more refined and distilled increasing its usefulness to stakeholders.

The first phase of knowledge creation is knowledge inquiry, which involves the creation of first-generation knowledge in its natural and unrefined state. Primary research studies are a good example of this type of first-generation knowledge. The second phase is knowledge synthesis, which involves creating second-generation knowledge by aggregating existing knowledge. Examples include systematic reviews, meta-analysis and meta synthesis. The third phase is knowledge tools/products, which consists of synopses such as practice guidelines, decision aids and rules, and care pathways. These tools provide clearer, more concise, useful, and user-friendly knowledge to stakeholders [93].

The second component of the KTA framework is the action cycle, which represents the activities and process involved in applying knowledge in practice. The action cycle is iterative, and each step can be revisited as needed during the implementation of research. The main steps in the action cycle are: 1) identify the problem, 2) identify, review and select the knowledge or research relevant to the problem, 3) adapt the identified knowledge or research to the local context, 4) assess barriers to using the knowledge or research, 5) select, tailor and implement research, 6) monitor the use of knowledge, 7) evaluate the outcomes, and 8) sustain ongoing knowledge use [93].

The KTA framework is widely used in healthcare and academic settings, involving projects with patients, the public, nursing and allied health professionals 94. For example, a study by Torres et al. 95 used the KTA framework to implement an Evidence-Based Practice (EBP) model in paediatric nursing. The authors addressed gaps between evidence generation and clinical practice by tailoring the program to the local context and involving relevant stakeholders. They integrated the full KTA framework including knowledge creation and the action cycle within real-world clinical settings [95].

Integrated - Promoting Action on Research Implementation in Health Services (I-PARIHS)

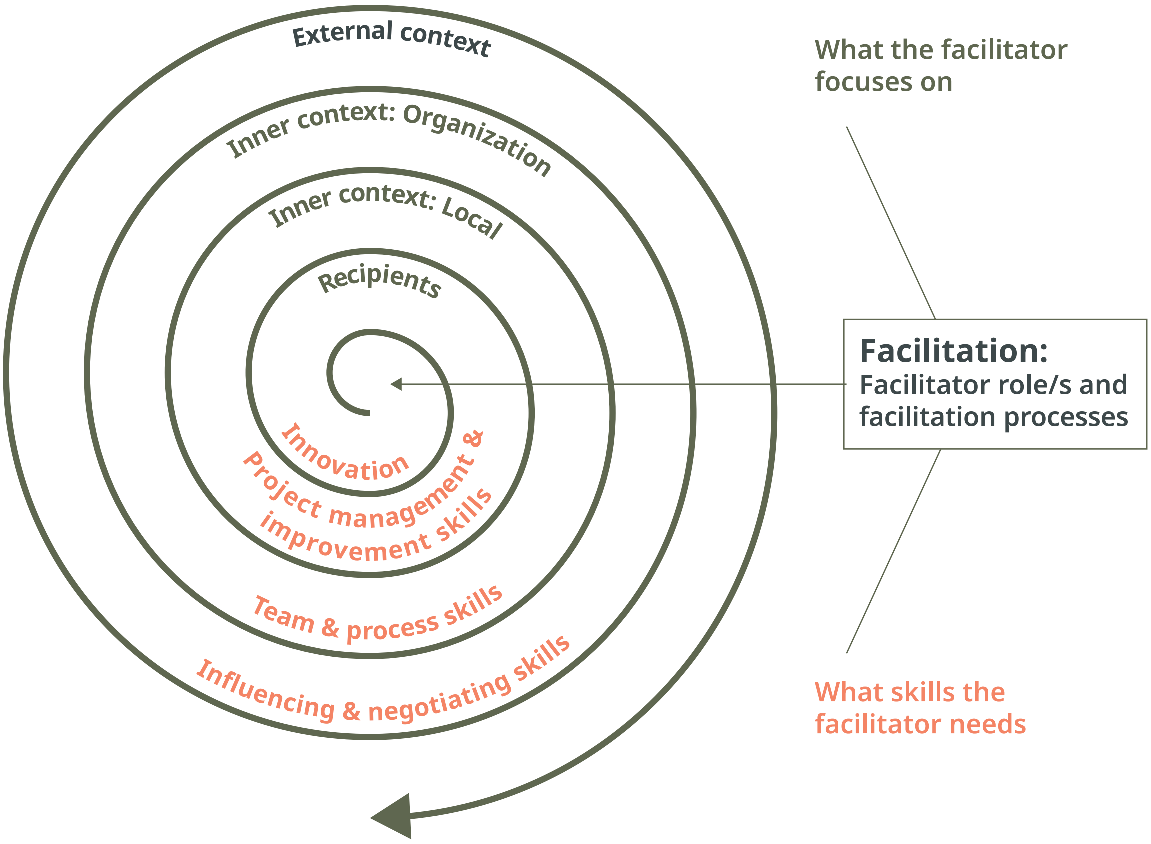


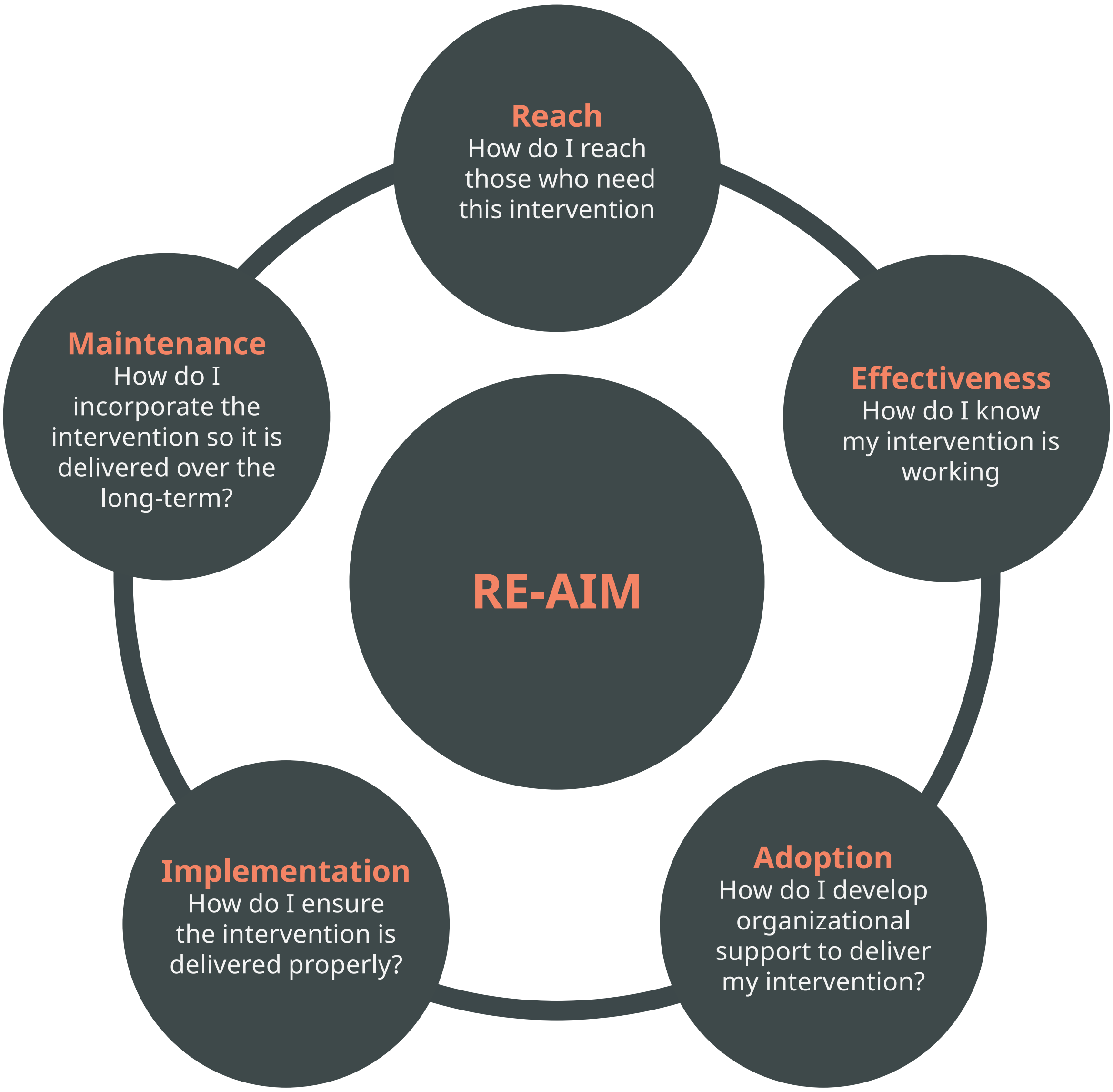
Figure 2:The I-PARIHS Framework

The I-PARIHS framework is an updated version of the original PARIHS framework, addressing its gaps and focusing on more practical and comprehensive implementation of research. The original PARIHS framework was designed to guide the successful implementation of evidence-based research into practice. It defined successful implementation as depending on the interaction of three key elements: 1) the nature of the evidence, 2) the context in which the proposed change is implemented and 3) the facilitation process that supports the change [96].

Building on these original elements, the updated I-PARIHS framework defines successful implementation as dependent on four core elements: facilitation, innovation, recipients (individual and collective) and context (inner and outer). Facilitation is positioned as the active element that integrates the other three. In this model, the successful implementation of an intervention is determined by the achievement of project goals and the uptake and embedding of the innovation into real-world practice [96].

I-PARIHS is commonly used when introducing new healthcare improvement systems and policies, and to identify barriers and enablers affecting implementation success. For example, Roberts et al., [97] incorporated I-PARIHS to guide the introduction of patient-reported outcome measures (PROMs) into a medical oncology outpatient department. In this program, the core constructs of I-PARIHS (i.e., facilitation, innovation, context and recipients) were useful for identifying factors directly influencing implementation. The authors found that facilitation played a particularly vital role in overcoming implementation barriers and recommended having a dedicated facilitator to support the transition when PROMs are implemented [97].

RE-AIM: Reach Effectiveness Adoption Implementation Maintenance



RE-AIM

Reach
How do I reach those who need this intervention

Effectiveness
How do I know my intervention is working

Adoption
How do I develop organizational support to deliver my intervention?

Implementation
How do I ensure the intervention is delivered properly?

Maintenance
How do I incorporate the intervention so it is delivered over the long-term?

Figure 3: RE-AIM Framework

RE-AIM [98] is one of the widely used implementation frameworks for planning and evaluating public health interventions [99]. Its focus is to assess the real-world impact of health research programs [99].

RE-AIM assesses five dimensions of implementation (the strategies used to move interventions in a program into practice), and the program's ultimate impact depends on the combined effects of each of these dimensions.

1. REACH: This is an individual level measurement of participation in a program affecting patients or employees. It measures the absolute number or the proportion of individuals who are willing to participate in a program.
2. Efficacy: This dimension assesses both the positive and negative impacts of a program by measuring behavioural, quality of life, participant satisfaction, and physiological outcomes. It also considers the heterogeneity of effects and reasons for success or failures.
3. Adoption: This considers the absolute number of representatives in a setting (e.g., worksites, health departments, communities) who are willing to initiate a program. It also identifies the reasons for adoption and non-adoption of interventions in relevant settings. Adoption is mostly measured through direct observations, semi-structured interviews, and surveys.

4. Implementation: This dimension measures the extent to which programs are delivered as intended at both setting and individual levels. At the setting level, it is measured by the fidelity of the intervention to the protocol and the consistency of delivery within the timeframe. It also includes any adaptations made and any costs incurred. At the individual level, it measures the clients' use of the intervention and any strategies used.
5. Maintenance: This dimension considers how an intervention is sustained for more than six months and maintained at both the individual and organisational levels and the extent to which the program has become institutionalised or a routine practice within an organisation. It also considers the reasons for maintenance, discontinuation and re-adoption of the intervention [98,99].

RE-AIM has been used mostly in public health and behavioural change research and has increasingly been adopted in other diverse contexts such as clinical, community and corporate settings [99]. Some examples of interventions that have used RE-AIM include those in the fields of aging, mental health, cancer screening, dietary changes, physical activity, medication adherence, women's health, child well-being, e-health, smoking, diabetes prevention and chronic illness self-management [100,101].

A good example of using RE-AIM in intellectual disability research in clinical settings is the study by De Veer et al. [102] This study aimed to improve palliative care for people with ID by implementing six evidence-based tools across 10 care services specifically supporting people with ID, using a participatory action research method. The RE-AIM framework was applied to evaluate the impact of these interventions. The authors used a mixed-methods design for the evaluation including data sources such as questionnaires, group interviews and field notes. They defined the RE-AIM dimensions as follows. 1.) Reach: The included the number of professionals reached by the care services, the number of teams involved, the characteristics of individuals they cared for and the extent to which people with ID and their family members were involved in the interventions. Data sources included field notes and interviews. 2.) Effectiveness: This was measured by the perceived impact of the implementation tools on palliative care policies in care settings, the care competencies of professionals and the overall quality of palliative care. Differences between pre-test and post-test conditions were measured quantitatively. 3.) Adoption: This was assessed by the willingness of care professionals to use the tools, based on responses to two questions in the post-test questionnaire. 4.) Implementation: This was measured by the involvement of representatives in the participatory action research group and the specific tools implemented by them with data collected from field notes and interviews. 5.) Maintenance: This was measured by the expectations of integrating the tools into clinical practice, using responses from post-test interview questions. Overall, this study provides valuable insights into the tools and strategies used to improve palliative care practices in care services through the application of the RE-AIM framework [102].

RE-AIM with PRISM: Practical Implementation Sustainability Model

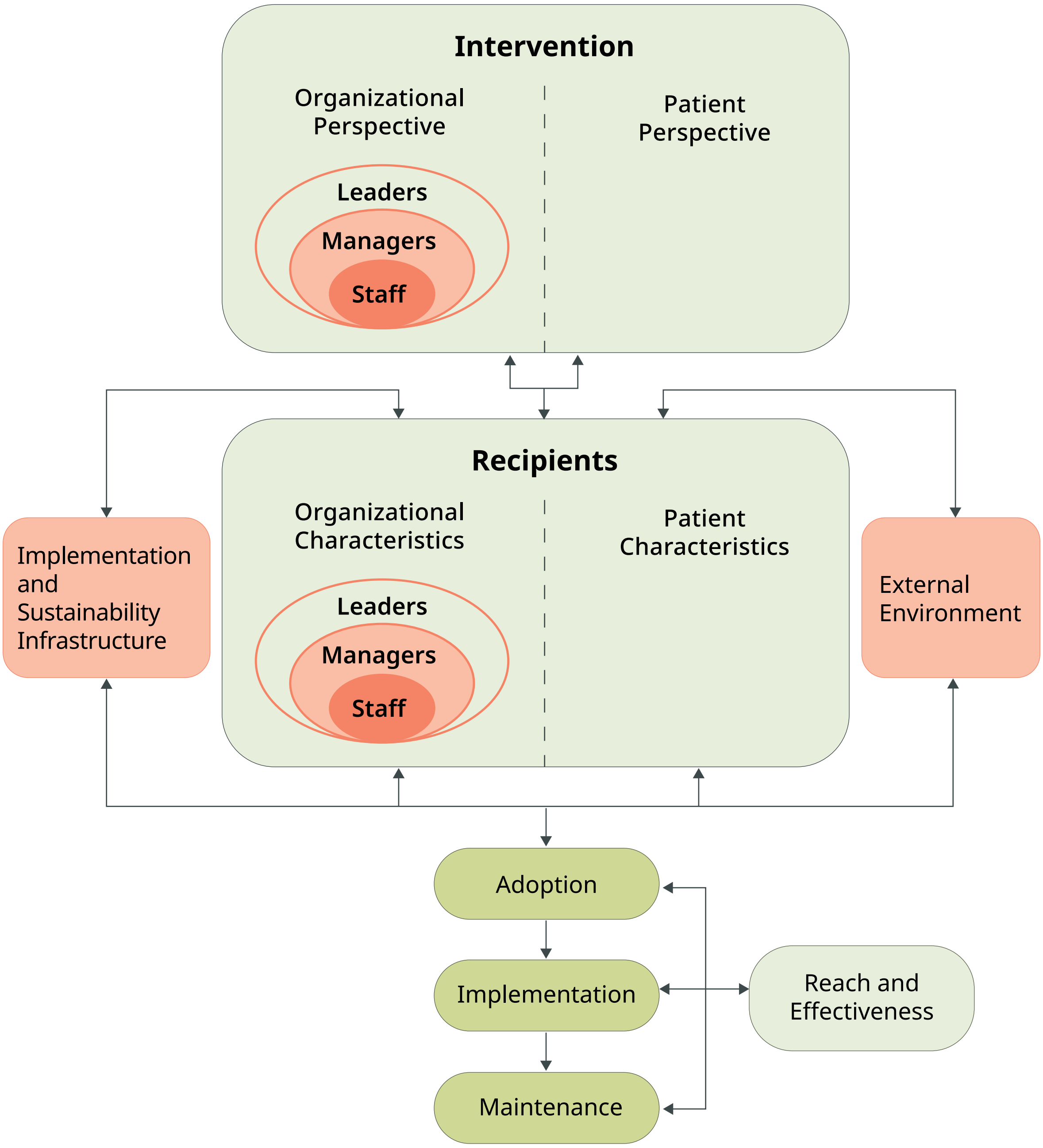


Figure 4:PRISM with RE-AIM

Practical Implementation Sustainability Model (PRISM) is an expanded version of the RE-AIM framework, adding contextual factors that interact with an intervention and its strategies to make RE-AIM outcomes achievable. It provides researchers with an opportunity to apply a pragmatic and intuitive model that improves the translation of research interventions into real-world settings such as clinical and community practices [103].

There are four domains in the PRISM framework. 1.) Perspectives on the intervention are considered at both organisational and patient levels. Organisational readiness, the perceived strength of evidence supporting the intervention and its compatibility with existing workflows are assessed to understand the organisational and staff perspectiveson the program. 2.) Characteristics of the implementing settings include organisational staff, patients and family recipients. Clinical leadership, management support managers and delivery staff are considered when examining organisational characteristics that affect the organisation's ability to successfully implement change in clinical settings. On the other hand, patient's characteristics include age, gender, culture, health literacy and social needs. 3.) The external environment consists of factors such as relevant policies, distribution of resources, market forces, and regulatory requirements. 4.) Implementation and sustainability infrastructure refers to characteristics such as training facilities and support, dedicated implementation teams, ongoing audits and feedback, and other resources required for monitoring and sustaining programs [104].

PRISM is mostly used in primary and secondary prevention, mental health, cancer, reproductive health, infectious diseases and health equity interventions targeting underserved populations, where research interventions are primarily conducted in clinical outpatient and community settings [104]. An example of using the PRISM framework is the study by Trinkley et al., [105] in which the authors achieved implementation success for their intervention compared with a commercially available tool . The aim of this study was to compare the effectiveness of an enhanced clinical decision support (CDS) tool using the PRISM framework. The incorporated iterative and multilevel stakeholder input along with dynamic interactions with the internal and external environments influencing the intervention were identified and addressed [105].

Interactive Systems Framework (ISF)

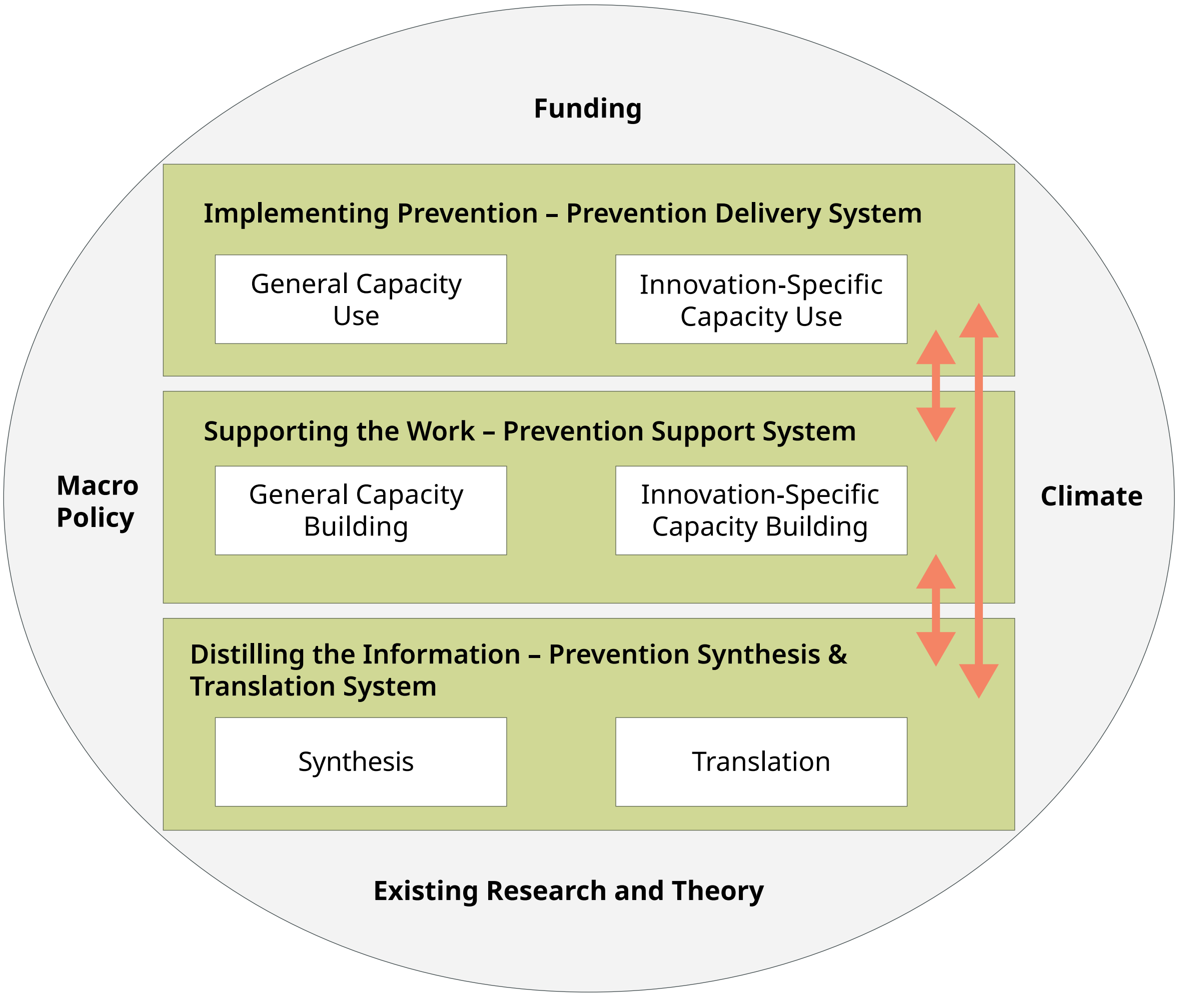


Figure 5: Interactive Systems Framework (ISF) – Original figure of the framework (has an updated version now)

The interactive systems framework (ISF) for dissemination and implementation of preventative health interventions. It consists of three main systems: 1) the prevention synthesis and translation system, 2) the prevention support system, and 3) the prevention delivery system. The prevention synthesis and translation system gathers information about innovations and translates it into user-friendly formats. The prevention support system provides the necessary training, technical assistance, and other supports to users. Finally, the prevention delivery system implements the innovation in real-world settings [106]. These three systems work together to successfully disseminate and implement science-based prevention programs, policies or processes.

ISF has been designed to meet the needs of multiple perspectives of stakeholders including funders, researchers, practitioners, and technical assistance providers [106]. This framework helps identify key stakeholders and highlights the importance of communication among them [107].

An example of using the ISF framework is a study conducted by Lesesne et al., 108 to promote science-based approaches to teen pregnancy prevention. The aim of the project was to accelerate the adoption of evidence-based program at the community levels. This project proactively applied the ISF framework and its three systems to structure and disseminate implementation strategies, demonstrating the feasibility of actively using ISF in large-scale prevention programs [108].

Summary of Knowledge Translational Frameworks

Framework

KTA

Origin

Ian D. Graham et al., in 2006 [93]

Strengths

- One of the commonly used conceptual frameworks [94].
- Adapted in diverse healthcare settings from smaller-scale to larger-scale projects [94].
- Flexible in use and able to fit local conditions and needs [94].
- Lacks complex jargons, represents a simple diagram and is user friendliness [94,109].
- Begins with research evidence and builds upon it through synthesis and translation [109].
- Incorporates sustainability [109].

Limitations

- Lack of defined measurements and strategies[94].
- Possible confusions about how the two phases interact [94].
- Potential for misapplication [94].

Framework

I-PARIHS

Origin

Gill Harvey, Alison Kitson in 2005 [96]

Strengths

- More comprehensive and integrated model [96].
- Defines the role of individuals and teams across both internal and external contexts (i.e., local, organisational and policy levels) [96].
- Offers flexibility and adaptability to diverse settings and interventions [96].
- Based on both theory and case studies adding greater practicality to implementation [96].
- Availability of several support tools and guidance [110].

Limitations

- May be overlap between constructs (e.g., innovation, context and recipients), indicating a need for clearer conceptualisation of the concepts [96, 111].
- May be complex to understand[110].
- Requires more explicit guidance on operationalising the framework with standard tools [110].

Framework

RE-AIM

Origin

R. E. Glasgow in1999 98

Strengths

- Applied broadly across diverse fields [99,112].
- Focuses on intervention fidelity - the extent to which the intervention is implemented across different settings [99].
- Addresses both internal and external validity, targeting both individual & organisational level outcomes [99].
- Supports both qualitative and quantitative methods [99].
- Availability of updated information [99]
- Easy accessibility and availability of supportive resources online [113]

Limitations

- Confusion in understanding certain definitions [112].
- Often requires information from multiple resources and stakeholders [112].
- Lack of use of mixed methods across the framework [99].

Framework

PRISM

Origin

Feldstein A.C. and Glasglow R.E. in 2008 114

Strengths

- Contextual and pragmatic in nature [103].
- Integrates sustainability [103].
- Incorporates multiple perspectives [103].
- Combined with RE-AIM
- Easily accessible resources available online [104]
- Applicable for various stages of a project (e.g., planning, development, implementation, evaluation) [103].

Limitations

- May be complex to understand [103]
- Overlap and confusion can occur since it is combined with RE-AIM [103].

Framework

ISF

Origin

Wandersman et al. in 2008 106

Strengths

- Provides three comprehensive systems that help successfully implement and disseminate prevention programs, policies and practices [107].
- Useful for understanding key systems, functions and relationships that influence implementation [106, 107].
- Helps identify key stakeholders and highlights the need for communication among multiple stakeholders [106].

Limitations

- Does not identify how to promote interactions between the three systems [106,107].
- Originally developed for prevention science context [106]

Appendix C: Ethical Guidelines in Australia for People with Intellectual Disability

1. NHMRC National Statement on Ethical Conduct in Human Research (2025)

National Statement on Ethical Conduct in Human Research 2025 | NHMRC

The National Statement document guides all human research in Australia. Chapter 4.5 addresses research involving people experiencing physical or mental ill-health or disability. It highlights how to make informed and supported decisions, obtain ongoing consent, avoid unnecessary exclusion of people with disability and how to maintain participant dignity and autonomy throughout the research process.

2. Australian Human Rights Commission

Disability Rights | Australian Human Rights Commission

The Australian Human Rights Commission (AHRC) offers several guides and advice to assist persons and organisations to avoid any discrimination towards people with disability. Disability rights outlined in the AHRC are aligned with the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

3. NSW Agency for Clinical Innovation

Principles for research on intellectual disability | Agency for Clinical Innovation

NSW Agency for Clinical Innovation outlines several principles for research on intellectual disability. This is a state-level guidance developed specifically for research with people with ID. It emphasizes the importance of providing opportunities for people with ID to be included as participants in research since the outcomes directly influences them.

4. NDIS Research Guidelines

Evidence Informed Practice Guide

The NDIS Research Guidelines provides guidance for research linked to the National Disability Insurance Scheme. They mainly focus on evidence-based practice and ensure that studies are inclusive, person-centred and directly relevant to people with disability. It highlights the importance of co-production and generating practical outcomes to shape the NDIS policy and services.

5. UNSW Disability Innovation Institute Guidelines (2020)

Guidelines | Disability Innovation Institute 16686_UNSW_DIIU_DoingResearchInclusively_EthicalIssues_FA_Web.pdf

UNSW Guidelines highlights the ethical issues in co-production and inclusive research with people with disability in the university context in Australia. It provides a practical guidance for academic researchers in obtaining ethics approvals for codesigned research as well as for ethics committee reviewers who reviewing, approving and monitoring these projects.

6. Australian Code for the Responsible Conduct of Research

Australian Code for the Responsible Conduct of Research 2018 | NHMRC

Australian Code for the Responsible Conduct of Research sets national standards including research integrity and accountability across all research fields including intellectual disability research. It ensures that all research is conducted ethically and with honesty providing guidance on maintaining research integrity, transparency, authorship, funding, data management and storage, conflicts of interest and responsible supervision and mentoring.

7. Human Research Ethics Committee (HREC)

In addition to above guidelines, all the research should go through a responsible HREC committee which will check compliance with the National Statement on Ethical Conduct. These HREC research committees are based at universities, research institutions and other organisations. An approval whether the research study meets the ethical requirements according to the National Statement should be obtained before the research begins.

Appendix D: Australian groups conducting or supporting research with people with Intellectual Disability

Note that the list is not exhaustive and is in no particular order.

The Centre for Disability Research and Policy

Based at the University of Sydney, this centre includes some ID-related health research but generally focuses on people with disability more broadly.

https://www.sydney.edu.au/medicine-health/our-research/research-centres/centre-for-disability-research-and-policy.html

Research in Disability and Community Inclusion

This centre is based at Flinders University and explores a broad scope of topics, with some health topics included.

https://www.researchdci.flinders.edu.au/

Melbourne Disability Institute (MDI)

Within the MDI, research hubs include the Healthy Trajectories Child and Youth Disability Research Hub, which focuses on people with child-onset disability. The hub partners with consumers to conduct interdisciplinary and inter-sectoral research, addressing health needs amongst this group.

https://disability.unimelb.edu.au/

The Australasian Society for Intellectual Disability (ASID)

ASID is a peak body pursuing research in ID in Australia and Aotearoa New Zealand (NZ) that informs policy and practice that make a difference in the lives of people with ID . ASID has state divisions in all states and territories of Australia except NT and WA, and a NZ division. The society hosts two journals: the *Journal of Intellectual and Developmental Disability and Research and Practice in Intellectual and Developmental Disabilities*, in addition to conferences.

https://asid.asn.au/

The Centre for Disability Studies (CDS)

Based at the Sydney school of health sciences (University of Sydney), this group specifically conducts research into ID with a range of partners. Current partners include NCEIDH (focusing on improved health outcomes), the Mercy foundation (reducing homelessness amongst people with ID), the Fragile X Association of Australia (identifying support needs and gaps), and the Daffodil Centre (increasing awareness of cervical screening amongst people with ID). The CDS also hosts the *Inclusive Research Network*, including people with and without ID who conduct research on topics important to people with ID in their lives, including topics related to health research.[23]

https://cds.org.au/

Queensland Centre of Excellence in Autism and Intellectual Disability Health (QCEAIDH)

This Mater organisation combines clinical care, medical workforce education, and research to improve health and wellbeing outcomes of people with intellectual and developmental disability, and autism, across the life span. QCEAIDH research is inclusive, conducted using codesign principles, and engages with national and international research partners. Research aims include better understanding of health experiences and prevalent health issues, new treatment options, and improving healthcare services.

https://www.qceidah.com.au/home-2/research/

Intellectual Disability Network

Through the NSW Government Agency for Clinical Innovation, this network aims to improve experiences and delivery of health services for people with ID , through research alongside clinical leadership and education.

https://aci.health.nsw.gov.au/networks/intellectual-disability

The Living with Disability Research Centre

Based at La Trobe University, this centre focuses on translational research specifically regarding social inclusion and participation amongst people with ID. This includes understanding how to support mainstream services, such as health services, to be more inclusive for people with ID.

https://www.latrobe.edu.au/lids

The Kids Research Institute Australia

This is the home of the IDEA (Intellectual Disability Exploring Answers) Database. Within the Child Disability team, researchers at this institute conduct research around varied aspects of the experiences of children with ID.

https://www.thekids.org.au/our-research/wellbeing-and-mental-health/child-disability/

Inclusion Australia

Inclusion Australia does not conduct research but links people with ID and researchers as part of their advocacy. The organisation has developed a guide for researchers working with people with ID:

https://www.inclusionaustralia.org.au/wp-content/uploads/2023/01/Working-with-People-with-an-Intellectual-Disability-Guide-for-Researchers.pdf

Council for Intellectual Disability

Part of NCEIDH, the council provides resources for communication between people with ID and health workers, and online training for health workers learning to better include people with ID:

https://cid.org.au/issues/health/

First Peoples Disability Network (FPDN)

This is a national organisation representing, and governed by, Australian first peoples living with disability, and their families and communities.

https://fpdn.org.au/

Down Syndrome Australia

The Down Syndrome Federation provides support and advocacy for people with Down syndrome and their families, while also providing information and support for schools and health and other professionals.

https://www.downsyndrome.org.au/

Fragile X Association of Australia

This information and advocacy organisation also maintains a registry of individuals with Fragile X premutations, and their family members, who may be contacted for research, including treatment and intervention studies.

https://www.fragilex.org.au/

Queenslanders with disability network (QDN)

QDN advocates for people with disability in a broad range of areas, including accessible, integrated and quality healthcare services.

https://qdn.org.au/

Appendix E: Theoretical and conceptual underpinnings of research practices with people with ID

In this section we delve deeper into some theoretical and conceptual underpinnings of research practices in health research of people with ID.

Advancing Inclusive Research Practices

1. Equitable Research Participation

The NHMRC National Statement on Ethical Conduct of Research states: *There is an ethical imperative to include people with physical or mental ill-health or disability in research and to facilitate their independent decision-making*.67 p83 This ethical imperative is based firstly, on Human Rights statements such as the UN Convention on the Rights of Persons with Disabilities[115] that affirms people with ID's right to participate in all areas of life, including research. Secondly, the imperative is based on understandings of justice and equity where excluding people with ID leads to systemic inequities in health outcomes, access to services, and policy. Inclusion makes findings from research relevant and applicable to all sectors of the population. Finally, the imperative aligns with concepts of autonomy, ensuring people with ID are supported (e.g., with Easy Read versions of documents) to enable independent decision-making, without assuming they are not capable.

2. Inclusive Research and Codesign

The term inclusive research refers to involving participants in research beyond simply being treated as ‘subjects’ or ‘respondents.1 This involvement can take many forms ranging from serving as a member of an advisory board or council to acting as a co-researcher or even leading and controlling research as a part of a collaborative team.1,3 Advisory groups, often composed of organisational representatives, family members, and people with ID provide valuable input into research activities. Furthermore, approaches that place people with ID and their community advocates in leadership and power sharing roles have also been found effective and acceptable.[1]

Fostering self-advocacy, which means speaking up for yourself and others, making choices, and acting on them, is closely linked to inclusive research and has directly shaped how it developed. Promoting self-advocacy often requires support from others, usually people without disability, to help make it more effective. In the same way, inclusive research involves people with intellectual disability as co-researchers, supported by professionals or academic researchers. Inclusive research grew out of participatory and emancipatory research, both of which aim to shift power to the people most affected by the research. Therefore, the role of the researcher is not to take control, but to provide guidance and support so that people with intellectual disability can fully participate as researchers, share their perspectives, and advocate for their rights [19].

In conducting inclusive research, it is important to understand disability not merely as a collection of impairments, but as a significant aspect of people's lives. This shift of perspective turns the focus towards recognising and addressing the contextual barriers that hinders the involvement of people with ID in research, rather than thinking that all challenges are due to their cognitive impairments. At the same time, this does not mean that the presence or impact of impairments should be ignored instead, appropriate measures should be taken to accommodate those limitations [19].

In addition, the knowledge generated through inclusive research is largely experiential which builds on the lived experiences of people with ID [19]. For this reason, the co-researchers with ID are often described as "experts by experience" [19,20] and their perspectives should be integrated and interpreted in every stage of the research process meaningfully [19]. Therefore, when conducting research with people with ID, all above factors need to be considered and applied in practice to obtain more impactful research outcomes.

Appendix F: Useful Resources

Here are some useful resources to refer to when conducting research with people with intellectual disabilities in Australia.

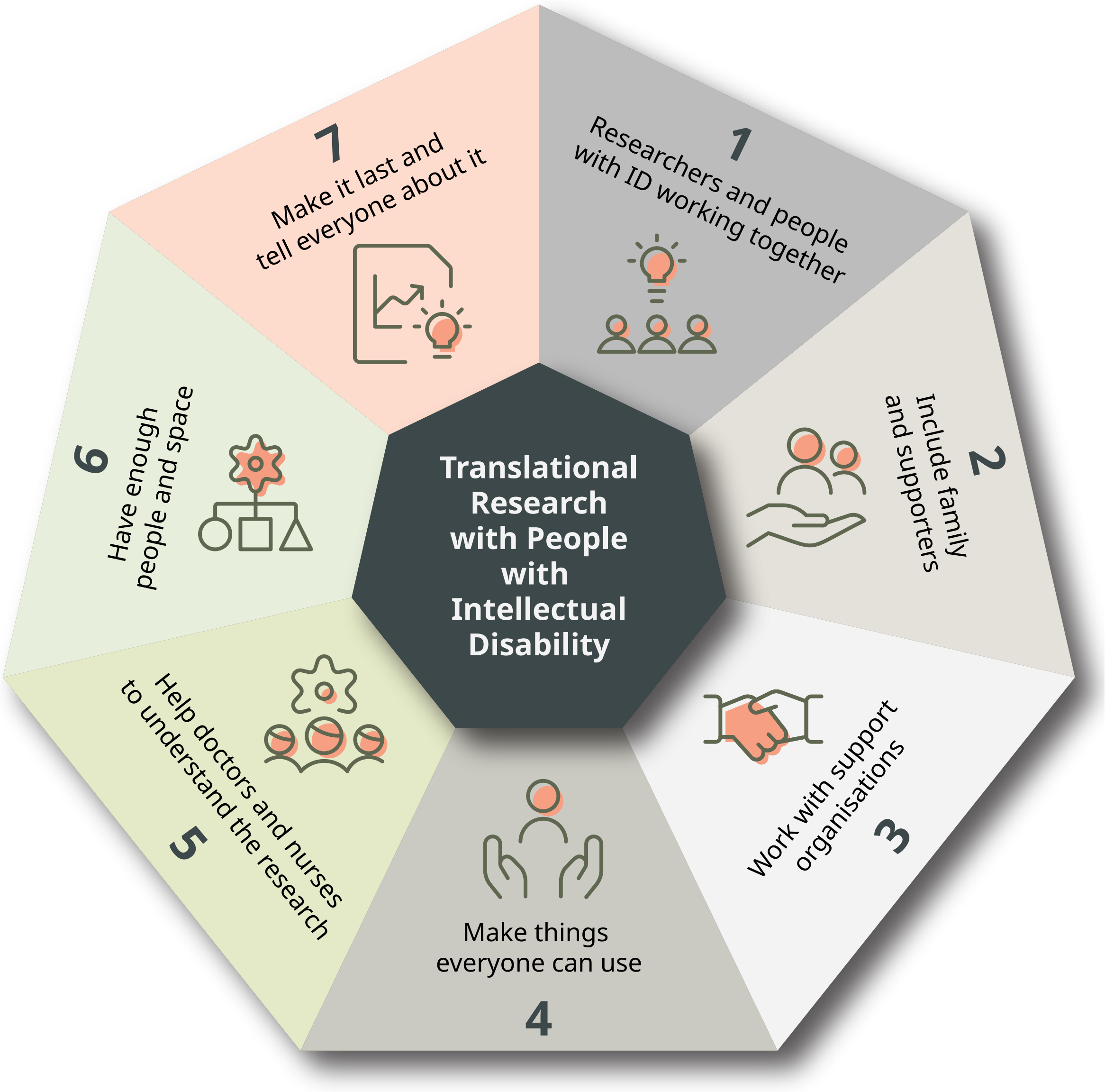
1. National Statement on Ethical Conduct in Human Research 2025 | NHMRC - NHMRC Ethical Guidelines includes a series of guidelines (under chapter 4.5) to guide researchers on conducting research involving people with ID.
2. United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) | Australian Human Rights Commission – This is an international convention which provides a set of fundamental human rights of people with disability.
3. Inclusion Australia – The national voice of people with an intellectual disability and their families – This is the national body responsible for providing expertise and advice on advocating rights of people with ID in Australia.
4. Resources | Intellectual Disability | Agency for Clinical Innovation – This provides a set of resources about understanding intellectual disability and several guiding principles for doing research on intellectual disability.
5. Recommended websites | Agency for Clinical Innovation – Here is a list of websites recommended by the intellectual disability health network which are useful in the context of intellectual disability.

6. National Roadmap for Improving the Health of People with Intellectual Disability
7. Australian Government Department of Health, Disability and Ageing – This is the National Roadmap released by the Australian government for improving the health of people with ID and to address any health inequalities faced by them.
8. National Disability Research Partnership | Australia – They provide funds for research led by and with people with disability.
9. Executive summary - Guidelines for engaging with people with disability | Disability Gateway – Disability Gateway provides a set of practical guidelines for engaging with people with disability in research, testing, development and decision making of processes, products, services and policies.
10. Easy Read | Style Manual – This is the manual provided by the Australian Government on creating Easy Read Style documents.
11. Guiding principles of quality health services for people with intellectual disability
12. Agency for Clinical Innovation – This website provides a set of guiding principles for the delivery of quality health services for people with ID. It is based on the United Nationals Convention on the Rights of Persons with Disabilities. It also provides a set of resources including toolkits and links to other useful information.

Appendix G: Easy Read version of the Framework

A Framework for Research with People with Intellectual Disability

This Framework tells us how to do good research for people with intellectual disability. Good research fixes things that don't work. It also makes good new things.



The framework has 7 parts to it.

1. This says we should all work together. People with ID should be part of the research team. We should all talk about what we think.
2. This says we need to include family members and support people. We should listen to what they say about the research, too.
3. This reminds us to work with partners like Down Syndrome Australia.
4. This talks about making sure new things we make work for different people.
5. We listen to what doctors and nurses say about our research. We help them understand what works best for people with ID.
6. This reminds us to check we have enough people and space to do the research.
7. This makes our research last. People in other places can use our research too.

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