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Evaluation Plan of the Intellectual Disability and Mental Health (IDMH) National Disability Insurance Scheme (NDIS) Residual Functions Program

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Abbreviations

| | |
|-------------|---|
| 3DN | Department of Developmental Disability Neuropsychiatry at UNSW Sydney |
| AH&MRC | Aboriginal Health and Medical Research Council |
| AIHW | Australian Institute of Health and Welfare |
| CALD | Culturally and Linguistically Diverse |
| CEA | Cost Effectiveness Analysis |
| CHeReL | Centre for Health Record Linkage |
| HoNOS | Health of the Nation Outcome Scales |
| HoNOSCA | Health of the Nation Outcome Scales - Children and Adolescents |
| HREC | Human Research Ethics Committee |
| IDMH | Intellectual Disability Mental Health |
| K10 | Kessler Psychological Distress Scale |
| LHD | Local Health District |
| Ministry | NSW Ministry of Health |
| NDIS | National Disability Insurance Scheme |
| NSLHD | Northern Sydney Local Health District |
| NSW | New South Wales |
| P&HSREC | NSW Population and Health Services Research Ethics Committee |
| QALY | Quality Adjusted Life Years |
| SCCS | Self-controlled case series |
| SHN | Specialty Health Network |
| SPRC | Social Policy Research Centre |
| UNSW Sydney | University of New South Wales |

Terms

| | |
|-------------------------------|---|
| Co-design | Collaborative, shared approach to design. Including end service users and other people with lived experience to work alongside people with professional experience |
| Concrete reference tools | Tools like picture cards that help people to understand what we are asking them. The tools can help everyone stay on topic and facilitate conversation |
| Data linkage | Joining together data about each person from several sources |
| Markov model | Economic analysis to assess program health outcomes, service use and related cost effectiveness |
| Mixed-methods | Collection of types of data, using different methods of data collection and analysis – for example in this evaluation qualitative and quantitative methods and co-design are used |
| Participatory research design | Service users and other people with similar lived experiences are involved in the design process. Part of the co-design methods |

| | |
|-----------------------------------|---|
| Peer-based research | Service users and other people with similar lived experiences are involved in the design, implementation and review of the research |
| Program logic | A document that lists the Program activities and intended outcomes and shows the relationships between the program inputs, activities, outputs and outcomes |
| Residual Functions Program | Short term for the Intellectual Disability Mental Health National Disability Insurance Scheme Residual Functions Program |
| Qualitative methods | Collection of detailed information from some stakeholders. Often through interview but can also be through other methods such as photos or stories |
| Quality Adjusted Life Year (QALY) | A QALY is a measure of health outcome that combines length of life with health-related quality of life. QALYs are used in economic evaluation to help understand how effective health programs are to improve people's health and wellbeing |
| Quantitative methods | Collection or analysis of data that is quantifiable, that means it can be counted. |

Summary of the evaluation plan

The Intellectual Disability Mental Health National Disability Insurance Scheme Residual Functions Program (called 'Residual Functions Program' for short) is a NSW Ministry of Health (Ministry) Program.

The Residual Functions Program aims to develop services to better support people who experience both mental health issues and intellectual disability.

There are **three streams** of activities in the Program. These streams are:

1. **Support for LHDs & SHNs:** Ten NSW Local Health Districts (LHDs) and two Specialty Health Networks (SHNs) were funded to enhance clinical and capacity building services.
2. **Support for ID Health Teams:** The Ministry funded an IDMH Clinician in each of the six Intellectual Disability Health Teams across NSW to provide clinical and capacity building supports.
3. **Centralised coordination:** Centralised, coordinated management of capacity building activities and resources that support the improved clinical care of people living with intellectual disability and co-occurring mental illness.

Evaluation of the Residual Functions Program

The Social Policy Research Centre (SPRC) at UNSW Sydney will evaluate the Residual Functions Program together with 3DN at UNSW Sydney. The evaluation commenced in December 2019 and runs until February 2021.

This evaluation plan outlines how the SPRC and 3DN will evaluate the Residual Functions Program.

The evaluation will assess the processes, outcomes and economic costs and benefits of the Residual Functions Program.

The evaluation objectives (or aims) are to:

1. Assess the effectiveness of the services to meet the Residual Functions Program objectives
2. Examine the benefits, outcomes and innovation from the Program
3. Identify the critical factors or service elements which contribute to the greatest outcomes
4. Identify opportunities to improve service quality and effectiveness
5. Identify risks and needs in the provision of intellectual disability and mental health care
6. Inform NSW Government decision-making about future policy directions for the Program
7. Provide recommendations about any ongoing need and associated objectives for the Program beyond June 2021, including an assessment of risks and benefits if the Program is not to continue.

Evaluation approach

The evaluation will use a mixed methods approach. A mixed method approach collects different types of data, using different methods of data collection and analysis. The mixed method approach that will be used in this evaluation includes:

- Co-design of research methods

- Analysis of qualitative data from interviews
- Analysis of quantitative data collected by program providers and data linkage.

The Co-Design of research methods process will aim to improve the evaluation approach and methodology - or how the evaluators will do their work. The co-design process will include collaboration of:

- the evaluators, who include people with a lived experience of intellectual disability and mental health challenges
- stakeholders from the Ministry
- relevant peak bodies and
- consumer advocacy groups.

Qualitative Data collection involves talking to people in interviews or focus groups about their experiences of the Program. We will take the recommended actions to protect people from COVID-19 during the interviews.

Quantitative Data collection involves obtaining anonymous health data of Program consumers from various data sets within the Ministry. Quantitative data will be used to measure how well the Program is working and whether the Program provides value for money.

The evaluation includes **ethical, inclusive and culturally relevant approaches** to data collection and analysis.

Details about the inclusive and culturally sensitive approach can be found in Section 3.2 of this plan.

Evaluation Methods

The evaluation will incorporate data from a wide range of qualitative and quantitative sources. The data collected will be measured against the program logic and evaluation objectives to assess the effectiveness and outcomes of the Program.

The Program Logic lists the Program activities and intended outcomes. The evaluators use the program logic to measure how the Program is working in relation to its intended aims. The draft Residual Functions Program logic can be found in Appendix A.

Data collection and analysis will include four types:

1. Review of program documentation
2. Qualitative interviews and focus groups
3. Analysis of quantitative data
4. Economic modelling

Details of each of the four types of data collection and analysis are in Section 3.1 of the plan.

Timeline

The evaluation will be conducted in three stages:

- Phase 1: Project set-up, co-design, evaluation plan and ethics submissions (December 2019 – March 2020)
- Phase 2: Qualitative data collection (April – August 2020)

- Phase 3: Data analysis, final reporting and presentations (September 2020 – January 2021)

Table 2 in Section 3.3 of this plan outlines the evaluation timeline.

Quality assurance

The Project Governance will be managed and overseen through:

- **Meetings and reports** between SPRC and the Mental Health Branch from the Ministry.
- An **Evaluation Reference Group**, which will include relevant Government agencies, peak bodies, community organisations and people with lived experience of intellectual disability and mental health challenges.
- Advice on culturally appropriate and trauma-informed methodology, and on implications of the evaluation for Aboriginal and Torres Strait Islander, and for Culturally and Linguistically Diverse (CALD) mental health consumers, will come from: **Aboriginal and Torres Strait Islander** and **Culturally and Linguistically Diverse (CALD)** members of the evaluation team; and from expert advisors from the SPRC and the Centre for Aboriginal Health at NSW Health.

The Communication plan for the evaluation is provided in Table 4 in Section 4.2.

Ethics applications include strategies to minimise the risk of psychological harm and trauma to Residual Functions Program consumers. The applications will ensure voluntary participation and

confidentiality in the qualitative and quantitative research. Details of the ethics process are provided in Section 4.3.

Risk management strategies are provided in Table 4 in Section 4.4 of the plan.

The final evaluation **report**, including easier-to-read and short video versions, will be published on the SPRC website, with approval from the Ministry.

1 IDMH NDIS Residual Functions Program

The Intellectual Disability Mental Health National Disability Insurance Scheme Residual Functions Program (called 'the Residual Functions Program' or 'the Program' for short) aims to develop services to better support people who experience co-occurring mental health issues and intellectual disability.

The NSW Ministry of Health (the Ministry) provided funding for the Residual Functions Program for three years until 2021.

Funding has been used to establish three streams of activities to improve the capacity of mainstream mental health services to work more effectively with people living with intellectual disability and co-occurring mental illness as well as their families. The three streams are:

- **Support for LHDs and SHNs:** Ten NSW Local Health Districts (LHDs) and two Specialty Health Networks (SHNs) were funded to enhance clinical and capacity building services.
- **Support for ID Health Teams:** The Ministry funded an IDMH Clinician in each of the six Intellectual Disability Health Teams across NSW to provide clinical and capacity building supports.
- **Centralised coordination:** The Residual Functions Program also allows for the centralised, coordinated management of capacity building activities and resources that support the improved clinical care of people living with intellectual disability and co-occurring mental illness.

Program Logic

The Program Logic is a document that lists the Program activities and intended outcomes. The Program Logic shows how program inputs, activities and outputs, process outcomes and outcomes for direct consumers fit together. The evaluators use the program logic to measure how the program is going. The Program Logic for the Residual Functions Program was developed with the Ministry and will be refined during the evaluation. The Residual Functions Program Logic is in Appendix A.

Evaluation of the Residual Functions Program

The Ministry commissioned the Social Policy Research Centre (SPRC) at UNSW Sydney to evaluate the Residual Functions Program. The evaluation commenced in December 2019 and runs until February 2021. This evaluation plan outlines how the SPRC will evaluate the Residual Functions Program. This includes the planned approach, methodology and quality assurance processes for the evaluation. This plan will be refined with stakeholders during the initial phase of the evaluation.

2 Evaluation approach

The evaluation assesses the processes, outcomes and economic costs and benefits of the Residual Functions Program. The evaluation uses a mixed methods approach. A mixed methods approach collects and examines different sources of data, using different methods of data collection and analysis. The mixed methods approach used in this evaluation includes:

- co-design of research methods
- analysis of qualitative data from interviews
- analysis of quantitative data collected by Program providers and data linkage.

Co-design of research methods process occurs during the first part of the evaluation. The co-design process improves the evaluation approach and methodology or how the evaluation will do things. The co-design process includes collaboration of the evaluators, who include people with a lived experience of intellectual disability and mental health challenges, with stakeholders from the Ministry, relevant peak bodies and consumer advocacy groups.

Qualitative data collection involves talking to people in interviews or focus groups about their experiences of the Program. The evaluators will talk to service users and their families, service providers, and other key stakeholders.

Quantitative data collection and analysis involves obtaining anonymous health data of Program consumers from various data sets within the Ministry.

The **evaluation results** will contribute to evidence around how best to support mainstream mental health services, such as hospitals and public mental health clinics, to work more effectively with people living with intellectual disability and co-occurring mental illness as well as their families.

The evaluation will also provide recommendations regarding continuation of the Residual Functions Program beyond the initial three-year funding period.

The evaluation aims are listed below. They will form the basis for developing evaluation questions during the initial co-design phase of the project. The evaluation aims are to:

1. Assess the effectiveness of the services to meet the Residual Functions Program objectives
2. Examine the benefits, outcomes and innovation from the Program

3. Identify the critical factors or service elements which contribute to the greatest outcomes
4. Identify opportunities to improve service quality and effectiveness
5. Identify risks and needs in the provision of intellectual disability and mental health care
6. Inform NSW Government decision-making about future policy directions for the Program
7. Provide recommendations about any ongoing need and associated objectives for the Program beyond June 2021, including an assessment of risks and benefits if the Program is not to continue.

The evaluation includes **ethical, inclusive and culturally relevant approaches** to data collection and analysis. This is particularly important as the Residual Functions Program supports marginalised population groups (people with intellectual disability and co-occurring mental illness).

The qualitative data collection uses participatory research design, including peer-based research methods and research team members with lived experience. This is to ensure that the research is sensitive to the needs of people with intellectual disability and lived experience of mental health challenges.

The research will also be sensitive to the needs of people from Aboriginal and Torres Strait Islander and culturally diverse backgrounds. The evaluation team includes advisors and researchers from these groups. During the fieldwork, we will ensure that the interviewees have access to cultural support from appropriate people who understand and identify with the culture of the interviewee. How culturally appropriate support is accessed will depend on the preference of the interviewee and the support available. Some of the options are listed below:

- interviewees can bring their own support person - family, friend or elder - to the interview
- we can ask service providers if they have Aboriginal and Torres Strait Islander or CALD staff available to support consumers from these backgrounds who want to take part in interviews
- we can contact relevant local organisations and ask for their support with recruiting consumers and supporting them.

3 Methods

The evaluation uses a mixed-methods design as described above in Section 2. The evaluation incorporates information from a wide range of qualitative and quantitative sources. The information (or data) collected will be measured against the program logic and evaluation objectives to assess the effectiveness and outcomes of the Program.

3.1 Data collection methods

Data collection consists of four components:

1. Review of program documentation
2. Qualitative interviews and focus groups
3. Analysis of quantitative data
4. Economic modelling

Each component is described below. Details of the methods will be refined in the initial co-design phase of the evaluation.

Table 1 summarises the sampling framework. The table outlines: the data collection method, how much data will be collected (sample size), what the timeframe is for collection and where the data will be collected from. Each method is described after the table.

Table 1 Methods and sampling framework

| Method | Sample sizes | Timeframe | Data source |
|---|---|-------------------------------|--|
| Program documentation | All parts of the program | December 2019 to January 2021 | Available from three Program streams |
| Qualitative face-to-face interviews with consumers | Up to 10 per location = total up to 20 | April to June 2020 | Fieldwork visits 2 Program locations – 1 metropolitan and 1 regional |
| Qualitative interviews with families (matched to consumers) | Estimate <1/2 of consumers nominate family = total up to 10 | April to July 2020 | Fieldwork visits 2 Program locations |

| Method | Sample sizes | Timeframe | Data source |
|---|-------------------------------------|---|--|
| Focus groups/interviews with service providers | 5 providers per location = 10 total | April to July 2020 | Fieldwork visits 2 Program locations and phone |
| Focus groups/interviews with other stakeholders | 8 -12 representatives | May to July 2020 | Focus groups, individual interviews where required |
| Quantitative program data | All Program consumers | Program entry to July 2020 | Available Program data collected across 3 Streams of service delivery |
| Linked consumer outcome data | All Program consumers | 1 year before Program entry to March 2020 | Available data linkage content through Centre for Health Record Linkage (CHeReL) or the Ministry |
| Economic data | All Streams and service elements | Program start to July 2020 | Program funding, cost data and resource usage from the Ministry and data linkage |

3.1.1 Review of program documentation

The evaluation will review Residual Functions Program documentation from the three streams (LHDs & SHNs, ID Health Teams and the Ministry - as outlined in Section 1), as available. The documents may include Expressions of Interests from the funded LHDs and SHNs and initial progress reports. The Ministry will send the program documentation to the SPRC to analyse against the program logic. The review will provide a baseline for understanding the Residual Functions Program and its implementation. The review will inform the evaluation methodology, and it may indicate possible improvements to the Program.

3.1.2 Qualitative interviews and focus groups

The evaluators will conduct interviews and focus groups in two Program sites with Program stakeholders including:

- consumers
- families

- frontline staff
- LHD managers
- and other local stakeholders.

The sites have been agreed with the Ministry and include one city and one regional LHD. We aim to include a broad range of consumers in the sample, regarding gender, age, cultural background, location and mental health and intellectual disability status.

Research experience and relevant literature¹ suggest that fieldwork in a sample of two Program sites is sufficient to allow the evaluators to capture the views and experiences of a wide range of participants and to reach theoretical saturation, that is, no new findings appear and all themes and concepts are well developed.

In addition, we will conduct interviews and focus groups with state-wide stakeholders face-to-face in Sydney, or by phone.

Together, these methods will capture the diversity among all Residual Functions Program sites and services. Program diversity will also be captured through quantitative and economic data across the full sample of all Program sites (see below).

Qualitative data collection will assess Residual Functions Program support, satisfaction, outcomes and innovation arising from the Program as well as opportunities to improve service quality and effectiveness.

We will speak to consumers face-to-face unless they have other preferences. With consumer permission, families will be interviewed face-to-face during the site visits, alternatively by phone. Local LHD managers and staff and other relevant local service providers will be interviewed during the site visits individually, in small groups or post-visit by phone. Similarly, state-wide stakeholders such as Ministry staff, mental health and intellectual disability peak bodies and community organisations and referring partners will be invited to individual interviews or small focus groups, depending on practicality and their preferences.

All interviews and focus groups will be semi-structured. Semi-structured means that the interviewer (person asking the questions) will flexibly use a list of suggested questions. The interviewee (person being interviewed) can respond to the questions or they can just tell their story.

¹ Crouch, M. & McKenzie, H. (2006). The logic of small samples in interview-based qualitative research. *Social Science Information*, 45(4), 483-499. DOI: [10.1177/0539018406069584](https://doi.org/10.1177/0539018406069584)

We use a flexible, **inclusive** approach to conduct research with people with intellectual disability and mental illness. A range of accessible methods will be available, including:

- standard interviews
- observation
- informal discussion
- storytelling and photo story vignettes
- group activities
- written or documented responses.

Interviews will be conducted with easy read questions and the use of 'Concrete Reference Tools' such as picture cards.

Interviewers include the university researchers who are trained in these methods and the Lived Experience Researchers (also called peer researchers) with intellectual disability and/or mental health issues. Interviewers will also be supported by evaluation advisors from Aboriginal and Torres Strait Islander and from Culturally and Linguistically Diverse (CALD) backgrounds.

In response to the COVID-19 pandemic, we have developed strategies to help protect interview participants and researchers during fieldwork. These strategies include social distancing and hygiene measures consistent with current health advice. Where consumers and service providers prefer, we will conduct interviews remotely.

Recruitment processes

How people will be invited to participate in interviews and focus groups will be decided during the co-design phase of the evaluation. This will ensure that the process fits with the Residual Functions Program, the consumer group and the fieldwork locations.

We expect that the recruitment process for this evaluation will be similar to that used in other evaluations the evaluators have done. This process is described below.

Recruitment of service users: Consumers will be invited by service providers to share their experience.

- **Step1 Recruitment of service users:** Service providers will be given information and resources to help them explain the research to possible interviewees. This includes information that ensures that the consumer understands that they can choose to participate or not.
- **Step 2 Recruitment of service users:** Service providers will make initial contact with the consumers, provide information about the evaluation and obtain permission to pass their contact details on to the evaluators or to set up an interview time.

Recruitment of family members: Family members will be invited by service users.

- **Step 1 Recruitment of family members:** During the interviews with consumers, the researcher will ask whether the consumer has a **family member** we could also talk to (we will check with support workers first if that is alright).
- **Step 2 Recruitment of family members:** If the service user agrees, the consumer (or service provider on their behalf) will contact the family member and invite them to participate; if they agree, the consumer or service provider will forward contact details to SPRC, or the family member will contact the SPRC directly.

Recruitment of service provider staff and other stakeholders

Service provider managers in the fieldwork sites will identify suitable staff for the interviews and ask them if they would like to participate. Other stakeholders will be invited by the Ministry to participate.

Who will be invited to participate:

All participants in the interviews and focus groups will be 14 years or older to avoid ethical risks.

Service providers will identify consumers who have been in the Residual Functions Program the longest to collect the most meaningful outcome data and experiences of the Program. Service providers will also consider any other selection criteria as agreed in the co-design to gain diversity in the sample. For example: the aim is to interview a broad range of consumers of different sex, age, cultural background, location and mental health and intellectual disability.

Family members will be identified through nomination by the consumer during or after the interview (as described above).

Service providers in the fieldwork sites and **other stakeholders** will be identified through discussions with site managers and subject to criteria decided upon in the co-design process.

Consent processes

Participation in the interviews or focus groups is voluntary. All participants must be freely able to give their consent to participate.

Consent processes and forms will be finalised during the co-design phase. In previous evaluations, we used the processes described below. Any changes for this evaluation will consider the particulars of the Residual Functions Program, the consumer group and the fieldwork locations.

The **consent process for consumers** will involve the following steps:

1. SPRC will produce information sheets and consent forms about the evaluation written in an accessible way for consumers, with advice from service providers about length, design and wording
2. Service providers will talk through the information sheets and what the evaluation involves with service users
3. Researchers will collect informed consent from service users before the interviews. A spoken consent can be recorded.

The **consent process for families** of consumers will involve the following steps:

1. SPRC will produce information sheets and consent forms about the evaluation written in an accessible way for families, with advice from service providers about length, design and wording
2. Service users (or service providers on behalf of the service user) forward the information sheet to the family member nominated by the service user
3. Researchers will collect informed consent from family members before the interviews.

The **consent process for service providers and other stakeholders** will involve the following steps:

1. SPRC will produce information sheets and consent forms about the evaluation
2. The Ministry or service providers forward the information sheet to nominated participants

3. Researchers will collect informed consent before the interviews/focus groups.

Analysis of qualitative data

The data from the interviews and focus groups will be thematically analysed against the evaluation questions – which means that the evaluators will look at how what people told them fits with the questions that the evaluation aims to answer. The interview and focus group data will be examined and sorted into themes using analysis software called NVivo.

3.1.3 Analysis of quantitative data

The evaluators will analyse quantitative Program data collected by the three streams of service delivery (i.e. LHDs & SHNs, ID Health Teams and the Ministry - as outlined in Section 1) and transferred by the Ministry to assess the effectiveness of Program implementation and outputs.

The data set consists of i) the data routinely collected across NSW Health for all consumers, and ii) the data that is collected as part of the Program - as per Data Guidelines May 2019. Where numbers allow, we will look at individual services, LHDs, Streams and the overall Residual Functions Program.

In addition, the Ministry will link consumer outcome data from across the Department (which is called data linkage) so the evaluation can measure Program impact. For example, to assess whether there are changes in health service usage among Program consumers, we will use the self-controlled case series (SCCS) method with two steps.

- Step One: For each Program site we will conduct a SCCS to compare health service usage patterns of each consumer before and after joining the Residual Functions Program. Where possible we will also compare health outcomes before and after joining the Program.
- Step Two: using Residual Functions Program level data from all sites, the approach is the same as in phase one, however, to estimate impact of the Program in each LHD, we will use the SCCS method and include time factors for each LHD in the model.

The data linkage will look for any NSW public health service usage 1 year prior to enrolment in the Program (this does not have to be in the same LHD) and compare how this changes after engagement with the service.

The evaluators will also compare the demographics and overall patterns of service use to the linked data set held by 3DN, which explores demographics, health and health service usage of people with intellectual disability in NSW.

The data sources will be collected and analysed for the full sample of Residual Functions Program consumers.

The co-design process will determine consent requirements and processes for the collection and use of quantitative data in the evaluation, as well as available data sources and the analysis plan.

3.1.4 Economic modelling

The evaluators will develop economic modelling to integrate program funding and cost data with healthcare service usage patterns developed through the quantitative analyses. The data will be developed into a time series to calculate average costs for the services provided to consumers before and after entry to the Residual Functions Program. Healthcare services will include hospital admissions and lengths of stay, emergency department presentations and community based mental health services (Program logic Appendix A).

The evaluators will also aim to integrate mental health outcomes into the economic modelling through the Kessler Psychological Distress Scale (K10), which is a routinely collected measure. The K10 is a simple self-report measure of psychological distress, which can be used to measure improvements (or declines) to a person's mental health over time. Where study group sample sizes allow (i.e., it is large enough to provide statistically significant findings), the K10 scores will be used to estimate changes in Quality Adjusted Life Years (QALYs). A QALY is a measure of health outcome that combines length of life with health-related quality of life. QALYs are used in economic evaluation to help understand how effective health programs are at improving people's health and wellbeing.

The economic evaluation will develop a Markov model framework to assess cost effectiveness of the Residual Functions Program. A Markov model is an economic approach to assess program health outcomes, service usage and related cost effectiveness. The economic evaluation will also identify resource usage cost offsets potentially resulting from reduced hospital admissions or less use of other health services.

The economic modelling will also examine available comparative patterns of health service usage of people with intellectual disability in NSW through the separate large linked data set held by 3DN.

3.2 Inclusive and culturally sensitive approaches

Lived experience: SPRC will recruit and support people with lived experience of mental illness and intellectual disability to contribute to all stages of the evaluation, from design through data collection to analysis and reporting.

During the co-design process we will refine the qualitative data collection and peer research methods with input from expert advisors for mental health, intellectual disability, Aboriginal and Torres Strait Islander people and people from CALD backgrounds.

Our fieldwork protocols will contain inclusive and culturally appropriate recruitment strategies, safety protocols and sensitive research practices, as outlined in Section 2. Depending on their preferences, lived experience researchers will also be involved in the fieldwork itself, data analysis and commenting on draft reports.

The lived experience research is organised by the research team's mental health peer researcher. NSW Council for Intellectual Disability will support lived experience researchers with intellectual disability.

Aboriginal and Torres Strait Islander expertise will be sought from local Aboriginal organisations and the Residual Functions Program workers in the fieldwork sites. We will build on local LHD contacts, or on the relationships we have developed through previous evaluations to partner with local Aboriginal organisations.

In addition, the SPRC evaluation team includes an academic Aboriginal and Torres Strait Islander advisor, and one of the lived experience researchers recruited for the evaluation identifies as Aboriginal. The Centre for Aboriginal Health at NSW Health will also provide expert advice.

Similarly, we will seek **CALD expertise** from Residual Functions Program workers and from local organisations in the fieldwork sites. The evaluators will also draw on the expertise of the SPRC CALD advisors.

3.3 Timeline

The evaluation will be conducted in three phases:

- Phase 1: Project set-up, co-design, evaluation plan and ethics submissions (December 2019 – June 2020)
- Phase 2: Qualitative data collection (June–August 2020)

- Phase 3: Data analysis, final reporting and presentations (September 2020 – January 2021)

Detail is provided in Table 2 below. If any issues should impact on timeframes during the evaluation, the Ministry and SPRC together will manage variations to the evaluation timeline. Potential issues may relate to resourcing at the Program sites or the Ministry, or to COVID-19.

Table 2 Evaluation timeline

| Phase 1 | Dec 2019 – Jun 2020 |
|--|----------------------------|
| Project start | Dec 2019 |
| Initial meeting | Jan 2020 |
| Decide communication plan | Jan |
| Review quantitative data sources | Jan |
| Collect and review program documentation | Jan-Mar |
| Co-design process: <ul style="list-style-type: none"> • Develop evaluation questions • Refine research methodology incl peer methodologies • Develop program logic • Select fieldwork sites • Finalise sampling framework • Finalise fieldwork protocols | Jan-May |
| Ethics applications | Jan – Jun |
| Engage key contacts and stakeholders in fieldwork sites | Mar – Jun |
| Recruit and train peer researchers | Feb – May |
| <u>Deliverables:</u> Evaluation Framework, Program Logic | May |
| Ethics approvals | June |
| Phase 2 | Jun – Sep 2020 |
| Fieldwork in 2 Program locations | Jun – Sep |
| Focus groups/interviews with other key stakeholders | July – Sep |
| Feedback to Program and evaluation governance groups | ongoing |
| Phase 3 | Sep 2020 – Jan 2021 |
| Qualitative data analysis (interviews, focus groups, Program documents) | Sep – Oct |

| | |
|--|--------------------|
| Quantitative data analysis (Minimum Data Set MDS and linked data) Wave 1 | Sep – Oct |
| Economic analysis and cost modelling | Sept – Oct |
| Triangulation of qualitative and quantitative data | Nov |
| <u>Deliverable:</u> Draft Evaluation Report (also referred to as Interim Summative Evaluation Report/Mid-term report) | Nov 2020 |
| <u>Deliverable:</u> Final Evaluation Report (also referred to as Final Summative Evaluation Report) | 28 Feb 2021 |
| Project end | 28 Feb 2021 |

4 Quality assurance processes

4.1 Governance

This project will be managed and overseen through the following mechanisms.

SPRC will report to the **Mental Health Branch**, NSW Ministry of Health. Fortnightly project meetings have been agreed to, and the frequency can be adjusted in consultation with the Ministry as needed. Meetings include updates on evaluation progress and findings and any potential variations to the project scope, budget or deliverables.

An **Evaluation Reference Group** will provide governance for the evaluation. The Ministry will involve stakeholders through the IDMH Advisory Group, which also advises IDMH Hubs (these are recurrent services). The Evaluation Reference Group will include relevant Government agencies, peak bodies, community organisations, people with lived experience of intellectual disability and mental health challenges as well as Aboriginal and Torres Strait Islander representation and advice on CALD mental health consumers. The Evaluation Reference Group will advise on evaluation design and methodology, comment on deliverables and provide general evaluation guidance. SPRC will attend meetings and present evaluation progress and findings as required and appropriate.

4.2 Communication plan

Table 4 summarises the communication plan for the evaluation. It aims to ensure that all stakeholders are engaged and confident in the evaluation and informed about its progress. SPRC will communicate the final evaluation findings to all stakeholders in various appropriate formats in February 2021.

Table 3 Stakeholder engagement strategy

| Stakeholder type | Engagement point or method | Times |
|-------------------------------|---|--|
| Program consumers | Introduction of evaluation by LHDs Interviews Feedback about evaluation findings (full public report and short, accessible version) | Jun 2020 Jun-Sep 2020 Feb 2021 |
| Families of Program consumers | Consumers/LHDs contact families Interviews Feedback about evaluation findings (full public report and short, accessible version) | Jun-Sep 2020 Jun-Sep 2020 Feb 2021 |

| | | |
|--|--|---|
| LHDs and other Program providers | Feedback about evaluation progress and findings: through representation on Evaluation Reference Group and direct communication from the Ministry | From Mar 2020 |
| LHDs and relevant service providers in the fieldwork locations | Fieldwork Feedback about evaluation progress and findings: through representation on Evaluation Reference Group and direct communication from the Ministry | Jun-Sep 2020 From March 2020 |
| Peer researchers in the fieldwork locations | Advice on fieldwork methodology and interview recruitment processes Fieldwork Contributing to analysis in evaluation report | From March 2020 Jun-Sep 2020 Sep 2020 to Jan 2021 |
| Government stakeholders | Phone interviews – individual or small group discussion (after the Ministry has informed stakeholders about the evaluation and they have agreed to participate) Feedback about evaluation findings (full public report and short, accessible version) | Jul-Sep 2020 February 2021 |
| Other state-level stakeholders | Phone interviews – individual or small group discussion (after the Ministry has informed stakeholders about the evaluation and they have agreed to participate) Feedback about evaluation findings (full public report and short, accessible version) | Jul-Sep 2020 February 2021 |
| Aboriginal and CALD advisors | Advice on evaluation design, methodology and analysis Feedback on final report | From March 2020 February 2021 |
| Evaluation Reference Group | Evaluation design and methodology advice General evaluation advice Feedback on final report | March 2020 as appropriate February 2021 |

4.3 Ethics

This evaluation requires six ethics approvals. Applications will include strategies to minimise the risk of psychological harm and trauma to Residual Functions Program consumers. The applications will ensure voluntary participation and confidentiality in the qualitative and quantitative research.

Ethics approval will be sought from the following ethics committees:

- **UNSW Human Research Ethics Committee (HREC)**, which will provide approval for the qualitative data collection
- **Aboriginal Health and Medical Research Council (AH&MRC) Human Research Ethics Committee (HREC)**, which will provide ethics clearance for Aboriginal and Torres Strait Islander involvement in the evaluation
- **NSW Population and Health Services Research Ethics Committee (P&HSREC)**, which will provide ethics approval for the program data linkage and economic and cost modelling analyses
- **Northern Sydney Local Health District (NSLHD) Human Research Ethics Committee (HREC)**, which will be the lead HREC for the qualitative fieldwork in two Program sites
- **LHD Research Governance Offices in the two fieldwork sites**, for Site Specific Approvals (SSAs) for qualitative fieldwork.

The research will adhere to the requirements outlined in the UNSW Code of Conduct and align with best-practice principles in the NSW Government Evaluation Framework, for example communicating evaluation results to various audiences.

4.4 Risk management

Table 4 outlines some of the challenges that could arise over the course of the evaluation, their potential consequences, their likelihood and mitigation strategies. The table will be refined during co-design, and risks will be monitored and addressed during the evaluation.

Table 4 Risks and mitigation strategies

| Risks | Likelihood | Impact on evaluation & stakeholders | Risk management response |
|---|------------|-------------------------------------|--|
| Evaluator will be required to effectively | High | High | Early communication with stakeholders to engage them in the evaluation process and to identify how |

| | | | |
|---|--------|--------|---|
| engage with multiple stakeholders dispersed across different locations. | | | <p>to best involve them in interviews and gain access to program and other data.</p> <p>Peer methods to build trust and quality working relationships with consumers and families.</p> <p>Evaluation experience with stakeholders and data holders (Ministry, InforMH, community service providers) will avoid and resolve engagement problems.</p> <p>Communicate progress to stakeholders throughout the project.</p> <p>Tele/video-conferencing for dispersed organisational stakeholders.</p> |
| Data may be limited in the early stages of the evaluation. | High | Low | Evaluation design so that early stages do not require access to program/outcome data. |
| Delay in data access from Ministry/LHDs and low data quality including data linkage | High | High | <p>Early communication with stakeholders and CHeReL to identify how to access program data.</p> <p>Transparency in how the data will be used and to address concerns about sharing data.</p> <p>Two strategies for linking consumer outcomes data to mitigate the risk of delay in accessing linked data.</p> <p>Past experience with LHDs/SHNs to access resources and their staff members research participation about intellectual disability mental health.</p> |
| Evaluator will be required to lead ethics approval processes within a short time frame. | Medium | High | Team is highly experienced with relevant ethics committees; and strong record obtaining ethics approvals for similar projects. |
| Submission of deliverables may be delayed. | Low | Medium | <p>Strong project management and risk management protocols.</p> <p>Project Manager will establish a detailed communication protocol to identify and manage risks (guarantees for deliverables below).</p> |
| Evaluation may fail to critically analyse the Program, and not produce useful and actionable recommendations. | Low | High | <p>Team renowned for rigorous research governed by university standards that produces comprehensive and useful policy guidance to inform program improvement and decisions.</p> <p>Mixed-methods approach from various data sources compensates for data limitations, and findings will be linked to actionable recommendations.</p> |
| Evaluation activities interfere with the delivery of services to consumers | Low | Medium | Evaluation design with focus on program data reduces impact on service providers and consumers. |

| | | | |
|--|-----|--------|---|
| Consumer data is not appropriately managed | Low | Medium | Experienced managing sensitive data, systematic data collection and storage methods. All personal data will be confidential, with access limited to evaluators for analysis. |
| Engagement of consumers and families in the project is not effective | Low | High | Experience engaging consumers, family members and service staff. Successful recruitment documentation and approaches for people with mental illness and ID. Experience working with formal guardians required to consent on behalf of the consumer. Self-controlled case series (SCCS) method to allow for small sample sizes. |
| The evaluation methodology is inappropriate | Low | Low | Mixed methods design and strong team to reduce this possibility. Leading Australian experts in intellectual disability/mental health, evaluation, and peer-methodologies. |

4.5 Reporting and data storage

The final evaluation report will be published, with approval from the Ministry, on the SPRC website. In addition, accessible versions of the report, including Easy Read and short video versions, will be published, with approval from the Ministry, on the SPRC website. The Executive Summary will be made available to all evaluation participants who indicate on the consent form that they wish to receive it.

The study findings will also be published in peer-reviewed journal articles and presented at national and international conferences. All data will be reported in such a way that no evaluation participant is identifiable.

Any data collected during this evaluation will be stored, in accordance with ethics and University requirements, for a period of seven years. Data will be stored in a de-identified form on a secure server, with access limited to the research team.

Appendix A Program logic for IDMH NDIS Residual Functions Program

Program aim: To improve the capacity of mainstream mental health services to work more effectively with people living with intellectual disability and co-occurring mental illness, and with their families and carers

| Inputs | Activities | | | Outputs | Process outcomes | Outcomes for direct consumers |
|--|--|---|---|--|--|--|
| <p>Funding</p> <p>\$4.1m per year for three years to develop programs to meet the needs of people living with intellectual disability and co-occurring mental illness</p> <p>Direct consumers: new clinical care Stream 1, 2</p> <p>Indirect consumers: enhanced service capacity Stream 1-3</p> <p>Funding is used for 3 Program streams:</p> | | | | <p>Funded LHDs, SHNs, Clinicians and central agencies implement funded services; outputs vary according to service</p> | <p>Increased coordination and engagement across health and service providers (e.g. improved partnerships between mainstream health and mental health to facilitate integrated care and streamline referral pathways)</p> <p>Improved access to appropriate services for people with intellectual disabilities and mental illness, including people with ID who may not traditionally access mainstream</p> | <p>Reduced rates of emergency department presentations</p> <p>Reduced rates of unplanned in-patient admissions</p> <p>Reduced re-admission rates to inpatient facilities</p> <p>Reduced length of stay in an inpatient facility</p> <p>Increased numbers of people with ID accessing ambulatory mental health services</p> <p>Increase in community episodes of care for people with ID</p> <p>[Potential inclusion of measures of</p> |
| <p><u>Stream1: Local Health District Programs</u></p> <p>10 Local Health Districts (LHDs) and 2 Specialty Health Networks (SHNs) received funding to facilitate enhanced clinical, coordination and capacity building services</p> | <p>Organisation</p> <p>Central Coast LHD</p> | <p>Program</p> <p>0-12 year old clinical service</p> | <p>Service elements</p> <p>Clinical service Consultation Liaison Capacity Building</p> | | | |
| | <p>Hunter New England LHD</p> | <p>Clinical Team</p> | <p>Clinical service Consultation Liaison Capacity Building</p> | | | |
| | <p>Justice Health and Forensic Mental Health Network</p> | <p>Custodial ID and MH Transitions</p> | <p>Clinical service</p> | | | |
| | <p>Murrumbidgee LHD</p> | <p>Clinical service and brokerage</p> | <p>Clinical service Consultation Liaison Capacity Building</p> | | | |
| | <p>Northern Sydney LHD</p> | <p>Education and enhancement of existing IDMH team</p> | <p>Capacity Building Education</p> | | | |
| | <p>Sydney LHD</p> | <p>Allied health clinician</p> | <p>Clinical service Consultation Liaison Capacity Building</p> | | | |

| Inputs | Activities | | | Outputs | Process outcomes | Outcomes for direct consumers |
|--|--|------------------------------|---|---------|---|--|
| | Sydney Children's Hospital Network | Clinical enhancement | Clinical service Consultation Liaison Capacity Building | | mental health services | wellbeing, mental health in the evaluation – K10, HoNOS, HoNOSCA, NDIS] |
| | South East Sydney LHD | Adolescent transition clinic | Clinical service Consultation Liaison Capacity Building | | Improved capacity of health services to provide specialist care for people with intellectual disability and co-occurring mental illness and for their families and carers | Improved cost effectiveness of mainstream mental health services based on healthcare cost offsets for outcomes mentioned above |
| | South West Sydney LHD | NDIS Pathways Clinician | Consultation Liaison Capacity Building | | | |
| | Southern NSW LHD | IDMH Clinic | Clinical service Consultation Liaison Capacity Building | | | |
| | Western NSW LHD | IDMH Clinic | Clinical service Consultation Liaison Capacity Building | | | |
| | Western Sydney LHD | Clinical team | Clinical service Consultation Liaison Capacity Building | | Improved patient flow through acute MH facilities due to better coordination and discharge planning | |
| <p><u>Stream 2: IDMH Clinicians</u></p> <p>An IDMH Clinician was funded in each of the six ID Health Teams across NSW, to provide clinical and capacity building supports</p> <p>Locations:</p> <ul style="list-style-type: none"> • Northern Sydney LHD • South East Sydney LHD - Kogarah Assessment Service • Sydney LHD • South West Sydney LHD | <p>- facilitate improved access to appropriate psychological and mental health care for people living with IDMH</p> <p>- may provide assessment and short-term clinical care</p> <p>- support the increased capacity of the Ministry and mental health staff to build skills and confidence to work with people who experience IDMH Activities</p> | | | | <p>Mainstream clinicians:</p> <ul style="list-style-type: none"> - have more exposure to people with ID - can access expert support and advice from IDMH clinician - report increased capacity and confidence to | |

| Inputs | Activities | Outputs | Process outcomes | Outcomes for direct consumers |
|--|--|-----------------------------|---|-------------------------------|
| <ul style="list-style-type: none"> • Hunter New England LHD • Western NSW LHD | | | provide care for people with ID - report improved access to specialist diagnostic and assessment services | |
| <u>Stream 3: Capacity Building</u> Centralised management of capacity building activities and resources in addition to Streams 1 and 2. | a state-wide, coordinated approach to developing and providing resources that support the improved clinical care of people with co-occurring ID and MH, and improved support for their families and carers | Capacity building resources | Improved data on: - Service activities - Prevalence of people with ID in MH services - Access to MH services for people with ID - Codesign of mental health services delivery | |