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

Evaluation report

Christiane Purcal, Peri O'Shea, Karen R Fisher, Janelle Weise, Fredrick Zmudzki, Preeyaporn Srasuebkul, Adrian Walker, Julian Trollor

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Social Policy Research Centre

Research Team
Karen R Fisher (Chief Investigator), Christiane Purcal, Fredrick Zmudzki, Peri O'Shea, BJ Newton, Julian Trollor, Janelle Weise, Preeyaporn Srasuebkul, Adrian Walker, Rachel Spencer, Erin Forrester, Katielee Simpson, Bani Aadam

For further information:
Professor Karen R Fisher, karen.fisher@unsw.edu.au, +61 2 9385 7800

Social Policy Research Centre
UNSW Sydney NSW 2052 Australia
T +61 2 9385 7800
F +61 2 9385 7838
E sprc@unsw.edu.au
W www.sprc.unsw.edu.au

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Abbreviations

3DN	Department of Developmental Disability Neuropsychiatry at UNSW Sydney
AMHOCN	Australian Mental Health Outcomes and Classification Network
AR-DRGs	Australian Refined Diagnosis Related Groups
CALD	culturally and linguistically diverse
HRQoL	Health related quality of life
IDMH	Intellectual Disability Mental Health
K10	Kessler Psychological Distress Scale (K10). The K10LM is a consumer-completed 10 item questionnaire designed to measure psychological distress. K10LM stands for “Last Month” where the usual rating period is at the interval of 4 weeks.
LHD	Local Health District
Ministry	NSW Ministry of Health
NDIS	National Disability Insurance Scheme
NOCC	Mental Health National Outcomes and Casemix Collection
NSW	New South Wales
QALY	Quality Adjusted Life Year
SHN	Specialty Health Network
SPRC	Social Policy Research Centre
UNSW Sydney	University of New South Wales

Terms

Co-design	Collaborative, shared approach to design. It includes end service users and other people with lived experience working alongside people with professional experience
Data linkage	Joining together data about each person from several sources
Mixed-methods	Collection of types of data, using different methods of data collection and analysis – for example, this evaluation uses qualitative and quantitative methods and co-design
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 name for the Intellectual Disability Mental Health National Disability Insurance Scheme Residual Functions Program
Qualitative methods	Collection of detailed information from stakeholders. Often through interview or small group, but can also be through other methods such as photos or stories
Quantitative methods	Collection or analysis of data that is quantitative – meaning numbers that can be counted
Economic methods	Analysis of program benefits, outcomes, costs and value to help decisions about future funding

Short summary of the report

The Residual Functions Program is a NSW Health program. It aims to develop services to better support people with both intellectual disability and mental health needs (IDMH). The Social Policy Research Centre (SPRC) at UNSW Sydney, together with the Department of Developmental Disability Neuropsychiatry at UNSW Sydney (3DN), evaluated the Residual Functions Program. They assessed whether the Residual Functions Program met its aim to improve access to mental health care for people with intellectual disability and how this could be done differently.

This evaluation report summarises the findings of the evaluation. The qualitative findings are from interviews and focus groups with program consumers, their families, service providers and other stakeholders in NSW. The quantitative and economic findings are from administrative data from NSW Health.

Despite its short time span, the Residual Functions Program showed achievements across its goals: more coordination and capacity among services, better consumer access to community mental health and disability support, and potentially improved consumer wellbeing. Early results also suggest the program is cost effective. Some suggestions for how NSW Health could build from these achievements are:

1. Program design and governance
    - share successes between the local Residual Functions Program and similar NSW programs
    - work towards a consistent approach across NSW, so that all consumers have better access to support from NSW mental health services and from intellectual disability support, which comes mostly from the NDIS
    - measure health and wellbeing outcomes for people with intellectual disability who receive mental health support, to confirm cost effectiveness.
2. Service coordination and capacity
    - have funded, ongoing local positions to liaise between local mental health services and NDIS providers and consumers. They would also liaise with other local areas and with the centralised IDMH Hubs
    - provide more general and specialist services for people with intellectual disability and mental health.
3. Consumer access to support
    - make existing services welcoming and respectful
    - promote future similar programs to consumers, to their families and to people who might refer consumers, so they know about it and can find support.

Executive summary of the report

The Intellectual Disability Mental Health National Disability Insurance Scheme Residual Functions Program (called ‘Residual Functions Program’ or ‘program’ for short) is a NSW Health program funded by the NSW Government from 2018 to 2021. It aims to improve service access to better support people who experience both mental health issues and intellectual disability.

The Social Policy Research Centre (SPRC) at UNSW Sydney, together with the Department of Developmental Disability Neuropsychiatry at UNSW Sydney (3DN), evaluated the Residual Functions Program between December 2019 and February 2021.

This evaluation report summarises the findings of the evaluation. The qualitative findings are from interviews and focus groups with program consumers, their families, service providers and other stakeholders in NSW. The quantitative and economic findings are from administrative data from NSW Health.

Program characteristics

The central part of the program provided funding to ten Local Health Districts and two Specialty Health Networks across NSW to improve clinical support and build service capacity and coordination. The programs varied widely to respond to different local needs. Programs identified and addressed a range of challenges that affected their local implementation. The challenges were partly due to COVID-19 and the short timeframe of the program.

Implementation of the program

Coordination and engagement: Coordination improved across health and other service providers, and with consumers and families. Providers appreciated having a local contact point for coordination between mental health and NDIS for people with highly complex care needs. Consumers and families liked the more coordinated, multi-disciplinary support.

Consumer access to services: Consumers received direct clinical support they had not been able to access before. This included clinical support in a community setting that was better focused on both mental health and intellectual disability needs. The support was offered closer to where consumers lived. Providers made consumers feel comfortable and respected when they came to the services. It was sometimes difficult to find out about the program. A shortage of services limited access to support.

Capacity of health services, disability and other support: Building capacity of services worked best where the Residual Functions Program combined training courses or webinars, with using the new knowledge in practical work like case meetings or direct consumer support. Intellectual disability and mental health service providers said that now they better understood each other's approach and the different kinds of support that consumers needed. They could also ask the local program contact person for advice. Most said the short-term funding of the program would make it difficult to maintain changes.

Availability of data: There was not enough quantitative data about consumers with intellectual disability and mental health challenges and their individual needs. Data were not shared enough between the mental health and disability sectors.

Culturally safe services: Service providers engaged interpreters and drew on mainstream culturally specific services, such as migrant resource centres or Aboriginal Medical Centres. Most consumers and families said the inclusive and respectful nature of the program services made them feel safe. Some consumers and families said safety strategies to meet the needs of people with intellectual disability and mental health problems were more important than cultural needs.

Impact of COVID-19 on implementation: COVID-19 slowed down program implementation. Staff recruitment was slow, and some training and coordination activities were delayed or cancelled. Telehealth was a good way to keep up service provision to consumers during lockdown. Telehealth will likely be used longer term for consumers who prefer it, for example because of distance or because they find it difficult to travel.

Project-wide implementation: All the consumers, families and staff agreed the program was a good idea with much potential. Program activities varied widely among LHDs. This suited local circumstances. Some providers and stakeholders liked the variation under a broad umbrella. Others wanted more direction from the NSW Ministry of Health (Ministry), with guidance and shared principles.

Many staff said it had been good to have the flexible funds from the program to address gaps in the system. All service providers and stakeholders said that recurrent funding was necessary for the future because people would always have these needs, so any gaps would reappear once the funding changed. Service capacity would need to be continuously renewed because staff moved on and programs changed.

Outcomes for consumers and families

The outcomes are largely from the qualitative data. It was difficult to make firm conclusions about outcomes and changes from the quantitative data, as this was collected over 3 months for most analyses and the sample was too small.

> When Sally started on the program, the doctor listened to Sally's story, acknowledged her trauma and helped her to understand how her childhood experience had affected her behaviour. The doctor also gave her different medication ... Now she loves to spend time with her housemates. Sally then worked with the support workers to extend her social circle. **Appendix E**

Health and wellbeing: The program improved mental health and wellbeing, according to most consumers interviewed and the people who supported them. The improvements were because the program offered support that people had not had before, considered the person's individual needs better, reviewed medications and supported the consumer to access community mental health care and NDIS. Consumers gained more confidence, engaged more with people and activities and had better physical health. The wellbeing of family carers also improved. Better support for their family member allowed the family carer to rest, pursue other activities and resume a usual family relationship with the consumer.

Access to services in the community: The program improved access for consumers and families to services in the community, also called ambulatory services. It increased the rate of treatment days in community mental health services by 69%. It also increased access to core mental health professionals in the community, including psychiatrist and psychologists.

The main service categories of community services also changed. The greatest increases during 90 days were in promotion, prevention or early intervention (11.20 times more likely than before), and emergency and hospital acute, clinical and social services (3.09 times more likely).

The aspects of the program that contributed to these changes were: providers working together; services located in the centre of the community; capacity building among health staff; and flexibility in where the program supported consumers, for example in hospitals, community health centres or GP clinics.

Contact with hospitals: The program did not change the measured rate of consumer contact with emergency departments or mental health inpatient services. The data indicate that the admissions and length of stay in mental health inpatient care and emergency department use did not increase, and either stayed the same and may have decreased for some people. The consumers and their supporters said they had fewer emergency department visits. When a consumer did go to hospital,

the program tried to make sure their mental health and intellectual disability needs were addressed as well as their physical needs. Hospital staff tried to start making links for the consumer to NDIS as soon as possible. But to do so, they needed better data about consumer needs, pathways, outcomes, services, inequalities (**section 4.4**).

Impact of COVID-19 on outcomes: Many consumers said they had missed out on community activities during periods of COVID restrictions. Ongoing program support ensured that many consumers maintained their level of mental health. Some consumers found the social isolation difficult, and their mental health got worse.

Economic evaluation

The program cost was $4.1 million per year, which was within the funding budget. In the first year, delays to implementation resulted in an underspend of $2.7 million, which was not shifted to later years.

The cost effectiveness analysis shows that the program achieved its primary goal of improving access to appropriate community mental health services and possibly all inpatient care. The economic model developed a base case of all program costs, plus the additional costs of increased mental health services used. The findings are preliminary, as the base case is a partial estimate of cost effectiveness. Limitations in the model were a short 3-month comparison, a small sample and incomplete data linkage.

A second way to measure the cost effectiveness was to compare quality adjusted life years (QALYs) from the base case to several conservative scenarios. This comparison also found the program was potentially cost effective. More longitudinal data analysis should investigate medium and longer term outcomes to confirm this finding. The base case for the QALYs was estimated from the consumers' reported mental health status measured by Kessler 10 (K10) scores. The scenarios were about the number of consumers and potential outcomes for consumers, family and carers, including avoided deaths, based on available evidence.

Implications for NSW Health

Despite its short time span, the Residual Functions Program showed achievements across its goals: more coordination and capacity among services than before, better consumer access to mental health and disability support, and improved consumer wellbeing. Some suggestions for how NSW Health could maintain these achievements and build on them were:

1. Program design and governance

- share successes between the local Residual Functions Program and similar NSW programs
- work towards a consistent approach across NSW, so that all consumers have better access to support from NSW mental health services and from intellectual disability support, which comes mostly from the NDIS
- measure health and wellbeing outcomes for people with intellectual disability who receive mental health support, to confirm cost effectiveness.

2. Service coordination and capacity
    - have funded, ongoing local positions to liaise between local mental health services, consumers and disability service providers. They would also liaise with other local areas and with the centralised IDMH Hubs
    - provide more general and specialist services for people with intellectual disability and mental health.
3. Consumer access to support
    - make existing services more welcoming and respectful
    - promote future similar programs to consumers, their families and the people who might refer consumers, so they know about it and can find support.

1 Introduction

The Intellectual Disability Mental Health National Disability Insurance Scheme Residual Functions Program (called ‘Residual Functions Program’ or ‘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) funded 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 (Stream 1)**: 10 NSW Local Health Districts (LHDs) and 2 Specialty Health Networks (SHNs) were funded to enhance clinical and capacity building services (**Appendix C**).
- **Support for ID Health Teams (Stream 2)**: 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 (Stream 3)**: 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 different aspects of the program fit together:

- program inputs, activities and outputs
- process outcomes
- and outcomes for direct consumers.

The evaluators used the program logic for the Residual Functions Program to measure how the program was going. The program logic was developed with the Ministry and refined during the evaluation. The Residual Functions Program Logic is in **Appendix A**.

2 Evaluation methods

The Ministry commissioned the Social Policy Research Centre (SPRC) at UNSW Sydney to evaluate the Residual Functions Program. The SPRC conducted the evaluation together with the Department of Developmental Disability Neuropsychiatry (3DN) at UNSW Sydney. The evaluation commenced in December 2019 and ran until February 2021. The evaluation plan (Purcal et al. 2020) can be found here.

The evaluation assessed the processes, outcomes and economic costs and benefits of the Residual Functions Program. The **evaluation aimed** to 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 aims were:

- identify opportunities to improve service quality and effectiveness
- identify risks and needs in the provision of intellectual disability and mental health care
- inform NSW Government decision-making about future policy directions for the program
- give recommendations about any ongoing need and associated objectives for the program beyond June 2021, including assessing risks and benefits if the program is not to continue.

The evaluation used **mixed methods**. Mixed methods evaluations collect and examine different sources of data by using different methods of data collection and analysis. The mixed methods in this evaluation included:

- co-design of research methods
- analysis of qualitative data from interviews, focus groups and program documents
- analysis of quantitative data collected by program providers and data linkage
- economic modelling.

Co-design of research methods occurred during the first part of the evaluation. The co-design process improved the evaluation approach and methods about how the evaluation did things. The co-design process involved collaboration of the evaluators, who included people with a lived experience of intellectual disability and

mental health challenges, with stakeholders from the Ministry, relevant peak bodies and consumer advocacy groups.

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

Table 1 Methods and sample sizes

Method	Sample sizes	Timeframe	Data source
Program documentation	All parts of the program	December 2019 to September 2020	From the 3 program Streams
Qualitative interviews with consumers	6	October 2020	Fieldwork (2 program locations – 1 metropolitan and 1 regional)
Qualitative interviews with families	7	October 2020	Fieldwork
Interviews with service providers	12	July to October 2020	Fieldwork
Focus groups/ interviews with other stakeholders	16[1]	October 2020	Online focus groups and interviews
Quantitative program data	All program consumers	Program entry to November 2020	From the 3 program Streams
Linked consumer outcome data	Consumers in 9 Stream 1 programs[2]	1 year before program entry to September 2020	Available data through the Ministry
Economic data	All 3 program Streams	Program start to July 2020	From the Ministry and data linkage

Notes: [1] 2 people took part in both the focus groups and individual fieldwork interviews. [2] The Ministry was able to link data from 9 of the 12 programs in Stream 1, which identified people and the services that they used

Qualitative data collection involved talking to people in interviews or focus groups about their experiences of the program. The evaluators conducted interviews in two program sites with stakeholders including:

- consumers
- families
- frontline staff

- LHD managers
- other stakeholders.

The sites were agreed with the Ministry and included one LHD in the Sydney area and one regional LHD. In addition, we conducted interviews and focus groups with other stakeholders. These included representatives from program locations across the state.

Interviews and focus groups were in person, by phone or by video software. We spoke with 39 people (**Table 1**). Fewer consumers and families than we expected took part in interviews, and there were fewer interviews with consumers and families in the metro site than in the regional site. Some reasons were that:

- the program was new and did not have many consumers yet
- some program locations focused not on direct service provision to consumers but rather on capacity building for providers and coordination among services
- many consumers of the program had very high support needs, and providers felt they were not able to take part in conversations with the evaluators.

We also reviewed Residual Functions **Program documentation**, as available. The documents included Expressions of Interest from the funded LHDs and SHNs and progress reports. The review showed the intended outcomes of the program locations. It also showed some implementation issues the locations addressed. The review helped the evaluation to assess whether the program had achieved its aims and what lessons the locations had learned for the future.

Quantitative data collection and analysis involved obtaining anonymous health data of program consumers from various data sets within the Ministry. This included the data that were routinely collected as part of the program, to assess the effectiveness of program implementation and outputs. In addition, the Ministry linked consumer outcome data from across the Department so the evaluation could measure program impact.

Economic modelling

The economic evaluation developed preliminary program modelling based on the current cost and outcome data. The first stage established a base case combining consumer outcomes and health services used from the linked data with program costs. Health services included hospital admissions and lengths of stay, emergency department presentations and community mental health services (**Appendix A**).

Limitations were that the program was not fully established, so the time measured for change was only 3 months, and the data linkage was available only for Stream 1

consumers. Data were not available to measure what happens for people who are in the program for longer or after they leave the program. For this reason, the analysis could not include consumer pathways, or medium or longer term outcomes.

The economic evaluation developed a Markov model framework to assess cost effectiveness of the program. The model used the core base case (which is the partial analysis of available linkage data as a lower boundary) to extend conservative cost effectiveness scenarios. The scenarios included potential benefits for estimated Stream 1 consumers, potential outcomes for families and carers, and possible preventable deaths avoided. The scenarios were built using supplementary data sources and from what was known in the literature about mental health outcomes.

Appendix B has a summary of available data sources, outcomes and timeframes for the economic modelling. This includes details of program cost data, outcomes, target populations and the Markov model approach as well as limitations for the program cost effectiveness analysis.

More detail about the evaluation methods can be found in the evaluation plan (Purcal et al. 2020) and at **Appendix B**.

3 Program characteristics

This section describes the characteristics of the Residual Functions Program. The characteristics include the:

- program aims and activities
- demographic profile of consumers.

Findings about the program aims and activities came from the program documents, which are analysed in this section. Program documents were available for the Residual Functions Program Stream 1 (LHDs & SHNs - as outlined in **Section 1**). The available program documents from LHDs and SHNs were:

- Expressions of Interest
- Progress reports.

Findings about the consumer profile are based on the quantitative data that were routinely collected as part of the program.

3.1 Program aims and activities

The program aims to develop mainstream mental and physical health care capacity that will improve access for people with intellectual disability and mental health needs.

The **Expressions of Interest** for Stream 1 programs showed the focus and intended outcomes for each organisation and location, and the start dates (**Appendix C**). The programs varied widely in all aspects. Program focus included different age groups of consumers, offering clinical support to consumers, educating existing providers and transition support for consumers. Intended program outcomes matched the different emphasis of each program. Program start dates varied by more than one year. They started between 1 May 2019 and 1 July 2020.

Progress reports showed how the locations developed their activities and services over time. Progress reports were available from Stream 1 programs. The programs varied as to when they started reporting and how often they reported. A total of 40 progress reports were available for analysis at 16 December 2020.

The Ministry analysed the progress reports for operational reasons. That means the Ministry wanted to see how each program was progressing and whether the Ministry needed to work with program leads to solve any problems.

The progress report template included fields titled ‘Overall status and key issues summary’ and ‘Critical risks/issues and action plan’. We analysed the responses in these fields across the 40 available progress reports. **Appendix D** summarises the key issues, the challenges and the solutions mentioned in the reports. To maintain confidentiality, we did not specify which program mentioned which issues. Each key issue was mentioned by 1 to 3 programs. COVID-19 was mentioned by 4 programs.

Appendix D shows that the programs found solutions to some of the problems they encountered. These solutions could be shared across the Residual Functions Program and similar programs to improve practice. Other issues were not yet resolved. This indicates opportunities for the Ministry to work with a program or with all programs to address existing and anticipate new issues.

3.2 Consumer profile

Since Jim joined the program, the support workers at Jim’s home are doing some training about intellectual disability and mental health. They are also working with Jim and his mental health team to come up with ways to help Jim when he gets upset. Jim now takes less medication and he is not so sleepy. Last weekend Jim and his grandfather went fishing, and Jim was really looking forward to sharing the photos of his catch with his housemates. **Appendix E**

The data of 124 consumers who participated in the Stream 1 programs by September 2020 were available for analysis. Further data for three Stream 1 programs were not available for analysis as the data were not stored in accessible source systems. Consumer ages ranged from 7 to 72 years, with an average of 32 years (SD = 15.3). Most of the consumers were male (n=74). Most of them identified as not Indigenous (n=114) and were born in Australia (n=112).

Compared to other people with intellectual disability in New South Wales (as reported in 3DN’s administrative data set), a higher proportion of Stream 1 consumers used emergency department services, had inpatient stays, and used ambulatory mental health services in the 12 months before using the program. This difference suggests that the consumers in the program had more complex health needs that required more complex support across the health sector and other social services. The more complex needs and complex service use meant that we could not directly compare the two groups to measure change.

442 consumers received a service from the Intellectual Disability Health Teams across NSW (Stream 2) between January 2019 and November 2020. We could not quantify which of these consumers were seen by the clinicians funded in the Residual Functions Program.

A wide range of consumers took part in the interviews.

- They were consumers who lived in family homes, in supported living or in custody. No-one we spoke to lived independently.
- They ranged in age from children to older people.
- Some had no previous contact with mental health services or the NDIS, others had a long history of both, and some were in-between.
- Many consumers had high support needs, some had medium and few had low support needs.

In the interviews, there was also a wide range of families and carers of program consumers. Some had lots of support in their caring role, some had little. Some lived close to the consumer, others lived far away. Families who lived far away or who lived out of town relied on phone or online contact with services.

Appendix E has three short profiles to illustrate the experiences of consumers and family carers. Each profile contains characteristics from several consumers or families. This is to protect the anonymity of the people in the interviews.

4 Implementation of the program

The evaluation assessed how the Residual Functions Program was implemented, that is, how it was put into practice and what could be improved. This type of research is also called process evaluation. The main intended implementation (or program process) outcomes are listed in the program logic (**Appendix A**). This section reports on the following implementation topics:

- Coordination and engagement across health and service providers
- Consumer access to services
- Capacity of health services, disability and other support
- Availability of data
- Culturally safe services
- Impact of COVID-19.

The main data source for the process evaluation was the interviews and focus groups (**Section 2**). Some information was also in the quantitative data, particularly the routinely collected program data.

4.1 Coordination and engagement

The program aimed to achieve better coordination and engagement across health and other service providers, and with consumers and families.

The data shows that the program did succeed in enabling some improved coordination between mental health, disability and general health services, Justice Health, NDIS providers, other disability support such as teachers and housing providers, and with families and carers:

> It's about ensuring … our clinical service engages with the service providers and works quite collaboratively with the people, with their support workers, their house managers in their supported accommodation, so that it's not just done in the clinic. (Staff)

Better coordination between the stakeholders showed in the following ways:

- local Residual Functions staff liaised for a particular consumer with specialist health services like Justice Health and with other providers like NDIS or supported accommodation
- there was more collaborative clinical care than before, like case conferences, shared home visits and multi-disciplinary clinics

- starting a community of practice (this is providers sharing their experiences in a group)
- working on Memoranda of Understanding (these are agreements about how to work together).

On the ground, coordination and engagement with the NDIS included:

- identifying appropriate providers
- developing mental health resources for providers
- supporting consumers to prepare for NDIS applications and reviews, like organising assessments, developing goals and liaising with NDIS providers and NDIA planners.

Disability service providers (NDIS) and health professionals were eager to engage with the program and found it helpful. They appreciated having a local contact point for coordination between mental health and NDIS. Better collaboration meant that disability services gained better access to mental health services for their consumers and vice versa:

> The [Residual Functions Coordinator] got us a quick appointment with [the Residual Functions clinician]. So it moved, whereas before, we've had no escalation point. (Staff)

Consumers noted and liked the more coordinated, multi-disciplinary approach to support:

> When I first came here, no one was on the same page and no one had any idea what was going on. But now, with [Residual Functions Psychiatrist] and [Residual Functions team] and everyone, like, all my staff … I feel like we're one big team and that's really important to me. (Consumer)

Coordination and engagement activities also included raising awareness about the needs of people with intellectual disability and mental health problems; promoting the program; and forging new relationships:

> [I like] the way they link and bridge and the way they break down the silos and integrate all the various providers out there. (Staff)

Families and carers were pleased with the quality, frequency, reliability and availability of mental health and intellectual disability clinical support for the consumer. They were also pleased that they were involved in the process. This included remote meetings online or on the phone.

Another coordination program for people with high support needs, the Integrated Service Response (ISR) program, finished in October 2020. In the interviews and

focus groups, the providers and stakeholders who had used the ISR program regretted its loss. They said it had built up a network of knowledge about who could support consumers to address their needs, particularly consumers in inpatient care or custody. They felt that the Residual Functions Program had potential to fill the gap to some extent, but they were sceptical whether it could offer the level of intensive support that ISR had provided.

The program might benefit from:

- exploring options for coordinated, intensive support for consumers with high support needs into the future.

4.2 Consumer access to services

Through the program, consumers in the interviews received direct clinical contact they did not have before. For example, they had access to a psychiatrist, intensive behaviour support, medication reviews or multi-disciplinary support. Some consumers accessed support for the first time through the NDIS. The program supported them through the NDIS application process. One family carer in the interviews said they had not been able to get appropriate support for the person they cared for.

> Well I think our particular program has mainly helped people with intellectual disabilities have their medication reviewed. Because …GPs weren't as experienced dealing with the range of medications for both physical and behavioural issues that people presented with. And the psychiatrist we've got is a specialist in intellectual disabilities. So, I think having that specialist oversight has been really, really important. (Staff)

Some of the psychiatric support from the program replaced support previously provided by ADHC. One consumer did not have a regular psychiatrist at all before the program, just emergency department support. Consumers now saw a psychiatrist regularly:

> … we actually go and see him more regular [than our previous psychiatrist]. Like we're getting in four to six monthly where [our previous doctor], … it was taking 18 months to get back in. (Family)

Consumers said the support was now also more comprehensive, as there was more focus on mental health. Affordability of the program improved access too. Previously, privately funded clinical services had been too expensive for many consumers and families.

The program offered services locally, for example in several towns in a regional area. Consumers and families felt this reduced the stress of travelling long distances to appointments, which could make the consumer more agitated or fearful than they

might usually be. Regional service providers appreciated quicker access to locally based support, and that it helped consumers connect with their community:

> It is in the main street. It is part of the local community. So it is getting people out and seen in the local community. (Staff)

> It's a lot more convenient and it's a lot more easier. (Consumer)

The program had also helped people feel more comfortable to attend services. Service providers, consumers and families gave examples:

- short waiting times
- having things to keep consumers engaged while waiting, like art, magazines or a drink
- having spaces where consumers could wait separately from others if they wanted
- being flexible with how the consumer accessed the service, for example home visits or video consultations if the consumer preferred.

How the staff related to consumers and families also contributed to improved access. Consumers and families saw program staff as respectful, friendly and welcoming. Some examples were: the doctor spoke directly to the consumer and asked the consumer questions; consumers and families did not feel rushed; program staff took an interest in the consumers' and families' lives – having genuine conversations:

> He listens, he takes time, he's not spending the whole time just typing in the computer, he's actually sitting there and taking time to have a normal conversation with you. (Consumer)

Having support from people they trusted also helped consumers and families to access services. For example, staff in group homes facilitated access for residents.

Access to information was also important. Many family members and a few consumers said that program doctors and other staff went out of their way to ensure that consumers and families understood the information. For example they gave information in different ways and checked in with people to make sure they understood.

Access through the program to advice about behaviour support assisted disability support workers to manage behaviour in appropriate ways. It reduced the use of sedation (also called chemical restraint) to manage behaviour.

A few problems with access to the program came up in the interviews and focus groups. Several family members said it was difficult to find out about the program. They said many mental health, medical and disability services did not know about it.

Mental health providers and key stakeholders mentioned the same issue. This suggests information about the program could be better promoted.

Generally, a shortage of services limited access to support. Some gaps mentioned were, for example, professionals to do assessments, and NDIS services in rural areas. As program services were intensive and time limited, the number of people who could potentially access the program might also be limited. Many interviewees were concerned that some of the direct services offered by the program might not continue if the program ends.

The program might benefit from:

- wider promotion
- more services generally being available for people with intellectual disability and mental health.

4.3 Capacity of health services, disability and other support

Capacity building in the Residual Functions Program included both training and on-the-job collaboration in working with consumers. This was intended to build and share practical knowledge, skills and resources in the two sectors. Ultimately it was meant to meet the needs of consumers and families better.

Many staff (1153) participated in capacity building activities run by the programs, according to the available progress reports (**Appendix F**). The top two capacity building activities were defined as ‘other’ (n=437) and individualised activities (n=349). The activities with the least participation were clinical supervision (n=16) and group supervision (n=40).

Most staff who participated in the capacity building activities were from allied health and administration. Fewer participants were peer workers (n=9). Most participants were from NSW Health funded services (Mental health service: n=509 and health service n=174). Fewer participants were from private practice (n=18) and general practice (n=32).

Capacity building in the program seemed most successful where it combined both the elements of capacity building activities (like courses or webinars) and practical application (like case meetings or direct service provision).

Both mental health and disability providers voiced a strong commitment to working together to build capacity in both sectors and in other services that work with their consumers, such as NDIS providers, employment, housing and education. They saw capacity building as a way to:

- make the professional culture more open in both the intellectual disability and mental health sectors
- break down silos in service provision between the sectors
- question unhelpful assumptions about people with intellectual disability and mental health
- build professional relationships between the sectors, and with NDIS providers generally
- increase respective understanding
- draw on respective resources, for example NDIA information about NDIS services, access and assessment.

Despite the short timeframe of the program, most service providers and other stakeholders noted significant changes. They said capacity building had already changed support to people with intellectual disability and mental health needs. Examples included: disability services understood better the effects of trauma; less use of sedation to manage behaviour; and less fear in mental health services of working with people with intellectual disability.

More generally, some mental health staff now knew to ask the local mental health contact for information about NDIS and for solving problems in accessing NDIS. Some NDIS service providers now understood mental health better and they knew who to ask for advice and when to seek support. Therefore, they could better support mental health consumers than before the program.

Most service providers and other stakeholders felt that capacity building had the potential to improve service provision beyond the length of the program. Many were concerned that some changes might be difficult to sustain without the extra resources that the program offered. They felt the task to change culture and attitudes was immense. They said it might not be possible within the timeframe of the program to counteract many decades of negative assumptions and practice.

The program might benefit from:

- a plan for how to i) maintain training and collaboration and to maintain the culture change if the program finishes, and ii) continue to extend the reach to stakeholders outside NSW Health
- an evaluation of the impact that program activities have had on the capacity of different sectors to meet the needs of people with intellectual disability.

4.4 Availability of data

Service providers and other stakeholders said that data collection about people with intellectual disability and mental health problems was inadequate. They saw this as a barrier to offering adequate support. They also said data collection was a problem in all parts of the human service system, for example employment.

Some data issues mentioned for the Residual Functions Program were:

- consumers' needs were not recorded consistently when they went to hospital
- there was not enough data about consumers with intellectual disability in the mental health system, their pathways and outcomes
- service providers were confused about which data they should collect
- services needed to know who is missing out on mental health and NDIS support
- some clinicians were not keeping records of their direct service provision.

The program might benefit from:

- retraining hospital staff to record relevant data when people enter hospital
- efforts towards consistent data collection across IDMH sectors.

4.5 Culturally safe services

Service providers engaged interpreters when appropriate. The providers did not give examples of other strategies to ensure that services were culturally safe. It appeared that they may not have considered cultural safety for the consumer because the program was time-limited and specialised. Providers and stakeholders named the following reasons for the limited focus on cultural needs: lack of resources, lack of specific cultural expertise and lack of time.

When program services needed cultural expertise, they drew on mainstream culturally specific services within health and on partnerships with community services, such as migrant resource centres or Aboriginal Medical Centres.

Service providers reported that their person-centred, holistic services would include cultural elements if this was an identified need for the consumer and the family. One service provider's strategy was openness and willingness to learn. They asked each consumer and family 'what does disability mean for you?'

When consumers and families were asked about cultural safety, most said the inclusive and respectful nature of the service provision made them feel safe in the program. Some consumers and families found the question about cultural safety

confusing. They said that they did not have any specific cultural needs related to ethnicity. Others said safety strategies to meet the needs of people with intellectual disability and mental health problems were more important than cultural needs.

This could have implications for the way culturally safe services are offered to people with intellectual disability and mental health problems. An example might be: rather than using interpreters for people with little or no spoken language, a more culturally safe response would be meeting their particular ways of communicating:

> He doesn't speak any language, he just does sign. So I think the people at the community centre, they're also learning to sign to him now. He starts them on this journey. They also want to learn the sign language in order to communicate with him. (Family)

The program might benefit from:

- including cultural responsiveness expertise in program performance goals and resource allocations
- working with consumers, families and service providers to develop culturally appropriate responses.

4.6 Impact of COVID-19 on implementation

The program continued throughout 2020. Services adapted their support according to COVID-19 restrictions and guidelines. This ensured ongoing support while keeping consumers, families and service providers safe.

Key stakeholders and service providers reported that COVID-19 had slowed down program implementation, especially recruitment. The health sector's need for staff and other resources to respond to COVID-19 also affected the roll out of the program (**Section 3.1**). As a result, program staff said that some capacity building training was delayed or cancelled. Some coordination activities were also cancelled. Interview and focus group participants strongly supported an extension of the original timeframe to make up for these implementation challenges.

Some providers observed that COVID-19 increased their collaboration with Residual Functions staff in other LHDs so they could share resources and expertise. Some also said that there was more time to focus on education and other capacity building initiatives than there may have been before COVID-19.

The biggest legacy of COVID-19 so far appeared to be the use of telehealth. Some saw it as a necessary evil to endure during COVID-19 restrictions. Others saw it as an opportunity to set up longer-term systems that would improve program access when people lived far away or were too unwell to attend an appointment in person.

Some said the NDIS offered assistance for internet access during COVID. Most providers and consumers preferred face to face communication. All saw telehealth as a good option, if it was used by choice or specific circumstance rather than replacing face to face options:

> A boon has been that they've invested in better telehealth, so that's been good and we've now got the equipment that we were screaming for ages. (Staff)

Many consumers reported changes to their daily lives due to COVID-19. For example, they could not do some regular activities such as day programs, paid work, going shopping and catching public transport. Some group homes put on extra activities in-house. They also supported consumers to stay in touch with their families through phone, video and messaging. Most consumers looked forward to life going back to normal.

The program might benefit from learning from COVID-19 for future crises, for example:

- how to use online communication methods well for consumers' benefit.
- how mental health staff can work better with the person in their home when community access is difficult.

4.7 Program-wide implementation

Many service providers and other stakeholders commented on the implementation of the program overall. They spoke about its diversity across locations and about funding.

Program activities varied between locations (**Section 3.1**). For example, some locations concentrated more on improving direct service provision for consumers. Others focused more on coordinated activities and training, which would benefit consumers indirectly.

The program differed among LHDs because NSW Health had intended it that way. Each LHD could set up the program to suit their circumstances and needs. Some staff said there was no best practice model yet for this kind of coordination program. It was essentially a state-wide pilot program, and LHDs were working out what it could achieve as they went along.

Many staff said that a shared broad intention was sufficient and could be highly responsive to local needs. Some said more direction and feedback from the Ministry would help LHDs to learn from others and design their local program to make the most out of its opportunities. Some also said it would help to have a stronger

governance structure with committees that functioned well to unite experience, and more buy-in from the managers in the LHDs, Ministry and health settings.

Mental health staff said it had been good to have the flexible funds from the program to address gaps in the system. It appears the funds were applied pragmatically in response to immediate needs, rather than attempting to reach all consumers or services that might benefit.

All service providers and stakeholders said that recurrent funding was necessary for the future because people would always have these needs, so gaps would reappear once the funding changed. Service capacity would need to be continuously renewed. If the funding ceased, the positions and roles would no longer exist, so the lessons for service providers would be forgotten and consumers would be left with less appropriate support again.

All staff agreed the program was a good idea with much potential. Most service providers and other stakeholders stressed that the program had already achieved a great deal in a short time. But they said it could achieve much more if it went for longer.

What elements of the program were needed long term was not yet clear. Some said it was too soon to draw conclusions, others felt that long term funding of coordination roles was essential.

The program might benefit from:

- reviewing the governance structure
- sharing successes among the local programs
- exploring how the gains from the program could be sustained when funding changes.

5 Outcomes for consumers and families

The evaluation assessed outcomes of the Residual Functions Program for consumers and families. Intended outcomes are listed in the program logic (**Appendix A**). This section discusses:

- Health and wellbeing
- Services in the community (also called ambulatory services)
- Emergency department presentations
- Hospital admissions
- Length of hospital stays
- Impact of COVID-19 on outcomes.

Quantitative data were available only for Stream 1 of the program. Details of the quantitative results are in **Appendix G**.

5.1 Health and wellbeing

> Louise was referred to the program as part of her discharge plan from hospital ... Louise's medication was changed, and she became more settled and engaged. Now Louise's parents, Pat and Raj, are really enjoying her company – they had almost forgotten how funny she could be! The program also helped Pat and Raj apply for NDIS, and Louise is getting to know and trust new people who can help with personal care ... In a few weeks Louise is going to try respite in a house that they all visited. Louise is excited about the cats that live there. Pat and Raj are no longer dreading the future. **Appendix E**

The health and wellbeing of consumers in Stream 1 did not significantly change, as measured with the Health of the Nation Outcome Scales (HoNOS). An explanation might be the small sample size (n=33) and short follow up time of 3 months. The sample size of other mental health measures with a measurement both before and after starting in the program were too small to analyse (HoNOS 65+ for older people n=0; Health of the Nation Outcome Scales for Children and Adolescents HoNOSCA n=8; Kessler Psychological Distress Scale (K10) last month: n=16, and last three days: n=1).

Most consumers, families and service providers said that the program organised more and better support for people with intellectual disability and mental health (**Section 4.2**). They gave examples of how the program had improved the mental health and wellbeing of consumers and families.

Mental health improvements for consumers seemed to be largely because of more frequent, person-centred and trauma-informed approaches. This included a review of past treatments, medication and new NDIS support. As a result, consumers reported more confidence and independence and being more engaged in social activities:

> Now I'm off a lot of [medication], it really helps me be more focused, more alert, I'm not so always wanting to sleep … Now I find I want to live, I want to know people, I want to be able to do things and like [RFP doctor] really helped me come out of my shell. (Consumer)

> [I] have a [NDIS] case manager I see, and I have help doing other things, stuff like that. Like, getting out in the community. (Consumer)

Consumers' physical health also improved. Conditions such as epilepsy, insomnia or urinary tract infections were recognised and being better managed than before.

Service providers said that consumers often had more capacity to respond to the program if they had family support, and that many families were engaged in the program. Some risks arose from the program relying on family support. For example, a family carer did not take a consumer to an appointment at the psychiatry clinic because the carer forgot. This means the consumer missed out. It raises questions about how best to engage with both families and consumers (**Section 4.1**).

The program significantly improved family mental health and wellbeing. As families knew their family member was well supported, it allowed families to rest and engage in activities that enriched them:

> I feel that I don't have to stress so much … I can do things that I like to do. Just baking and things like that, which is my hobby. (Family)

Family relationships also improved. Family focus shifted from carer role to sibling or parent role because of better support and improved consumer wellbeing. Older family carers said they were less stressed because they knew that support was there for their family member as they aged. Louise's story in **Appendix E** illustrated these changes.

The program might benefit from:

- more support for consumers and families to attend appointments, for example transport and reminders
- exploring the reasons for the low use of mental health measures (HoNOS and K10) and developing strategies to support greater use.

5.2 Disability and mental health services in the community

Most consumers in the Residual Functions Program accessed services in the community rather than hospital services, according to the interviews. One provider estimated that 80% of their work was with people in the community (ambulatory services), while 20% was with hospital patients.

The quantitative data showed increased rates of community mental health treatment days after consumers joined Stream 1. The increases were statistically significant. The rate of treatment days increased by 69% per person per month. After starting the program, they were 2.7 times more likely to see a clinical psychologist, 2.4 times more likely to see a visiting medical officer psychiatrist, and 1.6 times more likely to see a psychiatrist registrar (during 90 days) than before joining the program.

The activities in community mental health services also changed, according to the quantitative data. The greatest increased rates in activities after the program were (during 90 days):

- skills, training, unspecific (3.53 times more likely)
- triage (3.06 times more likely)
- discharge client (2.2 times more likely)
- carer support (2.1 times more likely)
- case conference (1.9 times more likely)
- medication activity (1.88 times more likely)

The principal service categories also changed. The greatest increase in rates per 90 days were promotion, prevention or early intervention (11.20 times more likely), and emergency/acute - clinical/social (3.09 times more likely). Several aspects of the program seemed to improve access for consumers and families to community services:

- providers working together, for example in a multi-disciplinary clinic (**Section 4.1**)
- services located in the community, for example in a main shopping street or a community centre (**Section 4.2**)
- building capacity among staff in community mental health services (**Section 4.3**)
- flexibility about where the program supported consumers – for example in hospitals, community health centres or GP clinics.

The program might benefit from:

- an expanded focus on preventative health care initiatives
- the development of specific streams or clinical care pathways within community mental health services for people with intellectual disability
- capacity building that prioritises community clinicians so that they are able to meet the increased need demonstrated in the data.

5.3 Contact with hospitals

Consumers' contact with hospitals was probably affected by COVID-19 and the short time of 3 months for follow up data. Tables of the quantitative analysis are in **Appendix G**.

Emergency department presentations

The rate of emergency department presentations did not significantly change while participating in Stream 1 programs. The proportion of emergency department presentations resulting in an admission slightly reduced (from 23% to 19%), and the proportion of presentations in 2 triage categories reduced: resuscitation (from 20% to 16%) and urgent (from 43% to 37%).

One consumer said in the interview they went to emergency only once this year, since using the program. This was fewer than other years because the consumer now met a psychiatrist regularly for the first time. Service providers and other stakeholders thought the proactive support of the program reduced hospital admissions.

Some consumers mentioned in the interviews that they had been taken to hospital in an ambulance or a police car before the program. They found this stigmatising and humiliating. They would prefer to go to hospital in a car.

Admissions to NSW public hospitals

The number of hospital stays for mental and physical health increased for consumers in Stream 1, but psychiatric admissions did not significantly change. The 73% increase in the rate of inpatient episodes per person per month for all health hospital admissions was statistically significant. Consumers did not have a significant change in their rate of admissions to a mental health inpatient facility or the rate of unplanned admissions.

The more frequent hospital stays might be due to the small sample and short 3-month comparison. Or they might be because community mental health services in

the program identified mental and physical health needs that led to planned hospital stays.

There is some evidence from the interviews and focus groups that consumers in the program reduced contact with hospitals for their mental health. That could mean they were managing their intellectual disability and mental health with access to support in the community (**Section 5.2**).

Consumers in Stream 1 did not have a statistically significant change in the length of hospital stays (per person per month). The rate of re-admissions to a mental health inpatient facility was 19.4% before participating in the program and 29.4% after participating in the program. However, this change in the re-admission rate was not statistically significant, perhaps due to the small sample size.

The interview participants said that when a consumer entered the hospital, the program tried to ensure their mental health and intellectual disability needs were addressed as well as their physical needs. For example, when a consumer needed a scan, health workers might offer sedation to make the scan more comfortable for the consumer. Interviewees agreed the program was in its early stages. They said its collaborative approach offered an opportunity to learn from past experiences:

> …drawing on some examples where things have not gone very well, where somebody's repeatedly gone to ED and then ended up in hospital … it's good to use that as a learning exercise and say … at what point could we have … done things a little bit differently. (Staff)

Mental health staff said that they needed to make links for a consumer between mental health services and NDIS quickly, as soon as they were admitted to hospital. This was because it took a long time to organise NDIS support. The longer they waited to make links to NDIS, the longer the consumer had to stay in hospital. Making these links required appropriate data about consumers' intellectual disability (**Section 4.4**).

The program might benefit from:

- supporting hospital staff with good data about a consumer's characteristics, diagnosis and service needs and use, so they can link patients to the NDIS quickly, reducing the consumer's time in hospital
- following up consumers 12 months after participating in the program to see what impact the program had on contact with hospitals.

5.4 Impact of COVID-19 on outcomes

The assessed outcomes of the Residual Functions Program for consumers and families may have been impacted by COVID-19.

Many consumers said they missed out on community activities during the COVID restrictions (**Section 4.6**). Some service providers in supported accommodation were surprised at the positive spirit of consumers despite the changes. This observation helped to revise some preconceived ideas about consumers. Some providers also credited the ongoing support for consumers via the program during this time.

Some consumers found the social isolation difficult, and their mental health got worse during COVID. Others seemed to prefer the quiet times, and providers said they found it hard to encourage them back into their communities. Some key stakeholders spoke about the wider negative effect of COVID-19 on mental health and how it may increase the need for mental health programs.

Families applauded supported accommodation for increasing staff during COVID to replace day programs. Also, families said that contact with the consumers in supported accommodation did not suffer during COVID because of staff efforts to facilitate phone calls and COVID-safe visits.

The program might benefit from learning from COVID-19 for future crises, for example:

- how to address mental health issues that are due to social isolation.

6 Economic evaluation

The economic evaluation examined outcomes and benefits to consumers and families, the costs of the program, and an estimate of the number of consumers in the program over the short and long term. The analysis takes a base case of the quantitative outcome data for Stream 1 consumers and extends the base case by using conservative scenarios about further potential outcomes. It estimates program cost effectiveness for consumer groups during the study period and for potential outcomes over the following five years. This section provides a summary of the economic evaluation. Further detail is in **Appendix H**.

The program aims to develop mainstream mental and physical health care capacity that will improve access for people with intellectual disability and mental health needs. Without the program they might not have access or only have partial access. With the program, consumers and their families may have improved health, wellbeing and life expectancy.

The economic evaluation is based on the available consumer outcomes presented in Section 5. The economic modelling also used related findings from the 2020 Productivity Commission Inquiry into Mental Health. The evidence from that Inquiry is important because it can be applied to extend the analysis in the Residual Functions Program economic evaluation.

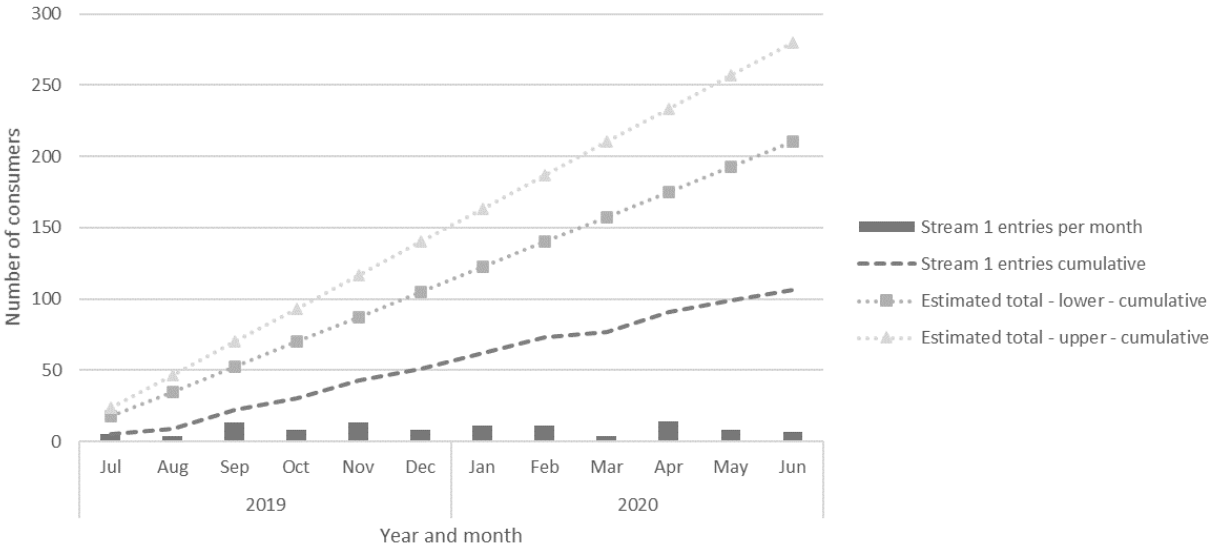
The Productivity Commission Inquiry examined service planning and reform in the wider mental health system. It recommended expansion of mental health services in Australia based on evidence of outcome effectiveness and related cost effectiveness (Productivity Commission, 2020). An overarching recommendation was to increase the efficacy of Australia's mental health workforce across developing skills, capabilities and collaboration. The recommendations are consistent with the aims and actions of the Residual Functions Program. They reflect the activities of the program including clinical services, consultation liaison, education, and capacity building activities.

The Productivity Commission health economic modelling indicated that service expansion is highly cost effective, including investing in community mental health (Productivity Commission, 2020). It established extensive modelling outcomes including Quality Adjusted Life Years (QALYs; see Section 6.4). Their estimated costs and benefits were very conservative, based on a single year of outcomes, which they argued are likely to be understated. The Residual Functions Program increases in community mental health services identified in the outcomes analysis (Section 5.2) are consistent with this aim of increasing service capacity and increasing access to support by people with intellectual disability.

6.1 Consumers in the program

The program Stream 1 provided funding to 10 LHDs and 2 SHNs. Stream 2 funded program clinicians to support the six ID Health Teams (Section 1). The number of Stream 1 consumers increased during the 12 months of the evaluation in 2019-20, Figure 1. By June 2020, 124 Stream 1 consumers had direct program support. The number of Stream 2 consumers was estimated based on the pre-program plan (Cvejic, Eagleson, Weise, & Trollor, 2018) because data about the actual number of consumers were not available. Stream 3 estimates were not included, although many consumers would also receive indirect benefits not captured in the conservative economic evaluation here.

Figure 1 Residual Functions Program total estimated consumer entries by month to June 2020



Sources: NSW Ministry of Health Mental Health Branch: Residual Functions Program data linkage (Stream 1), Program scoping study (Stream 2 estimated upper and lower median ranges). Stream 3 not included.
Note: Total cumulative figures include known Stream 1 plus estimated ranges for Stream 2.

6.2 Program costs

Funding of $4.1 million per year was provided for the NSW NDIS Residual Functions program to develop programs to better meet the needs of people with intellectual disability and mental health problems.

Program funding was approved for 3 years from 2018-19 to 2020-21, allocated across the 3 program Streams, Table 2. Delays to start-up in the first year and COVID-19 in the second year meant that some staff recruitment, training and coordination activities were delayed or cancelled. The delays meant that $2.7 million was not spent in year 1 and could not be spent in later years. Full budget allocation

started in 2019-20. The expected total program funding over the 3 years is $9.6 million.

Table 2 Residual Functions Program cost 2018-19 to 2020-21

Funding allocation	2018-19	2019-20	2020-21
Stream 1: LHD allocations	806,163	3,052,423	2,935,309
Stream 2: HSPB clinicians	453,000	906,138	906,138
Stream 3: Capacity building	50,000	100,000	100,000
Program evaluation	0	122,463	127,423
Total	1,309,163	4,181,024	4,068,870

Source: NSW Ministry of Health Mental Health Branch. Annual figures were not indexed.
Note: LHD=Local Health District, HSPB=Health and Social Policy Branch

The Residual Functions Program costs are aimed at achieving better access and use of existing community mental health service networks. In this context the program does not have large upfront costs in infrastructure and staffing.

6.3 Health service use and costs

The Stream 1 health services (Section 5) were used for the economic modelling of average health service use per month before and after program entry. This analysis was the base case for the modelling. The base case is the low cost effectiveness boundary for the models. The full-year program cost was averaged across the partial Stream 1 consumer group.

The Stream 1 health service use showed an increase in all hospital admissions and increased access to community mental health services (Section 5). This increased health service use was likely a positive outcome about better access to services when consumers needed them. Follow up data about health outcomes are not available, although the economic modelling includes the estimated cost of this improved health service use. Other research shows that improving access to services and improving the use of preventative and mainstream services, could lead to large cost offsets (Salvador-Carulla & Symonds, 2016).

Hospital admissions

The rate of all inpatient episodes per person per month increased, but the average length of stay (LOS) per admission did not change (Section 5). The hospital admission Diagnosis Related Groups (DRGs) show average LOS was higher than average LOS for all NSW reported DRGs. This is consistent with research showing higher use of health services for people with intellectual disability. Many consumers

had diagnoses associated with high costs of care. One quarter of admissions were for consumers with borderline personality disorders (15%) or schizophrenia (10%). Appropriate service use for consumers with these conditions can lead to positive outcomes and reductions in health service costs (Meuldijk, McCarthy, Bourke, & Grenyer, 2017; Hall, Caleo, Stevenson, & Meares, 2001).

Emergency department

Rates of emergency department presentations for Stream 1 consumers did not change (Section 5). Slight reductions were observed for emergency presentations that led to an inpatient admission and urgent presentations. The interviews indicated self-reported reductions in emergency use because of regular community clinical care.

Community mental health

The rates of community mental health treatment days, including increased access to clinical psychologists, visiting medical officer psychiatrist and psychiatric registrars all increased (Section 5). The interviews found the same benefit. This is reflected in the economic modelling through the increased cost of community-based support and the related K10 mental health outcome scores.

6.4 Health outcomes

Change in health and wellbeing of consumers in Stream 1 seemed positive but was not statistically significant due to the small number of post program K10 scores, as explained in Section 5.1. People in the interviews said that better access to support had improved the mental health and wellbeing of consumers and families.

Program cost effectiveness measures or estimates consumer outcomes and costs. This section describes how the health outcomes were estimated. It generates a conservative base case to analyse estimated cost effectiveness scenarios based on NSW data and published literature.

Health related quality of life (HRQoL) is a common measure in health economic evaluations including mental health (Luyten, Naci, & Knapp, 2016). It is measured with surveys before and after a program. The information is then used to estimate Quality Adjusted Life Years (QALYs). QALYs measure health outcomes as length of life and health-related quality of life. The Residual Functions Program did not have surveys like this.

Other health economic research addresses this gap by using validated correlations between the Mental Health National Outcomes and Casemix Collection (NOCC)

reporting protocols and common quality of life instruments including the Australian developed Assessment of Quality of Life (AQoL) (Mihalopoulos, Chen, Iezzi, Khan, & Richardson, 2014). This work includes the K10, which is part of Residual Functions Program reporting. It is an innovative approach to use these methods in mental health program evaluation with no additional administrative effort or cost.

The analysis estimated QALYs by using K10 scores from NSW data. The K10 data in the program indicated possible improvement in mental health. But the data were insufficient to use in the economic evaluation because the sample was too small and the 3 month time too short to measure change (Section 5.1).

To supplement the small program sample of consumers, K10 scores in the NSW community mental health (ambulatory) data were compared for consumers with similar diagnoses as the Residual Functions Program consumers. These NSW K10 scores were consistent with (slightly lower) the scores in the small sample for the program. Table 3 compares K10 scores from the program to NSW scores in NOCC (AMHOCN, 2019) for NSW adults receiving community mental health services during 2018-19. K10 scores improved over time in both groups and across all diagnoses.

The purpose of the comparison is that it shows a similar possible improvement in K10 scores for consumers in the program to the range of improvements in the larger NSW group of consumers. The process validated using the K10 scores in the economic modelling.

Table 3 Residual Functions Program and NSW community mental health K10 scores 2018-19

	Residual Functions Program				NSW community mental health (NOCC)			
Diagnosis	**n**	**%**	**K10 before**	**K10 after**	**n**	**%**	**K10 before**	**K10 after**
Schizophrenia [1]		14%			3238	45%	21.2	17.0
Mood Disorders		4%			889	12%	29.4	22.8
Personality Disorders		27%			293	4%	31.5	28.8
Other Mental Disorder		28%			1914	27%	26.4	20.6
Total	12	100%	28.7	24.6	7229	100%	27.3	20.2

Source: InforMH Residual Functions Program data linkage and Australian Mental Health Outcomes and Classification Network (AMHOCN) data cube reporting for NSW adult K10+LM scores for MH ambulatory reporting 2018-19

Notes: 1. Schizophrenia grouped with Paranoia and Acute Psychotic Disorders. Shaded cells indicate sample sizes <5 not reported to protect confidentiality. NOCC sample size based on reported follow up scores where diagnoses are more comprehensive. Percentage columns do not sum to 100% as minor diagnosis groups have been excluded.
2. NOCC scores are new referral consumers (before program entry) and 91-day review point following commencement of support services.

6.5 Program cost effectiveness

The cost effectiveness analysis combines the costs of the program (Table 2) with the cost of the changes in health services of the Stream 1 consumers, compared to the estimated QALYs from the K10 scores (Table 3) (Mihalopoulos et al., 2014). This section presents estimated ranges of cost effectiveness used in the Productivity Commission (2020) inquiry. These ranges indicate increasing estimated cost effectiveness to the left of each figure.

The cost effectiveness analysis is only partial because:

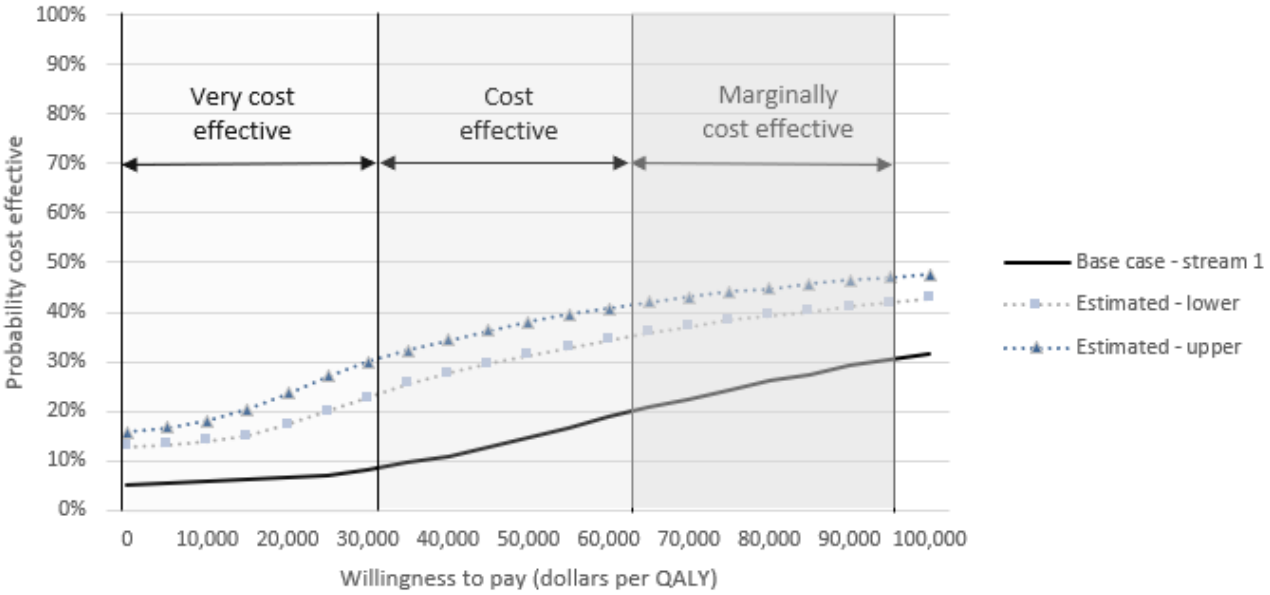
- data were not available about all consumers
- the health service use was only short term
- the clinical endpoints were not available to measure outcomes.

The aim of this modelling approach is to present a conservative framework that can be used to examine possible future outcomes. Details of the methods and assumptions are provided in Appendix B, and further details of results are included in Appendix H.

Program base case benefit to consumers

Figure 2 shows a low probability of even marginal cost effectiveness (about 30%) for the base case of Stream 1 consumers (the solid black line). The low probability of cost effectiveness is expected because it only includes the partial short term Stream 1 consumer outcomes and total program costs.

Figure 2 Program cost effectiveness – base case benefit to consumers



Sources: NSW Ministry of Health Mental Health Branch: Residual Functions Program cost data and data linkage (Stream 1), Program scoping study (Stream 2 estimated upper and lower median ranges). Stream 3 not included.

Notes: Total cumulative figures include known Stream 1 plus estimated ranges for Stream 2. Estimated over a 5 year timeframe.

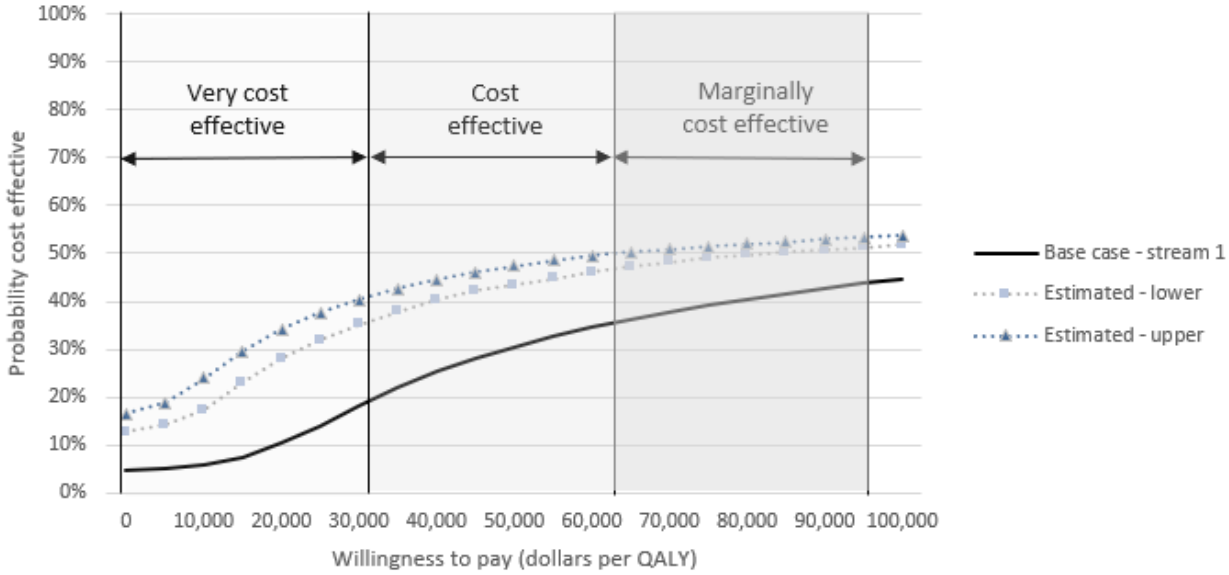
Figure 2 also shows that results improve to near the marginally cost-effective range when Stream 1 and 2 consumers are both included (the dotted lines), although the estimated results have many uncertainties. The base case is consistent with the interviews, which showed improved mental health and wellbeing due to better access to support that suited consumer needs. The consistency suggests that the wellbeing improvements in the small base case in Figure 2 probably underestimate the program's health-related quality of life benefits.

Benefit to consumers and potential benefit to family and carers

The cost effectiveness could also be higher than the base case if quality of life improvements to family and carers are included. The interviews found that the wellbeing of family and carers improved because of better support to consumers and their families. The Productivity Commission Report (2020) found similar benefits to families that contributed to cost effectiveness.

Figure 3 shows that cost effectiveness would increase if it was assumed that the program achieves even a small (0.2 QALY) improvement for a single family member or carer. Only interview data were available to support this assumption. Family and carer outcomes data are not currently measured in the program.

Figure 3 Program cost effectiveness – benefit to consumers, family and carers



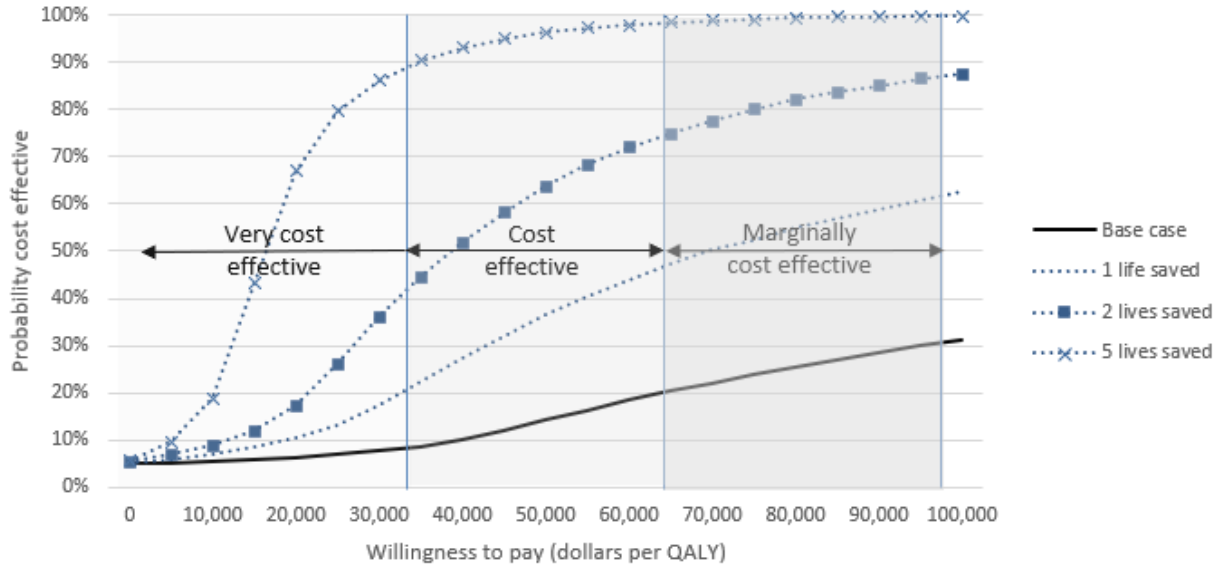
Source: NSW Ministry of Health Mental Health Branch: program cost data and data linkage Stream 1. Residual Functions Program cost data.
Notes: Total cumulative figures include known Stream 1 plus estimated ranges for Stream 2. Assumption of 0.2 QALY improvement for one family member or carer. Estimated over a 5 year timeframe.

Potential deaths avoided

An additional perspective to analyse cost effectiveness is to consider potential deaths avoided due to better access to services in the program. The program did not collect data about premature death, but the outcomes analysis showed better access to health services (Section 5), which reduces the risk of premature death. As many as 38% of deaths of people with intellectual disability may be avoidable if people had better access to health care (Trollor, Srasuebkul, Xu, & Howlett, 2017).

Figure 4 shows that the estimated cost effectiveness increases with the assumption of at least one death avoided. A single death avoided shifts the results to the marginally cost effective range. Five deaths avoided could shift the estimated result to the very cost effective range.

Figure 4 Program cost effectiveness – potential deaths avoided



Source: NSW Ministry of Health Mental Health Branch: program data linkage. Residual Functions Program cost data. The model discounts all costs and outcomes at 3.5% per year
Notes: Stream 1 consumers only. Estimated over a 5 year timeframe.

Figure 4 is based on cautious estimates of possible outcomes, where a 1% reduction in death is the same as 2 deaths avoided, and a 5% reduction could potentially lead to over 10 ID deaths avoided.[1] The analysis uses a conservative scenario to add QALYs based on estimated lives saved.[2] The outcome from avoidable deaths could also result from multiple consumers having extended life years for part of the model 5 year timeframe.

Cost effectiveness of the benefit to consumers and other potential benefits

The analysis shows that the likelihood of the program being cost effective increases substantially when preventable deaths avoided or potential benefits to families and carers are also included (Table 4).

Table 4 shows the benefits to consumers as the starting point, with a conservative gain of 0.7 QALY, over the 5 year model horizon. Improvements to quality of life outcomes for family and carers increase the gain to 1.4 QALYs, which is potentially in the marginally cost-effective range. Preventable deaths avoided add even more gains of at least 2.9 QALYs, which are in the cost-effective and very cost effective ranges. The potential benefits from family and avoided deaths are analysed independently in these scenarios, but combining them could result in further

[1] Based on 1% * 278 potentially avoidable deaths = 2.8
[2] 0.52 QALYs per year for 5 years = 2.6 QALYs per death avoided.

increases in total program cost effectiveness. These potential benefits are presented as conservative plausible examples of program benefits subject to longitudinal assessment when data are available.

Table 4 Residual Functions Program cost effectiveness results

	Cost		Effectiveness		
Base case and potential benefits	**Total cost**	**Additional cost**	**QALYs**	**Additional QALYs**	**Cost per QALY**
Base case - consumers					
Comparison: Before program	$69,632		3.5		
Program base case	$276,119	$206,487	4.2	0.7	$293,977
Estimated Stream 2 - lower range	$190,048	$121,071	4.2	0.7	$176,162
Estimated Stream 2 - upper range	$167,939	$98,348	4.2	0.7	$130,827
Family and carers*					
Comparison: Before program	$69,678		7.0		
Program consumers, family and carers	$278,257	$208,579	8.4	1.4	$148,256
Estimated Stream 2 - lower range	$189,973	$119,996	8.4	1.4	$86,870
Estimated Stream 2 - upper range	$165,686	$96,825	8.4	1.4	$63,915
Deaths avoided					
Comparison: Before program	$69,387		3.5		
1 death avoided *	$277,160	$207,773	6.4	2.9	$72,021
2 deaths avoided **	$279,371	$209,198	8.6	5.1	$41,210
5 deaths avoided ***	$277,517	$207,633	15.1	11.6	$17,841

Source: NSW Ministry of Health Mental Health Branch: program data linkage. Residual Functions Program cost data.

Notes: Cost effectiveness is the estimated costs per QALY. * Marginally cost effective range. ** Cost effective range. *** Very cost effective range. Estimated over a 5 year timeframe.

6.6 Summary

The economic evaluation examined Residual Functions Program funding in the context of outcomes from the quantitative analyses and qualitative interviews. The program cost is $4.1 million per year. In the first year, delays to implementation resulted in an underspend of $2.7 million, which was not shifted to later years.

The analysis shows that the program is achieving its primary goal of improving appropriate access to community mental health services and possibly inpatient care. The economic model established a base case of all program costs, plus the additional costs of the increased mental health services used. The base case finding is a cautious partial estimate and does not indicate program cost effectiveness. It is a minimum basis to examine the extended scenarios. Limitations in the model were a short 3-month comparison, a small sample and incomplete data linkage.

The program cost effectiveness was examined by comparing quality adjusted life years (QALYs) from the conservative base case to extended conservative scenarios. These comparisons suggest the program is potentially cost effective. More longitudinal data analysis should investigate medium and longer term outcomes to confirm this finding. The base case for the QALYs was estimated from the consumers' reported mental health measured by Kessler 10 (K10). The scenarios were about the number of consumers and potential outcomes for consumers, family and carers, including avoided deaths, based on what is known in literature.

The economic evaluation was undertaken in the context of the recent Productivity Commission inquiry into mental health in Australia. The inquiry recommendations include substantial reform and expansion in mental health services, such as community-based supports, with emphasis on developing equitable access. The inquiry established comprehensive economic analysis. This indicates that expanding mental health services is highly cost effective, including from a cost per QALY perspective as undertaken in the preliminary program modelling. This implies that programs such as the Residual Functions Program aimed at improving access to mainstream mental health services are likely to support improved outcomes, program effectiveness and related cost effectiveness.

7 Implications for NSW Health

The evaluators considered what the evaluation findings meant for NSW Health and support for people with intellectual disability and mental health problems. The implications are summarised below in three topics. These topics cover the program outcomes in the program logic (**Appendix A**). The implications apply to the remainder of the Residual Functions Program in 2021 and to similar mental health services in the future.

1. Program design and governance

Differences between the programs across the various LHDs helped because they could respond to local issues. It appears useful to have consistency in principles for service design and a well-functioning, overarching governance structure. NSW Health might consider how to:

- organise governance for IDMH, like committees and advisory groups, to make the program most useful
- provide feedback and direction for the remainder of the program to maximise any improvements
- share successes among the local Residual Functions programs and similar NSW programs
- involve peers with lived experience in shared learning
- plan to maintain improvements to service collaboration, culture and consumer support after the program changes
- work towards a consistent approach among LHDs, so that all consumers have access to clinical support and coordination between mental health and intellectual disability (NDIS) support, and their diverse needs are met, such as culture and location.

2. Service coordination and capacity

Better coordination and capacity among local services were a focus of all LHD programs. The varied local experiences led to some general lessons that NSW Health could apply to similar, future programs:

- It is important to have a funded, ongoing local LHD position to liaise between local mental health services, consumers and disability providers.
- In addition, local LHD positions are needed across NSW to coordinate with each other and with the centralised IDMH Hubs. The two IDMH Hubs in

Sydney offer training to health professionals and some clinical advice and support to professionals and consumers across NSW.

- The local and statewide coordination tasks mentioned above may be done by the same person in an LHD or by different people. NSW Health might consult with the LHDs on which is most useful.
- A local NDIA contact point to liaise with local mental health services is also necessary, because the many individual NDIS providers cannot do that.
- Local service providers need ongoing opportunities to share good experiences and practice. Examples are interagency groups and communities of practice.
- Use the 3DN training and resources already available.
- Support hospital staff to record comprehensive data when people enter hospital, including disability, culture and family support.
- Aim for consistent data collection across IDMH.

3. Consumer access to support

The program funding helped to address gaps in intellectual disability and mental health services. Consumers appreciated better access to support that was more appropriate and more respectful than before. People in the evaluation interviews and focus groups suggested that NSW Health should explore how to:

- Offer ongoing specialist services for people with intellectual disability and mental health
- Assist generalist services to be more accessible and respectful of people with intellectual disability and mental health needs
- Provide coordinated, intensive support to consumers with high support needs, to at least partially address the gap left by the ISR coordination program
- Work with consumers, families and service providers to develop culturally appropriate responses
- Use telehealth when consumers prefer it
- Support consumers and families to attend appointments, for example transport and reminders
- Address mental health issues that are worsened by social isolation, for example from COVID-19
- Promote any future IDMH programs and resources to consumers and all the people who might make referrals, including LHDs, GPs, pharmacies, NDIS, disability and mental health providers, Mental Health Line, Headspace.

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

Program logic summary

Funding for Streams	Activities in Streams	Process outcomes	Outcomes for direct consumers
1. LHD programs	- Clinical services - Consultation liaison - Capacity building - Education	- Health and service providers have better partnerships - Health services offer better specialist support - IDMH consumers leave hospital faster - IDMH consumers have better access to support - Mainstream clinicians provide better support to people with IDMH - More and better data on IDMH consumers and services	- Improved wellbeing - Fewer visits to emergency - Fewer hospital admissions - Less time in hospital - More use of outpatient services - Improved cost effectiveness of support
2. IDMH clinicians	- Consumer access - Assessment and clinical care - Support for staff		
3. Capacity building	- Centralised management of capacity building		

Full program logic

<table>
<tr><th>Inputs</th><th>Activities</th><th>Outputs</th><th>Process outcomes</th><th>Outcomes for direct consumers</th></tr>
<tr><td colspan="2">Funding
$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
Direct consumers: new clinical care Stream 1, 2
Indirect consumers: enhanced service capacity Stream 1-3
Funding is used for 3 program Streams:</td><td rowspan="2">Funded LHDs, SHNs, Clinicians and central agencies implement funded services; outputs vary according to service</td><td rowspan="2">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)
Improved access to appropriate services for people with intellectual disabilities and mental illness, including people with ID who may not traditionally access mainstream mental health services
Improved capacity of health services to provide</td><td rowspan="2">Reduced rates of emergency department presentations
Reduced rates of unplanned in-patient admissions
Reduced re-admission rates to inpatient facilities
Reduced length of stay in an inpatient facility
Increased numbers of people with ID accessing ambulatory mental health services
Increase in community episodes of care for people with ID
[Potential inclusion of measures of wellbeing, mental health in the evaluation – K10,</td></tr>
<tr><td><u>Stream1: Local Health District programs</u>
10 Local Health Districts (LHDs) and 2 Specialty Health Networks (SHNs) received funding to facilitate enhanced clinical, coordination and capacity building services</td><td>
<table>
<tr><th>Organisation</th><th>Program</th><th>Service elements</th></tr>
<tr><td>Central Coast LHD</td><td>0-12 year old clinical service</td><td>Clinical service
Consultation Liaison
Capacity Building</td></tr>
<tr><td>Hunter New England LHD</td><td>Clinical Team</td><td>Clinical service
Consultation Liaison
Capacity Building</td></tr>
<tr><td>Justice Health and Forensic Mental Health Network</td><td>Custodial ID and MH Transitions</td><td>Clinical service</td></tr>
<tr><td>Murrumbidgee LHD</td><td>Clinical service and brokerage</td><td>Clinical service
Consultation Liaison
Capacity Building</td></tr>
<tr><td>Northern Sydney LHD</td><td>Education and enhancement of existing IDMH team</td><td>Capacity Building
Education</td></tr>
<tr><td>Sydney LHD</td><td>Allied health clinician</td><td>Clinical service
Consultation Liaison
Capacity Building</td></tr>
<tr><td>Sydney Children’s Hospital Network</td><td>Clinical enhancement</td><td>Clinical service
Consultation Liaison
Capacity Building</td></tr>
<tr><td>South East Sydney LHD</td><td>Adolescent transition clinic</td><td>Clinical service
Consultation Liaison</td></tr>
</table>
</td></tr>
</table>

<table>
<tr><th>Inputs</th><th>Activities</th><th>Outputs</th><th>Process outcomes</th><th>Outcomes for direct consumers</th></tr>
<tr><td></td><td><table>
<tr><td></td><td></td><td>Capacity Building</td></tr>
<tr><td>South West Sydney LHD</td><td>NDIS Pathways Clinician</td><td>Consultation Liaison
Capacity Building</td></tr>
<tr><td>Southern NSW LHD</td><td>IDMH Clinic</td><td>Clinical service
Consultation Liaison
Capacity Building</td></tr>
<tr><td>Western NSW LHD</td><td>IDMH Clinic</td><td>Clinical service
Consultation Liaison
Capacity Building</td></tr>
<tr><td>Western Sydney LHD</td><td>Clinical team</td><td>Clinical service
Consultation Liaison
Capacity Building</td></tr>
</table></td><td></td><td>specialist care for people with intellectual disability and co-occurring mental illness and for their families and carers

Improved patient flow through acute MH facilities due to better coordination and discharge planning

Mainstream clinicians:
- have more exposure to people with ID
- can access expert support and advice from IDMH clinician
- report increased capacity and confidence to provide care for people with ID

- report improved access to specialist</td><td>HoNOS, HoNOSCA, NDIS]

Improved cost effectiveness of mainstream mental health services based on healthcare cost offsets for outcomes mentioned above</td></tr>
<tr><td><u>Stream 2: IDMH Clinicians</u>

An IDMH Clinician was funded in each of the six ID Health Teams across NSW, to provide clinical and capacity building supports

Locations:
• Northern Sydney LHD
• South East Sydney LHD - Kogarah Assessment Service
• Sydney LHD
• South West Sydney LHD
• Hunter New England LHD
• Western NSW LHD</td><td>- facilitate improved access to appropriate psychological and mental health care for people with intellectual disability and mental health

- may provide assessment and short term clinical care

- support the increased capacity of the Ministry and mental health staff to build skills and confidence to work with people with intellectual disability and mental health</td><td></td><td></td><td></td></tr>
</table>

Inputs	Activities	Outputs	Process outcomes	Outcomes for direct consumers
<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 intellectual disability and mental health, and improved support for their families and carers	Capacity building resources	diagnostic and assessment services Improved data on: - Service activities - Prevalence of people with ID in MH services - Access to MH services for people with ID - Codesign of metal health services delivery	

Appendix B Details of evaluation methods

The evaluation assessed the processes, outcomes and economic costs and benefits of the Residual Functions Program. **The evaluation aims** were 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 used a mixed methods approach as described in **Section 2.** The information (or data) collected was measured against the program logic (**Appendix A**) and evaluation aims to assess the effectiveness and outcomes of the program.

Throughout the evaluation we used inclusive and culturally sensitive approaches to data collection and analysis. They are described in this section, followed by the different parts of data collection and analysis:

- Review of program documentation
- Qualitative interviews and focus groups
- Analysis of quantitative data
- Economic modelling and program cost effectiveness analysis

Inclusive and culturally sensitive approaches

The evaluation included **inclusive and culturally relevant approaches** to data collection and analysis. This was particularly important as the Residual Functions

Program supports marginalised population groups (people with intellectual disability and co-occurring mental illness).

The qualitative data collection used a participatory research design. This included peer-based research methods for interviews. It also included research team members with lived experience. These approaches ensured that the research was sensitive to the needs of people with intellectual disability and lived experience of mental health challenges. The lived experience research was organised by the research team's mental health peer researcher. NSW Council for Intellectual Disability supported lived experience researchers with intellectual disability.

The research was also sensitive to the needs of people from Aboriginal and from culturally diverse backgrounds. The evaluation team included advisors and researchers from these groups. During the fieldwork, we ensured that the interviewees had access to cultural support from appropriate people who understood and identified with the culture of the interviewee.

Review of program documentation

The evaluation reviewed Residual Functions Program documentation as available, see **Section 2**.

Qualitative interviews and focus groups

The evaluators conducted interviews and focus groups with program stakeholders as described in **Section 2**.

Interviews and focus groups assessed Residual Functions Program support, satisfaction, outcomes and innovation arising from the program as well as opportunities to improve service quality and effectiveness.

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

Service providers **identified** consumers and families who had been in the Residual Functions Program the longest to collect the most meaningful outcome data and experiences of the program. Service providers also considered 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 gender, age, cultural background, location and mental health and intellectual disability.

Service providers in the fieldwork sites were identified through discussions with site managers. Other stakeholders included managers and staff from all Residual

Functions programs across the state and relevant referral agencies. They were invited by the Ministry.

We **spoke** to consumers face-to-face, or on the phone if that was their preference. Families were interviewed face-to-face, or by phone or video. Local LHD managers and staff and other relevant local service providers were interviewed during the site visits individually, 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 were invited to individual interviews or small focus groups, depending on practicality and their preferences.

All interviews and focus groups were **semi-structured**. Semi-structured means that the interviewer (person asking the questions) flexibly uses a list of suggested questions. The interviewee (person being interviewed) can respond or not, or they can give more information if they choose. Questions were in inclusive, accessible formats such as easy read or pictures, where appropriate.

Interviewers included the university researchers who were trained in inclusive methods and the Lived Experience Researchers (also called peer researchers) with intellectual disability and/or mental health issues. Interviewers were also supported by evaluation advisors from Aboriginal and from culturally and linguistically diverse (CALD) backgrounds.

In response to the **COVID-19** pandemic, we developed strategies to protect interview participants and researchers during fieldwork. The strategies included social distancing and hygiene measures consistent with health advice. Where consumers and service providers preferred, we conducted interviews remotely.

Recruitment processes

How people were invited to participate in interviews and focus groups was decided during the co-design phase of the evaluation. This ensured that the process fitted with the Residual Functions Program, the consumer group and the fieldwork locations. The process is described below.

Recruitment of program consumers and family members: Consumers and family members were invited by service providers to share their experience.

- **Step 1**: The evaluators gave service providers information and resources to help them explain the research to possible interviewees. This included information that ensured the consumer and family member understood that they could choose to participate or not, to make sure that people did not feel like they had to do it.

- **Step 2**: Service providers made initial contact with the consumers or family members, provided information about the evaluation and obtained permission to pass their contact details on to the evaluators or to set up an interview time.

Recruitment of service provider staff and other stakeholders: Service provider managers in the fieldwork sites identified suitable staff for the interviews and asked them if they would like to participate. Other stakeholders were invited by the Ministry to participate.

Consent processes

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

The **consent process for consumers and families** involved the following steps:

1. SPRC produced information sheets and consent forms about the evaluation written in an accessible way for consumers and families, with advice from service providers about length, design and wording

2. Service providers talked through the information sheets and what the evaluation involved with consumers and families

3. Researchers collected informed consent from consumers and families before the interviews. A spoken consent could be recorded.

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

1. SPRC produced information sheets and consent forms about the evaluation

2. The Ministry or service providers forwarded the information sheet to nominated participants

3. Researchers collected informed consent before the interviews/focus groups. A spoken consent could be recorded.

Analysis of qualitative data

The data from the interviews and focus groups were thematically **analysed** against the evaluation aims and the program logic. This means that the evaluators looked at how what people told them fitted with the questions that the evaluation aimed to answer and with the intended outcomes of the program. The interview and focus group data were examined and sorted into themes using analysis software called NVivo.

Analysis of quantitative data

Program data sources

Stream 1 data

InforMH, Systems Information and Analytics Unit, NSW Ministry of Health, identified individuals in our cohort using a unique identifier (State Unique Patient Identifier, or "SUPI"). They then linked our cohort to relevant administrative health data sets (NSW Admitted Patient Data Collection, NSW Ambulatory Mental Health, and NSW Emergency Department Data Collection, NSW Mental Health Outcomes Collection).

Data for each participant was extracted for one year prior to enrolling in the program and three months after. Data was available for 9 of the 12 programs.

Stream 2 data

Ministry of Health collated the Stream 2 data from LHD reports.

Stream 3 data

The quantitative data reported in the available quarterly progress reports completed by each of the programs.

Program data analysis

Stream 1 data

We used the self-controlled case series method to compare health service use patterns, participant wellbeing and mental health outcomes before and after enrolment in the program. We considered data up to one year prior to an individual's enrolment date to be the pre-exposure (control) period, and data up to three months after the enrolment date to be the post-exposure (risk) period.

Poisson regression with fixed-effect models were used to determine whether rates of health service utilisation in the post-exposure period differed from the rates in the pre-exposure period. Variables that did not vary within an individual (e.g., sex, remoteness, and socioeconomic status) were not included in the model. We chose this method because we are unable to identify a control group of people with ID who did not access the Program. This is because ID is not recorded in the data routinely collected across NSW health services.

The analysis explored how the program impacted on health service utilisation across emergency, admitted, and community based public mental health services, including:

i) rates of emergency department presentations

ii) rates of unplanned in-patient admissions

iii) re-admission rates to inpatient facilities

iv) length of stay in an inpatient facility

v) treatment days in ambulatory mental health services

vi) health outcomes as measures on the Health of the Nations Outcome Scales (HoNOS, HoNOSCA, and HoNOS 65+) and Kessler-10 Scales (K-10).

Descriptive analyses were undertaken to explore the demographics of the cohort and type of community mental health services that they participated in.

Stream 2 data

Descriptive analyses were completed.

Stream 3 data

Descriptive analyses were completed on the available quantitative data. These analyses explored:

i) the numbers of people who participated in the activities

ii) the types of capacity building activities

iii) the professional background of people who participated in the activities

iii) which sector the people who participated in the activities came from.

Economic modelling and program cost effectiveness analysis

Program data sources and timeframes for economic modelling

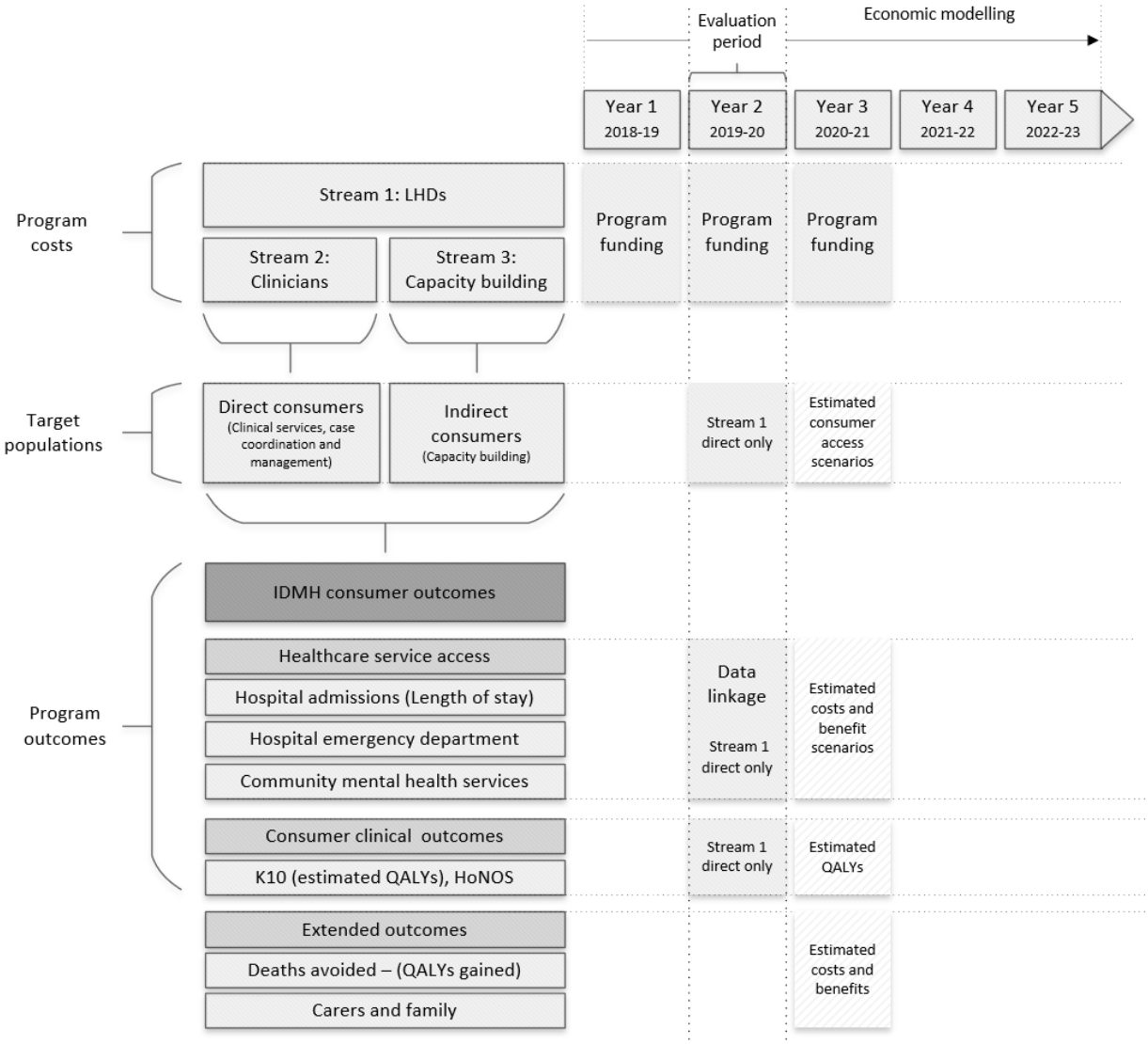
Development and implementation of the Residual Functions Program commenced in 2018-19 (year 1) providing the first complete operational year for the evaluation period in 2019-20 (year 2), Figure 5. Year 3 of the program (2020-21) was in progress at the time of the evaluation and years 4 and 5 are developed in the economic modelling to examine projected outcomes over a 5-year timeframe.

The Residual Functions Program supports consumers directly through Streams 1 (LHDs) and Stream 2 (clinicians) as well as indirectly through capacity building initiatives (Stream 3). The target populations for the economic evaluation were expected to be based on study cohorts identified through the data linkage. As only

Stream 1 data linkage was available within the evaluation period, Stream 2 consumer numbers are incorporated based on figures provided by the Ministry.

The available outcome data provide health service use as an interim endpoint. The changes in health services examined through the quantitative analyses before and after entry into Stream 1 reflect changes in access, but do not yet provide follow up data for clinical outcomes over the medium and longer term. For this reason, the economic starting point examines all program costs combined with changes in health service resource use and cost and builds supplementary scenarios to examine projected outcomes beyond the study period timeframe.

Figure 5 Program economic evaluation component summary and timeframes



LHD Local Health Districts, QALY Quality Adjusted Life Year

The economic analysis incorporates the Kessler 10 (K10) as a clinical outcome and develops modelling scenarios to examine extended outcomes based on published

research including potential avoidable ID deaths prevented and benefits for carers and families.

Program cost data

Program funding and cost data are available as aggregate annual budgets across the 3 program Streams for the complete 3 financial years from 2018-19 to 2020-21. Actual program spending is available for years 1 and 2 as at the time of the evaluation. As 2019-20 is the first fully operational year this has been used for calculating average costs per consumer per month for time series alignment with health services provided to consumers before and after entry to the Program. As outcome linked data are only available for Stream 1 consumers the total Residual Functions Program cost for 2019-20 has been used as the basis for average cost per consumer calculations.

Program cost offsets are estimated using the changes in quantities of health service resource use combined with unit costs. All costs have been indexed to 2019-20 Australian dollars using the Australian Bureau of Statistics health index .

Target populations

The numbers of direct program consumers include Streams 1 and 2 covering clinical support services, case coordination and management. Stream 1 consumer numbers are available through the data linkage and Stream 2 are estimated in ranges based on Ministry reporting. This provides a conservative base case calculated from Stream 1 consumers with extended Stream 2 consumer scenarios to assess the estimated change in average program cost per consumer.

The Residual Functions Program reach for consumers receiving improved care indirectly through Stream 3 capacity building activities is unknown. Estimated target populations have been reviewed based on IDMH planning in NSW. Indirect program contribution to outcomes are examined as scenarios based on the estimated NSW ID population.

Program outcomes

The quantitative linked data analyses for Stream 1 have been used in the economic evaluation to examine health resource use before and after entry to the Residual Functions Program. This includes hospital admissions and lengths of stay (LOS), emergency department presentations as well as community mental health services. The changes in health services following program entry establish cost offsets in the cost effectiveness analyses where services decline, with short term increases in hospital admissions, for example, reflected as program related health cost increases.

The health service use data provide an interim outcome used to assess whether the program is supporting improved system access for people with ID. Due to the limited study period timeframe this potentially focuses on short term increases in health costs, which is likely to be a positive outcome, without follow up data on consumer outcomes in the medium and longer terms, which may also be positive.

To articulate the preliminary timeframe of the evaluation the economic model base case includes only data available through the Stream 1 health linkage, as well as all program and health cost data. This defines a partial segment of the program as a basis to examine estimated costs and outcomes through extended scenario modelling based on supplementary data and relevant published literature.

Economic outcomes

The economic evaluation also aimed 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. The limited K10 before and after data linkage were examined in comparison with NSW published K10 reporting for a similar cohort to estimate changes in Quality Adjusted Life Years (QALYs) (AMHOCN, 2019). The K10 scores before and after program entry have been used to estimate QALYs using bridging transformation algorithms (Mihalopoulos et al., 2014). 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.

Health service use and costs

Health costs before and after engagement with the program were calculated based on services used from the data linkage quantitative analyses and valued based on unit costs using published sources and Australian Refined Diagnosis Related Groups (AR-DRGs), Table 5.

Table 5 Model parameters used in economic modelling

Parameter	Unit	Value	Distribution	Range	Source
Costs					
Admissions program	Per day	$2,145	LOS		1: Calculated from DRG
Admissions Pre program	Per day	$1,729	LOS		1: Calculated from DRG
Admitted LOS program	days	3.6	Gamma	SD 6.5	program data linkage
Admitted LOS Pre program	days	2.2	Gamma	SD 4.2	program data linkage
Emergency Department	Per presentation	$718	Constant		2: NHCDC Round 22
MH Ambulatory	Per day	$503	MHAMB LOS		3: IHPA round 22
MH-AMB LOS program	days	3.6	Gamma	SD 6.5	program data linkage
MH-AMB LOS Pre program	days	2.1	Gamma	SD 4.2	program data linkage
Outcomes					
QALY program	QALY weight	0.52	Beta	SD 0.13	4: K10 bridging algorithm
QALY Pre program	QALY weight	0.5	Beta	SD 0.26	4: K10 bridging algorithm

DRG = Diagnostic Related Group

Sources:

1: Independent Hospital Pricing Authority, DRG cost weights, round 22.

2: Appendix 16. NHCDC Round 22 Emergency Department line-item average cost per separation, actual, by jurisdiction

3: IHPA National Hospital Cost Data Collection Report: Public Sector, Round 22 (Financial Year 2017-18), Table 3, page 11, indexed to 2019-20.

4: (Mihalopoulos et al., 2014)

Admissions are calculated from Australian Defined Diagnosis Related Groups with daily cost calculated from total DRG cost divided by DRG LOS. Emergency department costs are based on NSW average cost per presentation reported by the Australian Independent Hospital Pricing Authority (Independent Hospital Pricing Authority, 2020). Community mental health costs are calculated using Australian

Independent Hospital Pricing Authority reported costs for average cost per episode, reflecting multiple support services (Independent Hospital Pricing Authority, 2020).

All cost figures are reported in 2019-20 Australian dollars indexed using the Consumer Price Healthcare Index (Australian Bureau of Statistics, 2020).

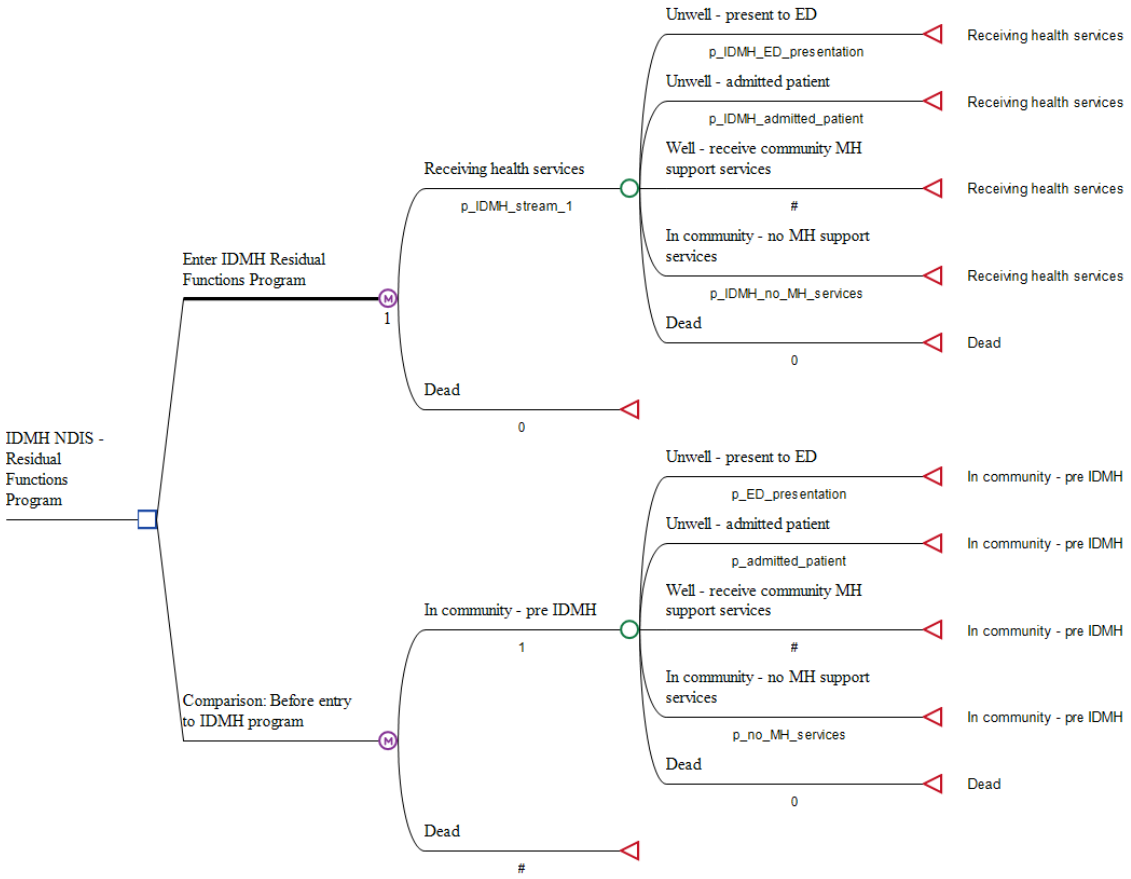
Economic modelling

The economic component of the evaluation developed a Markov model framework to assess health service use, program costs and outcomes to estimate cost effectiveness. The model establishes before and after program health service Streams, estimated consumer QALY outcomes combined with average program cost per consumer, Figure 6.

The base case model integrates the available Stream 1 consumer outcomes. As Stream 1 is a partial subgroup of total program activity, scenarios were developed based on supplementary data sources, program target populations and relevant literature to extend the estimated cost effectiveness.

The model simulates 10,000 replications to provide an estimate of the mean cost and QALYs per person. Probabilistic Sensitivity Analysis (PSA) was undertaken to quantify the joint uncertainty in the data based on defined distributions for each model parameter input. Results are presented as cost effectiveness acceptability curves indicating estimated probability of the Residual Functions Program being cost effective in terms of cost per QALY. The model cost effectiveness bootstrap scatter plots are provided in Appendix H for reference.

Figure 6 Economic program Markov model structure



The modelling was undertaken from the perspective of NSW Health as the lead program funding agency.

Limitations to the economic modelling

As for all evaluations of health programs there are a number of limitations particularly related to the partial data available for outcome linkage and the limited post program timeframe to establish follow up consumer outcomes. As there are no outcome data available for consumers supported through Stream 2 it is assumed that the Stream 2 estimated cohort achieve the same average outcomes as Stream 1 consumers.

The quantitative data linkage utilized a self-controlled case series design for before and after entry to the Residual Functions Program, using each person as their own control. This approach was implemented due to the limitations with identifying a suitable ID comparison group who did not receive the program service.

The pattern of service use may be escalated during time of episodic mental health episodes, which may also align with engagement in the Residual Functions Program. This may implicitly result in health service use declining following program entry to a stable longer-term level. This relative change in pre and post program services

measured at a time of increased risk may reflect regression to the mean (Linden, 2013).

Attributing improvements (or deterioration) of outcomes to the Residual Functions Program are complicated by the lack of a comparison group. While clinical consultation liaison and capacity building can facilitate access to services and improve service coordination, it cannot ensure the quality and effectiveness of the services that are provided. Improvements in outcomes may also take some time to manifest themselves and may not be identified in the timescale of the evaluation.

The full program costs are included in the economic modelling but program outcomes are incomplete as benefits are often lagged and diffused or difficult to quantify. For this reason, program related consumer improvement over time is not comprehensively assessed and the estimated benefits are unknown or understated. In this context the preliminary cost estimated cost effectiveness bases case and scenarios are necessarily conservative and the identified increased health costs in the evaluation period short-term may result in substantial ongoing benefits in the medium and long-term.

Appendix C Stream 1 programs: focus, outcomes and start dates

Organi-sation/ Location	Program focus	Proposed outcomes	Start date[1]
Central Coast LHD	0-12-year-old clinical service	Established pathways between services to enhance access to services and quality of care. Improved standards on training staff so they are proficient in supporting people with intellectual disability and mental health needs.	1 May 2019
Hunter New England LHD	Clinical team	Increased education and training of staff, connecting pathways between services and increased access to programs for people with intellectual disability and mental health needs.	1 Jun 2019
Justice Health and Forensic Mental Health Network	Custodial IDMH transitions	Improved skills of staff and therefore reduced rates of recidivism.	1 Jun 2020
Murrum-bidgee LHD	Clinical service and brokerage	Developed capacity of mental health services and disability services to improve the access to specialist services for people with intellectual disability and mental health needs.	1 Jul 2019
Northern Sydney LHD	Education and enhancem ent of existing IDMH team	Increased capacity of clinicians and CMOs to effectively communicate with and collaborate with people with intellectual disability and mental health as this will ensure improved service.	1 Sep 2019
Sydney LHD	Allied health clinician	Increased capacity to work more closely with carers and service providers of people with complex health and social care needs. Strengthened linkage between CMOs and government agencies to improve crisis resolution.	1 Jun 2020
Sydney Children's	Clinical enhance-ment	Improved ways to support children with intellectual disability and mental health needs. Better pathways between the hospitals and	30 May 2019

Organi-sation/ Location	Program focus	Proposed outcomes	Start date[1]
Hospital Network		specific MH services for children with ID. Closed gap between leaving adolescent services and entering adult programs.	
South East Sydney LHD	Adolescent transition clinic	Better collaboration between all stakeholders to ensure early access to comprehensive assessment and treatment or safe transition out of care.	1 Jan 2020
South West Sydney LHD	NDIS pathways clinician	Clear pathways of communication to ensure consumers with intellectual disability and mental health are having their unique needs met.	1 Apr 2020
Southern NSW LHD	IDMH clinic	Established network that supports the clinical care of people with an intellectual disability and mental health diagnosis. Strengthened supports for local clinicians, primary care and NGO staff to allow best practice care with a person centred and trauma informed approach.	1 Dec 2019
Western NSW LHD	IDMH clinic	Integration of holistic service pathways to ensure people with intellectual disability and mental health needs have better physical and mental health outcomes. Improved staff knowledge as this will enhance their capacity within IDMH services.	1 Jul 2020
Western Sydney LHD	Clinical team	Capacity building of the LHD's mental health workforce with requisite knowledge, skills, cultural sensitivity and trauma informed practice. This will allow for better support and easier navigation of the system for consumers with intellectual disability and mental health.	1 Jul 2020

Notes: [1] Approximate start dates from InforMH.

Appendix D Challenges and solutions in Stream 1 progress reports

The progress report template included fields titled ‘Overall status and key issues summary’ and ‘Critical risks/issues and action plan’. We analysed the responses in these fields from the 40 progress reports submitted by the LHDs to the Ministry.

Key issues in reports	Challenges mentioned in reports	Solutions implemented by the project and mentioned in reports
Recruitment	No response to repeated advertising for some positions	Flexibility: advertised again under different banner, with location negotiable
		Patience: there was delay in re-advertising due to COVID-19
Staff turnover	Resignations of staff at various levels – team leader, social worker	Successful recruitment: some positions have been filled
Reporting	Local team not working in MHB electronic reporting system	Communication: liaising with MHB to align reporting
Agency collaboration	Responsibility for people with MH and ID is split between multiple agencies, which is a barrier to joint planning and causes service gaps	(none offered)
	Engaging GPs is challenging	Continue to promote program opportunities
		Develop GP interest group
Training	Sustainability after program finishes	Play stronger strategic role in local Communities of Practice
		Coordinate training before program finish
	Competing training priorities	Develop a quick reference guide for staff
Engagement of service providers	Providers may disengage to avoid additional work	Develop resources for MH and health sector, e.g. directories of registered NDIS services; a quick guide; and rapid response tools
		Use joint care planning to develop a single, cross-agency/cross-provider

Key issues in reports	Challenges mentioned in reports	Solutions implemented by the project and mentioned in reports
		care plan for people with intellectual disability and mental health
Quality control	Maintain standard of services after program finishes	Create an online repository and interactive information forum for service providers
COVID-19	Precludes service provider visits in prison, thereby precludes holistic support	(none offered)
	Delay in program start	Started late
	Delay in program progress	Adjustment: narrowing the scope of the project by adjusting activities and milestones
NDIS pathway	Support for psychosocial NDIS applications in custody ended 1/6/20 – causes service gap	(none offered)
Geography	Non-metro location restricts access to specialty psychiatry clinic	Flexibility: clinics are offered in several regional centres
Availability of data	Lack of data to identify agency consumers with intellectual disability and mental health	Develop new protocols for capturing data
	Lack of capturing clinical work data	Develop service codes

Appendix E Profiles of consumers and families

The names are not those of any person interviewed. The stories are composites of more than one consumer story as told to us by consumers, families and staff.

Sally

Sally wants to find paid work. When Sally was a young girl, she was abused and neglected. Until recently Sally lived in a house where she often felt scared of the people she lived with. When Sally moved into her current home, she did not trust her new support workers and housemates. At first she stayed in her room and did not communicate with them very much.

When Sally started on the program, the doctor listened to Sally's story, acknowledged her trauma and helped her to understand how her childhood experience had affected her behaviour. The doctor also gave her different medication. Sally then found it easier to talk with others in her home. Now she loves to spend time with her housemates. Sally then worked with the support workers to extend her social circle, first to the day centre and then to paid employment.

Jim

Jim likes spending time in the bush with his grandfather on weekends. Jim lives in supported accommodation with three other people and a support worker. He communicates without speech. Sometimes Jim gets upset and he shouts at the people he lives with or the support worker. Jim had to take lots of medication, which made him sleepy and feel a bit sick. Sometimes Jim felt even too tired and sick to go into the bush with his grandfather.

Since joining the program, the support workers at Jim's home are doing some training about intellectual disability and mental health. They are also working with Jim and his mental health team to come up with ways to help Jim when he gets upset. Jim now takes less medication and he is not so sleepy. Last weekend Jim and his grandfather went fishing and Jim was really looking forward to sharing the photos of his catch with his housemates.

Louise, Pat and Raj

Pat and Raj have 3 children. Their youngest, Louise, is aged 38 years, and lives with them. Louise has intellectual and physical disability and a mood disorder. Louise needs daily support with personal care and needs constant company except for a few hours. Pat and Raj love Louise and would do anything for her. Responsibility for her care has meant that they have been unable to spend long

visiting their other children and grandchildren as Louise can get upset and agitated if they visit is more than an hour. Pat and Raj, who are both in their early seventies, have also been worried about what will happen to Louise when they become too old to care for her.

About 6 months ago Louise was taken to the emergency department by ambulance after she became very agitated and tried to hurt herself. Louise spent a few days in the inpatient unit before being discharged home with Pat and Raj. This had happened many times before. Pat and Raj were frustrated that Louise's mood settled at the hospital but there did not seem to be a plan for any long-term change afterwards to prevent future emergency visits, which were traumatic for Louise and them.

This time however, Louise was referred to the program as part of her discharge plan from hospital. Pat and Raj were invited to participate in making a plan with Louise and her new care team. They were asked what they wanted for Louise and themselves. Louise's medication was reviewed and she became more settled and engaged. Now Pat and Raj are really enjoying Louise's company – they had almost forgotten how funny she could be! The program also helped Pat and Raj apply for NDIS and Louise is getting to know and trust new people who can help with personal care. Louise is still living at home with Pat and Raj but last week they took a couple of their grandchildren to the movies, leaving Louise at home with her new carer to watch Netflix. In a few weeks Louise is going to try respite in a house that they all visited. Louise is excited about the cats that live there. Pat and Raj are no longer dreading the future.

Appendix F Stream 1 Capacity building activities

Summary of Capacity Building Activities as reported in Stream 1 progress reports

	Category	Number (%)*
Distribution of Activities	Formal face to face learning	158 (14%)
	Group supervision	40 (3%)
	Clinical Supervision	16 (1%)
	Inservice	153 (13%)
	Individualised 1:1 activities	349 (30%)
	Other	437 (38%)
Distribution of Disciplines	Nursing	132 (11%)
	Allied Health	377 (33%)
	Medical	132 (11%)
	Peer Workers	9 (1%)
	Support Workers	156 (14%)
	Education	70 (6%)
	Administration	276 (24%)
Distribution of Sectors	NSW Health	174 (16%)
	NSW Health Mental Health	509 (45%)
	NDIS funded services	152 (14%)
	General Practitioner	32 (3%)
	Private Provider	18 (2%)
	Specialist Disability Service	62 (6%)
	Community Managed Organisation	126 (11%)
	Corrective services	48 (4%)

Source: Reports from 10 programs

Notes: n=1153. *excludes missing data

Appendix G Quantitative results

Summary of health service use patterns, participant wellbeing and mental health outcomes before and after enrolment in Stream 1 programs

Participant Demographics

Table 1: Demographics of participant in Stream 1 of the Intellectual Disability Mental Health National Disability Insurance Scheme Residual Functions Program* (N=124) up to September 2020

Variable	Category	n (%)
Sex	Female	50 (40)
	Male	74 (60)
Indigenous status	Indigenous	10 (8)
	Non-indigenous	114 (92)
Born in Australia	No	12 (10)
	Yes	112 (90)

*Data available for 9 of the 12 locations

Emergency Department Presentations to a NSW Health Facility

Table 2: Regression analysis of the rates of emergency department presentations per person per month before and after commencing Stream 1

		IRR	95% CI	p
Self-control case series regression (n=55)	Before (Reference)	1	-	-
	After	1.28	0.83 – 1.98	0.27

Table 3: Descriptive characteristics of emergency department presentations before and after commencing Stream 1

Variable	Category	One year before program commencement n (%)	Three months post program commencement n (%)
Visit type	Emergency presentation	366 (96)	105 (96)
	Other	15 (4)	4 (4)
Mode of arrival	State ambulance vehicle	241 (63)	71 (65)
	Private vehicle	125 (33)	32 (29)
	Other	14 (4)	6 (6)
Mode of separation	Admitted	86 (23)	21 (19)
	Departed	295 (77)	88 (81)
Triage category	Resuscitation and Emergency	75 (20)	18 (16)
	Urgent	164 (43)	40 (37)
	Semi-urgent	123 (32)	45 (41)
	Non-urgent	19 (5)	6 (6)

Admitted patients to a public NSW hospital

Table 4: Regression analysis of rates of all admitted patient episode per person per month before and after commencing Stream 1

		IRR	95% CI	p
Self-control case series regression (n=62)	Before (Reference)	1	-	-
	After	1.73	1.22-2.44	0.002

Table 5: Regression analysis of length of stay per admitted patient episode per person per month before and after commencing Stream 1

		IRR	95% CI	p
Self-control case series regression (n=62)	Before (Reference)	1	-	-
	After	0.87	0.44-1.74	0.70

Table 6: Regression analysis of rates of unplanned admitted patient episode per person per month before and after commencing Stream 1

		IRR	95% CI	p
Self-control case series regression (n=56)	Before (Reference)	1	-	-
	After	1.67	1.09-2.58	0.02*

*the overall model is not significant (p=0.07) so our finding is not significant.

Table 7: Regression analysis of length of stay per unplanned admitted patient episode per person per month before and after commencing Stream 1

		IRR	95% CI	p
Self-control case series regression (n=56)	Before (Reference)	1	-	-
	After	0.89	0.40-2.01	0.79

Table 8: Regression analysis of rates of admitted patient episode to a psychiatric facility per person per month before and after commencing Stream 1

		IRR	95% CI	p
Self-control case series regression (n=42)	Before (Reference)	1	-	-
	After	1.3	0.73-2.31	0.37

Table 9: Regression analysis of length of stay per admitted patient episode to a psychiatric facility per person per month before and after commencing Stream 1

		IRR	95% CI	p
Self-control case series regression (n=42)	Before (Reference)	1	-	-
	After	0.49	0.16-1.48	0.21

Table 10: Re-admission rate to a psychiatric facility (per episode)

Before (incident rate)	After (incident Rate	RR	95% CI	p
0.19	0.29	1.51	0.43-4.44	0.43

Ambulatory mental health services in the community

Table 11: Regression analysis of rates of ambulatory treatment days per month before and after commencing Stream 1

		IRR	95% CI	p
SCCS Regression (n=92)	Before (Reference)	1	-	-
	After	1.69	1.05-2.72	0.03

Table 12: Provider type of ambulatory mental health services before and after commencing Stream 1^

Provider type	One year before program commencement Rate per 90 days	Three months post program commencement Rate per 90 days	Rate Ratio
Nurse Manager	52	174	3.36
Specialist Medical Practitioner	9	26	2.89
Clinical Psychologist	18	48	2.70
Clinical Nurse Consultant	30	76	2.58
Visiting Medical Officer Psychiatrist	13	30	2.40
Nurse (other)	15	34	2.23
Occupational Therapist	33	59	1.77
Registered Nurse	165	291	1.76
Psychiatric Registrar	13	21	1.68
Psychologists (non-clinical)	31	50	1.61

^provide types of small sell sizes have been excluded from table

Table 13: Activity provided by the ambulatory mental health services before and after commencing Stream1^

Activity Code*	One year before program commencement Rate per 90 days	Three months post program commencement Rate per 90 days	Rate Ratio
Administration	29	36	1.23
Assessment	191	274	1.44
Assistance with	9	5	0.57
Carer support	16	33	2.10
Care conference	16	30	1.90
Counselling and education	27	23	0.86
Care management, NOS	146	211	1.45
Counselling	19	31	1.68
Care Planning	112	164	1.46
Discharge client	2	5	2.22
Psychotherapies	25	20	0.79
Documentation & report writing	132	202	1.54
Clinical review	27	41	1.55
Medication activity	200	377	1.88
Service Coordination	49	70	1.42
Skills training, unspecified	4	15	3.53
Standard Measures	8	10	1.25
Transport or accompany client	16	6	0.39
Triage	4	13	3.06

NOS: not otherwise specified
^provide types of small sell sizes have been excluded from table
* The code associated with the Mental Health classification value that best describes the service/activity that is being undertaken by the service provider. The activity may or may not be client related

Table 14: Principal service category of ambulatory mental health services before and after commencing Stream1^

Principal service category*	One year before program commencement Rate per 90 days	Three months post program Commencement Rate per 90 days	Rate Ratio
Acute - Clinical	186	254	1.37
Consultation (to a service unit not funded from the MH program)	22	21	0.97
Emergency - Clinical	11	15	1.36
Acute - Social	4	8	2.29
Promotion, Prevention or Early Intervention NOS	1	14	11.20
Consultation (to a Mental Health Service Unit)	8	22	2.84
MH Service NOS	8	23	2.97
Mental Health Promotion	11	22	2.05
Emergency/acute - Clinical/social	6	17	3.09
Rehabilitation - Clinical	118	128	1.09
Mental Illness Prevention	34	45	1.31
Non acute - Clinical/social	93	200	2.16
Extended - Clinical	111	242	2.18

NOS: not otherwise specified, MH: mental health
^provide types of small sell sizes have been excluded from table
* The primary purpose or treatment goal of the activity or service contact

Mental health outcomes

Table 15: Regression analysis of HoNOS scores before and after commencing stream 1

		IRR	95% CI	p
Self-control case series regression (n=33)	Before (Reference)	1	-	-
	After	0.67	-1.83-3.17	0.53

Appendix H Economic evaluation

The economic evaluation presented in this section develops a core base case using the available quantitative outcome data for Stream 1 consumers. This provides a partial starting point for examining the total estimated program cohort and other extended program outcomes.

Evaluation of the Residual Functions Program is not examining development of dedicated new health capacity for people with ID. The ongoing development of mental health services in Australia is well established and based on evidence that investing in mental health is increasingly cost effective (Luyten et al., 2016). The Residual Functions Program is nested within the wider health system, with established strategy and justification for service planning. The Residual Functions Program focuses on development of mainstream capacity to improve access for people with ID, in effect aimed to leverage and better utilise established mainstream health services.

The Residual Functions Program aims to facilitate individuals gain quality access where they might have previously only received limited supports, partial assessment of physical and mental health conditions, or their health needs may have been undiagnosed or unmet. The latent implications for those with ID and their families is characteristically difficult to assess, with only indirect indicators for unmet health need and ID population studies indicating substantially lower health status, wellbeing, and life expectancy for people with ID.

Program and mental health services

The evaluation is being undertaken in context of wider mental health system review, service planning and reform. Core findings from the recently released Productivity Commission Inquiry into Mental health present evidence based recommendations for further expansion of mental health services in Australia, supported by health economic modelling indicating further service expansion is highly cost effective (Productivity Commission, 2020). Although intellectual disabilities, autism spectrum disorders and neurocognitive disorders were not in scope of the review, the report noted that the recommended reforms would likely be relevant to people who live with these conditions. The report also notes that these groups are indirectly in scope of the report where individuals also have a mental health disorder which is in scope.

In addition to highlighting core principles relevant to the Residual Functions Program the Productivity Commission report emphasizes actions that governments should take immediately to begin improving people’s lives, including:

- working towards filling gaps and addressing barriers in the services available to people who need support due to mental ill-health, and their families and carers

- remove barriers to collaboration within and between different parts of the mental health system, by actively encouraging information sharing and coordination between health service providers

- by creating systems and processes that bring together the range of treatments and supports that people may choose

- improve coordination and integration between health and other services to better promote recovery

These aspects are directly aligned with the program with the central aim to improve the capacity of mainstream mental health services to work more efficiently with people living with intellectual disability and co-occurring mental illness.

The recommendations also note the priority to increase access for mental health services with accessible gateways to mental health services so people can make informed choices between a range of options that are evidence-based and clinically recommended for the individual, given their condition and circumstances.[3] The findings for the general population indicate barriers in the current system related to services not being available, not knowing about support options, or their location or cost mean they cannot be accessed.

These barriers as discussed previously are known to be more problematic for people living with intellectual disability as they experience high rates of physical and mental health problems as well as many additional obstacles accessing suitable mainstream health services (Reppermund et al., 2019). The recommendations explicitly note the shortfall in community ambulatory services and that State and Territory Governments, with Commonwealth support, should increase funding for community mental health services to the level required to meet population needs, implicitly including people living with intellectual disability.

Increasing the efficacy of Australia's mental health workforce is an overarching recommendation across developing skills, capabilities, and collaboration.[4] These dimensions are central to the clinical services, consultation liaison, education, and capacity building activities the Residual Functions Program is delivering. Support for

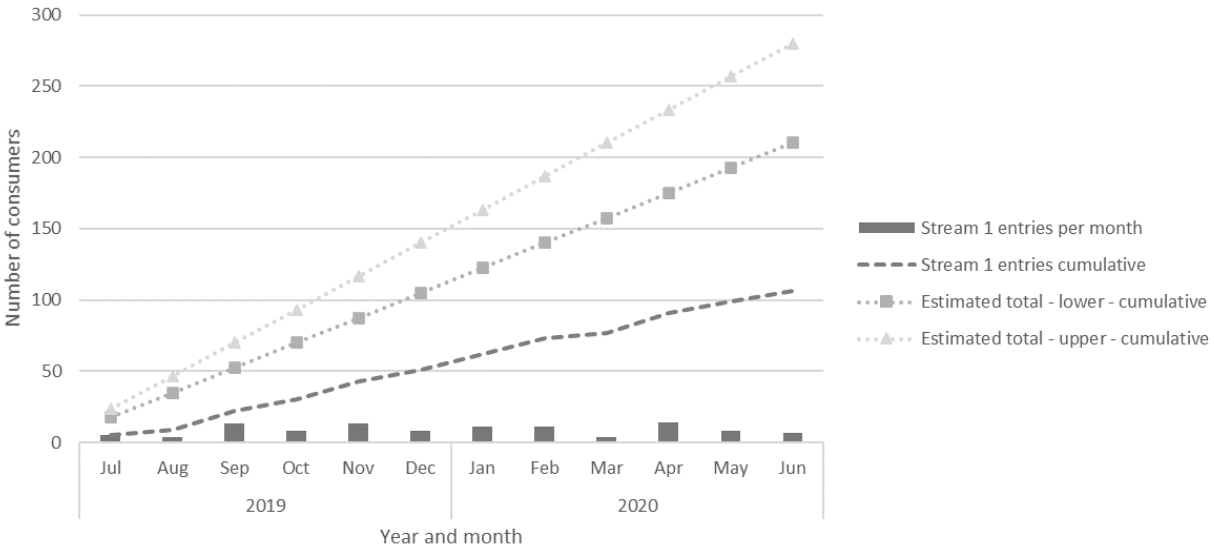
[3] Recommendation 10
[4] Recommendation 16

families and cares is noted as a necessary mechanism for all mental health services through their role in contributing to the recovery of individuals with mental illness.[5]

Program establishment and development

Since commencement of the first fully operational year in 2019-20, the number of Stream 1 consumers entering the program has risen consistently over the 12 months of the evaluation period, Figure 7. The total number of Stream 1 cumulative consumers increased to 106 as at June 2020 providing a partial subgroup of direct program support. As data linkage for stage 2 consumers was not available within the evaluation timeframe, program numbers have been estimated based on the pre-program scoping study (Cvejic et al., 2018). The upper and lower Stream 2 bands indicate the range of estimated median numbers of referrals per year across all LHDs and specialty network.

Figure 7 Residual Functions Program total estimated consumer entries by month to June 2020



Sources: NSW Ministry of Health Mental Health Branch: Residual Functions Program data linkage (Stream 1), Program scoping study (Stream 2 estimated upper and lower median ranges). Stream 3 not included. Note: Total cumulative figures include known Stream 1 and estimated Stream 2 ranges.

The indirect capacity building component of the program is inherently difficult to estimate and has not been included in total program consumer numbers. This is consistent with the conservative approach taken and where additional people with ID are receiving indirect benefits this would result in additional program effectiveness and related cost effectiveness above estimates presented in the following sections.

[5] Recommendation 18

Program costs

Funding of $4.1 million per annum was provided for the NSW NDIS Residual Functions program to develop programs to meet the needs of people that experienced comorbid mental health issues and intellectual disability. This funding has been used to establish three Streams of support to improve the capacity of mainstream mental health services to work more effectively with people living with intellectual disability, comorbid mental illness and their families and carers.

Program funding was approved for 3 years from 2018-19 to 2020-21, allocated across the 3 Streams, Table 6. As a result of delays in the year 1 start-up implementation, which was further impacted by COVID-19 in year 2, some staff recruitment, training and coordination activities were delayed or cancelled. The year 1 delays resulted in an underspend of $2.7 million in 2018-19 which was not rolled over to subsequent years. The full budgeted annual allocations commenced from 2019-20 giving an expected total program funding over the 3 years of $9.6 million.

Table 6 Residual Functions Program cost 2018-19 to 2020-21

Funding allocation	2018-19	2019-20	2020-21
Stream 1: LHD allocations	806,163	3,052,423	2,935,309
Stream 2: HSPB clinicians	453,000	906,138	906,138
Stream 3: Capacity building	50,000	100,000	100,000
Program evaluation	0	122,463	127,423
Total	1,309,163	4,181,024	4,068,870

Source: NSW Ministry of Health Mental Health Branch. Annual figures were not indexed.
LHD=Local Health District, HSPB=Health and Social Policy Branch

The Residual Functions Program costs are aimed at helping people with ID better access and utilise existing community mental health service networks. In this context the program does not include substantial upfront investment in infrastructure and staffing.

Health service use and costs

The Stream 1 health service use presented in the quantitative analyses have been developed into the economic modelling based on before and after program entry mean figures per month. As outlined in the program develop section, health linkage data were only available for Stream 1 consumers. This has been used as a base case in the cost effectiveness modelling, representing a lower boundary as it includes the full year average program cost per consumer on the Stream 1 subgroup, and does not capture potential improved outcomes related to post program increases in health service costs.

The Stream 1 health data linkage provided statistically significant results indicating increased hospital admissions as well as increased access to community mental health services, section 5. These increased health services following entry to program reflect a positive interim program outcome for the study group sample. The economic modelling includes the estimated cost of this improved health service increase but follow up data on associated health outcomes is yet to be established.

Prior research has shown that health services and costs in people with intellectual disability are higher than the general population including higher unmet needs and lower use of preventative and generic mainstream health services (Salvador-Carulla & Symonds, 2016). This research also reports that people with intellectual disability and comorbid mental disorders have the highest rates of specialised health service use and cost. In the case the program is improving access to identify unmet needs and improve the use of preventative and mainstream services, the associated cost offsets could potentially be substantial.

Hospital admissions

The quantitative analysis shows a statistically significant increase in the rates of admitted patient episodes per person per month for the Stream 1 consumer study group. While the rate of hospital admissions increased there was no increase in the average length of stay (LOS) per admission before and after entry to the program.

Review of the hospital admission Diagnosis Related Groups (DRGs) indicates the average LOS, while not changing significantly before and after program entry, reflected higher than average LOS for NSW reported DRGs. This is consistent with research showing higher use of health services for people with intellectual disability. The consumers have a high proportion of diagnoses associated with high costs of care. One quarter of admissions were for consumers with borderline personality disorders (15%) or schizophrenia (10%). Appropriate service use for consumers with these conditions can lead to positive outcomes and reductions in health service costs. (Meuldijk, McCarthy, Bourke, & Grenyer, 2017) (Hall, Caleo, Stevenson, & Meares, 2001).

The health needs and costs for schizophrenia are also high for individuals, their families, the health system and often longer term persistent societal implications including through employment loss (Knapp, 2000). This provides supporting perspective that the increased admissions reported for the program consumers likely represent a positive interim outcome with potentially significant medium- and longer-term benefits for program effectiveness and related cost effectiveness. The potential health outcome improvements resulting from improved program health service access are not fully reflected in the economic modelling, but present potential improved cost effectiveness subject to validation through longitudinal follow up.

Emergency department

There was no significant change in the overall rates of emergency department presentations for Stream 1 consumers, although slight reductions were observed for ED presentations resulting in an admission and for urgent ED presentations. The qualitative interviews indicated self-reported reductions in ED because of newly established regular care through a psychiatrist for the first time.

Community mental health

The Stream 1 program data show a statistically significant increase in the rates of community mental health treatment days, including increased access to clinical psychologists, visiting medical officer psychiatrist and psychiatrist registrars. The qualitative interviews also reported that most consumers were accessing services in the community rather than through hospitals.

This is reflected in the economic modelling through the increased cost of community-based support. There were indicative results from K10 linkage data that mental health ambulatory services were improving mental health outcomes. These results were not statistically significant given the small study group sample size, particularly limited by the small number of post program K10 scores reported. Supplementary K10 figures for NSW mental health ambulatory reporting, including diagnosis subgroups relevant to the program study group, are consistent with the program data linkage. Based on this supplementary validation and using the conservative K10 improvements (which were lower than the wider NSW reported figures), the economic modelling includes this outcome converted to estimated Quality Adjusted Life Years (QALYs) using K10 bridging algorithms.

This provides the only available preliminary clinal outcome for inclusion with the increased program costs. As presented in following sections this provided a conservative base case for examination of extended estimated cost effectiveness scenarios based on supplementary data sources and published literature.

Underpinning the increased community mental health services, recent Productivity Commission recommendations include substantial additional investment in mental health ambulatory services, supported by detailed economic analysis indicating the services are cost effectiveness including QALY returns (Productivity Commission, 2020). The Productivity Commission emphasises that the costs and benefits are very conservative, based on a single year of outcomes, and benefits are therefore likely to be understated. The report emphasises that community ambulatory services fall well short of general Australian population needs and that State and Territory Governments, supported from the Commonwealth Government, should increase funding for these services to the level required to meet population needs. The Residual Functions Program increases in community mental health services

identified in the quantitative analysis are aimed to leverage this recommended increased capacity for people with intellectual disability.

Health related quality of life

Health related quality of life (HRQoL) is commonly a core outcome in health economic evaluations based on standardised questionnaires reported before and after an intervention. These instruments provide the basis for estimating Quality Adjusted Life Years (QALYs), a measure of health outcome that combines length of life and health-related quality of life in a single metric. Evaluating the effectiveness and related cost effectiveness of mental health programs routinely applies methodologies established and used for decades in other areas of the health system. Ongoing health economic research consistently indicates that these approaches, particularly including quality of life aspects, increasingly establish a strong economic case to increase investments in mental health (Luyten et al., 2016).

There are however complexities with administering and collecting specific quality of life instruments for use in economic evaluation, which are often not suitable or may not be sufficiently sensitive in complex mental health settings. Although these tools are non-clinical and generally consist of 5 to 12 multiple choice questions, they present an additional survey component, often difficult given complex client populations and disadvantaged groups such as in the program.

For this reason, health economic research has been establishing validated correlations between the Mental Health National Outcomes and Casemix Collection (NOCC) reporting protocols and separate commonly used quality of life instruments including the Australian developed Assessment of Quality of Life (AQoL) (Mihalopoulos et al., 2014). This work includes the Kessler Psychological Distress Scale (K10) which is part of program routine reporting. This provides an innovative approach to incorporate these methodologies into mental health program evaluation with no additional administrative overhead.[6]

The NOCC reporting of K10 includes clinical assessment to avoid cases where specific survey instruments are not appropriate for some consumers. Scoring of each question is reported as 1 to 5 with additional responses indicating protocol exclusion or unable to rate. This provides the assessment for whether the K10 is appropriate for individual consumers and reflects the complexity of the program cohort.

As a result of the limited outcome data available for the evaluation the economic modelling is based on the data linkage through K10 to QALY, which showed an indicative improvement but was limited by small sample sizes particularly for

[6] The Kessler 10 psychological distress measure (K10LM) is a consumer-completed ten item questionnaire designed to measure psychological distress. K10LM stands for “Last Month” where the usual rating period is at the interval of 4 weeks.

consumers reporting K10 scores after entering the Residual Functions Program. The quantitative analysis presented in section 5 indicates improvements in K10 scores following entry to the Residual Functions Program but did not establish statistically significant results due to the small sample of consumers who reported before and after entry scores.

To examine and verify the program K10 results figures were compared to NOCC reporting through the Australian Mental Health Outcomes and Classification Network (AMHOCN, 2019). Figures were reviewed for the study group available through the program data linkage compared with NSW adults receiving mental health ambulatory services during 2018-19, Table 7. The reported NOCC scores are based on new referral consumers (before program entry) and the subsequent 91-day review point following commencement of support services.

Table 7 Residual Functions Program and NSW community mental health K10 scores 2018-19

	Residual Functions Program				NSW community mental health (NOCC)			
Diagnosis	**n**	**%**	**K10 before**	**K10 after**	**n**	**%**	**K10 before**	**K10 after**
Schizophrenia [1]		14%			3238	45%	21.2	17.0
Mood Disorders		4%			889	12%	29.4	22.8
Personality Disorders		27%			293	4%	31.5	28.8
Other Mental Disorder		28%			1914	27%	26.4	20.6
Total	12	100%	28.7	24.6	7229	100%	27.3	20.2

Source: InforMH Residual Functions Program data linkage and Australian Mental Health Outcomes and Classification Network (AMHOCN) data cube reporting for NSW adult K10+LM scores for MH ambulatory reporting 2018-19

Notes: 1. Schizophrenia grouped with Paranoia and Acute Psychotic Disorders. Shaded cells indicate sample sizes <5 not reported to protect confidentiality. NOCC sample size based on reported follow up scores where diagnoses are more comprehensive. Percentage columns do not sum to 100% as minor diagnosis groups have been excluded.
2. NOCC scores are new referral consumers (before program entry) and 91-day review point following commencement of support services.

From the limited indicative program sample the mean K10 scores improved from 28.7 to 24.6 (lower scores indicate improvement). This compares to an overall improvement in NSW scores from 27.3 to 20.2, reflecting the complexity of program consumers with a higher score at programme entry. The scores by diagnosis consistently show K10 improvement across the main program diagnosis groups accounting for 73% of the study group sample. The comparative K10 scores also indicate that improvements are consistently greater across each diagnosis group and in total.

The purpose of this comparison is not to imply that the program group may have better K10 outcomes, although this appears plausible. This comparison is primarily used to validate that the reported program improvements are within NSW reported ranges and although the small sample was not sufficient to establish statistical significance the results are not only consistent with NOCC outcomes but are likely to be conservative with the program group showing a mean K10 improvement of 2.1 compared with larger sample comparative diagnoses of at least this level and 7.1 for the total group.

The quantitative analyses also examined the proportion of consumers changing K10 category based on ranges for low, medium, high and very high total scores. Again, although the study group sample size was limited, particularly for scores following program entry, there was a reduction in the number of consumers reporting high and very high scores to the moderate normal level, reflecting as improvement from a clinically significant range to a non-clinically significant range.

Program cost effectiveness

The Residual Functions Program cost effectiveness modelling integrates all program costs and the available Stream 1 changes in health service costs, combined with estimated QALYs gained through proxy K10 transformations (Mihalopoulos et al., 2014). As presented in the methodology the available data provide only partial details on the total target program population, only interim outcomes through health service use, and limited clinical endpoints to examine program costs in terms of outcomes.

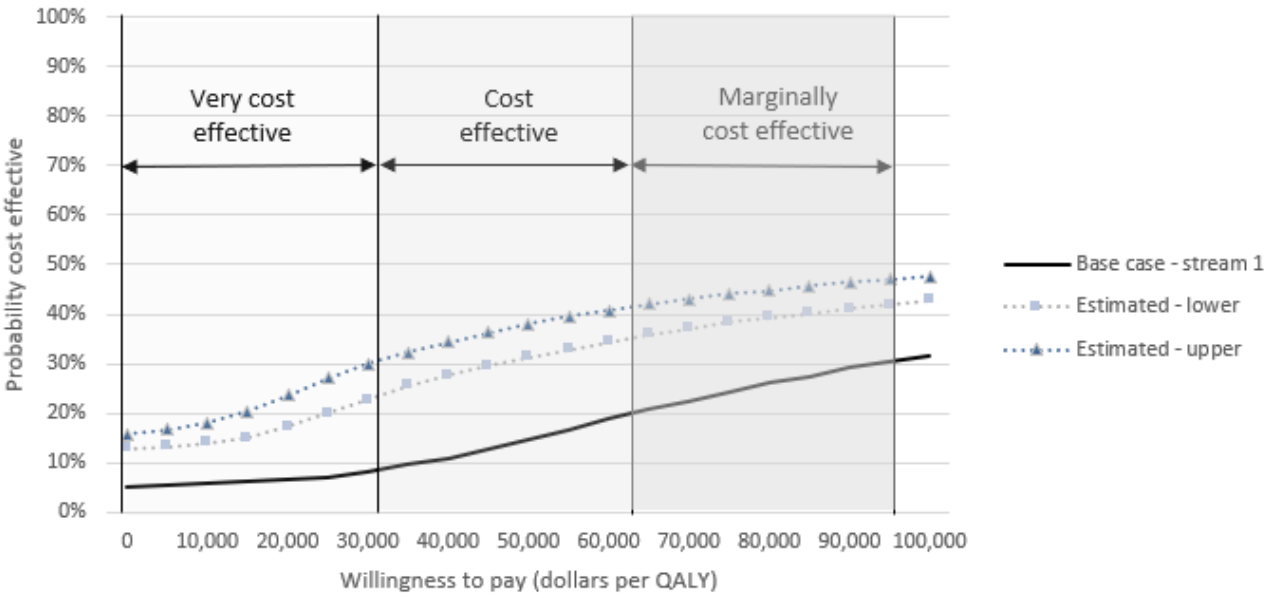
Given the limited data and high level of uncertainty the modelling approach is conservative and aimed to develop a framework to examine additional plausible outcomes. The model base case includes all program costs but includes only a subset of potential benefits based on the study period short term timeframe. In this context, although the Residual Functions Program does not yet have available data on these outcomes, there are potentially substantial lagged additional benefits to the program.

Incremental cost effectiveness ratios have been estimated based on the mean cost before entry and following engagement in the Residual Functions Program and the associated estimated QALY gain for the study group. The Markov model specification includes variation across all parameters as standard deviations and the cost effectiveness ratio estimates were assessed using probabilistic sensitivity analyses. This provides nonparametric bootstrapping resampling to examine the joint uncertainty across all model parameters. This section presents the estimated program cost effectiveness results for the initial base case followed by extended scenarios considering family and carers and potential avoidable ID deaths prevented.

Program base case – Stream 1 program consumers

The economic Markov model results are presented as scatter plots of cost effectiveness estimates across cost-effectiveness planes, provided in Economic evaluation . The distribution of estimates reflects the high variation in model parameters, consistent with the limited linkage datasets and small sample sizes. In this section the base case bootstrap replications are presented as cost effectiveness acceptability curves, representing the likelihood that the Residual Functions Program is cost effective at increasing levels of willingness to pay (WTP) per QALY, Figure 8. The levels of cost effectiveness are shown based on ranges identified by the Productivity Commission Mental Health Report (Productivity Commission, 2020), reflecting increasing cost effectiveness in segments further to the left of the figure. The program base case reflects low probability of being even marginally cost effective at around 30%. The base case results are as expected as they are based on the partial Stream 1 consumer outcomes combined with total Residual Functions Program costs. The base case provides an estimated lower boundary based on Stream 1 available data linkage consumer numbers (shown as solid black line).

Figure 8 Program cost effectiveness – base case benefit to consumers



Source: NSW Ministry of Health Mental Health Branch: program data linkage. Residual Functions Program cost data.

Notes: Total cumulative figures include known Stream 1 plus estimated ranges for Stream 2. Figures estimated over 5 year model timeframe.

The Stream 2 program data linkage was not available during the evaluation period, but it is known that program clinicians have been supporting consumers. Including the reach of the number of Stream 2 consumers increases estimated cost effectiveness as average program cost per consumer decreases. To represent total estimated program consumer numbers two supplementary variations have been run

based the program pre-program scoping study (Cvejic et al., 2018). The upper and lower Stream 2 bands (dotted lines) indicate the range of estimated median numbers of referrals per year across all LHDs and specialty network, as presented in section 6.1.

Including total estimated Stream 1 and Stream 2 consumers, assuming similar conservative K10 outcomes to Stream 1, the estimated results start to approach a marginally cost-effective range, although with substantial uncertainty. This extended base case remains a lower boundary as it reflects all available estimated costs without outcome data for plausible program related benefits.

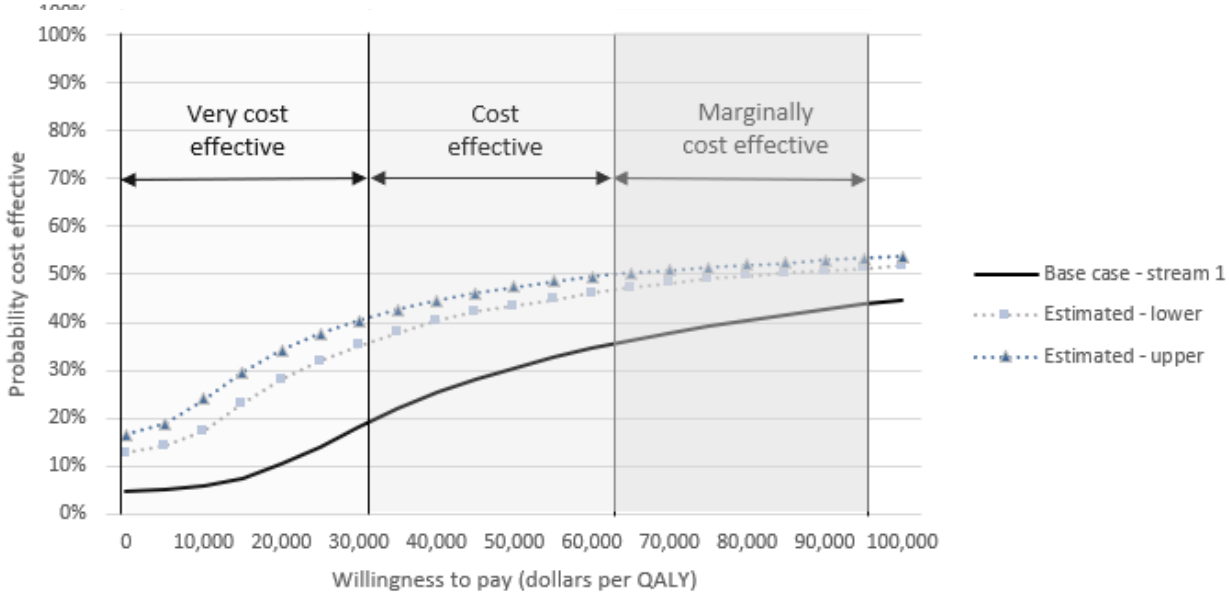
The base case is consistent with the evaluation interview series which reports perceived improved mental health and wellbeing for most consumers due to more support than people had had before, better consideration of the person's individual needs, reviewed medications and helped coordinate access to the NDIS. In this perspective the small base case wellbeing improvements are highly conservative, and it is plausible that the health-related quality of life improvement is understated. The recent Productivity Commission Mental Health Report suggests increased access to mental health is highly cost effective, estimated at $11,000 to $30,000 per QALY (Productivity Commission, 2020). In context of the Residual Functions Program generating increased mental health access, it is plausible the program is supporting similar levels of improved outcomes, at least for some consumers, which would imply improved program cost effectiveness further to the left band towards or below $30,000/QALY. However, as there is currently insufficient program data to verify this comparison the Productivity Commission estimated benefits are presented only as potential cost effectiveness upside.

Program scenario 1: Family and carers

The qualitative interviews indicate that the wellbeing of family carers also improved because of the program as better support for their family member allowed the family carer to rest, pursue other activities, and resume a usual family relationship with the consumer. This suggests that quality of life improvements also extend to family and cares and if so these related outcomes are resulting from the established total program costs, that is, cost effectiveness is arguably higher.

The Productivity Commission Mental Health Report indicates that investment in mental health programs is likely to contribute to cost effectiveness through benefits to carers and families (Productivity Commission, 2020). The report provides estimated costs per QALY indicating that recommendations are mostly highly cost effective and for carers and families are potentially cost saving, ie where improved outcomes are achieved and costs are lower through extended offsets.

Figure 9 Program cost effectiveness – scenario 1 benefit to consumers, family and carers



Source: NSW Ministry of Health Mental Health Branch: program data linkage. Residual Functions Program cost data.
Notes: Total cumulative figures include known Stream 1 plus estimated ranges for Stream 2. Assumption of 0.2 QALY improvement for one family member or carer. Figures estimated over 5 year model timeframe.

As a conservative scenario, if it is assumed that program is supporting a similar small (0.2 QALY) improvement for a single family member or carer, the program cost effectiveness would increase, Figure 9. As there is substantial uncertainty in family and carer outcomes and data are not currently available for the program study group, this scenario is not presented to imply a specific potential result. The scenario simply illustrates that even very modest outcomes that might extend to family and carers will contribute to cost effectiveness. Given the magnitude of recent evidence, such as the Productivity Commission recommendations, there is potentially significant upside in estimated program cost effectiveness above the partial base case.

Potential deaths avoided

As previously the evaluation is limited in outcome data for Stream 1 consumers and mortality data are not in scope for the evaluation. However, research has demonstrated that the barriers to accessing health services for people with ID not

only result in poor physical and mental health compared to the general population, but also leads to premature death (Trollor et al., 2017). This linked data research shows that adults with ID experience substantial premature mortality and overrepresentation of potentially avoidable deaths, indicating as high as 38% of ID deaths may be avoidable. From a NSW ID cohort sample of 19,362 between 2005 and 2011 there were 732 deaths (4%) at a median age of 54 years. This suggests as many as 278 people with ID could have potentially avoided premature death if they had accessed appropriate health services. The higher ID death rates are reflected across all age bands.

This evaluation does not explicitly examine premature death as an program outcome, but the economic model provides a framework to examine the scale of extended endpoints. The data linkage outcomes show that consumers health service use through hospital admissions as well as community mental health services increased following entry to Stream 1 if the Residual Functions Program. It follows that the risk of progressing illness or premature death is reduced with health access supported through the program. While there is clearly substantial uncertainty in these estimated figures, the scale provides weight to possible outcomes where even a 1% reduction equates to 2 deaths avoided and a 5% reduction potentially would lead to over 10 ID deaths avoided.[7]

The recent Productivity Commission inquiry into mental health notes the contentious debate related to attempting to value life, with reference to estimated value of $4.9 million and related value of a statistical life year at $213 000 per year in 2019 (Productivity Commission, 2020). This evaluation does not attempt to incorporate the value of life lost, although if this figure were used the program annual program cost would be offset from a single death avoided per year.

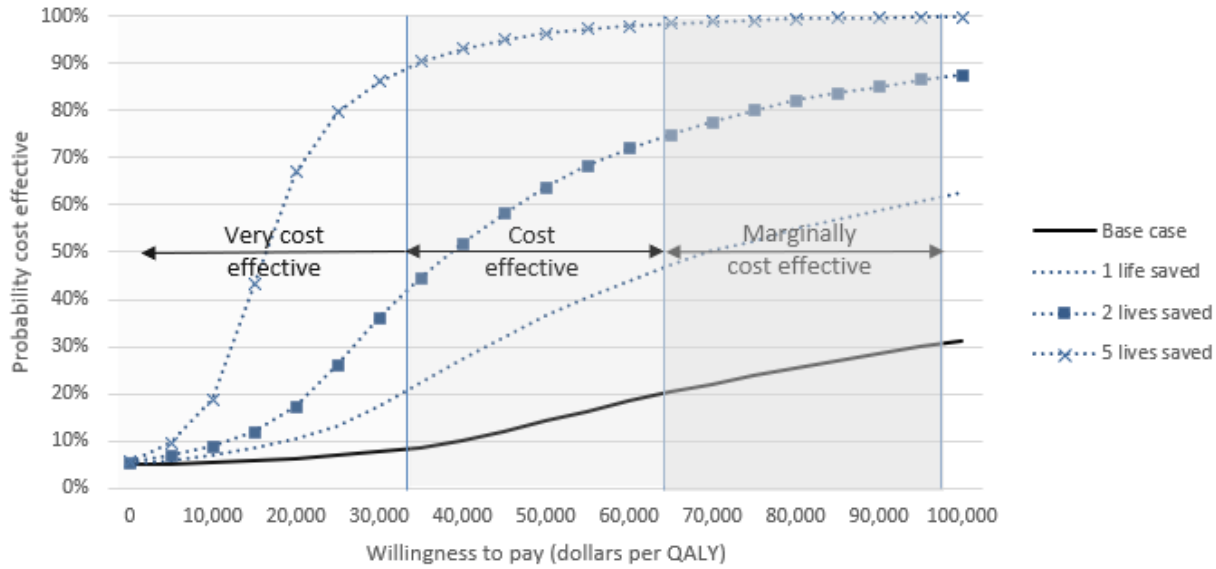
Instead, the approach to examine program cost effectiveness implications from potential avoided deaths is to establish a further model scenario to add contributing QALYs based on estimated lives saved. Consistent with all model parameters the model assumes that extended life years are at the same QALY level estimated for Stream 1 program consumers following entry to the program.[8] This reflects the lower level of health experienced by people with ID as noted by the productivity commission indicating a normal QALY range in Australia based on HILDA is 0.6 to 0.8 (Productivity Commission, 2020).

In context of potential deaths avoided due to improved health access three scenarios were run in the economic model. A single death avoided as a base reference, 2 deaths avoided representing a potential 1% reduction in avoidable deaths resulting

[7] Based on 1% * 278 potentially avoidable deaths = 2.8
[8] 0.52 QALYs per year for 5 years = 2.6 QALYs per death avoided.

from entry to the Residual Functions Program, and a further assumed reduction based on 5 deaths avoided, Figure 10. In addition to these conservative scenarios being based on low percentage reductions in avoidable deaths, the outcome would be equivalent if multiple individuals cumulatively extended life years to the same 2.6 QALY level. The model discounts all costs and outcomes at 3.5% per annum.

Figure 10 Program estimated cost effectiveness – deaths avoided 3 scenarios



Source: NSW Ministry of Health Mental Health Branch: program data linkage. Residual Functions Program cost data. The model discounts all costs and outcomes at 3.5% per year.
Notes: Stream 1 consumers only. Figures estimated over 5 year model timeframe.

The Productivity Commission report also notes the association of mental health and the high number of suicides in Australia. In 2018 it is reported that 65% of the 3,046 people who took their own lives in 2018 had a mental illness (Productivity Commission, 2020). Additionally, there were high numbers of attempted suicides of between 30,000 to 90,000 in 2018 with severe implications for individuals, their families and the health system. Given these statistics the Productivity Commission report includes a priority recommendation that Commonwealth, State and Territory Governments should agree to an explicit target to reduce the gap in life expectancy between people with severe mental illness and the general population.[9] This is implicitly relevant to programs such as program aimed at disadvantaged populations where premature death is disproportionately high.

The health-related quality of life outcome in the previous sections focused on improved HRQoL associated with entry to the Residual Functions Program. The QALY outcome measure implicitly integrates length of life as well as wellbeing so in the case life expectancy is increased or deaths are avoided, this results in increased

[9] Recommendation 14

QALYs from the same program funding, which would increase estimated cost effectiveness. A single death avoided supports an estimated 'marginally cost effective' range, 2 deaths avoided would further increase the QALY outcomes and in the case 5 deaths were avoided, a modest case given the NSW estimated avoidable ID deaths, the program would plausibly be within a 'very cost effective' cost per QALY range. As for potential carers and family outcomes, it is not known whether deaths are being avoided, but this scenario indicates that estimated program cost effectiveness is increasingly sensitive to avoidable deaths prevented, adding to the perspective that there is further potentially significant upside to estimated program cost effectiveness.

program base case and scenario analyses

Each of the figures presented in the previous section show estimated probability of the Residual Functions Program being cost effective at progressive estimated costs per QALY. The summarised results illustrate the base case is a partial boundary as a starting point for extended outcome scenarios, Table 8. In the case program is improving quality of life outcomes for family and carers, the estimated incremental QALY gain increases from the conservative base 0.7 over the five-year model horizon, to 1.4, potentially supporting a marginally cost-effective cost per QALY range.

Table 8 Residual Functions Program cost effectiveness results

Base case and scenarios	Total cost	Incremental cost	QALYs	Incremental QALYs	Cost per QALY
Base case					
Comparison: Before program entry	$69,632		3.5		
DMH base case	$276,119	$206,487	4.2	0.7	$293,977
Estimated Stream 2 - lower range	$190,048	$121,071	4.2	0.7	$176,162
Estimated Stream 2 - upper range	$167,939	$98,348	4.2	0.7	$130,827
Scenario 1: family and carers					
Comparison: Before program entry	$69,678		7.0		
program including family and carers	$278,257	$208,579	8.4	1.4	$148,256
Estimated Stream 2 - lower range	$189,973	$119,996	8.4	1.4	$86,870
Estimated Stream 2 - upper range	$165,686	$96,825	8.4	1.4	$63,915
Scenario 2: Deaths avoided					
Comparison: Before program entry	$69,387		3.5		
1 death avoided	$277,160	$207,773	6.4	2.9	$72,021
2 deaths avoided	$279,371	$209,198	8.6	5.1	$41,210
5 deaths avoided	$277,517	$207,633	15.1	11.6	$17,841

Source: NSW Ministry of Health Mental Health Branch: program data linkage. Residual Functions Program cost data.

Notes: Cost effectiveness is the estimated costs per QALY. * Marginally cost effective range. ** Cost effective range. *** Very cost effective range. Figures estimated over 5 year model timeframe.

In the scenario of avoidable ID deaths prevented the estimated incremental QALY gains are more substantial, contributing to more significantly cost-effective ranges. Although the two scenarios are outlined independently it is plausible that a combination of family and carer benefits with avoidable ID deaths could result with proportional increased estimated program cost effectiveness. These potential scenarios are presented as conservative plausible examples of program benefits subject to longitudinal assessment when data are available.

Mental health equity

Efficiency of the mental health systems may not result in equitable access for disadvantaged groups, such as people with complex needs including intellectual disability. The program is directly aimed at building improved equity across mainstream mental health services for people living with intellectual disability.

The NSW strategic framework for mental health notes the higher burden of mental illness for some groups in the community, including people with intellectual disability (NSW Ministry of Health, 2018). It is recognised that there are significant service gaps for people with multiple issues, for example, when mental illness and intellectual disability affect each other. The recent Productivity Commission report into mental health also emphasises that mental health funding arrangements are recommended to be reformed to support efficient and equitable evidence based mental health service provision.[10]

In health economics there have been methodological advances in recent years to start to examine trade-offs between health cost effectiveness and equity in the distribution of health related outcomes (Cookson et al., 2017). This work aims to extend established cost effectiveness analysis to recognise that who benefits from a ‘cost effective’ program may depend on community diversity across health risks, service access and related capacity to benefit. In this context the goal of improving total health benefits may conflict with reducing social inequity, for example where service delivery to disadvantaged populations requires additional costs.

This perspective adds further consideration to the program evaluation as improved mental health equity combined with marginal estimated cost effectiveness arguably represent a positive scenario.

[10] Recommendation 23

Other potential extended outcomes

In addition to the evaluation quantitative and qualitative findings and economic model scenarios there are a range of interrelated outcomes potentially resulting from improved health access through the Residual Functions Program.

The qualitative interviews found that program support was seen as accessible as it was affordable and was offered closer to where consumers lived. The possibility of health closer to home brings savings in transport costs and travel time for consumers and family or carers. As the evaluation has been undertaken during the COVID-19 pandemic it has been shown that some program health supports were effective through increased telehealth consultations. This may continue or scale further as a convenient and effective form or care.

The qualitative data show that the Residual Functions Program is building capacity of health services, disability and other supports through combined training courses or webinars, practical work, case meetings or direct consumer supports. This capacity building is developing improved coordination between intellectual disability and mental health service providers to better understand consumer needs as well as provide network contacts for advice. These indirect outcomes may be lagged and diffused and are difficult to identify and quantify. For this reason, the benefits related to capacity building Stream 3 activities are not currently incorporated into the evaluation effectiveness and related cost effectiveness.

The program implementation was impacted by COVID-19 resulting in delayed implementation and disruption to consumer support services. The extent of the impact of the pandemic is difficult to assess but may have retrained outcomes for the evaluation study period.

People with mental illness in contact with the criminal justice system tend to have complex needs, including substance use comorbidities and cognitive and intellectual disabilities (Baldry et al. 2015). NSW data linkage indicates that ID represent over twice the proportion of people aged to 24 years appear in corrective services datasets compared to a control cohort (17.9% vs 7.1%) (Reppermund et al., 2019). Where the Residual Functions Program is providing improved access and mental health it is plausible that progression of mental health conditions is being avoided and escalation of episodes that could result in contact with police, the courts or corrective services may be avoided along with related costs.

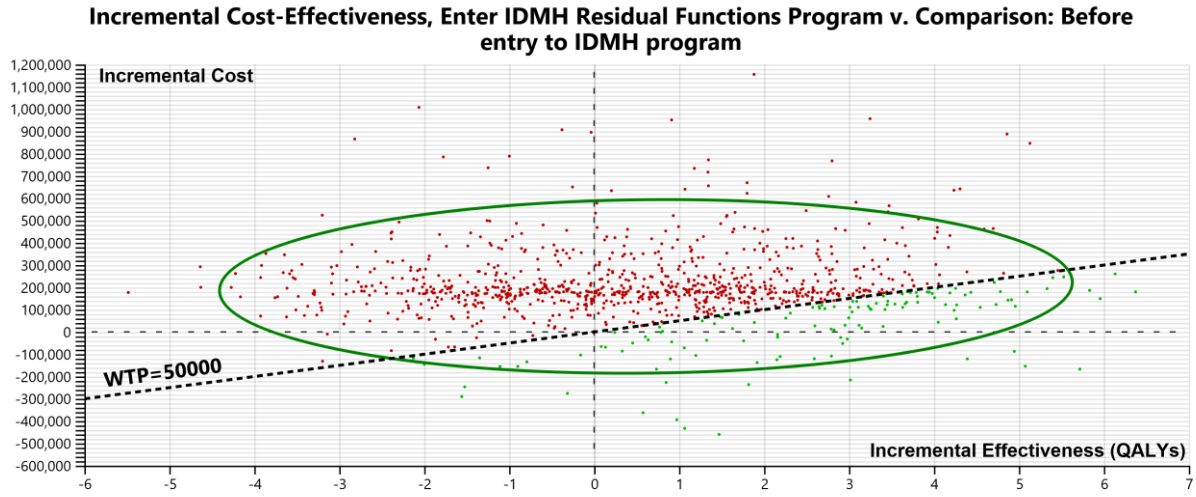
It is well recognised that mental health may affect participation and productivity for those who are employed, as well as presenting barriers to gaining and maintaining employment for those outside the workforce (Productivity Commission, 2020). This established research has demonstrated positive outcomes from employment in addition to income, including providing a sense of identity, purpose, and

connectedness, with better mental wellbeing, with lower rates of depression and anxiety as well as a key role in mental health recovery. The Residual Functions Program is likely to be contributing to these outcomes but are not reflected in the current economic assessment.

Economic modelling results

This appendix presents the program cost effectiveness model bootstrap replications on cost effectiveness planes for the base case and avoidable deaths prevented scenarios. These estimated cost per QALY scatterplots provide the basis for cost effectiveness acceptability curves presented section 6. The results emphasise the high variation in model parameters due to the small sample sizes and skewed service use of the study group. The ellipses indicate 95% confidence intervals for the estimates, beginning with the base case. Values to the right of the centre line indicate positive QALY gains following entry to the Residual Functions Program, at increasing cost as shown on the y axis. The scatterplot shows a willingness to pay (WTP) of $50,000 per QALY as the diagonal dotted line. Green point estimates to the right and below the WTP line represent estimated cost-effective proportion of estimates.

Figure 11 Program cost effectiveness scatter plot - base case



Source: NSW Ministry of Health Mental Health Branch: program data linkage.
Ellipse indicates 95% confidence interval, WTP Willingness to pay

The additional 3 distributions show the increasing likelihood of the Residual Functions Program being cost effective with scenarios assuming avoidable deaths prevented. The high variation remains throughout each scenario, but increasing proportions of cost effective estimates are reflected in the higher number of green point estimates below the indicated dotted willingness to pay threshold.

Figure 12 Program Cost Effectiveness scenario 2 – 1 life saved (2.6 QALYs)

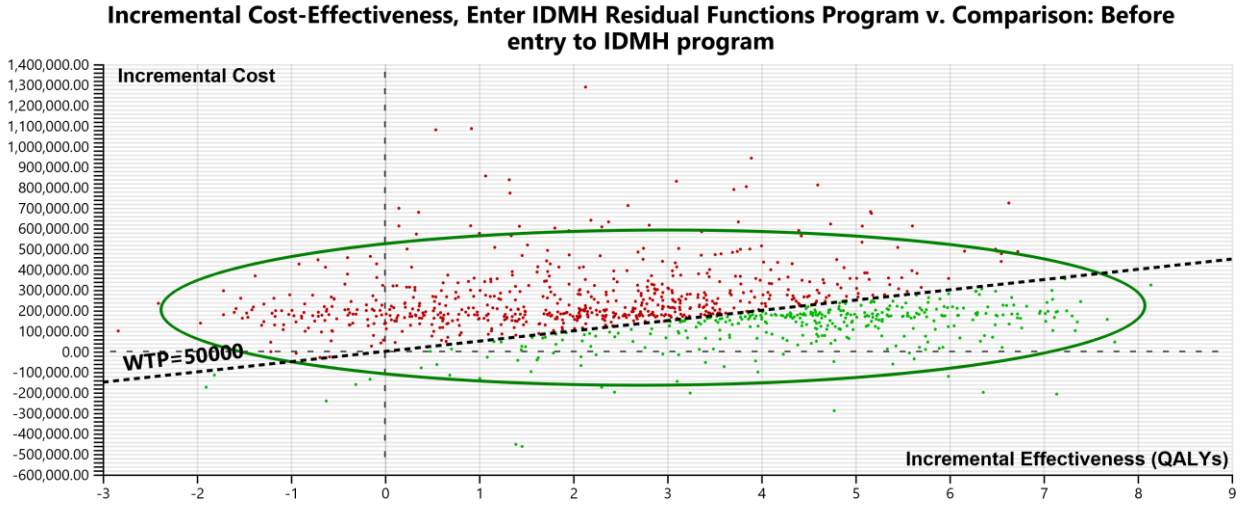


Figure 13 Program Cost Effectiveness scenario 2 – 2 life saved (5.2 QALYs)

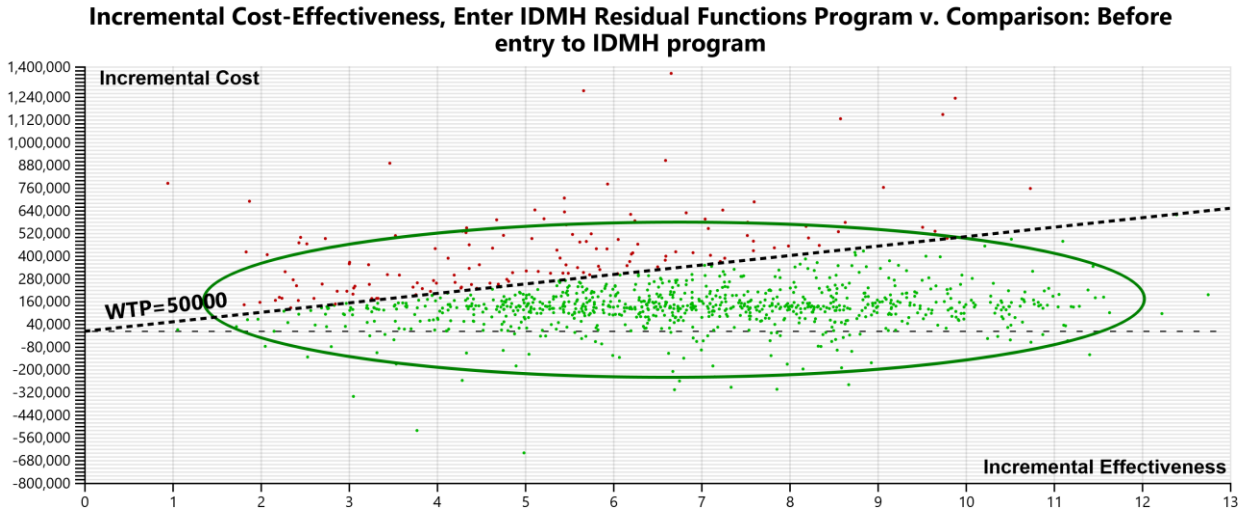
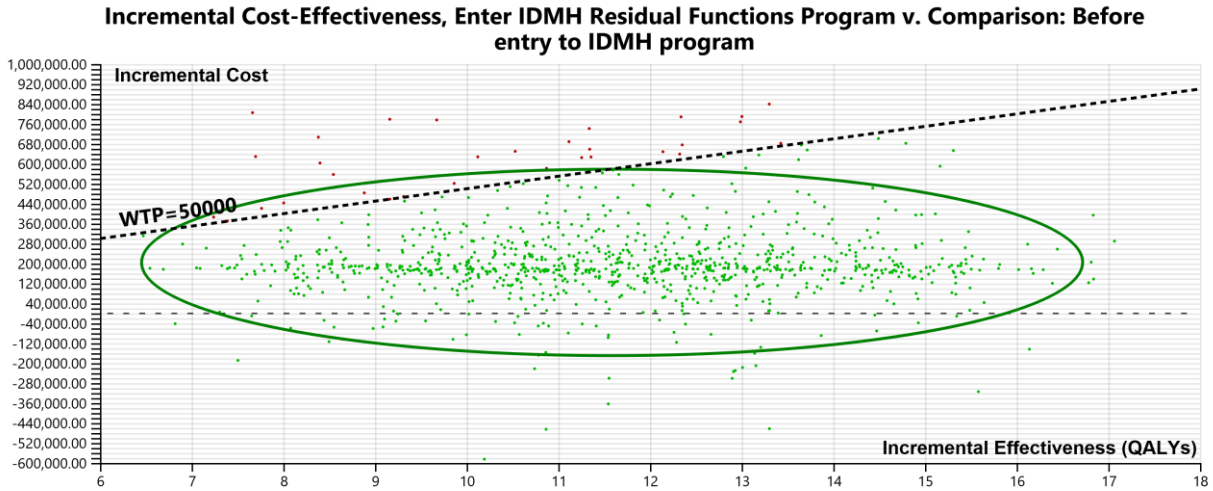


Figure 14 Program Cost Effectiveness scenario 2 – 5 life saved (13 QALYs)



Summary

The economic component of the evaluation examined Residual Functions Program funding in context of outcomes from the quantitative analyses and qualitative interviews. The program was approved for funding of $4.1 million per year, but because of delays in start-up implementation some staff recruitment, training and coordination activities were delayed or cancelled. The year 1 delays resulted in an underspend of $2.7 million in 2018-19 which was not rolled over to subsequent years.

In line with the limited data linkage available for the study period the economic modelling established a base case which integrated all program costs with the primarily interim endpoints of health service use. In this initial perspective the program is achieving a primary goal of improving access for consumers with statistically significant increases in hospital admissions and community mental health services. This represents a partial view of estimated program cost effectiveness as all program costs are combined with additional costs of increased health access (a positive interim result) but related outcome data are limited and focused on the short term.

In this context the approach taken was to examine available K10 scores for consumers before and after entry to the program to estimate quality adjusted life years (QALYs) using bridging algorithms. As the post program K10 scores were particularly limited, the sample size was insufficient to establish statistical significance. For this reason, supplementary review of NSW reporting of K10 scores was undertaken to verify estimated mental health improvements for related mental health ambulatory consumers, including cohorts with similar diagnoses to the program study group. This cross validation indicated that the program improvements were consistent with wider NSW outcomes following access to community-based support. Given inherent uncertainty in K10 outcomes the cross validation is presented to broadly verify this preliminary positive outcome, and to establish that the K10 post program changes are conservative compared to NSW state-wide outcomes. The K10 improvements are therefore potentially understated, however, in context of the limited outcome data, the approach in the economic modelling is consistently conservative.

For this reason, the program economic model base case does not establish program cost effectiveness. Rather the base case model developed a starting point boundary and framework to examine supplementary scenarios based on estimated consumer populations and extended outcome scenarios from relevant literature including benefits for family and carers as well as potential avoidable deaths prevented. Under consistently conservative assumptions the program scenarios indicate that the program is potentially cost effective. While these plausible scenarios suggest

potential program cost effectiveness, further longitudinal data analyses are required to further investigate medium- and longer-term outcomes.

The program economic evaluation has been undertaken in context of the recent Productivity Commission inquiry into mental health in Australia. The inquiry recommendations include substantial reform and expansion in mental health services, including community-based supports, with emphasis on developing equitable access. The inquiry established comprehensive economic analysis indicating that expansion of a range of mental health services are highly cost effective, including from a cost per QALY perspective as undertaken in the preliminary program modelling. This implies that programs such as program aimed at improving access to mainstream mental health services are likely to be supporting similar outcomes, program effectiveness and related cost effectiveness.

The equity of mental health access is an important aspect of the Residual Functions Program aimed at improving services for people with intellectual disability who face multiple barriers compared to the general population. Health economic evaluation methods are beginning to develop extended frameworks to recognise program outcomes which improve equity, given this implicit objective may require additional costs to provide services to disadvantaged groups with complex health conditions. From this perspective the Residual Functions Program is providing improved health access for people with intellectual disability and contributing to improved equity in the NSW mental health system, a complementary outcome in addition to potential program effectiveness and associated cost effectiveness.

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