



Embedding evaluation as part of core business: A customised, co-designed evaluation framework to improve outcomes for people with disabilities, their families and carers.

Phase One: Co-design of an initial prototype Evaluation Framework to guide evaluation at Onemda.



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EXECUTIVE SUMMARY

This report presents the findings of a project commissioned from the Centre of Health Services Management (CHSM) at the University of Technology Sydney (UTS), by Onemda.

Onemda commissioned the first phase of a four stage project to co-design an evaluation framework and toolkit to evaluate innovations, interventions, programs, services developed and introduced at Onemda. In this report the term project will be used to refer to innovations, interventions, programs and services. This report presents a prototype of an evaluation framework to guide evaluation of projects developed and implemented at Onemda.

Background

Co-designed innovations, including cutting edge therapies, assistive technology and evidence-based practices, programs and services (projects) have the potential to improve the lives of people with disabilities and their families and carers, by enhancing quality of life, capacity and independence. To do this we need to know which projects work, for whom, from whose perspective, and how they are best implemented in the real world. We need to know what 'good' looks like, from the perspectives of different stakeholder groups including people with disabilities. This requires a co-designed evaluation approach. A co-designed evaluation framework and toolkit to support individualised, rigorous, and systematic process and outcome evaluation does not yet exist. We used a co-design approach to enable people with disability, their families and support people to engage with the process of developing an evaluation framework prototype. The data collection

component captured the voices of those who receive and deliver projects so that they have opportunity to identify what is important to them and what they think should be measured when evaluating projects.

The aims of this study were to:

1. Identify best practice frameworks used to evaluate Human Centred Design and innovative interventions for people with disability;
2. Understand the perspectives of stakeholders (program participants, carers, providers and policy makers) on the most important domains to be evaluated when determining the impact of projects;
3. Identify relevant data collection systems, data management, custody and usage at Onemda;
4. Identify how to incorporate evaluation data collection into daily activities;
5. Co-design an evaluation framework prototype to be piloted in Phase 2 of the study.

The evaluation framework will support Onemda to conduct systematic evaluations on interventions/innovations as part of everyday practice.

Methods

A multi-method, triangulated co-design approach was used to develop this first iteration of the Onemda evaluation framework (prototype) and has been informed by:

- Published evaluation frameworks;
- A literature review of studies reporting evaluation of interventions developed using a human centred design approach for people with disability;
- Interviews with Onemda program participants;
- Interviews with Onemda program participants' parents;
- Interviews and focus groups with Onemda staff;
- Interviews with key stakeholders external to Onemda (NDIA and NDS);
- Facilitated interactive group discussion with program participants, Onemda staff, and members of the research team;
- Brainstorming session with Onemda staff and members of the UTS research team.

Findings

Findings from the study coupled with the findings of the literature review informed a set of principles factors to consider when implementing evaluation at Onemda. These principles and factors are reflected in the design of the evaluation framework prototype.

Principles to guide evaluation at Onemda

- Evaluation of every project at Onemda needs to consider how the project contributes to a program participant's self-worth and what they value;

- The design and development of an evaluation framework should be a continuous, evolving reflective process.
- Embedding evaluation in everyday practice enables Onemda to be a learning organisation;
- The needs and input of multiple stakeholders need to be considered across the evaluation process;
- Evaluation needs to be relation-based and include meaningful, authentic face to face or physical interaction where possible;
- The evaluation process needs to be uncomplicated; meaningful and beneficial;
- Consultation needs to occur early in the process and to be inclusive;
- In addition to skills development, emotional and social indicators such as self-worth, a sense of purpose, happiness and satisfaction should be considered when evaluating projects at Onemda;
- Evaluation of projects needs to include consideration of input from Onemda program participants and carers;
- Evaluation needs to consider whether project design and delivery is flexible and able to accommodate changes in individuals' needs over time;
- What matters to individuals and 'what good looks like' will change over time – evaluation measures need to evolve to reflect these changes for individuals;
- Protected time to share and reflect on evaluation findings will support meaningful use of those findings including informed consideration of changes in 'what good looks like' for individuals over time;
- A co-designed handover tool will support the sharing of evaluation-based lessons learned;
- One size does not fit all – the evaluation approach needs to “think outside the box” to take into account individual needs and preferences of program participants and their families;
- Evaluation needs to be individualised while at the same time able to be mapped to organisational goals and values;
- Evaluation needs to capture unintended consequences (positive and negative).

Factors to consider when implementing evaluation across the organisation

- Develop a shared understanding of terms and definitions (e.g. impact; outcome etc);
- Co-design clear goals, objectives and evaluation measures when designing a project;
- Map and incorporate current evaluation activities to inform iterations of the evaluation framework;
- Incorporate evaluation in a way that does not increase workload.

Evaluation Framework Prototype

The evaluation framework prototype, The Guide to Co-design Evaluation, includes 17 easy to read, interactive frames covering six stages involved in designing and evaluating a project: Project Introduction; Understanding the Project; Co-designing the Project; Project Outcomes; Implementing the Project; Evaluation over Time. Staff members are encouraged to complete The Guide to Co-Design Evaluation tool online at the initiation of a project; during the project; and at completion of the project. A 17th frame in the evaluation prototype collects feedback about users' experiences of using the evaluation framework prototype. This will enable evaluation of the prototype. This feedback will be used to make improvements to the evaluation framework prototype prior to a formal pilot in the next phase, Phase 2, of the study.

Conclusion and next steps

The goal of Phase One was to co-design an evaluation framework prototype. It is anticipated that the co-designed evaluation framework prototype through supporting co-designed evaluation at the project design stage, will also support and embed co-design in the development, implementation, and evaluation of a range of projects at Onemda.

An informal trial of the evaluation framework prototype is currently underway as a proof-of-concept with selected projects implemented prior to the end of August 2021. Early feedback suggests that The Guide to Co-Design Evaluation tool has generated discussions with program participants to support co-designing selected projects, leading to positive anticipated and unanticipated outcomes for program participants and staff.

The prototype will be iterated based on feedback collected as part of the informal trial prior to a formal pilot (Phase 2). Based on the Phase 2 findings, and subject to funding, the co-designed evaluation framework will be refined and implemented at Onemda (Phase 3), and an implementation toolkit to support implementation of the co-designed framework and dissemination of findings developed in Phase 4. Future work will develop the evaluation framework as an online tool available to support bespoke evaluation of diverse interventions across the disability sector.



1

BACKGROUND

1.1 – Background

New technology advances and therapies are significant contributors to transforming healthcare. However, a commonly cited, although unverified statistic, estimates that 80% of technology projects fail (Greenhalgh, 2019), due to uncertainty, abandonment and lack of adoption. Consequently, involvement of end-users at the design stage, and adequate evaluation and benefit measures are essential to ensure that innovations are fit for purpose and successfully integrated to provide optimal and sustained benefits to consumers and their families.

Co-design allows those “affected by a decision to have an influence on the decision making process” (Bühler, 2001:87), with consumers as “creative participants rather than passive recipients” (Suri & Howard, 2006:48) and is expressed simply as designing ‘with, not for’. Co-design is recognised one of the ten guiding principles of designing and delivering quality health services to people with intellectual disability (NSW Agency for Clinical Innovation, 2019). Codesigned projects have delivered impact in health and service design settings (Hagen et al., 2012, Steen et al., 2011). A co-design approach to developing an evaluation framework prototype is significant in this project because it values the contribution of a range of stakeholders, including people with an intellectual disability.

In addition to projects developed in the Innovation Centre, Onemda develops and implements a range of innovations, interventions, therapies, programs and services. In this document, the term project will be used to refer to these initiatives.

Dissemination of successful innovations will increase their potential to improve the lives of people with disabilities, their families and carers. To do this we need to know which therapies work, for whom, and how they are best implemented in the real world. This requires rigorous evaluation of the processes by which innovative therapies are developed and implemented, as well as their outcomes. Rigorous and systematic process and outcome evaluations are essential to embed feasible and effective projects, to inform policy and national practice standards, and to improve disability support and therapeutic practice. Fundamental to identifying, disseminating and sustaining effective projects in a manner that is practical and easy to adopt, is the systematic and rigorous collection and analysis of data that demonstrate the efficacy of a project, how it was developed, and how it was effectively implemented.

To better understand the benefit and value of projects in accordance with person-centred care models for people with a disability and their families and carers, we require not only evidence for the efficacy of the innovation, but also clear exposition of successful implementation processes and structures. This enables other users to:

- Choose innovations that have been developed and demonstrated to be effective at Onemda;
- Understand the components involved in successful implementation of those projects; and
- Continue to evaluate the implementation of these successful projects in their own settings.

This co-designed evaluation framework will support the systematic collection and analysis of qualitative and quantitative data on:

- How a project was developed;
- How and where the project was implemented, and at what cost;
- Whether the project achieved its desired outcomes;
- Whether there were unintended consequences (positive and negative) of the implementation of the project; and
- What processes and structures are required to spread and sustain successful projects.

The proposed evaluation framework prototype also includes processes to support formative evaluation. Formative evaluation focuses on ongoing development and improvement as projects evolve. Rather than waiting until a project has been finalised to evaluate it, formative evaluation encourages co-designed changes in the development and implementation phases to facilitate ongoing improvements.

The evaluation framework is informed by normalisation process theory (NPT)¹. This theory is used to examine the generative processes that underpin the implementation, embedding and integration of practices. It assumes that the implementation of real world projects are messy and complex, comprising multiple actors, objects and contexts. NPT is interested in the way in which complex contextual conditions affect the development, spread and sustainability of projects. NPT particularly examines: the individual sense-making that promotes or inhibits

the coherence of a practice/innovation to a user; the cognitive participation of users; collective actions that indicate investments in the project by users; and reflective monitoring that indicates the users' understanding and championing of the project. By looking at the environmental and social context, process and outcomes of any project, NPT allows evaluators to understand the impact of 'real' (as opposed to ideal) conditions on the project's implementation and sustainability. At its core NPT asks four questions of any project: what is it? who does it? how does it get done? why does it happen like that? There is a standardised, validated NPT survey tool which can be modified according to each project, which will provide answers to these questions both for individual projects and for Onemda's work as a whole.

Simply collecting data is not enough. The proposed framework and toolkit (to be developed in Phase 4) aim to integrate approaches that make data actionable (in knowledge management speak, turning data into knowledge) and to contribute towards building timely evidence on projects. The toolkit of resources to support implementation of the framework will build capacity in Onemda staff to become robust participants in evidence generation through well-developed evaluations.

Onemda, including Onemda's Innovation Centre aims to develop cutting-edge innovations to enhance the lives of people with disabilities. Embedding mixed-methods evaluation in the practices of the Innovation Centre requires a customised co-designed evaluation framework. The diffusion of successful innovations, coupled with embedded evaluation, will contribute to growing a body of evidence on effective innovations, as well as how to develop, implement, sustain, spread and communicate improvements in care.

Dissemination of the evaluation framework and toolkit to other organisations will increase impact for people with disability, their carers, support organisations as well as policy makers. As such this proposal fits well with Onemda's interest in and aims for enhancing client support and in building capacity within the sector.

1.2 – Problem Statement ---

Onemda's goal is that the design, development and implementation of every project, irrelevant of its type and magnitude, will be evaluated to facilitate feedback in order to encourage ongoing improvements and demonstrated value to users.

A co-designed framework and toolkit to support individualised, rigorous and systematic evaluation does not currently exist. This hinders reliable measurement of the effects of diverse projects and the dissemination of successful projects across disability services. This also means that systematic evaluation of these projects is less likely to occur. The lack of such a framework increases the risk that that evidence for effective projects and their successful implementation will not be captured, particularly when multiple projects are developed and trialled simultaneously.

The aims of this study were to:

- 1.** Identify best practice frameworks used to evaluate Human Centred Design and innovative interventions for people with disability ;
- 2.** Understand the perspectives of stakeholders (program participants, carers, providers and policy makers) on the most important domains to be evaluated when determining the impact of projects;
- 3.** Identify relevant data collection systems, data management, custody and usage at Onemda;
- 4.** Identify how to incorporate evaluation data collection into daily activities;
- 5.** Codesign an evaluation framework prototype to be piloted in Phase 2 of the study.



2

INTRODUCTION

There is an increasing use of person centred approaches to design innovations, to improve the lives and health of people with disabilities and chronic health conditions, their families and carers. Less well articulated is how co-designed interventions should be evaluated. Bombard et al's (2018) systematic review of engagement of consumers in the design of interventions revealed "A minority of studies formally evaluated patients' experiences of the engagement process ... some patients sought greater involvement and felt that their involvement was important but tokenistic, especially when their requests were denied or decisions had already been made." (Bombard et al. (2018: 1)

2.1 – Types of evaluation

Evaluation determines whether or not a project has successfully achieved its outcomes and how this has, or has not, been achieved. Different types of evaluation are required to determine the merit, worth or value of different aspects of a project. The most common types of evaluation include formative evaluation; process/implementation evaluation, outcome/effectiveness evaluation and impact evaluation. It is important to conduct process evaluation while implementing the project to determine what actually produces the final outcome. For example, if the outcome evaluation demonstrates that the desired outcomes have not been achieved, it may be because the implementation of the project differed from what was planned. Alternatively, if the desired outcomes were achieved and the project was tweaked during implementation, it is important to evaluate the types of changes made in order to be able to identify accurately why the project was successful and to be able to

“

**Evaluation
determines the
merit, worth, or
value of things.**

”

(Scriven, 1991)



faithfully replicate it. Table 1.1 developed by the CDC provides an overview of evaluation types, when they are used and why, and the type of information they provide. There is also useful information about different types of evaluation at the [Better Evaluation](https://www.betterevaluation.org/) website (<https://www.betterevaluation.org/>).

Table 1.1: Types and uses of evaluation

Evaluation Types	When to use	What it shows	Why it is useful
Formative Evaluation Evaluability Assessment Needs Assessment	During the development of a new program. When an existing program is being modified or is being used in a new setting or with a new population.	Whether the proposed program elements are likely to be needed, understood, and accepted by the population you want to reach. The extent to which an evaluation is possible, based on the goals and objectives.	It allows for modifications to be made to the plan before full implementation begins. Maximizes the likelihood that the program will succeed.
Process Evaluation Program Monitoring	As soon as program implementation begins. During operation of an existing program.	How well the program is working. The extent to which the program is being implemented as designed. Whether the program is accessible an acceptable to its target population.	Provides an early warning for any problems that may occur. Allows programs to monitor how well their program plans and activities are working.
Outcome Evaluation Objectives-Based Evaluation	After the program has made contact with at least one person or group in the target population.	The degree to which the program is having an effect on the target population's behaviour.	Tells whether the program is being effective in meeting its objectives.
Economic Evaluation: Cost Analysis, Cost-Effectiveness Evaluation, Cost-Benefit Analysis, Cost-Utility Analysis	At the beginning of a program. During the operation of an existing program.	What resources are being used in a program and their costs (direct and indirect) compared to outcomes.	Provides program managers and funders a way to assess cost relative to effects. "How much bang for your buck."
Impact Evaluation	During the operation of an existing program at appropriate intervals. At the end of a program.	The degree to which the program meets its ultimate goal on an overall rate of STD transmission (how much has program X decreased the morbidity of an STD beyond the study population).	Provides evidence for use in policy and funding decisions.

(Department of Health and Human Services, USA, CDC Types of Evaluation, <https://www.cdc.gov/std/Program/pupestd/Types%20of%20Evaluation.pdf>)(CDC Department of Health and Human Services, ND)

2.2 – Developing an evaluation plan

An evaluation plan helps determine what type of data needs to be collected, when, how and why in order to ascertain whether an a project has been successful, how it has been implemented and whether and how it can be improved. A clear evaluation plan will decrease the risk of collecting unnecessary or unhelpful data.

Formulating an evaluation plan at the same time as planning an a project will support a co-design approach as it requires input from people involved in the development, implementation and use of the project. Seeking input to the evaluation plan from these stakeholders will increase buy-in and reduce confusion about who needs to do what and when. A clear idea of the intended purpose of the project (goals, objectives, and outcomes) and how it will achieve this (strategies, activities) is essential to developing a clear evaluation plan (Smart, 2020).

A program logic model makes explicit the goals of a project, from the perspectives of the program participants, the families, Onemda staff, Onemda as an organisation and external funding bodies (See Appendix 7.1 for program logic resources). This information will inform the types of data to be collected and will likely streamline how much data are currently collected. This will reduce work in the data collection phase but might add some work in the analysis phase. There are set goals for programs, activities, and interventions established year by year. It is essential to dedicate time to plan goals and decide how to measure whether they have been achieved. A framework to encourage the capture of data to measure specified goals will also prompt those involved to think about the intended impacts and potential unintended consequences (positive and negative). Examples of unintended consequences noted previously will serve as prompts.

Smart (2020) outlines key steps of an evaluation plan (Figure 2). These include identifying the purpose of the evaluation and the evaluation audience (*why do I need to evaluate*); identifying the evaluation questions and evaluation design (*what do I need to find out*); selecting the outcomes and outputs for measurement and the indicators to measures these (*what will I measure*); selecting data collection methods (*how will I measure it*); deciding who to collect information from and consider ethical implications (*who will I collect data from*); developing a timeline (*when will I collect data*); data analysis, write up and dissemination (*what will I do with the data*). (See Appendix 8.1 for useful resources to support the development of an evaluation plan).



2.3 – An evaluation culture is key to embedding evaluation —

An evaluation culture is core to embedding evaluation in everyday practice. “An evaluation culture refers to a commitment within an organisation to deliberately seek out, act on and value evidence to better manage and deliver programs and services.” (El-Murr, 2021:1) Embedding a culture of evaluation requires top down and bottom up organisational support. Managers play a pivotal role in supporting a positive evaluation culture. An organisational evaluation culture can be enhanced when evaluation findings are acted on and inform change, when the whole organisation embraces evaluation and when the responsibility for evaluation is shared such that evaluation is everybody’s business (El-Murr, 2021:1). Reporting on findings of a study that investigated how managers and evaluation champions encouraged the use of evaluation findings and built a positive evaluation culture, El-Murr (2021: 1-6) outlines key considerations for managers, in the families and children services sector, to building a positive evaluation culture:

- In-house evaluation support and expertise to build staff capacity to use evaluation data;
- An ‘authorising environment’ (structures, rules, processes and people that have the authority to influence what is seen as important) that supports evaluation;
- High level endorsement that supports staff to undertake evaluation and to act on the findings: demonstrate the use of evaluation findings to contribute to change; openly recognise and value staff’s evaluation efforts; provide resources; enhanced understanding of client needs and experiences; provide clients with a ‘voice’; build a knowledge base;
- A clear strategy for how the organisation will conduct evaluation and use the findings to improve service delivery (not just administrative);
- Investment in building workforce capacity (access to technical support and staff development, provision of time to undertake training and to collect and evaluate data, invest in information systems to support evaluation, introduce staff to evaluation in empowering ways);
- Embed evaluation program logics into organisational planning, frameworks and policies;
- Streamline information management systems to support evaluation activities;
- Provide an overarching evaluation and research framework for the whole organisation including – who has responsibility for research and evaluation activities, how the evaluation findings will be used, and a schedule of the planned evaluation activities;
- Promote the use of evaluation for continuous improvement – inspire staff to see the data and use the data to inform change;
- Co-design evaluation (including program logic and data collection process) with staff to improve buy-in.

2.4 – Co-designing an evaluation framework prototype ---

The current project addresses factors considered key to building a positive evaluation culture outlined in 2.3. The co-design methodology used in this project ensures that the voices, perspectives and ideas of this group are included in the design process from the outset. The benefits of a co-designed framework to guide evaluation are first and foremost for people with disability, their families, carers and direct support workers, and Onemda. People with disability often require custom-designed individually tailored supports in the form of disability support plans. The development of a systematic evaluation framework (ready to pilot in Phase 2), will enable Onemda to understand the intricacies of why an intervention is effective or not, from whose perspective, and/or in what circumstance (who, why, how), before investing in scaling-up or conducting further trials.

The evaluation framework will be generalisable for use with different types of projects. It will support a co-design approach and will provide guidance on what evaluation approach to take based on the type of project. Once the evaluation framework is embedded (in future phases of the project) the systematic collection of formative and summative evaluation data can be translated to reduce duplication of effort and resources.



3 METHODODOLOGY

PHASE 1, STEP TWO

This project employed a multi-method approach which drew on the expertise of people with disability, parents, service providers, government agencies and health researchers to co-design an evaluation framework prototype to support bespoke evaluation of diverse interventions developed in the Onemda Innovation Centre and across Onemda as a whole.

3.1 – Data Collection

The qualitative data collection utilised a mixture of focus groups, individual interviews and a facilitated interactive group discussion to gain a nuanced understanding of the perspectives of key stakeholders (program participants, parents, staff, stakeholders) about what they value and what they think should be measured when evaluating new projects, how these could be measured, and by whom.

3.1.1 Methods

The researchers used focus groups and semi-structured interviews to collect data from program participants, parents, staff and stakeholders. The outbreak of COVID-19 meant that while the original plan was to conduct all interviews with program participants and focus groups with staff face to face, we had to move to Zoom and telephone interviews early in the pandemic, in order to meet both Government requirements and the ethical requirements to avoid the potential of transmitting any viruses.

3.1.2 Development of the interview/focus group schedules

The interview and focus group schedules were developed through an iterative process. Questions were open ended and covered topics to explore what participants perceived makes a good innovation/intervention/service (project) - that is, what is important for a project to achieve, and what was important to measure in order to identify if a project was performing well. Information about how data could be collected and by whom were also included in the interview and focus group schedule for parents, staff and stakeholders (Appendices 7.2 and 7.3).

In the first instance, the expertise of the Onemda and UTS research team and members of the Expert Advisory group informed the development of the initial interview and focus group schedules. Consultation with Onemda's LEAP Group and Kelly Schulz (Expert Advisory Committee member) on the information statement, consent form and interview schedule for Onemda program participants, resulted in language changes to some of the interview questions. These changes provided simpler and clearer questions which were reviewed by some members of the Expert Advisory Committee.

Onemda's LEAP Group is made up of participants from Onemda's LEAP Campus located in Templestowe (10 min away from the main campus in Doncaster East). The participants are all working towards goals around employment and greater independence - the LEAP Program was developed to meet their needs.

3.1.3 Sampling and recruitment

Purposive sampling (Cresswell & Plano Clark, 2011) includes those who are knowledgeable about, or have experience of, the phenomenon of interest. In this study, Onemda program participants, their carers, Onemda staff, Onemda Board member and stakeholders from NDIA and NDS were sampled. Recruitment of participants to the study followed four steps to ensure that study participants' participation was voluntary and informed.

Step One

Janice O'Connor at Onemda emailed a copy of the flyer to Onemda staff, carers, Onemda Board members, and relevant representatives at NDIA and NDS. She also provided a hard copy of the flyer to Onemda program participants who were eligible to participate (over 18 years old, capacity to consent to participate in this research and were able to communicate with/without support).

Step Two

The flyer for Onemda program participants directed those interested in the study to contact Janice O'Connor at Onemda or Deborah Debono or Chriss Bull at UTS if they wanted more information or wanted to participate. The flyer for carers, Onemda staff, Onemda Board members, and relevant representatives at NDS and NDIA directed those interested in the study to contact Deborah Debono or Chriss Bull at UTS.

Step Three

Information about the study was outlined in two flyers (Appendix 7.3). The flyer for Onemda program participants with a disability was written in simple English and included pictures. Each version of the flyer included information about who to contact if interested in finding out more about the study. When potential participants contacted Deborah, Chriss or Janice in Step Two, they were provided with the relevant Participant Information Statement and Consent Forms (PISCF) and asked if they were happy to be followed up a few days later regarding whether they had any questions and to find out if they wanted to participate in the study. This provided time for them to consider the information in the information sheet.

Step Four

Those who agreed to be contacted in Step 3 were followed up regarding their interest in participating in the study. At that time those who volunteered to participate were provided with information about interview/focus group times. After COVID-19 related restrictions were in place, times for zoom or telephone interviews and focus group sessions were negotiated.

3.1.4 Data collection

Semi structured Interviews

Semi structured interviews were conducted with Onemda program participants (n=8), parents, including a Board member (n=4), a Service Coordinator (n=1) and external stakeholders from NDIA and NDS (n=2). The purpose was to identify important domains and data collection methods to be included in an evaluation framework. Face to face semi structured interviews were conducted with two Onemda program participants and a Service Coordinator at the end of February 2020. The interviews were conducted in a quiet room. The interviews scheduled for March 2020 were rescheduled when COVID-19 restrictions were enforced. These interviews with six program participants were conducted via zoom in June 2020. Program participants interviewed via zoom had a staff support worker available during the interview. Parents and stakeholders from the NDIA and NDS were interviewed on the phone in March and April 2020. The interviews followed the interview schedules described previously (Appendices 7.2 and 7.3). With permission, interviews and focus groups were digitally recorded and transcribed verbatim by a professional transcription company. Interview transcripts were given a code and de-identified during transcription. The interviewer also made handwritten interview and conversation notes. Interviews with program participants were more informal to minimise anxiety about the interview process.

The duration of interviews varied between 16-30 minutes with program participants; 38-73 minutes with parents; 52 minutes with Service Coordinator; and 41-46 minutes with external stakeholders from NDIA and NDS.

Follow-up interviews were conducted with stakeholders from the NDIA and NDS in March and May 2021 to garner feedback on the proposed evaluation framework prototype.

Focus groups

Focus groups were conducted with Onemda service providers (n=11): direct support workers; and disability service provider managers and administrators. The first focus group (n=7) was conducted face to face in a meeting room at Onemda in February 2020. The second focus group (n=4) was conducted via Zoom in June 2020. Focus group discussions identified collective perspectives on important domains to be measured and data collection methods to be included in an evaluation framework and to identify how to incorporate data collection into their daily activities.

The focus groups were digitally recorded and professionally transcribed. The focus group facilitator also took notes during the interview. The duration of the focus groups was 46 and 58 minutes.

Facilitated group interactive discussion with program participants, staff, researchers – Miro Board

The facilitated co-design group interactive discussion was held in August 2020 with Onemda participants (n=4), staff (at both frontline and organisational levels) (n=4), and UTS researchers (n=4). This facilitated discussion provided a time and space for these relevant stakeholders to meaningfully contribute to the development of an evaluation process that would inevitably be used by them.

The restrictions caused by the COVID-19 pandemic meant that the interactive discussion was reformatted for an online environment, which proved both challenging and rewarding for all involved. Using a combination of video conferencing platform Zoom and online collaborative 'whiteboard' platform Miro, and engaging Onemda staff to physically support participants during the session, discussion participants were able to openly contribute to a series of questions and ensuing conversations about evaluation at Onemda and being a part of the community of stakeholders. With consent, the session was recorded digitally.

Prototype brainstorming session

An evaluation prototype development brainstorming session was conducted via zoom in December 2020 with Onemda staff (n=2) and UTS researchers (n=3). Discussion was informed by the findings emerging from the literature review, interviews, focus groups, facilitated group discussion, the context expertise of the Onemda staff and evaluation expertise of the researchers. The purpose of the discussion was to refine an early draft of the evaluation prototype that had been developed and to generate recommendations related to the implementation and refinement of the prototype.

Regular meetings to support iterative co-development

Janice O'Connor and Deborah Debono held regular meetings throughout the project to support co-development of a prototype that is context appropriate. Weekly to fortnightly meetings will continue as the prototype is trialled and refined.

3.2 – Analysis

Data analysis included: familiarisation with the transcribed data; analysis for themes; and interpretation of themes in light of the study questions. Transcripts were subjected to thematic analysis using hand coding. The steps were as follows: The transcripts were read and notes made on patterns, thoughts and ideas. Relevant sections of the data transcripts were read through several times, and segments of text, and sometimes paragraphs, labelled (coded). Sections of text that seemed to be ‘about the same thing’ (themes) in relation to the research questions were grouped together in themes. These themes were then compared across transcripts and with the findings of the facilitated interactive group discussion and literature review.

3.3 – Ethics

Ethics approval was granted by the Human Research Ethics Committee (HREC) at UTS (ETH19-4375). On-going discussions with colleagues from Onemda and members of the Expert Advisory panel were used to keep researchers alert for potential ethical issues throughout the study.

3.3.1 Confidentiality

In qualitative research there is a risk of conflating confidentiality and anonymity, and researchers are urged to be clear with participants about the types of outputs expected from the study (Goodwin, 2006). This information was included in the Participant Information Statement (PIS) and explained at the time of consent. Data are stored securely and de-identified. To maintain confidentiality, each transcript has a code. Because of the small numbers of participants and because we sampled from one organisation, illustrative quotes have not been included in this report to maintain confidentiality.

3.3.2 Informed consent

Study participants were provided with the Participant Information Statement and Consent Form. Program participants were provided with ‘easy to read’ versions that included pictures and information presented in a simple format. Potential study participants were provided time to consider whether or not they wanted to participate in the study. Written consent was provided and before commencing data collection, study participants were reminded what the study was about, asked if they had any questions, and reminded that participation was voluntary and that they could stop at any time. The researcher confirmed, via verbal consent, that study participants were still happy to participate before commencing interviews, focus groups or the interactive group discussion. Care was taken to determine whether a participant’s disability might increase susceptibility to discomfort or stress. Support staff were consulted to determine the level of risk or discomfort or distress and whether to conduct an interview.

3.3.3 Ethical practice

Ethical practice is a process that requires on-going negotiation, reflection and assessment of the context as the research unfolds. Accessing 'the field' was conducted in a respectful manner and participants' time and input was overtly valued. Onemda program participants and parents were provided with a \$30 gift voucher to acknowledge their time.

Participants with a disability were offered a support person to be present during the interviews and group discussion if they would like that. The interviewer used the following strategies when interviewing program participants:

- All support materials were made available in Easy Read English;
- More time was allowed for the participants to respond;
- The researcher checked in at periodic intervals to ensure participants were comfortable and willing to continue;
- Program participants with a disability were supported to use their communication aid;
- Support workers supported the person to communicate their own views;
- Short phrases were used;
- Onemda agreed to advise facilitators re visual or other supports for interview questions for participants;
- The interviewer was alert to all potential signs of stress or discomfort (including tiredness) throughout the interview and if required offered a rest/break or to reschedule;
- A Distress Protocol, was developed for this study to guide responses in the event that study participants or the researcher exhibited or felt distressed while participating in the study. The Distress Protocol was approved as part of the ethics application. There were no instances of identified distress during data collection.

4

FINDINGS & DISCUSSION

Common themes were recognised in the interview, focus group and facilitated group discussion data across participant groups (Appendix 7.6). The importance of measuring quality of life related outcomes (e.g. self-worth, purpose), in addition to the primary intended goals of a project, was a theme that emerged in the data collected from all participant groups. The findings of this study coupled with those of the literature review contributed to a set of principles to inform how evaluation is conducted at Onemda and the proposed prototype which is presented in the final section of the report. In this section, findings will be reported and discussed under two broad themes: Principles guiding evaluation at Onemda; and Factors to consider when implementing evaluation at Onemda.

4.1 – Principles guiding evaluation at Onemda

4.1.1 Purpose underpinning an evaluation framework

Program participants saw an evaluation framework as a way to tell staff whether they like something in the service or not. The study findings highlight the need for Onemda and the UTS research team to continue to explore diverse ways to engage participants in order to reflect needs and ways of interacting with the service. Principles are important in guiding the development and use of an evaluation framework. Participants highlighted a number of principles, which can be further built on and expanded as the prototype is piloted. These principles include:

- A living evaluation process – The design and development of an evaluation framework should be a continuous, evolving reflective process, not a ‘tick-box’ or ‘set and forget’ approach. When evaluation is embedded in everyday practice, Onemda becomes a learning organisation;

- Managing the needs of multiple stakeholders – The importance of striking a balance between the goals of individual participants, their families, and staff;
- Relationship-based – Whilst digital platforms might be useful to some degree, value was placed on meaningful, authentic face to face or physical interaction where possible;
- Uncomplicated – The evaluation process needs to be uncomplicated if it is to be embedded.

4.1.2 Early and inclusive consultation

Based on the findings of this project engagement with the evaluation framework should begin before the development of a project commences. There was broad consensus on **the importance of early consultation with those involved in, and impacted by, the development and implementation of projects**. Consultation should determine: the purpose of the project; desired benefits (value add) of the project - from whose perspective and for whom; the purpose of the evaluation; measures to be used to capture information about the identified desired outcomes of the project; measures to capture unintended outcomes (positive and negative); measures to capture how the project was implemented; who should be involved at various steps of the evaluation; and importantly, how the findings of the evaluation will be used. These findings align with those reported in the Literature Review.

Evaluation and co-design need to start at the project planning stage. **Whatever the focus of the design or evaluation, the principles of starting early, consulting widely, and treating everyone who contribute as unique and valuable, is essential.** Involvement of Program participants, parents and staff in the design of the evaluation was valued and considered satisfying and informative.

4.1.3 Importance of building and maintaining authentic relationships

Several study participants emphasised the importance of a relationship-based approach to evaluation, dependant on knowledge and familiarity with the program participants. They identified that many non-verbal ways of understanding each other can be missed or overlooked without strong interpersonal relationships. Study participants noted the importance of the implementation of projects being supported by caring staff who understand what program participants need.

Study participants spoke about the important role of regular staff who know the program participants well, including their idiosyncrasies. Being able to identify that something is ‘not quite right’ with the program participant, was important to accurate evaluation. The relationships between staff and program participants at Onemda are already friendly and genuine, and a person-centred evaluation framework should be built around the character of these existing rapports. It should include processes that support effective and frequent communication between services, carers and families including transparent and clear communication about funding and costs of projects.

Given the paucity of robust tools to measure quality of life and happiness with people with intellectual disability, it would be useful to collect data on how staff and families identify if things are going well or not for the program participants. For example, what are some of the patterns they recognise and share this knowledge, and how this knowledge is legitimated (or not). This information could feed into a bank of informal measures that staff and families use to evaluate the impact of projects.

4.1.4 Emotional and social indicators

As simple as it seems, self-worth, a sense of purpose, happiness and satisfaction are some of the key drivers for the success of projects for participants. These emerged as important desired outcomes of all projects across the interview and focus group data. These outcomes represented concepts such as self-worth; a sense of purpose, feeling useful; helping; contributing; a sense of achievement (e.g. being able to catch the train alone; creating new things; being able to work). Related concepts included feeling relaxed and having fun. Social interaction and friendship were also valued by program participants. It was noted that capturing these outcomes should be an essential component of the evaluation framework. Many of these concepts are ambiguous and subjective, and so the importance, for evaluation, will be on always delving deeper into what they mean for the individual and their network.

Study participants said that it was imperative that staff involved in collecting data know the program participant well. They explained that for program participants with high needs, signs of enjoyment might be as subtle as not turning away, a look on their face, or a smile. A literature scan highlighted that there are few tools to measure feelings of self-worth, happiness and “having a purpose” with people with intellectual disability. Recent correspondence with the Director, Evaluation, NDIA confirmed a gap in tools to measure Quality of Life for people with Intellectual Disability.

Relevant excerpts from a scoping study that examined measurement of quality of life for people with disabilities and their families have been included in Appendix 7.5. Links to potential tools have been provided in the evaluation framework prototype developed as a part of this study. It is anticipated that which of the provided tools are appropriate will be determined as the evaluation framework prototype is piloted.

In this report, we propose an innovative approach to collecting, analysing and reporting data and metrics for evaluation - Word Cloud Evaluation. A Word Cloud Evaluation methodology offers a method for collecting and visually representing over time, self-reported experiences linked with self-worth and purpose. This proposal is described in more detail in Appendix 7.6. This innovative methodology can be developed, piloted and refined in a future study.

4.1.5 Other evaluation indicators

Participants noted that funding drives evaluation. It was also noted that **projects need to be evaluated as to whether they are meeting the health and wellbeing needs of program participants, including their learning, behaviour, skills development, social interaction, and the extent to which it keeps individuals connected to their home as well as to their community.** Measures need to be included in the evaluation framework prototype, that assess whether a project builds the capacity of a person with disability and their family or carers to have choice and control over the decisions that are made around the support and services that they are provided or access. From the perspective of external government bodies, innovations should be evaluated on whether they achieve: 1) participation in community; 2) social participation; and 3) economic participation as a goal where relevant (workforce). An evaluation framework prototype also needs to include measures that assess whether and how a project achieves desired outcomes or goals based on the eight NDIS Domains.

In addition to the social and emotional values described in 4.1.4, **program participants identified that learning new things and skills development for a purpose was important to them.** The importance of evaluating skills development was also echoed in the interviews and focus groups with parents, staff and external stakeholders. **It was noted that in addition to evaluating whether new skills were gained, it is important to evaluate whether those skills are useful to the program participant and whether other skills are maintained, or even lost.**

Study participants also highlighted that the cost, accessibility, ease of use, engagement and disengagement of the participants, in relation to a project, are indicators that should be evaluated. Organisational measures including resources to design and implement an a project (e.g. number of staff; the lengthen of time), the number of projects designed and implemented across the organisation should be included in the evaluation of projects. Staff participants spoke to the importance of also evaluating how a project adds value to parents' lives.

4.1.6 Measuring how the projects are designed and delivered

Evaluating the extent to which there has been input from program participants and their parents and carers into the design of projects was considered important. So too was measuring whether design and delivery of projects have taken into account the differing needs of individuals. Flexibility to accommodate different individuals' needs and flexibility to accommodate changes in an individual's needs over time was considered important to evaluate.

4.1.7 What matters to an individual, or what they value, changes over time

Regularly revisiting with program participants and their families what is important to them, is relevant for all projects. Indicators that measure these things should be included for every project. It is necessary to consider what is happening over time for the individual. When support staff have worked with participants for some time, it is important to re-check whether there have been changes in what program participants have identified as important. Handover and sharing information about evaluation findings is an important strategy to support meaningful evaluation.

Scheduled time built in, for example at the end of the year, provides protected time for reflection of evaluation results individually and with other staff (across and within streams) to discuss and plan for the next year.

Handover, when the program participant transitions to work with a different staff member, could include information that is based on the evaluations the staff have done over the year - the data they have collected, the things that they have learned about the participant, the things to look out for in the coming year and when program participants engage with other projects. **The handover would also include information such as what the program participant values.** The handover can be used to signpost things to look out for – for new staff, and for participants who are moving or transitioning to different services. As part of co-designing an effective handover tool, it is important to consult staff about what they would like from a handover. Their experiences of receiving a good handover and a poor handover including information that they would have liked from a handover, ‘inside information’ such as a program participant’s wants and needs was said to be pivotal to the design of an effective handover tool.

4.1.8 How the evaluation is conducted: One size does not fit all

Clearly emerging from the data and aligned with the findings of the literature review was the importance of taking into account individual differences and needs of the program participants and their families. Parents and staff spoke of the importance of individualising evaluation rather than trying to use the same test or evaluation sheet for everyone. It was noted that evaluation would need to take into account multiple developmental domains including social, emotional and skills outcomes. These are highly individualised and meaningfully evaluating outcome was said to require one to think “outside the box”. For example, one parent identified that for his/her child, an undisturbed night’s sleep was an important indicator of a successful program. When his/her child slept well, it indicated that they were enjoying the program. Similarly, fewer visits to the GP for standard community illnesses such as flu, ear infections etc was another suggested indicator of a successful program. Program participants’ willingness to attend a program, their mood before and after attending a program, and the extent to which they contributed to the program, were also considered indicators for consideration.

A commonly identified point was the need to consider whether the evaluation allowed time for the person to get used to the project and the importance of **whether the goals of the project are being realised against a realistic timeframe. Short, medium and long term goals that are appropriate for each individual must be considered. Study participants identified the need for a range of data collection methods to choose from** (e.g. how you collect evaluation data from non-verbal program participants will be different from the methods you would use to collect data from program participants who are verbal).

4.1.9 Individualised and generalisable

Reiterated throughout the data was that **evaluation of projects for people with intellectual disability needs to be individualised while at the same time able to be mapped to organisational goals and values.** While the evaluation framework needs to incorporate the individual needs of participants, staff and carers, these need to be balanced with broader organisational goals and values (such as learning and innovation). Every project has a degree of specificity about what it is trying to achieve and the way in which it will be achieved. **Evaluation at Onemda needs to identify and measure individualised outcomes AND align data collection of individualised measurements for specific project outcomes to overarching organisational goals for a set of desired impacts for the people Onemda supports.** This was described to be necessary to enable comparison of the effectiveness and cost benefit.

4.1.10 Measure for unintended consequences

Study participants identified the importance of the evaluation framework including prompts to capture information about unintended consequences (positive and negative) of projects. One participant used an example of a car washing program to illustrate the need to measure unintended consequences (in this case positive). While the goal of the car washing program was to develop the program participant's skills, other outcomes included social interaction and a growth in confidence that translated to improvements in other activities. It was noted that evidence of change may take years to become apparent.

4.1.11 Supporting a culture that values evaluation of what program participants value

Critical to the evaluation for every project is measurement of: How the project contributes to a person's self-worth and other things they value. Therefore, it is vital to:

- identify what each program participant values;
- identify ways of measuring to what extent the project achieves this;
- collect and analyse data;
- use the findings to inform ongoing projects.

This will likely include broadening the focus from skills attainment to broader issues and reframing staff's views of what a good outcome is. To this end, there needs to be clarity

about how staff's performance is measured. If staff think their performance is being measured by the extent to which the program participants attain skills, then it is likely that this will be their focus. The organisation needs to make clear whether or not staff's performance is also measured against attainment in other areas e.g. understanding what the program participants like and dislike. **A Key Performance Indicator (KPI), for example, might be linked with how well staff members know the likes and dislikes of the program participants.** A measure of success for a staff member might be that by the end of six months they will be able to identify x number of things that matter to the program participant (that the program participant values).

Linking KPIs to evaluation illustrates the importance of evaluation to the organisation. Doing so offers potential for embedding a culture of evaluation at Onemda. Potential benefits and shortcomings of this approach require investigation and extensive consultation.

4.2 – Factors to consider when implementing evaluation at Onemda

4.2.1 A need for a collective understandings and definitions of terms

The interview and focus group data coupled with the findings of the facilitated workshop emphasised the importance of defining terms together (co-defining) by program participants, families, staff and others connected to Onemda. **A shared understanding of definitions is necessary to ensure people are working towards similar goals, and to avoid ambiguity.** It was highlighted, for example, that terms such as 'impact' and 'innovation' mean different things to different people. While program participants were uncertain what impact meant and how it affected them, staff understood impact to mean 'effect' in their work. Terms such as 'impact' should be continuously explored, as it can change depending on a range of factors (e.g. COVID-19).

4.2.2 Define clear goals and objectives when co-designing a project

As noted previously, it is important to collaborate with stakeholders to identify the goals of the project from different perspectives during the design of a project. **Deciding how to identify and measure success against these goals should be established before implementation of the project.** It is important to consider what measures show that the project has been beneficial, based on desired outcomes from the perspective of the program participant, as well as the specified NDIS related goals, specified in the program participant's plan.

Evaluation findings need to be relevant to program participants, their families, staff, Onemda as an organisation, and more widely – to the disability sector. There needs to be clarity around what is being measured, why, how, by whom, how often and for what (e.g. funding; parents; value add for the program participant, family, Onemda's mission

and goals, and society). It is necessary to identify, when planning the evaluation, how the evaluation findings will be reported in a way that is meaningful to various audiences.

There was an emphasis on the use of storytelling as an approach to better understand program participants' needs and goals. It was also suggested that 'myPlan' meetings provide a good touchpoint opportunity to explore and evolve evaluation.

Study participants suggested that workshops some training may be useful to support staff to think more broadly about and to identify project goals that may not be immediately obvious. **Consideration of how to capture data to identify changes in program participants' perceptions of self-worth over time needs to be encouraged as do discussions to contemplate other types of outcomes that could be measured.**

People collecting data for evaluation need to be upskilled, supported and rewarded to do so. There needs to be support to 'think outside the box' to identify what success looks like so that they can capture it.

4.2.3 Map and incorporate current evaluation activities: don't add without taking away

Evaluation activities are currently undertaken across the organisation. A shared and consistent approach to evaluation was reported to be needed. Mapping current evaluation activities and outputs to see how they can be incorporated with, and inform, future iterations of the evaluation framework prototype will be an important component of the pilot project. To illustrate, the Canadian Occupational Performance Measure (COMP) was being implemented at the time of data collection. A program participant's goals under their NDIS plan were tabulated and program participants and/or their family member provided a rating (1-10) on: 1) the importance of each goal to them; 2) their current performance on each goal; and 3) how satisfied they were with their current performance on the task/goal. These data are used by the therapy team to prioritise therapy to address goals under the program participant's NDIS plan.

Numerous study participants spoke about the number of evaluations with associated paperwork that have been introduced over time, such that they felt inundated with paperwork. There was a strong recommendation that **when new evaluation approaches are introduced, consideration needs to be given to how to replace or incorporate old evaluation approaches. They also highlighted the importance of incorporating evaluation in a way that does not increase workload.** For example, the collection of data to measure overarching, organisational outcomes that Onemda want to achieve for the people that they support, should be embedded as routine administrative periodic data collection from the people they support.

4.2.4 Evaluation needs to be easy and its value evident

A recurrent theme emerging from the data was that **the process of evaluation needs**

to be easy, meaningful and beneficial. Study participants noted that evaluation data should be collected from different sources, using tools and methods that are flexible enough to accommodate the needs of the participants and the goals of the project. They emphasised that, at the same time, data collection, analysis and reporting should be simple, that data should be hosted in a single system, and processes and resources put in place to support incorporation into current workflow. For example, sufficient iPads linked to the electronic data base should be made available to allow data collection with a program participant at the point of service delivery.

Study participants spoke to the importance of involving program participants and parents in the collection of evaluation data. The use of pictures and visuals to collect data and to report evaluation findings were offered as potential easy to administer options.

Study participants noted that **evaluation collection should be streamlined so that data can be collected and entered at point of interaction with the program participant rather than at the end of the day.** Once the IT system has incorporated what is needed, program participants could have the option of inputting their own data e.g. at the end of an activity. Importantly, study participants noted **the importance of the collection of data being systematically and consistently collected by all involved.**

Study participants identified different ways in which data were being collected and analysed, including pen and paper, electronically in the Z drive, or via Penelope the client management system used at Onemda. While pen and paper were noted to be easy, study participants reflected that this method was the least amenable to easy analysis and evaluation over time. The Penelope client management system was identified as a potential data management system to support embedding evaluation at Onemda. It was proposed that based on the findings of this study, and the proposed evaluation framework, Penelope be customised to support collection of evaluation data. **The types of evaluation data to be collected and entered into an IT system such as Penelope should be co-designed with program participants, families, staff. This will enable best practice communication with families and an evaluation of programs from the perspectives of program participants, families and staff that is based on regularly collected data.**

However, concerns were expressed that Penelope was 'clunky', time consuming and difficult to use. If Penelope is chosen as the data management system for collection and analysis of evaluation data, an evaluation of how to improve the user experience of Penelope would be warranted. Incremental introduction to staff of data to be collected using Penelope (e.g. How happy was the program participant? How engaged was the program participant?) while evaluating for barriers and enablers to using Penelope would be one way to initiate change. Subsequently, indicators to support collection of data to evaluate measures of what is important to a program participant and their families organisational measures and could be added to Penelope.

The benefits of embedding evaluation need to be evident to all involved. It was suggested that one way to engage program participants, parents and staff would be to demonstrate

timely improvements informed by evaluation findings, rather than having to wait six to twelve months for these to occur. It is currently the responsibility of lead instructors and coordinators to analyse data collected for the purposes of evaluation. However, given much of the data are currently collected using pen and paper is onerous and time consuming, the task of analysing data by revisiting piles of paper. Analysis of data on an access database that talks to an IT system, such as Penelope, will provide, at the click of a button, information in a format that is useful to all involved. This will enable streamlined access to evaluation data to inform timely reports and improvement cycles which will be beneficial to all stakeholders. The organisational benefits of using an IT system, such as Penelope, to manage evaluation data is that big picture, cross organisation trends can be identified. For example, which (types of) projects have been most successful across the organisation from multiple perspectives.

Collecting and reporting evaluation data will, therefore, ultimately reduce work for staff. The evaluation data are collected across the year in an easy to read and analyse format. The current practice is that at the end of the year, for each program participant, the data are collated and presented as a narrative/report of what the participant has done during the year – what has worked well, what goals they have achieved etc. Currently the staff need to use their memory and personal reflection on a program participant’s journey through the year. If the data were collected regularly in a format that fed into the narrative report, this would be particularly useful and much easier for staff. Appendix 7.7 offers a potential template for the delivery of the data/information in a way that supports staff to use the evaluation data to inform the development of their reports.

As noted previously, the process of co-designed evaluation (co-designing evaluation indicators etc) should begin at the design stage. **Collection and timely analysis of the evaluation data from the initiation of a project will support formative evaluation. This will enable evidence informed tweaks to the project, and if warranted, cessation of the project and redeployment of resources more appropriately.**

5

EVALUATION FRAMEWORK PROTOTYPE

5.1 presents the co-designed evaluation prototype to guide evaluation and support a co-design approach at Onemda. This prototype is based on the study findings and discussions with Onemda about its purpose and how the framework could be used.

A multi method approach was used to develop the prototype including:

- A desktop review of published evaluation frameworks;
- A literature review of studies reporting evaluation of interventions developed using a human centred design approach for people with disability;
- Interviews with Onemda program participants;
- Interviews with Onemda program participants' parents;
- Interviews and focus groups with Onemda staff;
- Interviews with key stakeholders external to Onemda (NDIA and NDS);
- Facilitated interactive group discussion with program participants, Onemda staff, and members of the research team;
- Brainstorming session with Onemda staff and members of the UTS research team;
- Weekly-fortnightly discussions between Onemda and UTS researchers over the project to iteratively refine the prototype.

The proposed stages of the evaluation process for projects, using the prototype, are:

- Project accepted for testing/use in Onemda;
- Determine desired outcome and from whose perspective;
- Develop, through consultation, a set of metrics for impact or effectiveness and implementation;
- Co-design how they will be measured, collected and analysed;

- Undertake measurements;
- Collect and analyse measurements;
- Communicate to participants and other stakeholders;
- Use results to iterate on project;
- Use results to reflect on and evolve evaluation framework/process

An online version of the prototype (presented in 5.1) will be informally trialled as a proof-of-concept in August 2021. The proof-of-concept trial will inform subsequent iterations of the prototype prior to a formal pilot (Phase 2). As a part of this proof-of-concept trial, the draft prototype will be used to guide evaluation of the prototype itself.

A formal pilot (Phase 2) will be conducted once ethics approval and funding have been obtained. The pilot phase will include interviews, focus groups, facilitated group discussions, and other research activities) with program participants, parents and Onemda staff to explore:

- whether the stages included in the evaluation framework prototype represent an ideal evaluation process;
- ideas about how each of the stages might be carried out in various ways;
- barriers to the evaluation framework being implemented in practice;
- further considerations and questions.

Each exploration of the prototype will contribute to refining the model. Whether or not the evaluation framework takes the currently proposed visual form should itself be tested, as program participants, parents and staff might have other ideas about what it should look like. Information gathered on usability and impact will also be used to inform iterations.

5.1 Prototype Evaluation Framework ---

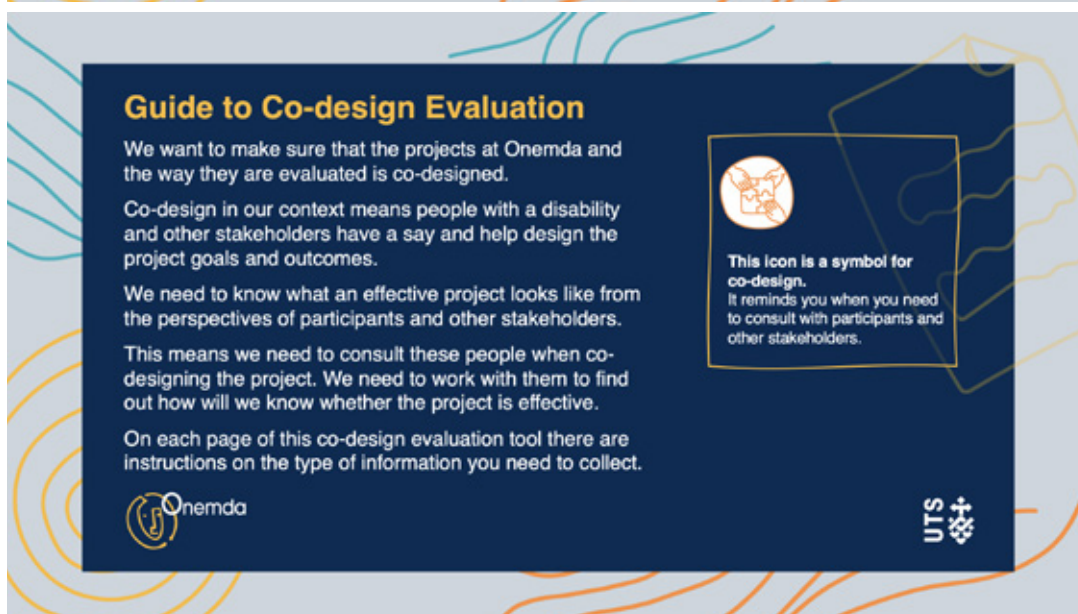
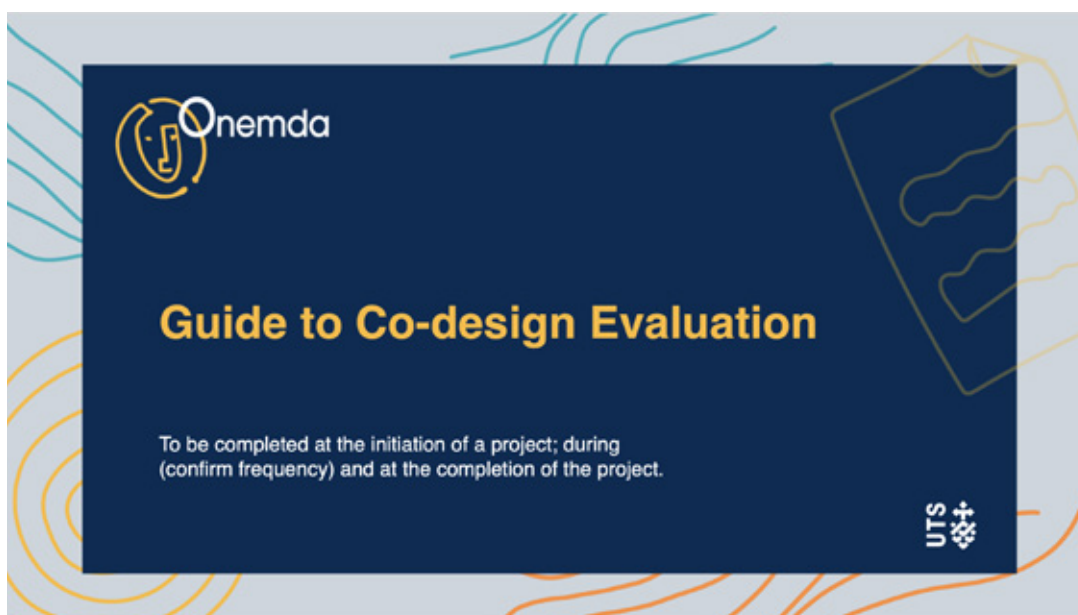
As noted previously, the evaluation framework prototype was iteratively developed across numerous meetings between Onemda and UTS, and was informed by input from a literature review, program participants, parents, Onemda staff, stakeholders from NDIA, NDS, researchers and a graphic designer from UTS. Versions of matrices developed as part of the project and that informed the final iteration of the prototype have been included in Appendices 7.9, 7.10, 7.11, 7.12, 7.13.

The draft evaluation framework prototype, *The Guide to Co-design Evaluation*, presented below, includes 17 easy to read, interactive frames covering six stages involved in designing and evaluating a project at Onemda: Project Introduction; Understanding the Project; Co-designing the Project; Project Outcomes; Implementing the Project; Evaluation over Time.

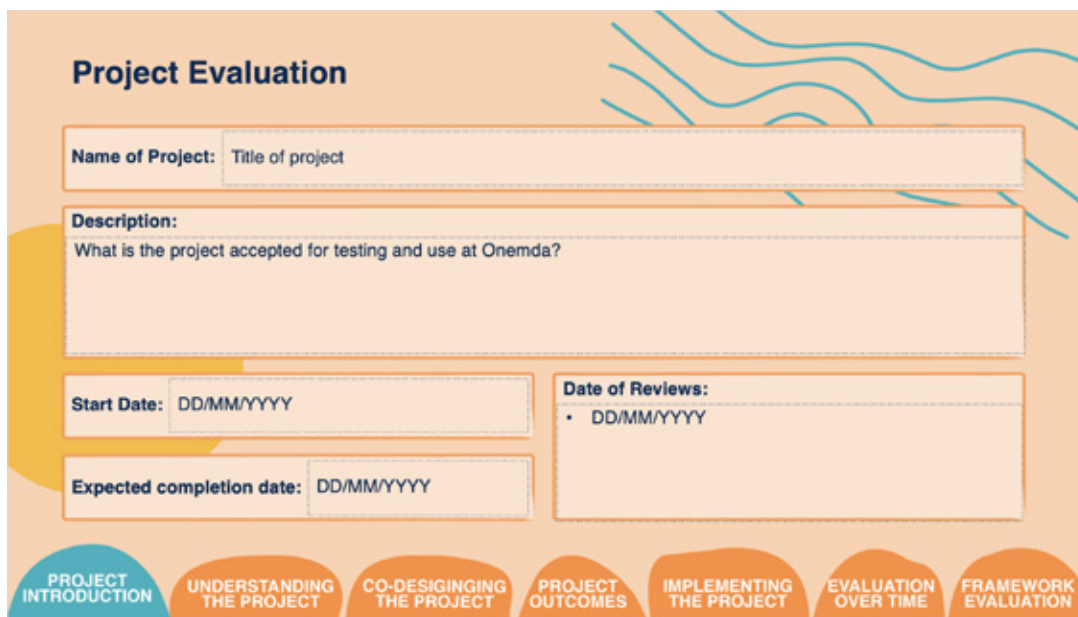
Staff members are encouraged to complete *The Guide to Co-Design Evaluation* online at the initiation of a project; during the project; and at completion of the project. Doing so encourages consultation and input from different stakeholders about the objectives and design of the proposed project and how it will be evaluated. Information about the type of

information that needs to be collected and instructions about what to do with it and next steps are also included in the Guide.

The first two frames of the prototype introduce The Guide to Co-design Evaluation, including its purpose and what to look for when completing the frames. What is meant by 'co-design', its purpose and how it can be operationalised at Onemda is described in the second frame. A symbol depicting co-design is introduced in the second frame. This symbol is used to remind those completing the online prototype when they need to consult with participants and other stakeholders (frames 6,7,8,9,10,12,15). On four of the frames (9,12,14,16), users are prompted with: "What are you doing to keep stakeholders informed about this stage of the project?"



The third frame of the prototype captures information about the proposed project including a short description of the project, anticipated start and completion date, and dates the project should be reviewed.



Project Evaluation

Name of Project:

Description:

Start Date:

Expected completion date:

Date of Reviews:
•

PROJECT INTRODUCTION UNDERSTANDING THE PROJECT CO-DESIGNING THE PROJECT PROJECT OUTCOMES IMPLEMENTING THE PROJECT EVALUATION OVER TIME FRAMEWORK EVALUATION

The fourth, fifth and sixth frames prompt users to think about, and capture information to better understand the project, including: identified need for the project; evidence to support the design of the project; the desired outcome of the project and from whose perspectives.



Understanding the Project

We need to know what an effective project looks like from the perspectives of participants and other stakeholders. Other stakeholders might include families/carers, Onemda staff, Onemda organisation, community members, NDIA, NDS and other.

This means we need to consult these people when co-designing the project. We need to work with them to find out how we will know whether the project is effective.

PROJECT INTRODUCTION UNDERSTANDING THE PROJECT CO-DESIGNING THE PROJECT PROJECT OUTCOMES IMPLEMENTING THE PROJECT EVALUATION OVER TIME FRAMEWORK EVALUATION

EVIDENCE OF NEED

What is the identified need for the project?

Write answer here

What is the evidence to support the design of the project?

Write answer here

Who identified the need for the project?

Write answer here

PROJECT
INTRODUCTION

UNDERSTANDING
THE PROJECT

CO-DESIGNING
THE PROJECT

PROJECT
OUTCOMES

IMPLEMENTING
THE PROJECT

EVALUATION
OVER TIME

FRAMEWORK
EVALUATION

EVIDENCE OF NEED

What is the desired outcome of the project?

Write answer here

From whose perspective is this the desired outcome? Who thinks this is a good outcome?

e.g: Participant, Family, Staff, Organisational, NDIS, Other)



What are you doing to keep stakeholders informed about this stage of the project?

PROJECT
INTRODUCTION

UNDERSTANDING
THE PROJECT

CO-DESIGNING
THE PROJECT

PROJECT
OUTCOMES

IMPLEMENTING
THE PROJECT

EVALUATION
OVER TIME

FRAMEWORK
EVALUATION

The seventh frame reminds the user of the importance of seeking stakeholder input to co-design the project goals and outcomes and provides tips about how to do this.

Co-designing the Project



A reminder that in this context co-design means people with a disability and other stakeholders have a say and help design the project goals and outcomes.

Co-design requires consultation. This can be done in a number of ways – you could fill out this form together, you could run a workshop to gather ideas and then fill out the form, you could talk with them and then fill out the form etc.

The most important thing is to not do it alone.

PROJECT INTRODUCTION UNDERSTANDING THE PROJECT **CO-DESIGNING THE PROJECT** PROJECT OUTCOMES IMPLEMENTING THE PROJECT EVALUATION OVER TIME FRAMEWORK EVALUATION

Frames 8, 9 and 10 capture data and, in so doing prompt the user to consider, how the project will be implemented, who will or could be involved, how outcomes will be measured, training needs to collect and analyse outcome measures, and how often and when project implementation and outcomes will be evaluated. Users are encouraged to consider whether validated or new data measures are most appropriate. A hyperlink in frame ten to a bank of validated tools and measures, to be compiled by Onemda, will allow users to access easily tools that are appropriate for the evaluation they are designing and conducting.

 **CO-DESIGNING EVALUATION**

Where is the project to be implemented?
Write answer here

Who does it?
Write answer here

Who else could be involved?
Write answer here

PROJECT INTRODUCTION UNDERSTANDING THE PROJECT **CO-DESIGNING THE PROJECT** PROJECT OUTCOMES IMPLEMENTING THE PROJECT EVALUATION OVER TIME FRAMEWORK EVALUATION



CO-DESIGNING EVALUATION

What are you doing to keep stakeholders informed about this stage of the project?

Co-design how outcome measures will be collected and analysed:

Write here



What training is needed to collect and analyse data? Is training available?
If training is required and not available, talk to your line manager before proceeding with project.

Write here

What date(s) will you review both how the project is being implemented and what the outcome measures are telling you about how the project is going?

TIP: Put date(s) in your diary as a reminder!

Write here

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CO-DESIGNING EVALUATION

Will you use a validated tool to measure the outcomes or will you develop your own process?

These tools can be access here:
[INSERT HYPERLINK HERE]

Write answer here

Considerations and questions?

Write answer here

Building new data measures?
or
using existing measures?

Is it in the right format? Does it need changing? etc.

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Frames 11 and 12 prompt and capture data on project outcomes. Frame eleven provides Onemda's strategic objectives, Quality of Life goals (based on Schalock and Verdugo, 2012), and NDIS Domains. Users are reminded that every project should meet at least: one of Onemda's Strategic Goals; one Quality of Life measure; and one NDIS domain measure. Frame twelve requires users to identify the desired outcomes (long, medium and long term), how these will be measured, and which of the Strategic, Quality of Life and/or NDIS domain measures the outcomes map to.

CAPTURING SHORT, MEDIUM & LONG-TERM GOALS

Every project should meet at least one of Onemda's Strategic Goals; at least one Quality of Life measure; and at least one NDIS domain measure

Onemda	Quality of Life <small>Schalock and Verdugo (2012)</small>	NDIS
O-1 Deliver outstanding and impactful services which enrich and extend our participants.	Q-1 Personal Development: Education status; personal skills; adaptive behaviour	N-1 Domain 1: Choice and control
O-2 Grow Onemda's established profile as a trusted and progressive leader within key target audiences.	Q-2 Self-determination: Choices/decisions; autonomy; personal control; personal goals	N-2 Domain 2: Daily living
O-3 Bring Onemda's unique value proposition to markets in need.	Q-3 Interpersonal relations: Social networks; friendships; social activities; relationships	N-3 Domain 3: Relationships
O-4 Optimise organisational capacity to deliver on our vision.	Q-4 Social Inclusion: Community integration/ participation; Community roles; supports	N-4 Domain 4: Home
O-5 Continue to build and shape a brilliantly skilled, passionate and high performing workforce.	Q-5 Rights: Human (response, dignity, equality); Legal (legal access and due process)	N-5 Domain 5: Health and wellbeing
O-6 Continue to embed research, innovation and technology into service delivery activities.	Q-6 Emotional wellbeing: Safety and security; Positive experiences; Contentment; Lack of Stress	N-6 Domain 6: Lifelong learning
	Q-7 Physical wellbeing: Health & nutrition status; recreation; leisure	N-7 Domain 7: Work
	Q-8 Material wellbeing: Financial status; employment status; housing status; possessions	N-8 Domain 8: Social, community and civic participation

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PROJECT OUTCOMES & SUCCESS MEASURES

↻ What are you doing to keep stakeholders informed about this stage of the project?

STAKEHOLDER	WHAT OUTCOME DO YOU HOPE TO ACHIEVE?	S/M/L	WHAT IS THE SUCCESS MEASURE? <small>(Based on consultation with stakeholders)</small>	HOW DO WE MEASURE THIS? <small>(Based on consultation with stakeholders)</small>	ONEMDA	QUALITY OF LIFE	NDIS
Onemda participant	Write answer here	Short/ Med/ Long	Write answer here	Who collects and analyses the data, where will it be stored?	e.g. O-1, O-4, O-6	e.g. Q-2, Q-3, Q-8	e.g. N-1, N-3
Insert Stakeholder group	Write answer here	Short/ Med/ Long	Write answer here	Who collects and analyses the data, where will it be stored?	e.g. O-1, O-4, O-6	e.g. Q-2, Q-3, Q-8	e.g. N-1, N-3
Insert Stakeholder group	Write answer here	Short/ Med/ Long	Write answer here	Who collects and analyses the data, where will it be stored?	e.g. O-1, O-4, O-6	e.g. Q-2, Q-3, Q-8	e.g. N-1, N-3
Insert Stakeholder group	Write answer here	Short/ Med/ Long	Write answer here	Who collects and analyses the data, where will it be stored?	e.g. O-1, O-4, O-6	e.g. Q-2, Q-3, Q-8	e.g. N-1, N-3

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Frames 13 and 14 collect data on the project implementation: how it is/was implemented; why it is implemented like that; unintended outcomes; and resources required to implement and evaluate the project.

HOW WAS THE PROJECT IMPLEMENTED?

The next section of the framework captures what happened when the project was implemented so that we can understand what worked and what didn't work and why.

This will help us understand what next steps are appropriate for this project.

Describe how the project happens or gets done:
Write here

Why does it happen like that?
Focus on what people DO rather than what they think

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HOW WAS THE PROJECT IMPLEMENTED?

Were there unintended consequences of the project?
Write here

What resources were needed to implement and evaluate the project? (dollars, staff, time, equipment, other)

Implementation resources (costs) Write here

Evaluation resources (costs) Write here

Other comments:
Write here

 What are you doing to keep stakeholders informed about this stage of the project?

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Frames 15 and 16 support evaluation over time. Frame 15 prompts the user to provide information on the evaluation findings for each of the identified outcomes (“What did you find out?”), what will be done as a result of the findings (“What are you going do about it? What needs to change?”) and where the data related to the project (including evaluation data) is being stored. Frame 16 prompts the user to identify, based on the evaluation data, whether the stakeholder: is enjoying the project; has gained anything out of the project; and whether there have been changes towards the outcomes they would like to achieve. The user is asked to decide if the project will: continue without changes; continue with changes to make it better; discontinue the project. The user is asked to provide information about how the implementation and outcome evaluation measures informed their decision. If the decision is made to continue the project, the user is asked to indicate the outcome measures that will be used to evaluate its impact.

SHORT, MEDIUM & LONG-TERM OUTCOMES

OUTCOME & MEASURE <small>(What data is being collected?)</small>	WHAT DID YOU FIND OUT?	WHAT ARE YOU GOING TO DO ABOUT IT? <small>WHAT NEEDS TO CHANGE?</small>	WHERE IS DATA FOR THIS PROJECT STORED?
Write outcome here	Is the project enjoyable, what have people (not just Program participants) gained out of the project, what changes have happened in relation to project outcomes?	Write here	Write here
Write outcome here	Is the project enjoyable, what have people (not just Program participants) gained out of the project, what changes have happened in relation to project outcomes?	Write here	Write here
Write outcome here	Is the project enjoyable, what have people (not just Program participants) gained out of the project, what changes have happened in relation to project outcomes?	Write here	Write here

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WHAT IS NEXT FOR THIS PROJECT?

What are you doing to keep stakeholders informed about this stage of the project?

Is the stakeholder enjoying the project?
Have they gained anything out of the project?
Have there been any changes toward the outcomes they would like to achieve
(e.g. movement toward Strongly Agree on a Likert scale)?

MOVE TICK INTO APPROPRIATE BOX

Continue project without changes

Continue project with changes to make it better

Discontinue the project

Why? How did the outcome and implementation measures inform your decision?

Write here

If continuing the project how are you going to measure its impact?

Write here

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Frame 17 collects data about users' experiences of using the evaluation framework prototype. This feedback will enable evaluation of the prototype. This feedback will be used to make improvements to the evaluation framework prototype prior to a formal pilot in the next phase, Phase 2, of the study.

FRAMEWORK EVALUATION

This evaluation framework has been designed by Onemda and UTS to help disability services to co-design projects and evaluations. We also want to find out whether projects are working from the perspectives of Participants and other stakeholders.

You are the first people to pilot this evaluation framework prototype. We are going to use your feedback and experiences to improve this prototype so that it is easier and not too time consuming to use.

Use results to reflect on and evaluate the evaluation framework

Write here

PROJECT INTRODUCTION UNDERSTANDING THE PROJECT CO-DESIGNING THE PROJECT PROJECT OUTCOMES IMPLEMENTING THE PROJECT EVALUATION OVER TIME **FRAMEWORK EVALUATION**

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CONCLUSION

The initial objective for Phase one of this project was to co-design, with program participants, families, Onemda staff and with input from external stakeholders, a prototype evaluation framework to guide consistent and systematic evaluation of innovations developed in the Research & Innovation Centre at Onemda. As the project progressed, we expanded the scope of the brief to co-design a prototype for a high level evaluation framework that can be used to guide and embed evaluation of projects implemented at Onemda, not just those developed in the Research & Innovation Centre. To do this, we have co-designed a broad framework that prompts staff to consult, when designing the project, program participants, families and other staff to identify what 'good' looks like (what are the desired outcomes), how it will be evident if 'good' has been achieved and how it was achieved (what needs to be measured), how can it be measured (what data needs to be collected, how and by whom), analysed (who will do the analysis and how) and reported (who will the evaluation outcomes be reported to, and how). Early consultation such as this, facilitates co-design of projects at Onemda.

The types of evaluation data collected will vary between participants. For example, a smile might indicate engagement with an activity for one person, while not looking away might indicate engagement for another. In this case, the indicator being evaluated is 'engagement' even though the way it is being evaluated is individualised. Likewise, 'what matters to me' (what 'good' looks like) will vary between stakeholders. These individualised indicators will be mapped to shared categories allowing evaluation across the organisation and over time.

An important finding of this project is that whether and how a project contributes to program participants' feelings of self-worth and quality of life should be evaluated. The way in which this is measured will vary between participants.

Consultation with stakeholders when the project is being designed will identify what is important from their perspectives and therefore what they want measured and the best way to do so. This will enable Onemda to determine how successful a project is in achieving outcomes from the perspectives of program participants, families, staff and Onemda. The metrics needed to measure what "good" looks like may differ across stakeholders. The evaluation framework prototype will guide users to capture data to meet the needs of the different stakeholders.

Next Steps

An informal trial of the evaluation framework prototype is currently underway as a proof-of-concept with selected projects implemented prior to the end of August 2021. Early feedback suggests that The Guide to Co-Design Evaluation tool has generated discussions with program participants to support co-designing selected projects, leading to positive anticipated and unanticipated outcomes for program participants and staff.

The prototype will be iterated based on feedback collected as part of the informal trial prior to a formal pilot (Phase 2).

Identify and secure funding to complete the final three phases of the project.

Phase Two:

Pilot the evaluation framework prototype at Onemda

1. Identify and recruit champions to form a team to implement the prototype evaluation framework.
2. Conduct interviews and observations to identify barriers to implementation of the framework, feasibility and perceived impact of the evaluation framework.
3. Collect and analyse data collected by processes and structures included in the evaluation framework.
4. Conduct rolling NPT surveys of people involved in development and implementation of projects at Onemda.

Phase Three:

Refine and implement the evaluation framework

1. Analyse observation and interview data to identify barriers to implementation, feasibility and impact of those projects using the evaluation framework. This will include using implementation science informed approaches to identify barriers and to operationalise matched behaviour change techniques to target those barriers. Analysis of data collected using the evaluation framework will be used to identify ways in which the evaluation framework can be improved.

Phase Four:

Develop an implementation toolkit to support implementation of the evaluation framework toolkit and disseminate findings

1. Consult the literature and conduct interviews and focus groups with consumers, carers, providers and managers to co-develop a toolkit to support implementation, dissemination and sustainability of the evaluation framework.
2. Disseminate findings through community-based presentations, conference presentations and publications in relevant journals to target relevant audiences.

Future work to develop the evaluation framework as an online tool available to support bespoke evaluation of diverse interventions across the disability sector. UTS is committed to supporting social impact evaluation for not-for-profit organisations. Currently our Social Justice Centre is developing an online Toolbox and online courses to support evaluation best practice (<https://open.uts.edu.au/measuringsocialimpact.html>). We will explore future opportunities to collaborate with this team for dissemination. Alternatively, our rapid prototyping unit, UTS Rapido (<https://rapido.uts.edu.au>) could be engaged to develop a Onemda branded tool suite.

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7

APPENDICES

7.1 Useful resources

The following useful resources have been developed by Child Family Community Australia (CFCA), Australian Institute of Family Studies' information hub for evidence, resources and support for professionals working in the child, family and community welfare sector.

Identifying evaluation questions

A short article for people new to evaluation who are planning to conduct or commission an evaluation.

Planning an evaluation: Step by step

A practical guide for people who are new to evaluation and need some help with developing an evaluation plan.

A guided tour through measuring outcomes (link is external)

An instructional video that steps audiences through how to measure outcomes.

Tips for commissioning an external evaluation

A short article for anyone planning to commission an evaluation from an external evaluator

How to develop a program logic for planning and evaluation

This website provides an explanation of program logic, templates and instructional video that steps audiences through program logic.

7.2 Interview Schedule with Onemda program participants —

Introduction and informed consent: 10mins

- Welcome
- Confirm that the participants have understood the information in the Participant Information Statement and have signed the Consent form
- State purpose of individual interview [to find out what you think makes a new product, service or program good]
- It will take about 30 minutes – we can stop at any time if you are tired or do not want to keep going
- I will record the discussion or take notes
- Voluntary participation and right to withdraw without giving a reason

Interview questions

1. What services have you used/ do you use? (e.g. employment, day program, mobility aids, medical equipment, communication supports, etc.)
2. What do you hope that Onemda will help you with?
3. Do you use any technology – for yourself or in your home? [Discuss e.g. How did you get these? Who organised them? Were they designed especially for you?]
4. What would a good service look and feel like to you?
5. What would a good program look or feel like to you?
6. What would a good innovation look and feel like to you? That is, a new idea, product or way of working that creates change or better outcomes in some way.
7. When Onemda introduces a new service or innovation what do you think is important to monitor to decide whether it's working? [e.g. How much it costs and for whom; how does it link with NDIS plans; how is support provided? Who by?]
8. Do you have any other comments you would like to make?

Thank you very much for your time

We have a \$30.00 gift card to acknowledge your time and contribution to this project.

Would you like the gift card in physical version - posted or left at Onemda

7.3 Interview and Focus Group Schedule: Parents, Staff and Stakeholders

Introduction and informed consent: 10mins

- Welcome
- Confirm that the participants have understood the information in the Participant Information Statement and have signed the Consent form
- State purpose of individual interview/focus groups [to identify what should be measured when evaluating the development and implementation of innovative technologies, services or programs for people with a disability] Discussion takes about 30-60 minutes, in it we will ask about your views in relation to the development and implementation of programs technologies, services or programs for people with a disability
- The discussion will be recorded
- Voluntary participation and right to withdraw without giving a reason

Interview and focus group questions

1. Can you tell me about your experience in the development, implementation and evaluation of new ideas, products, services or programs for people with a disability? [Prompt: What was your experience like?]
2. What would a successful service, program, idea, product or new way of working look and feel like to you? [What is important? What are the hallmarks of a successful service, program, idea or new way of working?]
3. What do you think is important to someone with a disability or carer who use technologies/services/programs - what do they think should be measured when evaluating them?
4. When Onemda introduces new ideas, products, services or programs what do you think is important to measure? [e.g. How much it costs and for whom; how does it link with NDIS plans; how is support provided and by whom?]
5. How would you measure the success of new ideas, products, services or programs? [What sort of information should be collected to identify if an intervention/innovation is successful/feasible/useful?]
6. Where/when/how can that information can be collected and from whom? [What sorts of information are currently collected and how (e.g. is technology used ipads, phones, computers etc)?]
7. Who is/are the best person/people to collect the information?
8. What are/might be barriers or challenges to collecting the types of information that have been suggested?
9. Do you have any other comments you would like to make?

Thank you very much for your time

Parents: We have a \$30.00 gift card to acknowledge your time and contribution to this project. Would you like the gift card in physical version - posted or left at Onemda.

7.4 Distress and safety Protocol: Interview and focus group participants

The following protocol will be put in place should a participant become distressed and require either additional or ongoing assistance.

Procedure for Onemda staff and Board members:

Onemda has an Employment Assistance Program that is available for Staff & Board Members. Onemda can provide 1:1 counselling by a trained psychologist under this program as well as group debriefing sessions.

Procedure for Onemda participants and carers:

For Onemda program participants and carers debriefing and counselling is provided by trained social workers and psychologists employed by Onemda. People can refer themselves for these services, otherwise these services can be recommended by support workers who have been trained to identify signs of distress in participants and carers.

Strategies to assist those distressed during an interview or focus group.

Care will be taken to determine whether the participant's disability might increase susceptibility to discomfort or stress. Support staff will be consulted to determine signs of participant distress, the level of risk or discomfort or distress and whether to conduct an interview or focus group.

Should a participant become uncomfortable or distressed while discussing any topic during the interview/focus group, the interviewer will take the following actions:

1. The researcher will suggest that it is appropriate that the interview/focus group be terminated.
2. If the participant wishes this to happen, the interview or their participation in the focus group will be ceased.
3. If the participant is an Onemda program participant, the interviewer will alert Onemda staff to ensure that appropriate support is provided (see above).
4. In the case where a counsellor is not readily accessible at the time of the interview, a member of the research team who is a health professional will spend time with the participant and provide assistance, within the scope of their abilities, to discuss their concerns and support them. Counsellors/ psychologists will be available at Life Resolutions, an external counselling service.
5. The Chief investigator who will be conducting the interviews and focus groups will identify whether to recommend that the participant speak to a counselling professional to discuss their concerns.
6. The intended outcome of the activation of this protocol will be a comprehensive assessment and the presentation of options regarding ongoing counselling or other management as appropriate.

7. A follow-up phone call will be made by the interviewer the following day to ensure that the participant is well and to determine feasibility of a follow-up interview if one is planned.

Distress and safety Protocol: Researcher

The following protocol will be put in place should a researcher become distressed or be at risk during field work and require emergency, additional or ongoing assistance. A range of services could be offered depending on her circumstances.

Strategies to assist those distressed during an interview.

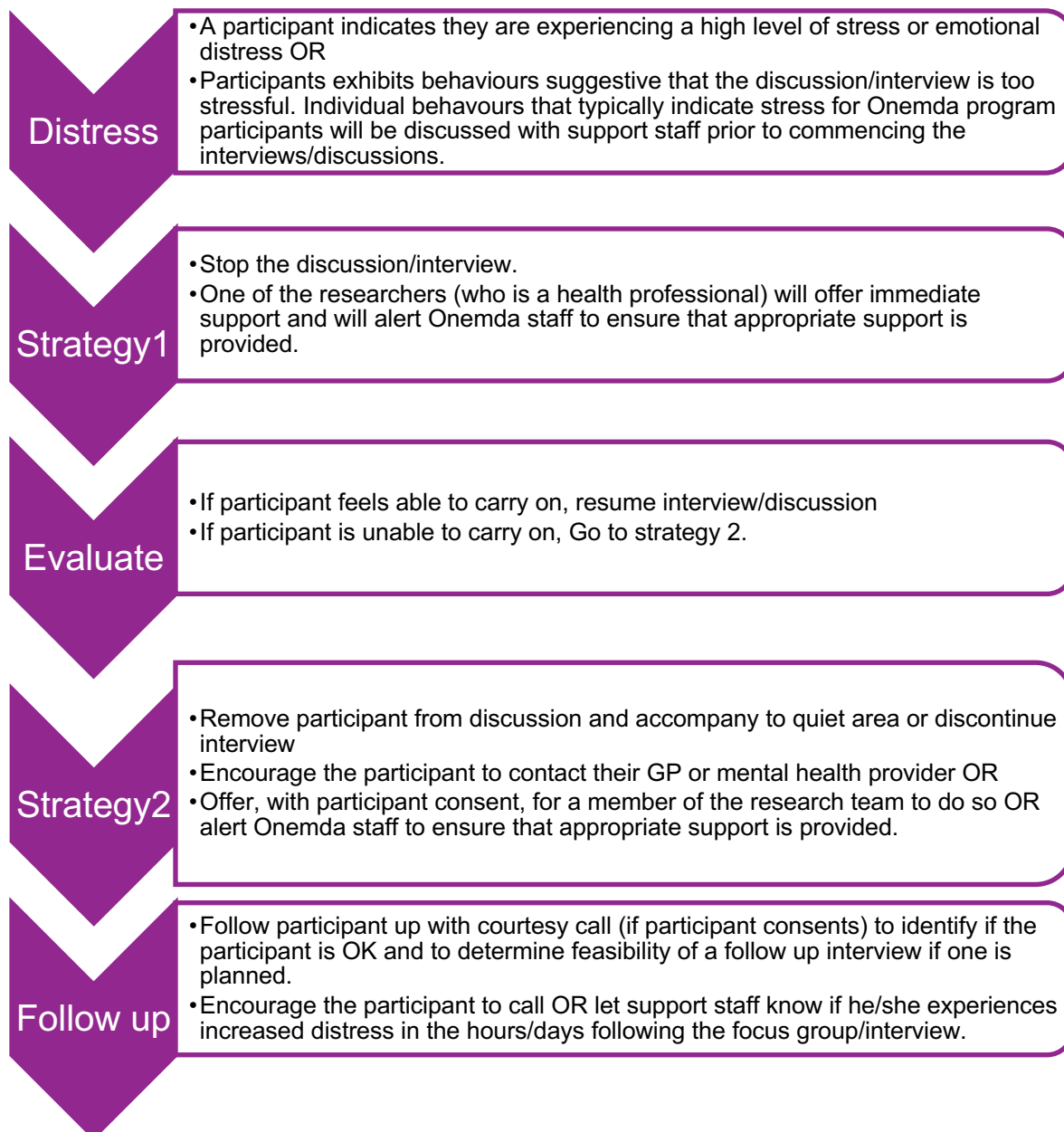
1. The researcher have regular meetings with the research team and supervisor prior to, during and at the conclusion of interviews and focus groups. These meetings will address potential difficulties and reinforce the need for the researcher to disclose any potentially distressing encounters.
2. The researcher will be referred to a counselling professional to discuss their concerns or a referral made to the UTS Employee Assistance Program
3. The researcher will always carry a mobile phone while working in the field and will share the contact details and location of the interviews with research team.

Conclusion

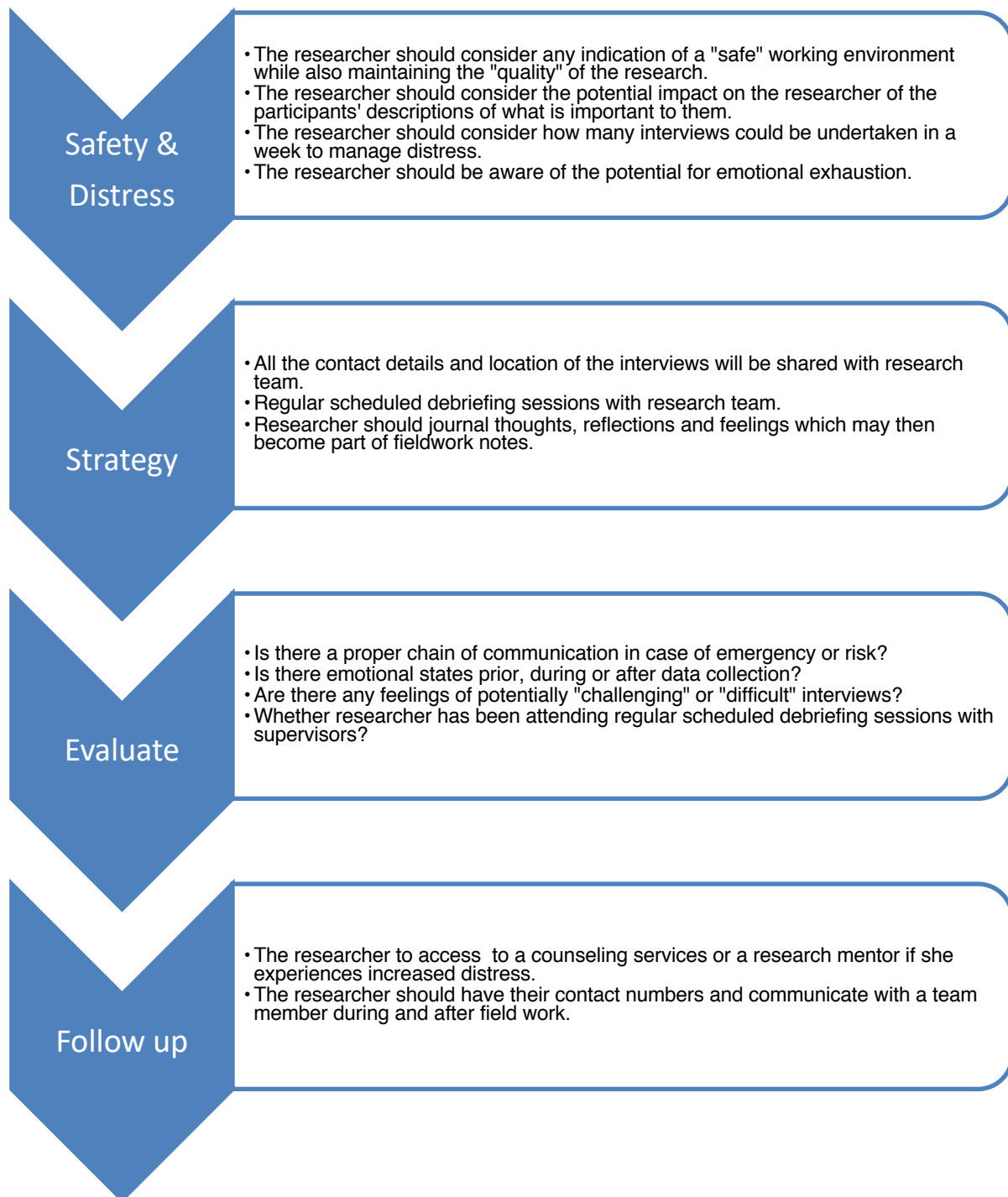
It is the researcher's duty of care to ensure that there is a balance consideration of the benefits of research against the risks. The researcher will ensure these strategies are put in place prior to commencing the interviews or focus group discussions.

Below is the step by step guided protocol adapted from Draucker C B, Martsof D S and Poole C (2009) Developing Distress Protocols for research on Sensitive Topics. Archives of Psychiatric Nursing 23 (5) pp 343-350)

Participants' Safety & Distress Protocol




Researcher's Safety and Distress Protocol



7.5 Summary excerpts from Davidson et al (2017) Measuring the Quality of Life of People with Disabilities and their Families: Scoping Study Final Report. ---

The following summarises, a 2017 scoping study (Davidson et al., 2017) of ways in which quality of life of people with disabilities and their families are measured.

WHO definition of Quality of Life is: *“Individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.”* (<https://www.who.int/tools/whoqol>) 

Definition of Family Quality of Life

Davidson et al (2017, p. 19) summarise Park’s (2003) definition of Family Quality of Life (FQOL) *“...conditions where the family’s needs are met, and family members enjoy their life together as a family and have a chance to do things which are important to them”.*

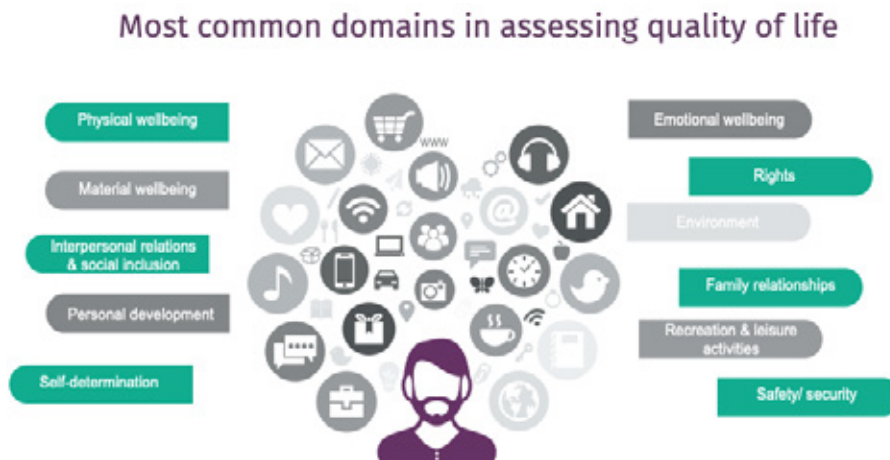
Measuring FQOL is important because *“FQOL can be used to measure outcomes from a wide range of family contexts and could be useful in measuring the effectiveness of interventions.”* (Davidson et al, 2017: 19)

Davidson et al (2017) note that when measuring quality of life for adults with disability: *“Both objective and subjective measures are important. The most common domains in QoL assessments are physical wellbeing, material wellbeing, interpersonal relations and social inclusion, personal development, self-determination, emotional wellbeing, rights, environment, family relationships, recreation and leisure activities, and safety/security. Subjective quality of life may, or may not, be closely associated with services provided. There are a wide range of measurements used to assess QoL. It is important to involve those whose QoL you wish to measure in the development and design of the relevant measure.”* (Davidson et al, 2017: 20, not the original author’s italics)

“Verdugo et al. (2005) have recommended that the measurement of QoL should include: the range of relevant domains; both objective and subjective measures; multivariate designs to explore relationships between personal and environmental factors and QoL; a systemic perspective that acknowledges factors at the micro and macro levels; the involvement of those whose QoL you are assessing in the design and implementation of the assessment.” (Davidson et al, 2017: 21, not the original author’s italics)

Vedugo et al. (2005) presented in Davidson et al (2017) summarised the most common domains in QoL assessments:

Figure 8.1: Most common domains in assessing quality of life (Verdugo et al (2005) presented in (Davidson et al, 2017: 22))



Measuring quality of life using proxies

“There is little consideration of people with complex disabilities in the subjective wellbeing literature. All possible supports should be explored before considering proxy responses. Proxy reporting tends to rate QoL lower than self-reporting. Minimise potential proxy bias by including very clear instructions, including both proxy-patient and proxy-proxy perspectives.

We recommend focusing on self-reporting within the disability QoL survey as much as possible, while it is expected that the general population survey will include at least some proxy reporting.” (Davidson et al, 2017: 33)

Measuring quality of life for families

“All studies focused on families in which there was a child with a disability. The Beach Centre FQOL Scale and the FQOLS/ FQOLS-2006 were the most commonly used tools. Nearly half of the studies were concerned with the development of measurement tools while the other half were focused on applying the available tools. Measuring FQOL is still in its infancy and more work needs to be done to address its complexities. We recommend including questions about the family in a general population survey, in addition to the self-reporting survey.” (Davidson et al, 2017: 33)

The following tools identified in the literature are specifically designed for use with people with intellectual disabilities. A comprehensive summary table of tools used to measure Quality of Life for people with disability is available on pages 47-48 of [Davidson et al’s 2017 report](#). 

- Quality of Life Questionnaire (QOL-Q) (Schalock & Keith, 1993)[specifically designed for people with intellectual disabilities]
- INTEGRAL Quality of Life Scale (M. Á. Verdugo et al., 2010)[specifically designed for people with intellectual disabilities]
- San Martin Scale (M. A. Verdugo et al., 2014) [specifically designed as a Proxy measure]

- Beach Center on Disability Family Quality of Life Scale (FQoL) (Hoffman et al., 2006; Park et al., 2003) [specifically designed for measuring QoL for families with children with an intellectual disability]
- Family Quality of Life Survey (FQOLS-2006) (Brown et al., 2013) [specifically designed for measuring QoL for families with a member with an intellectual disability]

7.6 Word cloud evaluation methodology– hybrid quantitative and qualitative representation of evaluation data _____

Word clouds provide an opportunity to visualise text data. Word clouds emphasise the frequency of words rather than their importance.

Words and images that represent words contributed by program participants, families, staff and Onemda would contribute to a co-developed word bank and the words categorised into different categories that will be useful for different projects. It will also be possible to have individualised word banks/image banks that represent words that reflect what individual program participants and their families value and think is important. Included words/images representing words would also capture data relevant to NDIS funding.

As different staff members work with the program participants, they will support them to identify the words or images that best describe their experience of an project. All staff will be able to evaluate using the word cloud providing multiple perspectives from different stakeholders and multiple perspectives over time resulting in a multi-dimensional evaluation. Changes in words/images over time will provide a visualisation of program participants' experiences over time. Word Cloud is a useful evaluation methodology that Onemda can apply across different sorts of programs and innovations and for a variety of purposes. For example, when undertaking a 12 week program, words/images (represented by words) could be collected prior to commencing the program and weekly across the program.

Word clouds is a useful methodology that Onemda can refine so that they can apply it in different ways. For example, Onemda could apply it to capture whether Onemda's core values are the values that are important to Onemda. When trying to evaluate the qualities that are harder to measure such as self-worth, quality of life, well-being etc, it would be possible to draw on a bank of words that are refined for the purpose/audience for the evaluation.

Word cloud over time will capture intended outcomes and unintended outcomes. It provides opportunity to evaluate broader impacts from those that the project was intending to achieve.


The proposed evaluation aligns with principles that were identified to be important in the literature review, the interviews and focus groups. This approach:

- Is not a tick box approach – Rather, it is a performance -based approach, built upon a foundation of principles, and not a list of boxes to check or uncheck. This allows for greater flexibility and diversity across evaluations but an alignment of goals.
- Is individualised – captures what is important to the individual and their families
- Provides a visual representation of how well an innovation/intervention (project) is meeting participant/family/staff/organisation needs over time
- Employs co-design to develop individualised and collective word/image banks
- Is not resource intensive
- Doesn't take too much time
- Utilises current Penelope IT system
- Is values based
- Has a unique ability to be captured quickly, values based qualitative data that is easily converted to quantitative analysis
- Documents people's roles: parents, staff, program participants can all complete the work cloud. This will highlight where there is alignment and where there is discord
- Can be used for short-term, medium-term and long-term objectives.
- Common language used
- Overarching words that convert words

Next steps

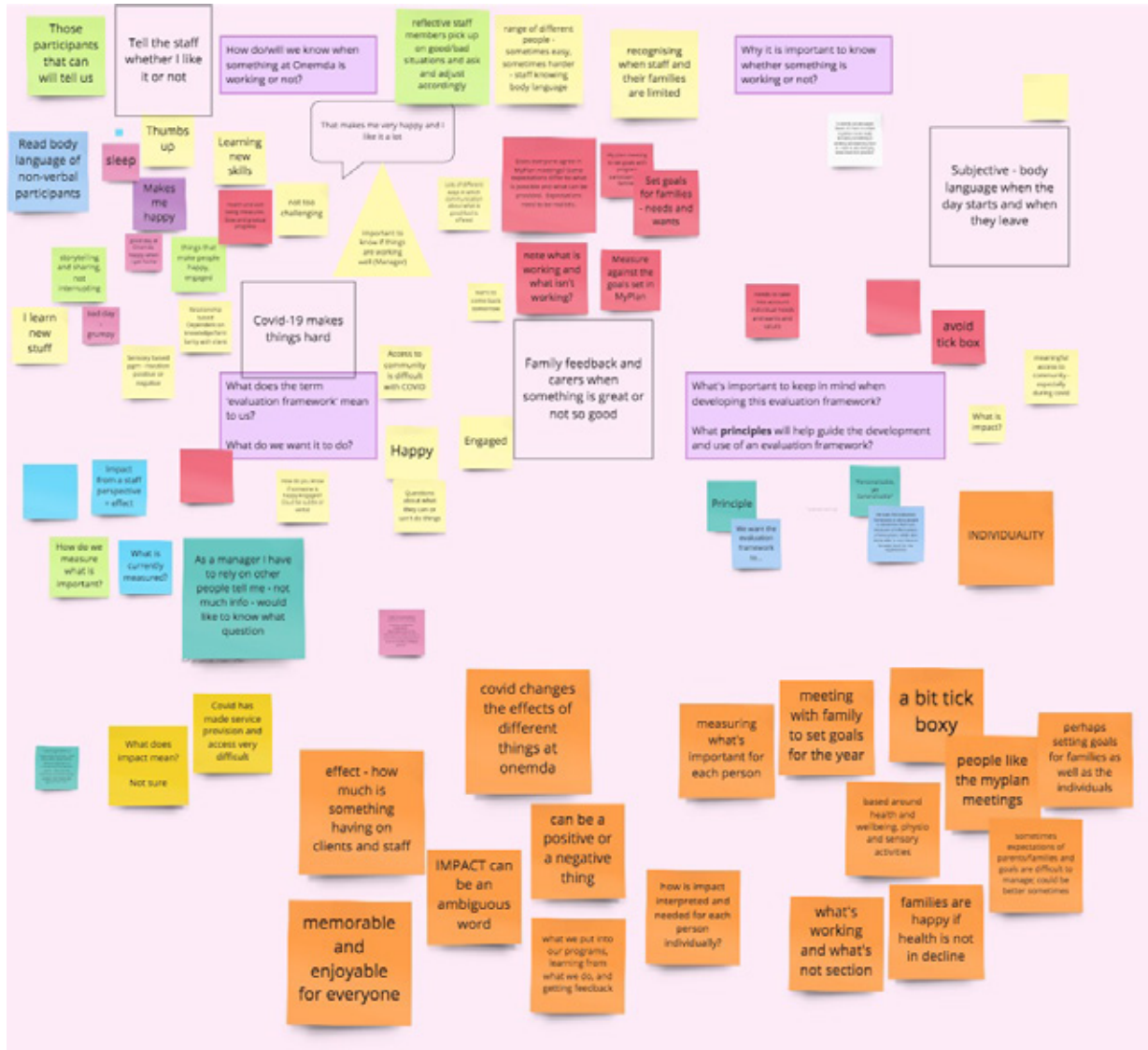
- A proof-of-concept pilot of this innovative evaluation methodology is recommended.
- Confirm that there are ipads etc available to collect data - so that Program participants can choose smiley faces, families and staff at point of care
- Load word cloud software – set up such that word cloud can be presented for individual Program participant, family, staff and collectively
- Co-design word bank based on interview data; focus group data, and consultation with Client Advocacy group – talk to the whole of the organisation to suggest words
- Garner 'quality of life' words from a variety of tools
- Garner 'self-worth' words
- Will need to include positive, negative and neutral words
- Key words need to be entered consistently, with consistent capitalisation
- Compound words need to be entered with a tilda between the words

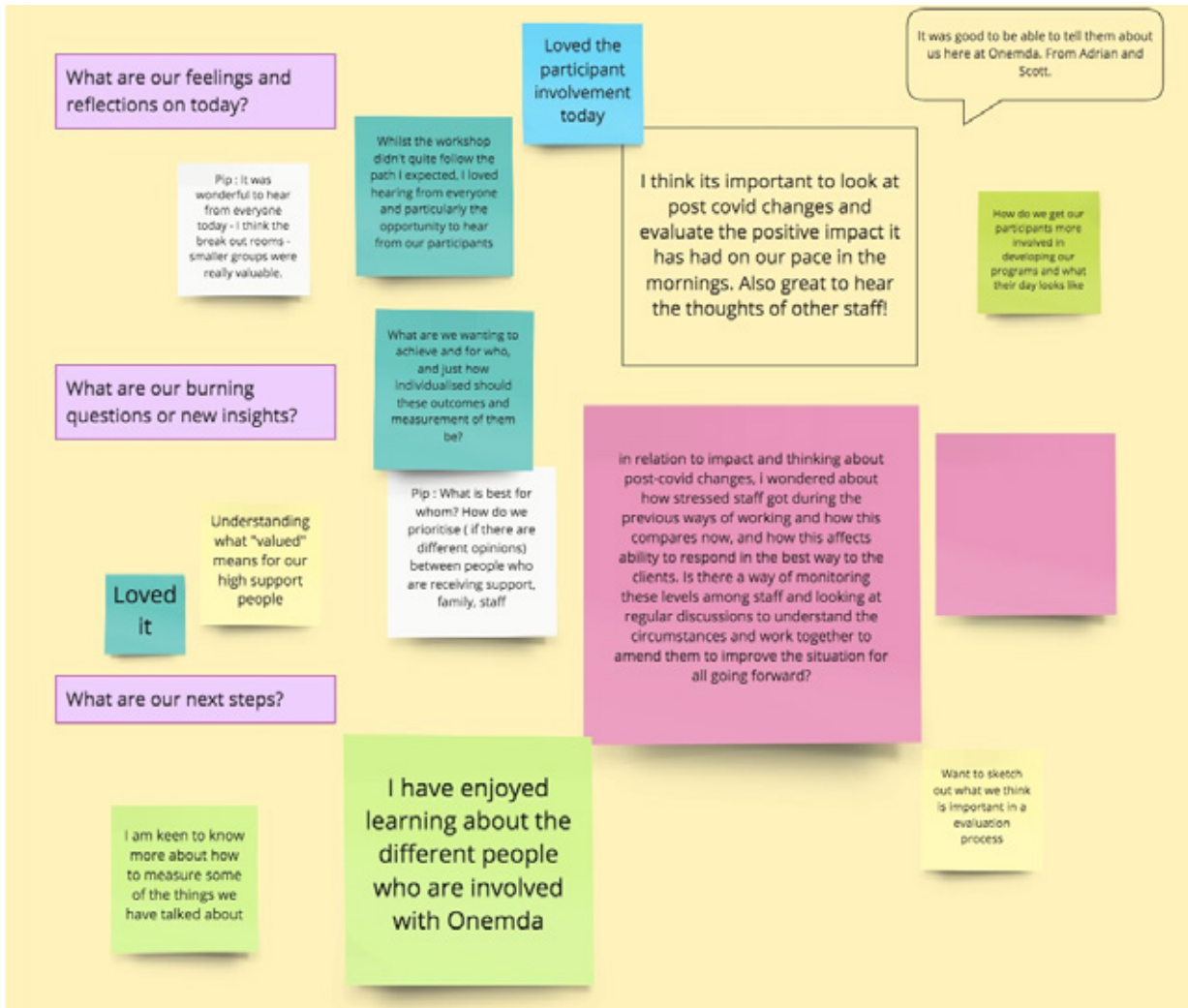
Other tips

- <https://21centuryedtech.wordpress.com/2012/05/14/12-valuable-wordle-tips-you-must-read-word-clouds-in-education-series-part-1/> 

7.7 Miro Board outputs from August 2020 facilitated workshop

The following pages depict the Miro board outputs to the main activities of the workshop.





7.8 Potential example of a template end of year report for families based on evaluation data collected through the year

At the beginning of the year, we identified that the following goals [Goal 1, Goal 2, Goal 3] were really important to the individuals, the families, the staff and Onemda as an organisation. To measure/identify whether these goals were met or being worked towards over the year, we used the following measures/metrics (*Program Participant: xxxx measure; Family: yyyyy measure; Staff: zzzz measure; Onemda: vvvv measure*).

At the end of the year, the scores on the quality of life and skills development measures were x, y, z. We also identified that these were the ratings and scores on the measures of a, b and c (*provide some description to help the reader interpret if there have been any changes, if it has remained the same etc – also include staff's perspective and illustrative examples*).

When we look at the changes in these measures over the last [X] years, we can see that

For example, while there may be small/no apparent changes in the metrics specifically measuring [XX] over this last year (short term), we can see that, based on the information we have collected (*ZZZZZZ metrics*) there have been changes in [*a related domain XX*]. We can also so that over the last [XX years] there have been movements to achieving [*XX long term goal*].

[As these data are collected over time, progress against medium and long term goals will also be able to be reported]

7.9 Early iteration of potential Evaluation Framework Prototype that were used during the development _____

Onemda Intervention/Activity: Deconstructing Innovations (projects)

'BEST'
Self-assessment toolkit for staff to recognise what we do well and what are the elements of our practice and service that we can improve.

The BEST Toolkit has been designed around Onemda 6 Key Principles of Service Delivery:
Customer Approach
Empowerment & Listening
Choice & Control
Fun
Value Drive
Wellbeing

What type of new thing or way of doing something is it?
i.e. product, service, technology, etc

How would you imagine it might work or be used?

Who is this thing for and who interacts with it?

Why is this important to do?
What value is this bringing to its users?
What needs is it trying to fulfil?

How do we know if it is a good idea or not?

How do we know if it's working well, doing what it's supposed to do, or doing something different/unexpected?

Onemda Intervention/Activity: Deconstructing Innovations (Projects)

Matilda

Matilda is a "social robot" that can play games, provide prompts, and has a range of other functions.

For example - Matilda can be programmed to provide prompts to participants in a cooking program.

Onemda have been using Matilda as an additional program resource for the past two years and a couple of key staff have been responsible for programming the robot and teaching staff and participants how to use the robot.

What type of new thing or way of doing something is it?
i.e. product, service, technology, etc

How would you imagine it might work or be used?

Who is this thing for and who interacts with it?

Why is this important to do?
What value is this bringing to its users?
What needs is it trying to fulfill?

How do we know if it is a good idea or not?

How do we know if it's working well, doing what it's supposed to do, or doing something different/unexpected?

Onemda Intervention/Activity: Deconstructing Innovations (Projects)

STEPS to Employment

Program to help Onemda participants get job-ready.
Teaches the 8 Employability Skills
Provides practical work placements
Educates and supports families
Links participants with employment (DES) & training (RTO) providers

What type of new thing or way of doing something is it?
i.e. product, service, technology, etc

How would you imagine it might work or be used?

Who is this thing for and who interacts with it?

Why is this important to do?
What value is this bringing to its users?
What needs is it trying to fulfil?

How do we know if it is a good idea or not?

How do we know if it's working well, doing what it's supposed to do, or doing something different/unexpected?

7.9 Table 7.9: Evaluation Overview

Domain/Goal/Outcome	
Level of Analysis:	Outcome Evaluation Questions:
– Individual service user	– Does the project improve the program participant's feelings of self-worth/quality of life? (see suggested links at ## following this table)
– Family/carer	– Does the project improve the program participant's achievement of [the desired goal/outcome] (from the program participant's perspective)?
– Staff	– Does the project improve the program participant's achievement of [the desired goal/outcome] (from the carer's perspective)?
– Organisation	– Does the project improve the program participant's achievement of [the desired goal/outcome] (from the staff's perspective)?
– External stakeholders	– Does the project improve the program participant's experience of [the desired experience] (from the program participant's perspective)?
	– Does the project improve the program participant's experience of [the desired experience] (from the staff's perspective)?
	– Does the project improve the program participant's experience [the desired experience] (from the family/carers' perspectives)?
	Implementation Evaluation Questions:
	– Was the project implemented as planned?
Action Planning:	
– What is the purpose of the evaluation? (e.g. to identify effectiveness of an project; to secure funding; to measure organisation performance; to inform ongoing developments of and project (formative evaluation) etc)	– Where will the information be recorded?
– What actions need to be taken to effectively evaluate the project against the target outcome?	– How frequently will the evaluation data be collected?
– Who needs to be involved in co-designing the outcome measures for the evaluation?	– When will the information/data be analysed?
– Who needs to take those actions?	– Who will analyse/make sense of the collected information/data?
– How the information be collected (potential methods)?	– Who will the evaluation outcomes be reported to?
	– How will the information be presented/reported?
	– Who will report the evaluation outcomes?
	– When will the findings be presented to the broader team?
	– Who will decide whether changes need to be made?
	– What steps will be taken if changes are needed?
Potential Quality of Life measurement tools	
– https://www.tandfonline.com/doi/pdf/10.3109/13668250.2017.1388913	
– https://www.3dn.unsw.edu.au/sites/default/files/Assessment%20Table_Quality%20of%20Life%20V2.pdf	
– https://pureadmin.qub.ac.uk/ws/portalfiles/portalfiles/164354073/Quality_of_Life_Scoping_study_final.PDF	
– Quality of Life Questionnaire (QOL-Q) (Schalock & Keith, 1993) [specifically designed for people with intellectual disabilities]	
– INTEGRAL Quality of Life Scale (M. Á. Verdugo, Gómez, Arias, & Schalock, 2010) [specifically designed for people with intellectual disabilities]	
– San Martin Scale (M. A. Verdugo, Gómez, Arias, Navas, & Schalock, 2014) [specifically designed as a Proxy measure]	
– Beach Center on Disability Family Quality of Life Scale (FQoL) (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Park et al., 2003) [specifically designed for measuring QoL for families with children with ID]	
– Family Quality of Life Survey (FQOLS-2006) (Brown, Hatton, & Emerson, 2013) [specifically designed for measuring QoL for families with a member with ID]	
	Potential Methods:
	– Quality of Life Measurement tools
	– Survey
	– Smiley face Likert scale
	– Word cloud
	– Administrative data (including economic data)
	– Daily notes
	– Observation
	– Checklists
	– Interview
	– Focus groups
	– Quantitative measures linked with desired outcome

7.10 Table 7.10: Evaluation Framework/Guide

To be completed at the initiation of a project; during (confirm frequency) and at the completion of the project.

Name of Project:	Start Date:	Expected completion date:
<p>Description: What is the project accepted for testing and use at Onemda?</p>		
<p>STAGE 1 - UNDERSTANDING THE INNOVATION</p>		
<p>EXPECTED OUTCOME</p>	<p>ORGANISATIONAL PRIORITY</p>	
<p>What is the desired outcome of the project? From whose perspective is this the desired outcome? (Participant, Family, Staff, Organisational, NDIS, Other)</p>	<p>How does the project fit in with Onemda's core values/ strategic plan?</p>	
<p>EVIDENCE OF NEED</p>	<p>INNOVATION DESIGN</p>	
<p>What is the identified need for the project? What is the evidence to support using this project? What was the rationale for the idea and from whom?</p>	<p>How was the project developed? Was it co-designed? What parties provided input (and at what stage of design)?</p>	
<p>STAGE 2 – CO-DESIGNING THE INNOVATION</p>		
<p>ABOUT THE PROJECT</p>	<p>CO-DESIGNING EVALUATION</p>	
<p>Where is the project to be implemented? Who does it? Who thinks this is a good outcome? Who else could be involved? Will you use a validated tool to measure implementation or develop you own process? Considerations and questions?</p>	<p>Co-design a set of desired measures (short, medium, long term) for outcomes. By stakeholder group – Participant; families; staff; Onemda, NDIS, etc Data – do we need to build new data measures or is this existing measures we can use to measure success (is it in the right format, does it need changing, etc) Co-design how outcome measures will be collected and analysed. (Prompts and examples provided) How often will evaluation data be collected for this project? How are measurements/metrics define? (e.g. what does self-worth mean for different stakeholders) What training is needed to collect and evaluation data?</p>	
<p>STAGE 4 – NEXT STEPS</p>		
<p>ITERATE PROTOTYPE/ IMPROVE PROJECT</p>	<p>FRAMEWORK EVALUATION</p>	
<p>Describe how the results inform:</p> <ul style="list-style-type: none"> – Continuation of the project unaltered – Changes to the project – Discontinue the project <p>If continuing the program how are you going to measure its impact?</p>	<p>Use results to reflect on and evaluate the evaluation framework</p>	

7.11 Table 7.11: Capturing short, medium and long term goals

Stakeholder	Define goal	Is this a short/medium/long term goal?	What is the success measure? (Based on consultation with stakeholders)	How do we measure this? (Based on consultation with stakeholders)
Program participant	Self-worth/ Quality of life			
Carer/family member				
Onemda staff				
Select the relevant strategic or value proposition(s)				
Onemda organisation	Deliver outstanding and impactful services which enrich and extend our participants			
Onemda organisation	Grow Onemda's established profile as a trusted and progressive leader within key target audiences			
Onemda organisation	Bring Onemda's unique value proposition to markets in need			
Onemda organisation	Optimise organisational capacity to deliver on our vision			
Onemda organisation	Continue to build and shape a brilliantly skilled, passionate and high performing workforce			
Onemda organisation	Continue to embed research, innovation and technology into service delivery activities			
Select the relevant Domain(s)				
NDIS	Domain 1: Choice and control			
NDIS	Domain 2: Daily living			
NDIS	Domain 3: Relationships			
NDIS	Domain 4: Home			
NDIS	Domain, 5: Health and wellbeing			
NDIS	Domain 6: Lifelong learning			
NDIS	Domain 7: Work			
NDIS	Domain 8: Social, community and civic participation			
Other				

7.12 Table 7.12: Evaluation over time

Pre-post Likert scale with qualitative comments that explain/support changes in the Likert scale scores. Short-term, medium term and long-term outcomes.

SHORT TERM EVALUATION (ONE YEAR)
<ul style="list-style-type: none">- Is the program participant enjoying the project?- Have they gained anything out of the project?- Have there been any changes toward the outcomes they would like to achieve (e.g. movement toward Strongly Agree on a Likert scale)?
MEDIUM-TERM EVALUATION (SECOND YEAR)
<ul style="list-style-type: none">- Is the program participant enjoying the project?- Have they gained anything out of the project?- Have there been any changes toward the outcomes they would like to achieve (e.g. movement toward Strongly Agree on a Likert scale)?
LONG-TERM EVALUATION (THIRD YEAR AND ON)
<ul style="list-style-type: none">- Is the program participant enjoying the project?- Have they gained anything out of the project?- Have there been any changes toward the outcomes they would like to achieve (e.g. movement toward Strongly Agree on a Likert scale)?

7.13 Table 7.13 Process evaluation

Evaluation of the way in which an project is implemented is also known as process evaluation. Data are collected to identify the process of implementation. Typical process evaluation data include how well the implementation plan was followed, whether adaptations were made to the project as it was implemented, participants', carers' and staff's perceptions of how well the project is implemented and how satisfied they are with it. The table offers different ways in which process evaluation can be conducted.

Process evaluation should be planned before the project begins and should continue throughout. Approach/Tool	Summary description	Links/questions
Normalisation Process Theory (NPT) http://www.normalizationprocess.org/	<ul style="list-style-type: none"> – An interactive online toolkit to think through implementation of projects. – 16 constructs of NPT represented as 16 items. – Online responses are calibrated as a graph. Negative responses are closer to the centre which may indicate a lack of engagement with the project. 	<p>http://www.normalizationprocess.org/npt-toolkit/how-to-use-the-npt-toolkit/</p> <p>http://www.normalizationprocess.org/npt-toolkit/</p>
NoMAD Survey Instrument (Finch et al., 2015)	<p>The NoMAD Instrument can be adapted so that it 'makes sense' for staff. It can be used to describe staff's views about how the implementation of a project has impacted their work; whether they view that it could become a routine part of their work; to identify if there have been changes in perceptions over time; or to identify areas that need work to support implementation of a project.</p>	<p>http://www.normalizationprocess.org/nomad-study/how-to-use-nomad/</p> <p>http://www.normalizationprocess.org/resources/</p>

7.13 Table 7.13 Process evaluation

NPT evaluation questions	A set of evaluation questions have also been developed for each element of the NPT framework. These include (Hall, Wilson, Stanmore, & Todd, 2017: 62):
	<ul style="list-style-type: none"> 1. Coherence: understanding <ul style="list-style-type: none"> – Is it different from our other projects? – Do we agree on the anticipated benefits? – Is it compatible with our broader values, ethics and priorities? – Do we understand what we have to do to use it? 2. Cognitive Participation: involvement <ul style="list-style-type: none"> – Are there key people influencing it? – Do we feel we can and should contribute? – Can we organise ourselves to contribute? – Can we define how we will use it? 3. Collective Action: ‘doing’ in practice <ul style="list-style-type: none"> – How successfully can we work with it? – Do we have the right training and skills? – Does our organisation support its use? – Do we trust the technology/innovation (in this case, the Household Model)? 4. Reflexive Monitoring: appraisal <ul style="list-style-type: none"> – Can we see its impact? – Do we think its impact is useful? – How do we evaluate it? (i.e. practice and process of evaluation) – Can we adapt it to suit our needs, or adapt our practice as a result of using it?



**Embedding evaluation as part of core business:
A customised, co-designed evaluation
framework to improve outcomes for people
with disabilities, their families and carers.**

UTS: DESIGN
INNOVATION
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