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Centre for Program Evaluation

Melbourne Graduate School of Education

Monitoring and Evaluation Framework for the Mansfield Autism Practitioner Service

Prepared for Mansfield Autism Statewide Service (MASS)

19 August 2022

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# List of Abbreviations

|  |  |
| --- | --- |
| Abbreviation | Full text |
| ABAS | Adaptive Behaviour Assessment System |
| ASD | Autism Spectrum Disorder |
| BSP | Behaviour Support Plan |
| CDC | Centers for Disease Control and Prevention |
| CPE | Centre for Program Evaluation |
| CRPD | Convention on the Rights of Persons with Disabilities |
| DBC | Developmental Behaviour Checklist |
| FQoL | Family Quality of Life |
| HRQOL | Health-related QoL  |
| MAP | Mansfield Autism Practitioner |
| MASS | Mansfield Autism State-Wide Service |
| MDI | Melbourne Disability Institute |
| MGSE | Melbourne Graduate School of Education |
| NDIS | National Disability Insurance Scheme |
| NDS | National Disability Services |
| PedsQL | Pediatric Quality of Life Inventory  |
| PET | Parent Education and Training |
| QoL | Quality of Life |
| QoLA | Quality of Life in Autism Questionnaire |
| SLES | School Leavers Employment Support  |
| WHO | World Health Organization |

# Definitions

|  |  |
| --- | --- |
| Autism  | “Autism is a complex, lifelong developmental disability that typically appears during early childhood and can impact a person’s social skills, communication, relationships, and self-regulation. Autism is defined by a certain set of behaviors and is a “spectrum condition” that affects people differently and to varying degrees” (Autism Society).  |
| Disability | “Long-term physical, mental, intellectual, or sensory impairment which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (Convention on the Rights of Persons with Disabilities [CRPD], Article 1, 2006) |
| Health  | “Is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization [WHO], https://www.who.int/about/governance/constitution). |
| Quality of Life (QoL)  | Technical: "An 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" (WHO, <https://www.who.int/tools/whoqol>).Simplified: [U Toronto] “the degree to which a person enjoys the possibilities of his or her life” |
| QoL family | “Family quality of life is concerned with the degree to which individuals experience their own dynamic sense of well-being and have the opportunity to engage with the possibilities in their lives within the family context, and how the family interacts around each member’s well-being and possibilities.” (adapted from Zuna et al., 2009) |
| Wellbeing  | “A positive outcome that is meaningful for people and for many sectors of society, because it tells us that people perceive that their lives are going well” (Centers for Disease Control and Prevention [CDC], https://www.cdc.gov/hrqol/wellbeing.htm).  |

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Contact Details

Associate Professor Amy Gullickson, Director
Centre for Program Evaluation, Melbourne Graduate School of Education
100 Leicester Street, The University of Melbourne, 3010 VIC

Phone: +61 3 9035 9682

E-mail: amy.gullickson@unimelb.edu.au

# Centre for Program Evaluation

The Centre for Program Evaluation (CPE) at the University of Melbourne is the premier academic organisation for transdisciplinary evaluation education and practice. We bring together three interrelated strands of evaluation:

* advancement of evaluation theory and methods
* teaching evaluation
* evaluation practice

CPE has a long-history of undertaking projects for government departments, non-government organisations, academic institutions, and community-based agencies across a wide range of policy and program areas with a focus on education, health, social wellbeing, and community development.

# Melbourne Disability Institute

The Melbourne Disability Institute (MDI) is an interdisciplinary research institute that was established by the University of Melbourne in 2018 to build a collaborative, interdisciplinary and translational research program to improve the lives of people with disability. Key members of the MDI team have deep knowledge and experience of the current rapid reforms underway in Australia’s disability sector. MDI also has relationships with some of the key leaders in disability research and practice nationally and internationally. Furthermore, half of the MDI team have lived experience of disability, enabling a multidimensional understanding of disability. The MDI research program is underpinned by strong conceptual approaches including Human Rights and Active Citizenship, Critical Realism, Capacity Approach and Integrated Knowledge Translation.

MDI’s vision is to transform the social and economic wellbeing and the health of people with disability through high-quality research, teaching and training, and knowledge translation.

# Mansfield Autism Statewide Services

Mansfield Autism Statewide Services (MASS) has been providing in-home services to children and their families since 1970. Underpinned by a ‘wrap-around’ model, MASS’ mission is to support autistic1 people to reach their goals and aspirations within their family and community, and to improve the lives of autistic people and their families by providing individualised and integrated services. MASS now provides a number of services to support autistic children and their families outlined in Table 2 below.

Table 1. MASS Services

|  |  |
| --- | --- |
| **Service** | **Description** |
| **Family Camp** | 5-night camps run for families in Victoria, which include outdoor and indoor activities and opportunities for families and children to meet and connect in a supported environment  |
| **Therapeutic Behavior Support Placement** | Supported residential placement for nine weeks with a focus on health and well-being that provides respite for families and opportunities for skill development for children  |
| **Mansfield Campus** | Specialised education from ages 5 – 18 years old, providing individualised learning. |
| **Dookie Campus** | Specialised secondary school from ages 11 – 18 years, providing individualised learning. |
| **Local Programs** | A variety of services including community outreach, respite, School Leavers Employment Support (SLES) and school holiday programs  |
| **Mansfield Autism Practitioner Service (MAP)** | In-home strengths-based support for families and children (described further below)  |

# Plain Language Summary

## The Project

Mansfield Autism Statewide Services (MASS) was a successful recipient of the Melbourne Disability Institute (MDI) Community Based Research Program Grants. The aim of these grants is to help community organisations conduct research or evaluation of programs that are making a difference in the lives of people with disability and their families/carers. MASS were partnered with the Centre for Program Evaluation (CPE) to develop a monitoring and evaluation framework for the Mansfield Autism Practitioner (MAP) service. The MAP service provides home based practical support to families living with autism. The framework is a plan that will help MASS evaluate the service and understand how well it is working and what can be improved.

## What we did

To prepare the framework, we completed the following activities:

* We talked to MASS to understand how the MAP service works and how it can support children with autism and their families.
* We looked for research about how to evaluate autism services and programs.
* We looked at how MASS was evaluating the MAP service.
* We suggested a plan for MASS to evaluate the MAP service, and talked to MASS and parents to see what they thought about it. The plan includes questions for children with autism and their families, and activities that MASS can do to better understand how well the MAP service is working for children and their families, and if there are aspects of the service that MASS can improve.

## What we found

The Quality of Life of children and their families is important

We found that it is important to know if the MAP service is helping children and their families improve their quality of life. A better quality of life means that they are happy and satisfied with their lives, and they are able to participate in the community in the way they want to. We found several ways to measure quality of life that MASS can use. After discussion with MASS, we recommend they use the following tools: DISABKIDS and KIDSCREEN (10 questions). These tools are the most appropriate because they allow children to explain what their quality of life is. MASS can adapt these questions so children find it easier to answer them (for example, adding pictures). For families, we recommend the tool Family Quality of Life (FQoL).

Talking to children, families, and people in their communities

In addition to the activities that MASS is already doing to know if the MAP service is helpful, such as sending surveys to the families, we recommend that they also interview the families and people in their communities to better understand how the MAP service is supporting children with autism and their families.

Next steps

These are the activities that MASS can do next to continue the evaluation of the MAP service:

* Adapting the questions about quality of life so it is easier for children and their families to let them know what their quality of life is. This will help MASS understand if the MAP service is helping families improve their quality of life.
* Doing interviews with children, parents, and other people in their communities. This will help MASS understand how helpful the MAP service is, and if there is anything they could improve.
1. Introduction

The purpose of this project was to develop a program logic and monitoring and evaluation (M&E) framework for the Mansfield Autism Practitioners (MAP) service. Quality of life (QoL) was identified as an outcome of interest to measure the effectiveness of the MAP service. This document outlines the proposed monitoring and evaluation framework for the MAP services delivered by MASS, which includes the methodology, literature review and data used to create the framework.

The key deliverables are:

* Development of a program logic and evaluation framework;
* Review of the literature on measurement tools;
* Review of MASS’ current data collection activities; and
* Consultations with stakeholders to refine the measurement framework.
	1. Mansfield Autism Statewide Services
		1. Mansfield Autism Practitioner Service

The MAP service offers a transdisciplinary model working within the family home. Mansfield Autism Practitioners (MAPs) are available at times when families need support most, working outside of school hours to deliver support at key times for families (mealtimes, transitions home from school, morning routines, sleep routines and times of self-care). MAPs stay within the family home, or in alternative accommodation nearby, providing intensive support to reduce disruptive behaviours and increase adaptive behaviours. MAPs have the unique opportunity to observe not only the client but their whole family and the context around them. This allows for rich data collection to understand functions of behaviours that then informs a successful Behaviour Support Plan. MAPs coach parents, carers, support workers and other important people in the client’s life in how to support the child to engage in positive behaviours, learn new skills and emotional and sensory regulation. This method of coaching builds the capacity of parents and other important people in the child’s life to support the child to reach their full potential so they can participate fully in their community. Data collected by MASS indicates that most clients using the MAP service also have goals related to behaviour and emotion regulation, social skills, communication, and goals related to the clients’ education. Under the National Disability Insurance Scheme (NDIS), funding transitioned from clients/families to the NDIS. To access the MAP service, families require funding under NDIS categories Capacity Building: Improved Relationships or Capacity Building: Improved Daily Living Skills.

Literature on Autism Spectrum Disorder (ASD) interventions has recently begun referring to this type of program as a “Parent Education and Training”. These programs include a combination of parent/family-centered goals and child-centered goals, and recognise the importance of supports that are appropriate and embedded into the family context (Dawson-Squibb et al., 2020). Parent Education and Training programs are described as a mixture of parent support programs (with education, self-efficacy and well-being outcomes targeted towards parents) and parent-mediated interventions (with skill development and behavioural outcomes targeted towards children, *via* their parents) (Dawson-Squibb et al., 2020).

A recent international scoping review of 32 Parent Education and Training programs found an assortment of different program goals and delivery types across 20 different countries, including Australia (Dawson-Squibb et al., 2020). Program goals included increasing parent understanding of autism, provision of behavioural support techniques, reducing parent stress and decreasing isolation. Despite common high-level goals, Parent Education and Training programs were found to be highly variable from one another, with a wide range of program delivery types, delivered by a wide variety of professionals including psychologists, social workers, speech pathologists and others.

* 1. Purpose of the MAP Monitoring and Evaluation Framework

The aim of this evaluation project is to develop a program logic and monitoring and evaluation framework for the MAP service, with the objective of allowing MASS to systematically collect data and evaluate the service on an ongoing basis.

We anticipate that the proposed monitoring and evaluation framework will guide future data collection activities by MASS, with a focus on evaluating service effectiveness, implementation, and cost benefits in the longer term. In turn, these findings may be used to apply for further funding to extend this framework and conduct further research or evaluation on the MAP service. The framework includes further guidance on data sources and suggested data collection points.

1. Methods

The MAP service monitoring and evaluation framework has been developed iteratively and collaboratively using concurrent and sequential methods. The processes for creating the framework are outlined below and summarised in a timeline of activities in Table 2.

Table 2. Activity Timeline

|  |  |  |
| --- | --- | --- |
| Activity | Date | Comments |
| Program Logic Workshop | 27th May 2021 | Attended by MAPs and MASS representatives |
| Literature Review  | June – October 2021 | MASS’ feedback on QoL and Family QoL definitions guided the review methodology. Literature review findings were presented to MASS as well. |
| Collaboration with MASS | Throughout projectProject commenced April 2021 | Includes M&E framework development and data collection stock take |
| Stakeholder Workshop | 5th November 2021 | Attended by parents, MAPs and MASS staff |

* 1. Program Logic Workshop

During this workshop, the evaluation team gathered stakeholders’ input and feedback on service activities and inputs, intended benefits of the MAP service, outcome indicators, and expected relationships between service activities and outcomes. The completed program logic can be found in Section 3.4.

* 1. Literature Review

A scoping review of the literature formed a component of the study and helped to inform the development of the monitoring and evaluation framework for MASS. This review aimed to explore the concepts and theories of quality of life targeted towards and applicable to autistic children and their parents and to review the existing QoL measurement tools relevant to MASS’ needs. The review was guided by the research objectives and informed by the MAP service’s logical framework. Methods for the literature review are presented in Appendix A.

Some of the objectives of the review included:

1. to identify theories and previous research studies on the concept of QoL and QoL for children with ASD and their families;
2. to review existing measurement frameworks and data collection tools geared towards children with ASD and their families;
3. to develop recommendations for suitable options for measuring QoL of children with ASD and their families; and
4. to develop recommendations for MASS to develop a tailored tool kit for ongoing data collection and monitoring of their MAP service.

QoL and QoL of the family are complex and multidimensional concepts, and the scoping approach to the review helped the evaluation team to appreciate the volume of relevant literature and available studies. It helped to clarify key concepts, definitions, and characteristic related to QoL. The review also provided an overview of existing measurement tools and identified associated gaps. A variety of conceptual, methodological and empirical research papers and documents addressing QoL studies in applied human and social sciences were reviewed.

Findings from this review are summarised in Section 3.2, and include validated measurement tools or scales that could be adapted to be employed in the evaluation of the MAP service.

* 1. Stakeholder Consultation
		1. Meetings and Collaboration with MASS

Collaboration with MASS occurred throughout the monitoring and evaluation framework development process through emails, shared documents and multiple meetings. This allowed the evaluation team to consult with MASS to ensure the framework was tailored and relevant to the MAP service.

* + 1. Data Collection Stock Take

The evaluation team conducted a stock take of data collection activities currently being employed by MASS to map current data collection activities and sources against those proposed in the evaluation and monitoring framework, with the objective of identifying potential gaps and suggesting methods to collect and analyse evidence on service effectiveness and impact. Results of the stock take can be found in Appendix B.

* + 1. Stakeholder Workshop

Consultations with MAPs, MASS stakeholders and a sample of families were conducted to gather further feedback and refine the evaluation and monitoring framework. This workshop took the form of two small focus groups with the objective of providing stakeholders with opportunity to participate in the development of the framework and to provide thoughts on how to make the data collection process accessible to families. Key points raised at the workshop are summarised in Appendix C and have contributed to the recommendations in the M&E framework.

1. Results: MAP Monitoring and Evaluation Framework

The following section outlines the components of the MAP Monitoring and Evaluation Framework, developed through a process of research and stakeholder input as set out in the previous sections.

This section is structured as follows:

* a proposed evaluation strategy
* a list of potential evaluation questions
* a measurement model and its components, including indicators, data sources, and methods.
	1. Proposed Evaluation Strategy

Effective evaluation requires an evidence-based framework that is centred on the program evaluation standards (Yarbrough et al., 2011). The Centre for Program Evaluation has adapted the Centers for Disease Control and Prevention (CDC&P) Framework for Program Evaluation (2011) and recommends this as a guiding strategy. This framework has been used extensively in public health, education and social science research. Depicted in Figure 1, this framework consists of three stages and facilitates collaboration with all stakeholders and encourages the development of a learning environment and feedback. The framework organises evaluation tasks between stages of engagement, program description, focusing the design, data collection, conclusion justification and research dissemination. The CDC&P Framework provides an overarching structure to organise the evaluation of the impact (Figure 1).



Figure 1. Adapted CDC&P Framework for Evaluation

* 1. Literature Review Findings

Quality of life is a complex concept that incorporates features of wellbeing, positive social involvement and opportunities to achieve personal potential. It includes objective measures (such as income, employment and participation), and subjective measures (such as satisfaction, self-determination, wellbeing, and happiness). Some of the challenges encountered in the review revolved around the subjectivity of the QoL and lack of consensus on its definition.

WHO defines QoL as “an individuals' perceptions 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. QoL is a degree to which a person enjoys the important possibilities of his/her life (The Quality of Life Research Unit, University of Toronto).

Most of the studies reviewed focused on the health aspects of QoL—this was particularly the case with studies focused on measuring QoL of people with disabilities. Health-related QoL (HRQOL) focuses on the impact of a particular illness, disorder and medical treatment on the daily functioning and well-being of a patient (John Hopkins Arthritis Centre). While health is an important component of QoL, it is important to consider other domains to ensure QoL is measured comprehensively.

Child’s QoL includes child’s perception of his/her social, physical, and emotional well-being, but should be also sensitive to the changes that occur throughout the development (PedsQL, https://www.pedsql.org/about\_pedsql.html).

Several studies determined that children with ASD have lower QoL than typically developing (TD) children and children with chronic health problems (Cottenceau et al., 2012). Although ASD is considered a lifelong developmental disorder, the degree of impairment in functioning because of the challenges associated with the impairment varies between individuals with autism (American Psychiatric Association, 2018). Thus, social indicators, such as having a family, friends, regularly participating in a sport, and having the support of a school may often positively influence QoL of autistic children. Furthermore, cross-cultural comparisons are particularly important in defining autistic child’s QoL, since the perceptions of ASD's causes, symptoms, diagnosis, and management may also depend on cultural factors (Dyches et al., 2004; Matson et al., 2017).

According to the QoL Research Unit at the University of Toronto, parents consider theirs’ and their children’s QoL as highly interconnected. A child’s QoL is dependent upon others in her/his life, including parents, siblings, peers, teachers, professionals, and community members. Zuna et al. (2009) defined family QoL as a dynamic sense of family well-being, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact.

Despite difference in opinions on QoL, there is a general consensus around Schalock and Verdugo’s (2002) model of QoL: individual QoL is a multidimensional phenomenon, composed of objective and subjective indicators and influenced by personal and environmental characteristics with the purpose of understanding people holistically (Schalock et al., 2002, 2007, 2010).

The most common domains used to assess QoL are physical, social, and material wellbeing; interpersonal relations and social inclusion; personal development; self-determination; emotional wellbeing; rights; environment; family; relationships; recreation and leisure activities; and safety and security. The domains used to assess a family’s QoL are physical, emotional and material wellbeing, disability related support, family interactions and parenting.

* + 1. Quality of Life Measurement Instruments

The most common tools used to measure the QoL of individuals include WHOQOL 100, WHOQOL BREF, WHOQOL-DIS, the Autism Quality of Life measure. KIDSCREEN (52, 27 and 10 item versions), the European DISABKIDS, Quality of Life Measure for Children with Long Term Disabilities and Pediatric Quality of Life Inventory (PedsQL) are often used to measure the QoL of children with disabilities, including autistic children. Quality of Life in Autism Questionnaire (QoLA) and the Family Quality of Life Scale (FQoL) are often used to measure QoL for parents and families. Table 3 provides more detailed information on the above QoL measurement instruments, including domains included in the measurement tool and administration notes. It is worth noting that some of these instruments may not be adequately sensitive to the unique challenges faced by autistic children and their families, particularly with respect to social and emotional aspects of life (Eapen et al., 2014). Some tools might be more appropriate than others to measure QoL of autistic children and their families. We have highlighted those instruments that we believe are more appropriate for MASS, based on ease of administration and/or the option for children to self-report their QoL (in addition to proxy reports if self-reporting is not possible): KIDSCREEN and DISABKIDS. Studies on the validity of Kidscreen-52 showed that the tool correlated with national measures of health-related QoL in the countries where KIDSCREEN has been employed, which suggests that the KIDSCREEN tool is a valid measure of QoL (Office of Quality of Life Measures, 2011a). In terms of internal reliability, Tzavara et al. (2012) found that all scales showed satisfactory internal reliability (i.e., the items measured the construct represented by the scale) when administered to a Greek adolescent population. We propose that MASS could use the short version of the tool, Kidscreen-10, which was developed using the longer versions of the tool and has been shown to have good validity and reliability. Similarly, DISABKIDS was developed using a step-by-step process where items were first developed from interviews, then refined statistically to achieve a shorter version of the scale that shows good validity and internal reliability (Office of Quality of Life Measures, 2011b). These instruments can be used as they are, combined, and/or adapted to MASS’ needs. If adapted or combined, we suggest that MASS first pilots their version of the tool with a sample of families to calculate internal reliability. The initial version of the tool could include additional items for each dimension (i.e., items tapping into the same aspect of QoL). After piloting the tool with a sample of families, it will be possible to identify the items that performed best and remove those that showed less reliability, resulting in a shorter and refined version of the MASS tool.

To measure Family Quality of Life we suggest using the Family Quality of Life (FQoL) scale, which consists of 25 items that measure satisfaction with five life domains. This scale has shown good internal reliability as well as test-retest reliability (i.e., the tool reliably measured FQoL over time) (Hu et al., 2011).

Table 3. QoL Measurement Instruments

|  |  |  |  |
| --- | --- | --- | --- |
| QoL Instrument  | Summary  | Domains  | Administration  |
| WHOQOL 100  | WHOQOL 100 consists of 100 items and measures QOL across six domains (1995) | Physical capacity Psychological stateLevel of independenceSocial RelationshipsEnvironmentSpirituality/Religion/Personal beliefs | Self-administered if respondents have sufficient ability to read;otherwise, interviewer-assisted or interviewer-administered forms should be used. |
| WHOQOL BREF | WHOQOL BREF is a 26-item instrument and is based on a four domain-structure (1996). | Physical health,Psychological, Social relationships, andEnvironment | Same as WHOQOL 100 |
| WHOQOL Disability Module  | This instrument is typically used to measure HRQoL of adults with physical disabilities or intellectual disabilities | WHO BREF domains & Discrimination, Autonomy & Inclusion | Same as WHOQOL 100 |
| The Autism Quality of Life measure (ASQoL) | a 9-item instrument designed as an ‘add-on’ measure to be used alongside the WHO QoL modules. The development of the instrument involved extensive consultation with autistic people about what might be particularly important in their experiences contributing to quality of life or missed out from the existing measures. |  |  |
|  [KIDSCREEN-52](https://www.kidscreen.org/english/questionnaires/kidscreen-52-long-version/) | The instruments assess children’s and adolescents’ subjective HRQoL.  | Physical well-beingPsychological well-beingMoods and emotionsSelf-perceptionAutonomyParent relations/home lifeSocial support and peers School environmentSocial acceptance/bullying Financial resources | It is a self-report (and proxy - whenever appropriate) measure applicable for healthy and chronically ill children and adolescents aged from 8 to 18 years. |
|  [KIDSCREEN-27](https://www.kidscreen.org/english/questionnaires/kidscreen-27-short-version/) | The instrument provides a profile and allows an interpretation of the five dimensions. | Physical well-beingPsychological well-beingAutonomy & Parents Peers & Social Support School Environment  | Answering the KIDSCREEN-27 requires only 10-15 minutes  |
|  [KIDSCREEN-10](https://www.kidscreen.org/english/questionnaires/kidscreen-10-index/)\*  | The results of the Rasch analysis provided a unidimensional global HRQoL index consisting of 10 items which sufficiently represents the longer KIDSCREEN profiles. |  | Answering the KIDSCREEN-10 Index requires only a few minutes. |
| European DISABKIDS HRQoL instrument\* | The European DISABKIDS project aims to enhance the Health Related Quality of Life (HRQoL) of children and adolescents with chronic medical conditions and their families. |  | This instrument consists of condition specific modules - 12-item short-forms (DCGM-12), 6-item Smiley versions (for children aged 4-7 years) and 7 condition-specific modules (asthma, arthritis, cerebral palsy, cystic fibrosis, dermatitis, diabetes, and epilepsy).  |
| [Quality of Life Measure for Children with Long Term Disabilities (Parents Perspective) (48 items)](http://sites.utoronto.ca/qol/projects/summaryReport_children.pdf) | This instrument measures quality of life for children with developmental disabilities, ages 3-12. Participants' children experienced a range of developmental delays and disabilities and some had multiple disability issues (i.e., physical, sensory, mental health, other). | Being – who the child is perceived to be; Belonging – the child’s connections to people and places; and Becoming – the child’s nurtured growth and development | Parents of children with a long-term developmental delay or disability are asked to rate 48 items for importance, satisfaction, and the degree to which they apply to their child's life. |
| [Family Quality of Life Scale (FQOL) - 25 items](https://www.midss.org/content/family-quality-life-scale-fqol)\* | The Family Quality of Life Scale (FQOL) is a 25-item inventory rate on a 5-point Likert-type scale. Its purpose is to measure several aspects of families' perceived satisfaction in terms of quality of family life. Family quality of life is measured under five domains. | Family Interaction, Parenting, Emotional Well-being, Physical / Material Well-being, and Disability-Related Support. | The FQOL Scale uses satisfaction as the primary response format. The anchors of the items rated on satisfaction are rated on a 5-point scale, where 1 = very dissatisfied, 3 = neither satisfied nor dissatisfied, and 5 = very satisfied.  |
| [Quality of Life in Autism Questionnaire (QoLA) for parents and caregivers of children with ASD](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3977417/) | The QoLA was designed to provide a measure of QoL in parents of children with ASD. The scale was developed for parents of children aged 2–18 years. The QoLA was designed with two subscales (Parts A and B).  | Personal developmentSelf-determinationInterpersonal relationsSocial inclusionRightsEmotional wellbeingPhysical wellbeingMaterial wellbeing | Part A contains some items that are reverse scored. Parents are asked to rate each item based on their experiences over the preceding four weeks. Items in Part A reflect each of Schalock et al.’s eight domains, with a particular weighting on emotional wellbeing, social inclusion, and interpersonal relationships. Part B (impact of ASD symptoms subscale) was designed to assess parents' perception of how problematic their child's autism-specific difficulties are for them. |

\*recommended for MASS

To aid with selection of QoL items, we have provided a list of potential survey questions by domain in Appendix B, part III. Note that some questions have been adapted from instruments other than the ones highlighted in the table above with the objective of including further items that match the domains in the measurement model presented in this document (Table 7).

* 1. Potential Evaluation Questions

As part of the monitoring and evaluation framework, we present below a list of potential questions to guide the evaluation of the MAP service. To design these questions, we first considered the aims and types of evaluation that MASS wanted to conduct on the MAP service. To that end, questions were grouped under: evaluation questions on the effectiveness of the service and impact on the child; questions about the effectiveness and impact on families and; questions about the implementation and alignment of the program with the needs of children and families. Within each group, questions target the outcome areas identified in the program logic. It should be noted that MASS may decide to first focus on specific or priority evaluation questions (e.g., conduct an impact evaluation on children and families, and/or a process evaluation on program implementation, resourcing and alignment with the needs of children and their families).

* + 1. Child

How valuable was the MAP service for a child’s health and wellbeing?

How well did the MAP service improve participants’ communication skills, both verbal and non-verbal?

How significant were these improvements for achieving child’s social and communication goals?

How substantial was the effect of the program on the behaviours of concern of the program participants, such as self-injurious behaviour, aggression, and property destruction, among others?

How substantially did the program outcomes improve psychological wellbeing of the participants?

How well did the program achieve the needed changes in the attitudes of individuals and families towards autistic children and their families?

How did the program outcomes contribute to child’s access to volunteerism and early employment?

Did the program change family dynamics?

How significant are the changes in the child/parent (s) and/or child/sibling (s) relationship?

How significant is the effect of the program on child’s participation in family life?

How valuable is the shift in child’s participation in a community?

Has the program increased child’s social network?

Has the program increased child’s participation in the community activities?

How valuable is this shift for child’s social wellbeing?

How valuable is the effect of the program on child’s education?

How significant are the changes in child’s academic achievements?

How important is school attendance for a child?

* + 1. Parent/Family

How valuable is the autism awareness program component for the families of autistic children?

* 1. How well did the program improve parental understanding of autism and their acceptance of their child’s condition?
	2. How significant was this shift for parents/family’s ability to provide supportive care to their child?

How valuable were program outcomes for the health and wellbeing of the family?

1. Did the program decrease the anxiety and stress levels of parents and siblings and how significant was this change?
2. Did the program improve family relationships and was this change sustained and amplified over time?

How substantially did the program increase family participation in community events, and their ability to form friendships and build social network?

How valuable were the program outcomes for parental participation in the workforce?

* + 1. Program

How relevant is MAP service to its participant’s needs?

How well does it fit with and complement other initiatives operating in the same space?

How well does it address and align with the needs and aspirations of autistic children and their families?

How appropriately designed is the MAP service for its clients (e.g., developmentally and age appropriate; culturally and contextually appropriate; accessibility; etc.)?

How effectively did the pre- implementation consultation ensure that the MAPs addressed the needs and concerns of MAP service clients?

To what extent did the MAP represent the best possible use of the available resources to achieve its program outcomes?

How well does it address the root causes and systemic and institutional discrimination towards autistic children and their families?

* + 1. Priority
1. What impact does the MAP service have on:
	1. Autistic children
	2. Their parents
	3. Their broader family unit (including siblings, aunts/uncles and grandparents)
	4. Community (including classmates, neighbors etc.).
		1. Additional
2. How is the MAP service unique from other services for autistic children?
3. What is the MAP service’s reputation and impact in the broader community?
4. Does the MAP service show good value for money?
5. What opportunities for improvement exist within the MAP service?

The below table outlines the data collection methods and how they will contribute to answering each of the areas of investigation/key evaluation questions (**Table 4. High-level Evaluation Crosswalk**

| Key Evaluation Questions /Areas of Investigation | Survey with Children | Surveys with parents  | Interviews with children  | Interviews with parents | Observations in family and school settings  | Focus group with MASS  | FGDs with parents & children  | FGDs with community members  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 1. How valuable was the MAP service for a child’s health and wellbeing? / Health and wellbeing  | X | X | X | X | X |  |  |  |
| 2. How well did the program achieve the needed changes in the attitudes towards autistic children and their families / Inclusive and accessible communities  | X | X | X | X |  | X | X | X |
| 3. How did the program outcomes contribute to child’s access to volunteerism and early employment? / Economic Security / Independence  | X | X | X | X |  |  |  |  |
| 4. How substantially did the program change family dynamic? /Inclusive and accessible communities  | X | X | X | X | X | X | X |  |
| 5. How valuable is the shift in child’s participation in a community / Inclusive and accessible communities  | X | X | X | X | X | X | X | X |
| 6. How valuable is the effect of the program on child’s education? / Independence / Learning and Skills | X | X | X | X | X | X | X |  |
| 7. How valuable is the autism awareness program component for the families of autistic children / Health and Wellbeing  | X | X | X | X | X | X | X |  |
| 8. How valuable were program outcomes for the health and wellbeing of the family / Health and Wellbeing  |  | X |  | X | X | X | X |  |
| 9. How substantially did the program increase family participation in community events, and their ability to form friendships and build social network? / Inclusive and accessible communities  |  | X |  | X | X | X | X | X |
| 10. How valuable were the program outcomes for parental participation in workforce? / Economic Security  |  | X |  | X |  | X | X |  |
| 11. How relevant is MAP service to its participant’s needs? / Relevance  | X | X |  | X |  | X | X |  |
| 12. How well does it fit with and complement other initiatives operating in the same space/ Relevance  | X | X |  | X |  | X | X | X |
| 13. How well does it address and align with the needs, and aspirations of autistic children and their families? / Program design  |  | X |  | X |  | X | X |  |
| 14. How well does it address the root causes and systemic and institutional discrimination towards autistic children and their families? /Relevance  | X | X | X | X | X | X | X | X |
| 15. How appropriately designed is the MAP service for its clients (e.g., developmentally and age appropriate; culturally and contextually appropriate; accessibility; etc.)?/ Program design  | X | X | X | X |  | X | X | X |
| 16. How effectively did the pre- implementation consultation ensure that the MAPs addressed the needs and concerns of MAP service clients | X | X | X | X |  | X | X |  |
| 17. To what extent did the MAP represent the best possible use of the available resources to achieve its program outcomes? / Relevance and value  | X | X | X | X |  | X | X |  |

). Each evaluation question can be addressed using data gathered through complementary sources (qualitative and/or quantitative), with the objective of providing a more comprehensive and detailed response to the evaluation questions.

**Table 4. High-level Evaluation Crosswalk**

| Key Evaluation Questions /Areas of Investigation | Survey with Children | Surveys with parents  | Interviews with children  | Interviews with parents | Observations in family and school settings  | Focus group with MASS  | FGDs with parents & children  | FGDs with community members  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 1. How valuable was the MAP service for a child’s health and wellbeing? / Health and wellbeing  | X | X | X | X | X |  |  |  |
| 2. How well did the program achieve the needed changes in the attitudes towards autistic children and their families / Inclusive and accessible communities  | X | X | X | X |  | X | X | X |
| 3. How did the program outcomes contribute to child’s access to volunteerism and early employment? / Economic Security / Independence  | X | X | X | X |  |  |  |  |
| 4. How substantially did the program change family dynamic? /Inclusive and accessible communities  | X | X | X | X | X | X | X |  |
| 5. How valuable is the shift in child’s participation in a community / Inclusive and accessible communities  | X | X | X | X | X | X | X | X |
| 6. How valuable is the effect of the program on child’s education? / Independence / Learning and Skills | X | X | X | X | X | X | X |  |
| 7. How valuable is the autism awareness program component for the families of autistic children / Health and Wellbeing  | X | X | X | X | X | X | X |  |
| 8. How valuable were program outcomes for the health and wellbeing of the family / Health and Wellbeing  |  | X |  | X | X | X | X |  |
| 9. How substantially did the program increase family participation in community events, and their ability to form friendships and build social network? / Inclusive and accessible communities  |  | X |  | X | X | X | X | X |
| 10. How valuable were the program outcomes for parental participation in workforce? / Economic Security  |  | X |  | X |  | X | X |  |
| 11. How relevant is MAP service to its participant’s needs? / Relevance  | X | X |  | X |  | X | X |  |
| 12. How well does it fit with and complement other initiatives operating in the same space/ Relevance  | X | X |  | X |  | X | X | X |
| 13. How well does it address and align with the needs, and aspirations of autistic children and their families? / Program design  |  | X |  | X |  | X | X |  |
| 14. How well does it address the root causes and systemic and institutional discrimination towards autistic children and their families? /Relevance  | X | X | X | X | X | X | X | X |
| 15. How appropriately designed is the MAP service for its clients (e.g., developmentally and age appropriate; culturally and contextually appropriate; accessibility; etc.)?/ Program design  | X | X | X | X |  | X | X | X |
| 16. How effectively did the pre- implementation consultation ensure that the MAPs addressed the needs and concerns of MAP service clients | X | X | X | X |  | X | X |  |
| 17. To what extent did the MAP represent the best possible use of the available resources to achieve its program outcomes? / Relevance and value  | X | X | X | X |  | X | X |  |

* 1. Logic Model

The MAP program logic model was developed during the consultations with the stakeholders. It describes the available resources for MAP program and the sequence of activities thought to bring about the change in the lives of autistic children and their families. The model below depicts the relationship among the resources MASS has to operate MAP program, the activities planned and the results that MAP program hopes to achieve (Figure 2).



Figure 2. MAP Services Logic Model

Some of the external factors and assumptions that may influence program implementation and achievement of its outcomes were voices during the stakeholder meetings. The factors and assumptions are listed below in Table 5.

**Table 5. List of External Factors & Assumptions**

|  |  |
| --- | --- |
| External Factors  | Assumptions  |
| NDIS funding model, guidelines and policies emphasise insurance model for one child, rather than holistic support for families. Impact/pressure on MASS services. Need higher level of admin and supervision.  | MAPs have sufficient time to engage with families, and they are provided with adequate training and support.  |
| Access to services requires early child diagnosis. | Families are open to receiving support and working with MAPs to achieve children and family goals. |
| Structure of the educational support system in Victoria, inflexibility in funding and resourcing. | MAPs are sufficiently funded. |
| Mental health and attitudes of parents. Limited access to support services. | Further supports exist in the community, and these are accessible. |
| Opportunities to provide support to MAPs, considering demands of their job. | Educators are open to working with MAPs. |
| Community attitudes can be enablers or barriers. | Community structures are responsive and allow for the inclusion of autistic people. |

1. Measurement Model

The measurement model is designed to be a practical tool for conducting the evaluation of the MAP service. The model (Table 7) was informed by the program logic, literature review and stakeholder engagement mentioned in the above sections. During this process, it was recommended that data collection should tap into existing methods and instruments to reduce the workload of MAPs and parents. Table 6 outlines the definitions for terms used in the measurement model.

Table 6. Definitions of Measurement Model Components

|  |  |
| --- | --- |
| Component | Definition |
| KEQ | The key evaluation question(s) the data will contribute to addressing.  |
| Construct | Set of criteria of that together describes the overall merit, worth and/or significance of the evaluand. They should be contiguous, commensurable, clear, concise and measurable. |
| Dimension | Factors of clusters of variables that together fully describe a construct. They should be contiguous, commensurable, clear, concise and measurable. |
| Variable | An element, component or item that can be measured or counted that may affect or be affected by the evaluand. |
| Indicator | A specific and observable parameter that corresponds to a particular outcome that captures the changes through quantitative, qualitative and descriptive means. These indicators maybe sentinel in nature. |
| Data source | The location or instrument of the data from which it will be extracted. |
| Data collection method | Data collection methods that can be used to capture and address the indicator |

* 1. Priority Measurement Model

Based on discussions with MASS, the measurement model has been divided into two stages: priority and additional outcomes. Due to the limited resources available to MASS, key outcomes for the program must be identified and prioritised in terms of monitoring and evaluation. These were identified by MASS and are presented in the priority measurement model below, which focuses on key areas for the primary beneficiaries of the program; children and families. Data collection methods are described in further detail below in section 4.3. Additional outcomes to be measured are listed in Appendix D as a possible framework for future monitoring and evaluation should resources be available to do so.

Table 7. Measurement Model – Priority

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Domain  | Variable | Indicator (of performance) | Who is the information about? | Who is providing the information?  | How will the data be collected?  | What’s the tool that tells us what to ask? (checklist or scale) | When will we collect the data? | Who collects the data (family, MAPs, external evaluator, MASS) |
| CHILDREN |  |  |  |  |  |  |  |  |
| Health and Wellbeing | Functional daily living skills and developmentally appropriate skills | Achieving child's skill development goals over time | Child  | MAP observation of child; Parents; Child; Siblings if any; community members (i.e., teachers).  | Existing and new (QoL instrument) data collection processes survey, interviews, and/or observations;  | MAP SMART goals, MASS functional skills assessment; Adaptive Behaviour Assessment System (ABAS)[[1]](#footnote-2), QoL Instrument  | Before and after intervention  | MAPs and/or external evaluator  |
| Increase in daily living skills (e.g., toileting, eating, dressing) over time | Before and after intervention |
| Social and Communication skills | Achieving child's social and communication goals over time | Child | Child\* (parent, if a child is unable to respond) | Existing (Client Satisfaction Survey; DBC; ABAS) and new data collection processes  | MAP SMART goals, ABAS, QoL instrument  | Before and after intervention – and/or annually  | MAPs |
| Self-regulation and independence | Child demonstrates increased emotional regulation - % decrease in DBC Disruptive Behaviour or Mean Item Score | Child  | Child\* (parent, if a child is unable to respond) | Existing data collection process and new data collection processes  | Developmental Behaviour Checklist (DBC)[[2]](#footnote-3); QoL Instrument  | Before and after intervention - & annually to measure  | MAPs |
| Behaviours of concern | Reduction in intensity and frequency - % decrease in DBC Intensity Scale or Total Behaviour Score | Child  | Child\* (parent, if a child is unable to respond), Family  | Existing data collection process | DBC or BSP (Behaviour Support Plan), ABAS, QoL instrument (Survey & Interviews), observations  | Before and after intervention | MAPs |
| Understanding of autism | Child has greater empowerment and self-acceptance | Child  | Child\*, Family  | Existing data collection process and new data collection processes  | MASS Initial access interview baseline; MA Client Satisfaction Survey, QoL Instrument  | Annual | MASS or MAP or an external evaluator  |
| Psychological and emotional wellbeing | Decrease in anxiety levels and improvement in health and wellbeing | Child  | Child\*, Family  | Existing data collection process and new data collection processes  | MASS Initial access interview baseline, QoL Instrument  | Annual | MASS or MAP or an external evaluator |
| Social and Community Connections | Family relationships | Child increases participation in family activities and routines | Child  | Child\*, Family | New data collection process (survey, interviews, and/or observations)  | MASS initial access interview; QoL Instrument, observations  | Before & after the intervention /Annual | MASS or MAP or an external evaluator |
| Improved relationship with siblings and family members | Child  | Child\*, Family | New data collection process (survey, interviews, and/or observations | MASS initial access interview; QoL Instrument,  | Before and after intervention/ Annual | MASS or MAP or an external evaluator |
| Participation in community | Increased ability to form and maintain friendships | Child  | Child\*, Family, School | New data collection process (survey, interviews, and/or observations | QoL Instrument | Annual | MASS or MAP or an external evaluator |
| Increased participation in social events; increased participation in community (e.g., extracurricular activities) | Child  | Child\*, Family, School | New data collection process (survey, interviews, and/or observations | QoL Instrument | Annual | MASS or MAP or an external evaluator |
| Learning and Skills | Participation in education | Attendance and time spent at school | Child  | Child, Family, School | New data collection process (survey, interviews, and/or observations | QoL Instrument | Before the intervention /school year and 6 months into school year  | MASS or MAP or an external evaluator |
| Child participation in the classroom | Child  | Child\*, Family, School | New data collection process (survey, interviews, and/or observations | QoL Instrument | Before the intervention /school year and 6 months into school year | MASS or MAP or an external evaluator |
| Child's satisfaction with learning experience; | Child  | Child\* | Survey, interviews, and/or observations | QoL Instrument | Before and after the school term  | MASS or MAP or an external evaluator |
| Economic Security  | Participation in workforce | Access to volunteering and early employment opportunities | Child  | Child (parent, if a child is unable to respond) | Survey, interviews | QoL Instrument | Annually  | MASS or MAP or an external evaluator |
| Economic participation and independence | Access to secure employment opportunities; financial independence; income | Child  |  | Survey, interviews | QoL Instrument | Annually  | MASS or MAP or an external evaluator |
| FAMILY |  |  |  |  |  |  |  |  |
| Health and Wellbeing | Psychological and emotional wellbeing | Increased optimism; decreased anxiety and stress | Family members  | Family | Survey, interviews | QoL Instrument | Annually  | MASS or MAP or an external evaluator |
|  | Understanding of autism | Increased understanding of autism in family and extended family members | Family members  | Family, Extended family | Survey, interviews | QoL Instrument  | Before and after intervention  | MASS or MAP or an external evaluator |
|  | Family confidence and care | Increased confidence to support child; increased ability to provide supportive care | Family members  | Family | Survey, interviews | QoL Instrument | Annually  | MASS or MAP or an external evaluator |
| Social and Community Connections | Family relationships | Improved family dynamics, sustained over time; family spends more time together; family engages in more activities together; family engages with extended family more often | Family members  | Family, Extended family, MAPs  | Survey, interviews | QoL Instrument,  | Before and after intervention | MASS or MAP or an external evaluator |
|  | Engagement in community | Increased self-confidence to leave home; | Family members  | Family, Extended family, MAPs, Community  | Survey, interviews | QoL Instrument | Annually  | MASS or MAP or an external evaluator |
|  |  | Ability to form and/or maintain friendships and social networks | Family members  | Family, Extended family, MAPs, Friends  | Survey, interviews | QoL Instrument  | Annually  | MASS or MAP or an external evaluator |
|  |  | Time spent participating in community and recreational events; | Family members  | Family, Extended family, MAPs | Survey, interviews | QoL Instrument  | Annually  | MASS or MAP or an external evaluator |

\*Note: *It is preferred that the child is given opportunity to respond on behalf of themselves, however it is acknowledged that in some circumstances, proxy reports from parents/family members may be necessary. Results using proxy reports should be interpreted with caution. (See more on the importance of child participation in data collection processes in Section 5.2.)*

* 1. Proposed Data Collection and Analysis Methods
		1. Existing Data Collection Processes

As was revealed from the data collection stock take process, MAPs currently collect data on several child outcomes as part of their regular practice. Standardised tools are the Adaptive Behaviour Assessment System (ABAS) and the Developmental Behaviour Checklist (DBC). It is recommended that these existing processes are leveraged as part of the monitoring and evaluation framework. As each child will have a unique set of goals and skills, this process will allow for outcome monitoring to be responsive to individual progress.

* + 1. Mansfield case study

In order to measure community impact, it was discussed that a case study on Mansfield, where MASS is located, would be useful to capture some of the ways MASS and the MAP service have influenced the communities understanding and acceptance of autism. MASS reported that some local businesses have created accommodations. MAPs also are involved at children’s local schools and work with educators to provide support for children in the school environment.

1. Next Steps and Recommendations

The M&E Framework and indicators described here have been developed utilizing robust co-design methods and processes, however when testing them in an evaluation, it is expected that further ‘fine tuning’ is done to ensure they are appropriate, relevant and overall useful. Some key refinements are outlined below to be considered in operationalising the M&E Framework.

* 1. Ethical Considerations

A review of the ethical considerations of involving autistic children in research (Cascio et al., 2021) recommended that children be supported to participate in the following key ways:

* Providing opportunity for the child to assent or refuse participation.
* Providing inclusive communication strategies that do not involve verbal or written communication, such as Talking Mats, photovoice, ‘five finger’ gesture system, and use of augmented and alternative communication (AAC).
* Involving adults with lived experience of autism in designing research/evaluation and data collection approaches.
	1. Hearing from kids

When discussing with stakeholders about how to facilitate data collection, the perceived difficulty in engaging children - especially children who may be non-verbal or have communication difficulties - was raised as a barrier to hearing directly from them. This is acknowledged in the literature around autism research as a common problem, where autistic children are less likely to be involved in research that is about them on account of their age, as well as communication differences (Parsons et al., 2020). Autistic children’s participation in social research aimed at understanding their experiences ‘. . .lags behind that of their non-autistic peers [such that] . . .our understanding of autistic children’s experiences from their perspective is limited’ (Ellis, 2017; p. 24 cited in Parsons et al., 2020, p. 163).

This tendency to rely on parents/caregivers and professionals as proxies for a child exists despite the growing evidence that parents and children have differing views and there is a “risk that parents’ own quality of life biases their assessment of their child’s quality of life” (Eiser & Jenney, 2007). Rand and Caiels (2015) reviewed the challenges of using proxies to assess QoL and concluded that proxies tend to rate QoL lower than a child self-reporting. They also concluded that proxy measures should include very clear instructions, should include both proxy-patient and proxy-proxy perspectives, and acknowledge potential bias (Davidson et al., 2017). Research on PET (Parent Education and Training) programs (such as MAPs) also often focus on parent outcomes more than child outcomes, however it is recommended that child outcomes be included (Dawson-Squibb et al., 2020).

Therefore, all other possibilities should be explored before considering the use of proxy responses, including the use of face-to-face interviews that may utilize alternative forms of communication (Davidson et al., 2017).

* 1. Refining QoL Tools

There is an emphasis in the literature to use a multidimensional model of QoL including both, objective and subjective measures to increase the validity of the measurement tool (Cummins, 1997; Schalock & Felce, 2004). Objective indicators are easily observable and can be verified, they include income, education, frequency of social interaction, friendships etc. Subjective measures (perceptual measures) represent how an individual perceives himself/herself, other people, situations, issues, etc.--for example, feeling happy, unhappy, miserable, satisfied etc.

When selecting an instrument from those available it may happen that no one scale is ideal. Under these circumstances, the researcher needs to make a clinical judgement about suitability from those available, compromising between the various attributes described above. QoL scale selection is not an exact science because it is often difficult to predict the performance of a scale in advance. If no scale is suited for a particular purpose, then researchers should consider developing a new one, but there are many currently available (Hyland, 2003).

The literature review of QoL measures revealed a number of possible existing scales that could be utilized by MASS in its evaluation of MAP service. Full scale listed in the attached to this framework document.

* + 1. Development of QoL tools and procedures

**Objectives**

* Develop simple and straightforward data collection tools, i.e., short interactive surveys, focus group discussions, and observations (to include pictures);
* Develop a “data collections purpose statement” to introduce data collection tools to MAP service’ beneficiaries.

**Possibilities**

1. Conduct 10-12 items surveys with parents and children every three months;
2. Conduct an observation of a visit (with pictures) every other month or same as a survey, every quarter;
3. Conduct a longer survey (ex. Family and Child’s QoL surveys) and focus group discussions with parents, children, MAP service providers and relevant stakeholders every year or every two years.
4. Add vignettes into the surveys to allow children and parents distance themselves from the questions. – Although, vignettes were not used in the reviewed QoL scales, their application could facilitate data collection processes, as they provide a less personal and therefore less threatening way of exploring sensitive topics (Barter & Renold, 1999).
	1. Next steps: Value for Money Evaluation

MASS previously conducted a cost-benefit analysis (CBA) of the MAP service, and they would like to conduct a further economic evaluation of the service. After discussion with MASS, we consider that a CBA approach may not be broad enough to encompass the unique holistic aspects and outcomes of the MAP service. Given the social impact of the service, we recommend that MASS conducts a value for money evaluation, which goes beyond the financial aspects of the service (King, 2020). A value for money evaluation would address the question ‘To what extent does the MAP service represent value for the resources used, and how can its value be improved?’ This approach aligns well with the monitoring and evaluation framework presented in this document, as a value for money evaluation employs different forms of evidence beyond financial data (e.g., case studies, interviews) in order to make an evaluative judgment about the value of the program. The table below provides examples of criteria in Value for Money Evaluations that MASS could employ:

Table 8. Value for Money Criteria

|  |  |
| --- | --- |
| Criteria | Example |
| Economy: getting the best value inputs | Manages program resources economically, buying inputs of the appropriate quality at the right price |
| Efficiency: maximising the outputs for a given level of inputs | Program produces the intended quality and quantity of deliverables, within the available resources |
| Effectiveness: ensuring that the outputs deliver the desired outcome | Program achieves its intended changes |
| Equity: ensuring that the benefits are distributed fairly | Needs-based planning and resource allocation contribute to reducing inequities |

1. Bibliography

American Psychiatric Association. (2018). *What is autism spectrum disorder?* https://www.psychiatry.org/patients-families/autism/what-is-autism-spectrum-disorder

American Psychological Association. (2009). *Publication Manual of the American Psychological Association*. Washington, DC: American Psychological Association.

Australasian Evaluation Society (2013). *Guidelines on ethical conduct of evaluation and code of ethics.* [www.aes.asn.au](http://www.aes.asn.au)

Autism Society. The autism experience: Understanding autism. <https://autismsociety.org/the-autism-experience/>

Barter, C., & Renold, E. (1999). *The Use of Vignettes in Qualitative Research.* Sociology of Survey, Retrieved from https://sru.soc.surrey.ac.uk/SRU25.html

Brinkerhoff, R. O. (2003). *The success case method: Find out quickly what’s working and what’s not.* San Francisco, CA: Berrett-Koehler.

Cascio, M. A., Weiss, J. A., & Racine, E. (2021). Making autism research inclusive by attending to intersectionality: a review of the research ethics literature. *Review Journal of Autism and Developmental Disorders*, *8*(1), 22-36.

Carcary, M. (2009). The research audit trail - Enhancing trustworthiness in qualitative inquiry. *Electronic Journal of Business Research Methods, 7*(1), 11–24.

Centers for Disease Control and Prevention [CDC]. (2018, October 31). *Well-Being Concepts.* https://www.cdc.gov/hrqol/wellbeing.htm

Commonwealth of Australia National Health and Medical Research Council (2018a). *Australian Code for the Responsible Conduct of Research 2018*. https://www.nhmrc.gov.au/

Commonwealth of Australia National Health and Medical Research Council (2018b). *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders 2018*. https://www.nhmrc.gov.au/

Commonwealth of Australia National Health and Medical Research Council (2018c). *National statement on ethical conduct in human research: 2007 updated 2018*. https://www.nhmrc.gov.au/

Convention on the Rights of Persons with Disabilities [CRPD]. (2006). https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html

Cottenceau, H., Roux,S., Blanc, R., Lenoir, P., Bonnet-Brilhault, F., & Barthélémy, C. (2012). Quality of life of adolescents with autism spectrum disorders: comparison to adolescents with diabetes. *Eur Child Adolesc Psychiatry, 21*(5), 289-96. https://doi.org/10.1007/s00787-012-0263-z

Creswell, J., & Plano Clark, V. L. (2017). *Designing and conducting mixed methods research* (3rd ed.). Retrieved from www.ebooks.com

Cummins, R. A. (1997). Self-rated quality of life scales for people with an intellectual disability: A review. *Journal of Applied Research in Intellectual Disabilities, 10*(3), 199–216. <https://doi.org/10.1111/j.1468-3148.1997.tb00017.x>

Davidson, E. J. (2005). Evaluation methodology basics: The nuts and bolts of sound evaluation. <https://dx.doi.org/10.4135/9781452230115>

Davidson, G., Irvine, R., Corman, M., Kee, F., Kelly, B., Leavey, G., & McNamee, C. (2017). *Measuring the Quality of Life of People with Disabilities and their Families: Scoping Study Final Report*. Department for Communities. https://www.communities-ni.gov.uk/publications/measuring-quality-life-disabled-people-and-their-families-scoping-study-final-report

Dawson-Squibb, JJ., de Vries, P.J. (2019).Developing an Evaluation Framework for Parent Education and Training in Autism Spectrum Disorder: Results of a Multi-stakeholder Process*. J Autism Dev Disord, 49*,4468–448. https://doi.org/10.1007/s10803-019-04176-w

Dawson-Squibb, J. J., Davids, E. L., Harrison, A. J., Molony, M.A., & de Vries, P. J. (2020). Parent education and training for autism spectrum disorders: Scoping the evidence. *Autism, 24*(1), 7-25. https://doi.org/10.1177/1362361319841739

Dyches, T. T., Wilder, L. K., Sudweeks, R. R., Obiakor, F. E., & Algozzine, B. (2004). Multicultural issues in autism. *J Autism Dev Disord, 34*(2), 211-22. https://doi.org/10.1023/B:JADD.0000022611.80478.73

Eapen, V., Crnčec, R., Walter, A., & Tay, K. P. (2014). Conceptualisation and development of a quality of life measure for parents of children with autism spectrum disorder. *Autism Res Treat, 2014*:160783. https://doi.org/10.1155/2014/160783

Eiser, C., & Jenney, M. (2007). Measuring quality of life. *Arch Dis Child, 92*(4), 348-50. http://dx.doi.org/10.1136/adc.2005.086405

Greene, J. C. (2007). *Mixed methods in social inquiry*. San Francisco, CA: Jossey-Bass.

Greene, J. C., Caracelli, V. J., & Graham, W. F. (1989). Toward a Conceptual Framework Mixed-Method Evaluation Design. *Educational Evaluation and Policy Analysis,* 11, 255–274.

Hu, X., Summers, J.A., Turnbull, A., & Zuna, N. (2011). The quantitative measurement of family quality of life: A review of available instruments. *Journal of Intellectual Disability Research, 55*(12), 1098-1114.

Hyland, M.E. (2003). A brief guide to the selection of quality of life instrument. *Health Qual Life Outcomes, 1,* 24. <https://doi.org/10.1186/1477-7525-1-24>

Jackson, S. F., & Kolla, G. (2012). A new realistic evaluation analysis method: Linked coding of context, mechanism, and outcome relationships. *American Journal of Evaluation, 33*(3) 339–349. https://doi.org/10.1177/1098214012440030

John Hopkins Arthritis Centre. Arthritis and health-related quality of life. https://www.hopkinsarthritis.org/patient-corner/disease-management/quality-of-life-and-arthritis/

King, J. (2020). Economic evaluation and value for money. Retrieved from <https://www.julianking.co.nz/vfi/econ/>

Manzano, A. (2016). *The craft of interviewing in realist evaluation. Evaluation, 22*(3), 343–360. <https://doi.org/10.1177/1356389016638615>

Matson, J. L., Matheis, M., Burns, C. O., Esposito, G., Venuti, P., Pisula, E., Misiak, A., Kalyva, E., Tsakiris, V., Kamio, Y., Ishitobi, M., & Goldin, R. L. (2017). Examining cross-cultural differences in autism spectrum disorder: A multinational comparison from Greece, Italy, Japan, Poland, and the United States. *European psychiatry: the journal of the Association of European Psychiatrists*, *42*, 70–76. https://doi.org/10.1016/j.eurpsy.2016.10.007

Martens, K. S. R. (2018). Rubrics in program evaluation. *Evaluation Journal of Australasia, 18*(1), 21–44.

Morris (2008). *Evaluation ethics for best practice: Cases and commentaries.* New York: Guilford Press.

Office of Quality of Life Measures (2011a). The KIDSCREEN-52. Retrieved from <https://www.kidscreen.org/english/questionnaires/kidscreen-52-long-version/>

Office of Quality of Life Measures (2011b). The KIDSCREEN-10 Index. Retrieved from <https://www.kidscreen.org/english/questionnaires/kidscreen-10-index/>

Owen, J. M. (2006). *Program evaluation: Forms and approaches* (3rd ed.). St Leonards, N.S.W.: Allen & Unwin.

Parsons, S., Kovshoff, H., & Ivil, K. (2020). Digital stories for transition: co-constructing an evidence base in the early years with autistic children, families and practitioners. *Educational Review,* 1-19. https://doi.org/10.1080/00131911.2020.1816909

Parsons, S., Ivil, K., Kovshoff, H., & Karakosta, E. (2021). “Seeing is believing”: Exploring the perspectives of young autistic children through Digital Stories Kathryn Ivil Efstathia Karakosta. *Journal of Early Childhood Research*, *19*(2), 161–178. https://doi.org/10.1177/1476718X20951235

Pawson, R. (2013). The science of evaluation: A realist manifesto. <https://dx.doi.org/10.4135/9781473913820>

Pawson, R., & Tilley, N. (2004). *Realistic evaluation.* Retrieved from http://www.communitymatters.com.au/RE\_chapter.pdf

Pawson, R. & Tilley, N. (2014). *Realistic evaluation.* London: Sage Publications Ltd. (Original work published 1997)

PedsQL. The PedsQL Measurement Model for the Pediatric Quality of Life Inventory https://www.pedsql.org/about\_pedsql.html

Punch, K. F. (2014). *Introduction to social research: Quantitative and qualitative approaches* (3rd ed.). London: Sage Publications Ltd.

Rand, S.E. & Caiels, J. (2016). *Using Proxies to assess Quality of Life: A Review of the Issues and Challenges.* Discussion paper. Quality and Outcomes of person-centred care policy Research Unit (QORU), University of Kent.

Roorda, M. (2018). *Developing defensible evaluation criteria: A manual for evaluators.* Unpublished manuscript. University of Melbourne, VIC: Centre for Program Evaluation.

Rycroft-Malone J., McCormack, B., Hutchinson, A. M., DeCorby, K., Bucknall, T. K., Kent, B., …Wilson, V. (2012). Realist synthesis: Illustrating the method for implementation research*. Implementation Science 7*(33), 1–10. https://doi.org/10.1186/1748-5908-7-33

Schalock, R. L., & Felce, D. (2004). Quality of life and sub-jective well-being: conceptual and measurement issues. In E. Emerson, T. Thompson, T. Parmenter & C. Hatton (Eds.), *International Handbook on Methods for Research and Evaluation in Intellectual Disabilities* (pp. 261–80). Wiley.

Schalock, R. L., & Verdugo, M. A. (2002). *Handbook on Qual-ity of Life for Human Service Practitioners.* American Association on Mental Retardation, Washington, DC.

Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., Keith, K. D., & Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: results of an international panel of experts. *Mental Retar-dation,40*, 457–70.

Schalock, R. L., Luckasson, R. A., Shogren, K. A., Borthwick-Duffy, S., Bradley, V., Buntinx, W. H., Coulter, D. L., Craig, E. M., Gomez, S. C., Lachapelle, Y., Reeve, A., Snell, M. E., Spreat, S., Tassé, M. J., Thompson, J. R., Verdugo, M. A., Wehmeyer, M. L., & Yeager, M. H. (2007). The renaming of mental retardation: understanding the change to the term intellectual disability. *Intellect Dev Disabil, 45*(2), 116-24. https://doi.org/10.1352/1934-9556(2007)45[116:TROMRU]2.0.CO;2

Schalock, R. L., Keith, K. D., Verdugo, M. Á., Gómez, L.E. (2010). Quality of Life Model Development and Use in the Field of Intellectual Disability. In R. Kober (Eds.), *Enhancing the Quality of Life of People with Intellectual Disabilities* (Social Indicators Research Series, Vol. 41). Springer, Dordrecht. https://doi.org/10.1007/978-90-481-9650-0\_2

Sucharew, H., & Macaluso, M. (2019). Methods for Research Evidence Synthesis: The Scoping Review Approach*. Journal of hospital medicine, 14*, E1-E3. https://doi.org/10.12788/jhm.3248

The Quality of Life Research Unit, University of Toronto. *The Quality of Life Model.* http://sites.utoronto.ca/qol/qol\_model.htm

Tzavara, C., Tzonou, A., Zervas, I., Ravens-Sieberer, U., Dimitrakaki, C., & Tountas, Y. (2012). Reliability and validity of the KIDSCREEN-52 health-related quality of life questionnaire in a Greek adolescent population. *Annals of General Psychiatry, 11*(3).

World Health Organization [WHO]. *Constitution.* <https://www.who.int/about/governance/constitution>

World Health Organization [WHO]. *WHOQOL: Measuring Quality of Life.* <https://www.who.int/tools/whoqol>

Wong, G., Westhorp, G., Pawson, R., & Greenhalgh, T. (2013). *Realist synthesis: RAMESES training materials.* Retrieved from http://www.ramesesproject.org

Yarbrough, D. B., Shulha, L. M., Hopson, R. K., & Caruthers, F. A. (2011). *The program evaluation standards: A guide for evaluators and evaluation users* (3rd ed.). Thousand Oaks, CA: Sage.

Zuna, N. I., Turnbull, A., & Summers, J. A. (2009). Family Quality of Life: Moving from Measurement to Application. *Journal of Policy and Practice in Intellectual Disabilities, 6*(1), 25-31. https://doi.org/10.1111/j.1741-1130.2008.00199.x

Zuna, N., Summers J. A., Turnbull A. P., Hu X. & Xu S. (2011) Theorizing about family quality of life. In R. Kober (Ed.), *Enhancing the Quality of Life of People with Intellectual Disability: From Theory to Practice* (pp. 241–78). Springer.

1. Appendices
	1. Appendix A. Literature review details

**Methodology and its Execution**

Scoping reviews require comprehensive and structured searches to ensure the capture of relevant and reliable findings and to decrease potential biases from inaccurately conducted reviews (Sucharew & Macaluso, 2019). The methodological framework for scoping reviews developed by Arksey and O’Malley and further refined by Levac et al. and the Joanna Briggs Institute includes the following steps: identifying the research questions and relevant studies, selecting studies, extracting and charting data, summarizing and reporting the results; and presenting findings to stakeholders for further feedback (Sucharew & Macaluso, 2019).

The QoL scoping review was conducted between May and October 2021. A variety of conceptual, methodological and empirical research papers and documents addressing QoL studies in applied human and social sciences were reviewed. Various online databases, such as JSTOR, Google Scholar, ProQuest, ScienceDirect, PsycINFO, RESEARCH GATE and SAGE among others were screened using search strings (ex. “QoL”, “family QoL”, “autism”, “QoL of children with intellectual disabilities” “Qol of children with developmental disabilities”, “QoL of autistic children”, “QoL of parents of autistic children” etc.). Abstracts, bibliographies and references of research studies, as well as MASS, National Disability Insurance Scheme (NDIS) and World Health Organization (WHO) documents among others were screened for relevant information as well.

The definitions explored in the review included QoL, family QoL, disability (social, medical and charity models) and impairment, autism or ASD, developmental and intellectual disabilities.

**Quality of Life & Family Quality of Life**

WHO defines QoL as “an individuals' perceptions 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”. QoL is also defined as a complex concept that incorporates features of wellbeing, positive social involvement and opportunities to achieve personal potential. It may include objective measures, such as income, employment and participation, and subjective measures, such as satisfaction, self-determination, wellbeing, and happiness (National Disability Service).

Family quality of life is characterized as a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact (Zuna et al., 2009).

Findings from the reviews, including relevant QoL definitions, concepts, and validated measurement tools and scales were documented in the QoL review form, which included at least 22 measurement frameworks developed for children and adults with disabilities, and at least 4 measurement frameworks developed to measure QoL of families and/or parents of children with disabilities.

* 1. Appendix B. Evaluand Document List

|  |  |
| --- | --- |
| Document | Notes |
| MAP assessments summary | Summary of current and proposed data collection with pros and cons according to MASS, including ABAS and DBC as parent satisfaction survey |
| MAP evaluation survey questions | Questions asked in client satisfaction survey |
| ABAS parent response sheet | Current child outcome data collection tool used by MAPs |
| ABAS teacher response sheet | Current child outcome data collection tool used by MAPs |
| DBC parent response sheet | Current child outcome data collection tool used by MAPs |
| DBC teacher response sheet | Current child outcome data collection tool used by MAPs |
| Bull 2012 thesis- Travelling Teacher Service MASS | Previous research on MASS |
| MASS CB Analysis Report FINAL 20110525 (00000004) | Previous research on MASS |
| MASS-ANNUAL-REPORT-2019-Dec-9-2020 | Previous research on MASS |
| RESEARCH EVALUATION PAPER(1) | Previous research on MASS |
| TTS exec summary Monash 1 | Previous research on MASS |
| nds-outcomes-framework-accessible-pdf-final |  |
| PB Outcomes framework 2015 DOCX |  |
| SIMT NDS Impact measurement tool research pilot |  |
| FinalAfterSchoolJobsReport27April2021 |  |

* 1. Appendix C. Stakeholder workshop notes

Workshop questions:

1. *Why do families use the MAP service? (What are the needs of families?)*
2. *What is a good outcome from using the service?*
3. *What activities lead to these outcomes?*
4. *What are the most important outcomes of the service?*
5. *How do you think these outcomes could be tracked?*
6. *What is a practical and accessible way to do this? (How often, how long for?)*

### What are the most important outcomes to measure?

#### Child outcomes

|  |  |  |  |
| --- | --- | --- | --- |
| **Health and wellbeing** | **Social and Community Connections** | **Learning and Skills** | **Economic Security** |
| * Functional daily living skills and developmentally appropriate skills
* Social and communication skills
* Self-regulation and independence
* Behaviours of concern
* Understanding of autism
* Psychological and emotional wellbeing
 | * Family relationships
* Participation in community
 | * Participation in education
 | * Participation in workforce
* Economic participation and independence
 |

**How can child outcomes be measured?**

|  |  |
| --- | --- |
| **Indicators** | **How to measure?** |
| * Achieving child's skill development goals over time
* Increase in daily living skills (e.g. toileting, eating, dressing,…)
* Achieving child's social and communication goals over time
* Child demonstrates increased emotional regulation - %decrease in DBC Disruptive Behaviour or Mean Item Score
* Reduction in intensity and frequency - %decrease in DBC Intensity Scale or Total Behaviour Score
* Child has greater empowerment and self-acceptance
* Decrease in anxiety levels and improvement in health and wellbeing
* Child increases participation in family activities and routines
* Improved relationship with siblings and family members
* Increased ability to form and maintain friendships
* Increased social network
* Increased participation in social events; increased participation in community (e.g., extracurricular activities)
* Attendance; time spent in mainstream classroom; child's satisfaction with learning experience;
 | * MAP SMART goals
* MASS functional assessment
* DBC
* ABAS
* BSP
* Quality of Life scale
 |

#### Family outcomes

|  |  |  |
| --- | --- | --- |
| **Health and wellbeing** | **Social and Community Connections** | **Economic Security** |
| * Psychological and emotional wellbeing
* Understanding of autism
* Family confidence and care
 | * Family relationships
* Engagement in community
 | * Participation in workforce
 |

 **How can family outcomes be measured?**

|  |  |
| --- | --- |
| **Indicators** | **How to measure?** |
| * Increased optimism; decreased anxiety and stress
* Increased understanding of autism in family and extended family members
* Increased confidence to support child; increased ability to provide supportive care
* Improved family dynamics, sustained over time; family spends more time together; family engages in more activities together; family engages with extended family more often
* Time spend participating in community and recreational events; ability to form and maintain friendships; social network expanded; increased self-confidence to leave home;
* Parental participation in workforce: access to employment, can work more hours, financial security. Parental participation in education (TAFE/higher ed)
 | * MAP SMART goals
* Quality of Life scale
* Surveys?
* Interviews?
 |

#### Community outcomes

|  |  |
| --- | --- |
| **Inclusive and accessible communities** | **Inclusive and accessible education** |
| * Community awareness and responsiveness to autism
 | * Schools/teachers awareness, understanding and practices
 |

**How can community outcomes be measured?**

|  |  |
| --- | --- |
| **Indicators** | **How to measure?** |
| * Increased understanding of autism
* Change in attitudes towards autism
* Autism friendly events and strategies
* Increased use of inclusive language in community events, activities, documents, etc
* Strategies in place that are responsive and mindful (e.g quiet times for shopping)
* Understanding of autism; understanding of inclusive practices; self-confidence to implement inclusive practices; use of reasonable adjustments
 | * Community case study?
* Surveys?
* Interviews?
 |

* 1. Appendix D. Additional Measurement Model

Table 9. Measurement Model – Potential Additional Areas for Measurement

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Domain | Variable | Indicator (of performance) | Data source (Who is providing information)  | How will the data be collected? | When  | Who |
| FAMILY |  |  |  |  |  |  |
| Material Wellbeing  | Economic Security  | Reduced care burden on parents |  |  |  |  |
|  |  | Parental participation in the workforce |  |  |  |  |
| Emotional Wellbeing  | Emotional Functioning  | Decrease in anxiety levels in parents; parents report increased emotional wellbeing |  |  |  |  |
| COMMUNITY |  |  |  |  |  |  |
| Social Inclusion | Inclusive and accessible communities | Increased understanding of autism  | Community members, MAPs, children and family members,  | QoL instrument (Survey, Interview, Observation)  | Annually  | MASS, MAPs, or external evaluator  |
|  |  | Change in attitudes towards autism |  |
|  |  | Autism friendly events and strategies |  |
|  |  | Increased use of inclusive language in community events, activities, documents, etc |  |  |
|  |  | Strategies in place that are responsive and mindful (e.g., quiet times for shopping) |  |  |
|  | Inclusive and accessible education | Understanding of autism; understanding of inclusive practices; self-confidence to implement inclusive practices; use of reasonable adjustments | Educators, children, families, MAPs  | QoL instrument (Survey, Interview, Observation) | Before and after the intervention; Annually  |  |
| PROGRAM |  |  |  |  |  |  |
| Approach  | Quality of support |  | MASS, MAPs | Surveys and Interviews  | Annually |  |
|  | Person-centered interventions  |  |  |  | Annually |  |
|  | Consistency in application of program principles |  |  |  | Annually |  |
| Staff | Training  | Number of training sessions, induction opportunities; opportunities for professional development; satisfaction with training and PD | MASS, HR | HR database  | Annually |  |
|  | Support  | Formal support provided to staff, opportunities for staff to support each other; availability of resources | MAP Manager | Surveys and Interviews | Annually |  |
|  | Recruitment  | % of candidates responding to recruitment ads; % of suitable candidates applying for role | HR | Surveys  | Annually |  |
|  | Satisfaction  | Satisfaction with role | MASS, MAPs, HR  | Surveys, Interviews  | Annually |  |
| Outreach  | Community Engagement  | Number and frequency of activities in the community; community knows about MASS | MASS, MAPs, community members | Surveys, MASS internal documents  | Annually |  |
|  |  | Number and frequency of collaborative activities with other support activities | MASS, MAPs  | Review of MASS internal documents  | Annually |  |
| Performance | Reach  | Number of clients/families; increase in number of clients/families over time; profile of clients/families | MASS, MAPs  | CMS; client satisfaction survey | Annually |  |
| Cost  | Economic cost | Fixed and variable program costs | MASS | Desk review | Annually |  |
| Reputation |  | MASS program appears in government reports and other publications; other practitioners are aware of program | MASS  | Desk review  | Annually |  |

* 1. Appendix E. Sample Survey Questionnaires

The below sample questionnaires were developed based on the literature review findings.

**I. Sample Short Survey for Children**

1. In general, how would you say your health has been for the last two weeks? – (a) excellent (b) good (c) poor – or use smiley faces J L
2. Have you been active? - Yes Sometimes Never or J L
3. Have you done any chores around the house?
4. Have you been getting along with others?
5. Did you get teased by other children?
6. Have you been happy at home?
7. Have you been happy at school?
8. Have you felt understood by your friends?
9. Have you been in a good mood?
10. Have you felt so bad that you didn’t want to talk to anyone?
11. Can you be yourself around your friends/people you know very well?
12. Do you get enough support from your teachers, if and when you need it?

**II. Short Survey for Parents**

1. Have you beensatisfied with your life?
2. Have you felt stressed?
3. Did you spend time with your friends?
4. Did you go out with your family?
5. Do you get support from others?
6. Do you have enough time for work?
7. Are you able to discuss an autism spectrum condition of your child with others?
8. Have you felt understood by others in community?
9. Have you had time to take care of the individual needs of every child?
10. Have you enjoyed spending time with your family?

**III. Measuring QoL**

The below table propose sample questions aimed at measuring program indicators across various QoL domains. The suggested instruments can be self-administered or proxy (if a child is incapable of answering the questions).

Instructions: Ask a child to self-rate items on a 3 or 5-point Likert-type scale (depending on the age and condition, smiley faces can be used) considering the statement in the context of the past week.

|  |  |  |
| --- | --- | --- |
| Domain  | MAP Service Program Indicators | Proposed Survey Questions  |
| Physical wellbeing | Increase in daily living skills (e.g., toileting, eating, dressing, …) over time | * In general, how would you say your health is?[[3]](#footnote-4) (on a scale from excellent to poor)

Thinking about the last week… (on a scale from not at all to extremely)* Have you felt fit and well? (KIDSCREEN)
* Have you been physically active?
* Have you felt full of energy? (KIDSCREEN)
* Have you done any chores around the house? (inspired by PedsQL[[4]](#footnote-5))
* Have you taken a bath or a shower by yourself? (inspired by PedsQL) (never – almost always)
* Did you have a good appetite? (never – almost always)
* Have you slept well during the night? (never to very often)
 |
| Social wellbeing  | Increased social network | * Do you spend time with other children? (adapted from PedsQL) (never – almost always)
* Did you make any new friends? (never – almost always)
 |
|  | Increased ability to form and maintain friendships | * Did you spend time with your friends? (KIDSCREEN)
* Have you had fun with your friends?
* Have you felt understood by your friends?
* How often do you meet your friends outside the school?
* Are you satisfied with your friendships? (ASQoL[[5]](#footnote-6))
 |
|  | Improved relationship with siblings and family members | * Have you been happy at home? (KIDSCREEN)
* Have you been able to talk to your parents when you wanted? (KIDSCREEN)
* Have you felt loved by your parents? (KIDSCREEN)
* Have you felt understood by your parents? (KIDSCREEN)
* Have you felt understood by your siblings?
 |
| Psychological and emotional wellbeing  | Increased optimism; decreased anxiety and stress | * Overall, would you say that your life has been enjoyable? (from not at all to extremely) (inspired by KIDSCREEN)
* Have you been in a good mood? (from never to always) (KIDSCREEN)
* Have you felt happy? (KIDSCREEN)
* Have you felt sad? (KIDSCREEN)
* Have you felt lonely? (KIDSCREEN)
* Have you had troubles sleeping? (inspired by PedsQL)
 |
|  | Behaviors of concern – reduction in intensity and frequency  | * Have you felt fed up? (KIDSCREEN)
* Have you felt so bad that you didn’t want to do anything? (KIDSCREEN)
* Have you felt so bad that you didn’t want to talk to anyone?
* Have you showed aggression (e.g., hitting, kicking, using offensive language, being destructive)?
* Have you felt that everything in your life goes wrong? (KIDSCREEN)
 |
| Self-perception | Understanding of autism - Child has greater empowerment and self-acceptance | * Are you at ease (OK) with an autism as an aspect of your identity? (ASQoL)
* Have you been happy with the way you are? (KIDSCREEN)
* Can you be yourself around your friends/people you know very well? (ASQoL)
* Would you like to change anything in you? (inspired by KIDSCREEN)
* Have you felt jealous of other children without autism?
 |
| Material wellbeing – Independence  | Income confidence  | * Have you had enough money to do the same things as your friends? (KIDSCREEN)
 |
| School environment  | Attendance; time spent in mainstream classroom; child's satisfaction with learning experience;  | * Have you been happy at school? (KIDSCREEN)
* Have you been keeping up with the school work? (PedsQL)
* Are you happy with what you are learning at school?
 |
|  | Continued engagement in formal and informal education  | * Have you enjoyed going to school? (KIDSCREEN)
* Have you been able to pay attention? (KIDSCREEN)
* Do sensory issues in the environment (ex. noise) make being at school difficult?
 |
|  | Improved participation in school/classroom  | * Have you been participating in class activities?
 |
|  | Increase understanding of autism in educators  | * Have you gotten along with your teacher? (KIDSCREEN)
* Have you been satisfied with your teacher (s)? (KIDSCREEN)
* Do you get enough support from your teachers, if and when you need it? (inspired by ASQoL)
 |

**IV. Measuring Family QoL**

|  |  |  |
| --- | --- | --- |
| Domain  | Program indicators  | Survey questions  |
| Emotional wellbeing (parent and family as a unit)  | Increased optimism; decreased anxiety and stress | * Adults in my family are satisfied with their lives (inspired by QoLA).
* Adults in my family feel stressed (inspired by QoLA).
* Adults in my family feel depressed or anxious.
* My family members show that they love and care for each other (Family QoL[[6]](#footnote-7))
* My family members have some time to pursue their own interests.
* Adults in my family feel in control of their lives (inspired by QoL).
 |
| Material wellbeing  | Parental participation in workforce: access to employment, can work more hours, financial security. | * We have enough money to meet our family needs (inspired by QoLA[[7]](#footnote-8)).
* My family has a way to take care of our expenses (Family QoL).
 |
| Physical wellbeing (parent and family as a unit) | Parental participation in education (TAFE/higher ed) | * Adults in my family have time to take care of the individual needs of every child;
* Adults in my family feel exhausted throughout the day;
 |
| Social wellbeing  | Time spent participating in community and recreational events; ability to form and maintain friendships; social network expanded; increased self-confidence to leave home;  | * My family members feel respected in the community.
* Adults in my family have time to socialize with their friends.
* My family feels isolated in the community (Peds Family QL inspired).
* Adults in my family do not have energy for social activities.
* Others do not understand my family (Peds QL family).
 |
| Disability related support  | Increased confidence to support child; increased ability to provide supportive care | * My family has outside help available to us to take care of special needs of all family members (Family QoL Scale).
* People are there for us when we need their help (QoLA inspired);
* My family has trouble getting support from others (Peds family QL[[8]](#footnote-9)).
* My family members have friends or others who provide support (Family QoL Scale).
 |
| Family interactions  | Increased understanding of autism in family and extended family members | * My family members talk openly with each other.
* It is hard for my family members to discuss an autism spectrum condition of their child with others.
 |
|  | Improved family dynamics, sustained over time; family spends more time together; family engages in more activities together; family engages with extended family more often | * My family enjoys spending time together.
* My family enjoys its interaction.
* My family members show that they love and care for each other.
* It is difficult for my family to reach a common decision (inspired by PedsQl).
 |



**Centre for Program Evaluation**
Melbourne Graduate School of Education
100 Leicester Street, The University of Melbourne, 3010 VIC

Phone: +61 3 8344 8394
Email: CPE-enquiries@unimelb.edu.au

1. ABAS - The Adaptive Behavior Assessment System, Third Edition, measures important behaviors a child displays at
home, school, and in other settings. This is an online questionnaire. [↑](#footnote-ref-2)
2. The DBC2 is a rating scale that assesses emotional and behavioural problems in children, adolescents and adults who have intellectual and developmental disability (IDD). IDD is defined as both intellectual and adaptive functioning deficits in conceptual, social and practical domains. This is an online questionnaire. [↑](#footnote-ref-3)
3. ### The KIDSCREEN, Health-related Quality of Life Screening Instrument for Children and Adolescents, <https://www.kidscreen.org/english/questionnaires/kidscreen-52-long-version/>

 [↑](#footnote-ref-4)
4. Pediatric QoL, https://www.pedsql.org/about\_pedsql.html [↑](#footnote-ref-5)
5. Autism Spectrum Quality of Life Questions (ASQoL), https://www.researchgate.net/publication/9011705\_The\_Quality\_Of\_Life\_Scale\_QOLS\_Reliability\_validity\_and\_utilization [↑](#footnote-ref-6)
6. Family Quality of Life Scale (FQOL), https://www.midss.org/content/family-quality-life-scale-fqol/ [↑](#footnote-ref-7)
7. Quality of Life in Autism Questionnaire (QoLA) for parents and caregivers of children with ASD, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3977417/ [↑](#footnote-ref-8)
8. PedsQL - Family impact module [↑](#footnote-ref-9)