

Mercy Connect Participant Satisfaction Survey



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Compassion

Hospitality Respect Innovation

Teamwork

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Executive Summary

Customer satisfaction in the disability sector is a powerful predictor of a person's lifestyle satisfaction and quality of life status. This is particularly relevant when people are engaged with an organisation with which they receive the majority of their services. These often include, supported accommodation, NDIS support coordination and daily activities. For a lot of participants receiving services through Mercy Connect this is the case. For Mercy Connect, a customer satisfaction survey provides the opportunity to gather information from its customer base regarding their satisfaction with the services provided to them, access to appropriate services and the ability to respond to any dissatisfaction that may be present so that future strategies may be formed with up to date and relevant information.

The 2019 Mercy Connect Participant Satisfaction Survey has given the participants who receive services through the organisation a voice. This has been the first time that a survey has been conducted by the organisation completely from the point of view, and in the words, of the participant. When reviewing earlier research findings in the field of intellectual disability, it has been shown that research does not often address multiple quality-of-life outcomes, rather it focuses on one aspect of a person's life such as accommodation, material wellbeing, emotional well-being or social relationships. Most of these studies have in the past relied mainly on informant based objective measures of a particular activity or benchmarks to assess peoples' lived experiences arguing that observational measures of engagement in meaningful activities and relationships are good proxy measures for many quality of life domains. This study is different. The 2019 Mercy Connect survey has collected information using both qualitative and quantitative data sources through two parallel surveys, covering multiple subject domains, in order to gain a holistic assessment of the level of satisfaction the people who receive services with the organisation have. This included the 2019 Participant Satisfaction Survey and the 2019 Family Satisfaction Survey. Both surveys echoed each other under the following subject headings:

- About where you live
- About your relationships
- About your weekends and spare time
- About your choices
- About the day program you attend
- About the staff who come to your house

All information has also been collected directly from participants in their own words without proxy responses, using multiple communication tools to aid in the collection of responses where needed to increase the accessibility of the survey.

Through the results collected, this study has shown that for the most part, the participants who receive services through the organisation are satisfied with the level of care they receive, the choices they have and where they live. When collating the results, the total data results were filtered and analysed in the separate categories of those people who live in group home accommodation and those who live in either Mercy Connect owed properties or private rentals who receive 'drop in' support services through Mercy Connect. While the overall picture of satisfaction was the same for each group and there was a high level of satisfaction with regards to accommodation and choices in their life, there were some slight variances in the levels of satisfaction with people who live on their own with drop in support. This group reported having a greater level of satisfaction around where they lived and with the degree of choice they have in multiple facets of their lives. Several themes came to light through the interviews conducted, with the most consistent being that people who have an intellectual disability want to live a similar existence with access to the same rights and opportunities as people who live without a disability. Simple tasks such as mowing their own lawn, going out to dinner with or spending time with friends in a social capacity, going on a holiday, owning a pet, living in their own house, a swimming pool and being better supported to reach their goals were the most consistently indicated improvements that could be made to the lives of the people supported by Mercy Connect in their own opinion.

The 2019 Participant Satisfaction Survey was run parallel to a second survey conducted, asking similar questions as to the level of satisfaction the parents and loved ones of our participants had with the services provided by Mercy Connect. This was conducted in a similar manner through an online data collection service which was made available through an email link sent electronically as well as being sent out through the mail, which helped to create a holistic view of our service provision and the life their family members live. While this survey presented insights into the organisations ability to service their family member, the results have not been intensely analysed or discussed in-depth throughout this report due to our intended focus of the participant, but have been used to draw some conclusions about how our participants feel about their life. The complete results of this survey can be found in the Appendix section and adds to the value of a total view of service provision; however it was felt that this information may minimise the firsthand lived experience data that was collected from the participants who are the recipients of the services we were evaluating.

This study further highlights the need and opportunity for future investigation and supplementary studies to be conducted in this area in a similar manner, from the view of the participants we serve. This study also presents the possibility to look further into the level of choice participants who live in group homes have over the type and suitability of the accommodation they live in, and how they would like this to be in the future. While this has been explored though different subjects outlined in this survey, an in-depth longitudinal study on how people with an intellectual disability would like their accommodation and personal support needs met would allow a truly person centered approach to housing and accommodation planning in the future. Studies such as these in the future would further help to align the organisation with its values of respect, teamwork and innovation, continually developing strategies to allow the participants that we service have a voice and continued choice and control over their lives.

Background

The Organisation

Mercy Connect, sponsored by the institute of the Sisters of Mercy, is a non-for-profit Catholic organisation providing a range of services to support adults, children and older people with a disability to live independently and be actively involved in their community. Mercy Connect delivers programs and accommodation services registered under the NDIS which are aimed at supporting people with disability to build skills and capacity to ensure they can participate in leading a meaningful life. Differing levels of accommodation support, from fully staffed supported independent living group homes, to drop in support servicing a wide range of people with varying degrees of ability. These accommodation options and the provision of support staff allow opportunity for participants to increase their independence, develop life skills and maintain autonomy in their lives. Through the implementation of day program activities conducted on 3 different campus' as well as in the community at large, Mercy Connect aims to provide facilitated learning and employment opportunities for people with a disability. Day program activities are developed to provide constructive learning opportunities as well as pre-employment skills workshops throughout the day. Program set up as well as supported living structures incorporate a person-centered practice model which Mercy Connect strives to achieve in all aspects of its service provision. It has an individualised approach to support services drawing on the strengths, needs and goals of the person with a disability.

Service Provision

Mercy Connect offer a range of services including supported independent living accommodation, drop-in accommodation support, community access, positive behavior support, NDIS support coordination and day program activities. Mercy Connect aims to promote independence and choice and facilitates increased access to the community as well as skill development to help people with a disability maintain independence in all aspects of their daily life. Mercy Connect aims to provide all their services within their values framework of compassion, hospitality, respect, innovation, teamwork and accountability. This project will look at the services provided by Mercy Connect to to determine the level of satisfaction of participant and families in relation to the supports we provide.

Aims and Significance

Customer satisfaction in the disability sector is a powerful predictor of a person's lifestyle satisfaction and quality of life status. For Mercy Connect, a customer satisfaction survey provides the opportunity to gather information from its customer base regarding their satisfaction with the services provided to them. The aim of this study is to allow the opportunity for every participant and their family members who receive services through Mercy Connect to have their say on how they experience services are being delivered by the organisation.

This Study is designed to service all participants regardless of their ability or communication levels to reflect their strengths and allow them a voice in order to direct their service provision. Additionally, this study seeks to build an evidence base about the support services Mercy Connect provides through the collection of data using the framework outlined below. This evidence base will help to inform the design and development of internal policy and the future direction of services provided by the organisation. Data for this project has be collected in both a qualitative and quantitative form from both participants and their families using self-reporting and assisted reporting methods with the inclusion of communication tools where needed to obtain a holistic view of the organisation's achievements and areas of improvement, allowing a platform for discourse on how to better service our clients, help to influence service provision and adapt current methods to suit the needs of individuals and the organisation as a whole.

Evaluation Framework/Research Approach

The evaluation framework for this project is adapted from the Supported Accommodation Evaluation Framework (SAEF) developed by the Social Policy Research Centre (SPRC) (Fisher, 2014), and Schalock (2002) participant outcomes and indicators of international measures of quality of life (QOL).

The SAEF framework has been developed and will be adapted in order to aid researchers to capture information relating to lifestyle satisfaction, in context of successful outcomes for individuals; evaluate the implementation of higher and lower intensity services and the use of mainstream services provided at Mercy Connect; capture information on how well implemented processes and services are working and their efficiency and sustainability for the future; understand different qualitative experiences of people engaged in service provision from Mercy Connect across

key (QOL) domains; inform agency and service provider policy and governance, planning and service delivery processes.

The field of intellectual disability is strongly influenced by the QOL paradigm, from a research, a practice-based and a policy-orientated perspective. This QOL framework supports the equality of persons which is reflected in concepts such as self-determination, emancipation, inclusion and empowerment (Morisse, Vandemaele, Claes, claes & Vandemaele, 2013). The current measure of QOL can be characterised by its multidimensional nature involving core domains and indicators; the use of methodological pluralism that includes the use of subjective and objective measures; the incorporation of a systems perspective that captures the multiple environments impacting people at the micro-, meso-, and macro-systems level; and increasing the involvement of persons with an intellectual disability in the design and implementation processes. The QOL framework consists of seven domains relating to 5 participant outcomes that will guide the formation and analysis of data throughout this project. These include:

Live with increased independence - Self-determination & Personal development. Live the way you want to - Rights & Autonomy Live in the home of your choosing – Material wellbeing Social inclusion and participation in the community – Relationships Healthy and fulfilling lifestyles – Physical and emotional wellbeing

This evaluation framework allows the researcher to analyse quantitative and qualitative data at more than one point in time in order to compare change over the course of time across a number of key outcomes and indicators consistent with international measures of QOL, including a person's independence, their level of choice and control, physical and emotional wellbeing, satisfaction with social relationships, social inclusion, community participation and material standard of living.

Research Plan

Methodology

This study has been conducted as a mixed method evaluation design which includes a combination of qualitative and quantitative data collection methods to assess the characteristics of service provision, and measure these against the quality of life outcomes. The format of this study will allow for longitudinal research designs to be carried out in the future to update and reassess the findings of this study. The research design has taken into account the individual needs, capabilities and barriers to participation by ensuring that questions and methods of collection are built on participants' strengths and capabilities. This includes the use of plain English; the use of visual aid cues such as a Talking Mats, specifically designed for participation in this survey, an emotion selector which was a simple low tech communication tool consisting of an A3 laminated card which displayed the answers available to be given in picture form to the majority of the survey questions, additional picture card prompts; and the inclusion of a trusted support person during any interviews with participants who may require communication or emotional support.

The inclusion of data collection from family members on their levels of satisfaction surrounding their loved one engaged with Mercy Connect services also allowed a further insight into the overall satisfaction of service users and the impact of the services provided. In many cases of traditional satisfaction surveys conducted with people who have an intellectual disability, families have acted as proxy respondents for participants who may not have the cognitive abilities to participate in formal surveys. This was decided against in this instance as the participant's voice and opinions, in their own words around their current living arrangements and daily lives was at the forefront of influencing practice and the ethos of this project.

Methods of Data Collection

Data for this project was collected in the form of 2 parallel surveys for participants and families, however, the main focus of this report is around the answers provided by the participants of Mercy Connect in their words. The Participant Survey consisted of a 34 question survey, comprised of 4 setting questions about the individual; 20 'How do you feel' questions relating to how the person felt about a certain subject including, about where you live, about your

relationships, about your choices, about the day program you attend and about the staff who come to your home; 2 'would you like' questions referencing if the person would like more, less or the same amount of contact with family, or people to live with; and 7 open-ended questions about how Mercy Connect could improve in that particular area. The family survey echoed the participant survey, however they were asked for a satisfactory level from "very satisfied" to "very dissatisfied" to be given for 22 questions under the same subject headings; the 4 same setting questions; 1 question to obtain how often their family member is attending organisational day program activities; 1 question with a scale of "very confident" to "not confident at all" about the complaints, compliments and feedback procedures of the organisation; 1 "yes"/"no" question regarding the family members likelihood of recommending the services provided by Mercy Connect to others looking for similar service provision; and 7 open-ended comment style questions requesting further information on the ability to improve or give feedback on the particular subject.

For the participant survey, data was collected through face-to-face interviews with participants either by using a paper or electronic copy of the survey, and was sent out both electronically and in paper copy to families with a return envelope depending on their method of information delivery usually received by the organisation. Communication aids were made available to all participants who engaged in the survey which took the form of a Talking Mat and emotion selector card as outlined below.

Communication Aids – Talking Mats

Talking Mats is a simple and practical pictorial approach to communication developed by Joan Murphy and Lois Muir at the University of Stirling (Murphy, 1998). It is a visual communication device that has proved to be a powerful, low tech communication framework which allows people with a disability to communicate their views. It also gives the opportunity for people with and without communication difficulties to think about issues discussed with them and provide them with a way to effectively express their opinions (Bornaman and Murphy, 2006). Whilst, Talking Mats was originally developed for adults with cerebral palsy using high tech communication aids, it has since been further developed and employed in use for a variety of people including both children and adults experiencing a varying range of communication difficulties. Having communication difficulties can mean having one or a number of the following challenges:

- Difficulty understanding the spoken and/or written word and/or other non-verbal communication;
- Difficulty expressing one's self through speech and/or writing or other non-verbal communication;
- Difficulty with language functioning affecting the person's ability to express all they want to get over in a meaningful, appropriate and/or socially acceptable way, or;
- Difficulty interacting with others in socially accepted ways.

Talking Mats and other communication aids address the issues associated with such issues. The traditional functional designs of the aids consists of three sets of picture symbols offered to the individual by attaching the pictures to textured mats, or in the case of this survey a laminated A3 sheet.

The communication aids developed for the 2019 Mercy Connect Participant Satisfaction survey included a single page emotion selector which represented each of the possible answers that could be given through visual selection and a Talking Mat, which echoed the original framework of the Murphy and Muir Talking Mats, but was adapted with the specific subjects and questions made into cards that could be placed on the mat to indicate how the participant was feeling about each question. These tools were both low-tech manual communication aids that could be utilised in a home or day program setting with the ease of the emotion selector being portable so that interviews could be conducted either sitting at a table or in an environment that was most comfortable for that participant, eg. in the garden. The ability to have multiple tools that were portable allowed the person who was using the tool to collect data in a flexible manner and adapt their interview method where needed, which proved useful when interviewing people who may need to or wish to move around, stand or take short breaks in between questions. Consumer testing was done with a number of participants to ensure that these aids were as useful and adaptable as possible. By selecting multiple participants with varying levels of ability and communication difficulties, testing ensured that any issues or could be addressed and changed before they were given to team leaders and training around their use commenced.

Sampling

The Mercy Connect Participant Satisfaction Survey was made available to all participants engaged with services at Mercy Connect and their families. These were adapted when needed to reflect the strengths of the person responding to the survey and their preferred communication style. Surveys were made available through face-to-face interviews and through the online survey tool Survey Monkey via an internet link for participants, and sent out via email and hard copies in the mail for family members. One over the phone interview was conducted for a family member who expressed difficulty reading the questions. 50 participant surveys and 23 family member surveys were collected and entered into the data collection base. Of the participant surveys, 31 male and 19 female participants with an age range from 18 – 65+ years were interviewed. 6 participants identified themselves as of Aboriginal or Torres Strait Islander origin with living arrangements of 35 in Mercy Connect group home accommodation, 10 in a Mercy Connect unit with 'drop-in' support, 3 in private rentals with Mercy Connect 'drop-in' support and 1 participant who owned their own home but received 'drop-in' support from Mercy Connect. Interviews were conducted at the convenience of the participant, in a setting of their choosing. These were conducted by Mercy Connect staff who had received training on interview style and with the communication tools provided.

Participant Considerations

This study has been designed to take into account the individual needs, capabilities, capacities and barriers to participation by ensuring questions, modes of delivery, response tools and methods are built on participants' strengths. The use of a survey through the online platform Survey Monkey allowed the easy distribution of material to each team leader and collection point for analysis. This was accompanied by resources of visual aids including emojis and photographs of faces to allow participants visual representation of emotional responses to assist in the sharing of information and facilitate effective communication when needed.

Allowances needed to be made for participants who had impaired cognitive abilities which may have restricted their ability to participate in formal surveys or interviews. As this study has not included the collection of proxy response data, not all participants were able to partake in its completion due to restrictions in cognitive ability and communication capabilities regardless of the attempts to create accessibility were implemented. The survey construct took into consideration that many Mercy connect participant's required tangible resources to help understand the concepts presented; had issues with reading and communication on varying levels; and are cognitively impaired to some degree. This meant that surveys were available in multiple formats such as by computer, or on paper, which was transferred to computer by their support person, and included plain English phrasing as per the Scope Easy English style guide (2019). The creation and implementation of communication tools were employed including a Talking Mat with specifically designed subject, question and location cards for this survey, and an emotion selector which relayed the possible responses available for the survey in the form of human and abstract (emoji) pictures. There was also the implementation of a separate card selector tool which contained laminated pictures of common answers being obtained through the survey which was used for the question 'If you could live in your dream home, what would be important to you?'. The abstract concept of a dream home, and the complex nature of the question containing two sections, while important, presented as difficult to answer for some people with lower cognitive capabilities and communication difficulties. This aid allowed a visual representation of ideas for people to select, in order to represent their ideal living conditions. This aid was used in particular to help 3 young men with communication deficits to select and answer what was important to them in their housing arrangements. The picture included items such as a pet and a pool, but also living arrangements such as living on my own, living in a city and living on a farm.

Limitations

Limitations and barriers to participation in research for people with intellectual and cognitive disabilities include, cognitive issues related to understanding abstract concepts, limited attention span; and communication issues related to limited vocabulary, unintelligibility, and fatigue. The format and presentation of questions asked to people with intellectual disabilities and the information that is attempting to be obtained can also present itself as a barrier to the meaningful participation within the study (Kroll, 2014). In this study, these barriers to inclusion of all participants has become immediately evident. Through the use of assisted-response data collection, the creation of a survey mirroring that of the participant survey for parents to respond to, and working within a strengths-based framework, the 2019 Participant Satisfaction Survey was produced with these barriers in mind, and adapted to suit the strengths of the individual wishing to participate in the study. The inclusion of communication aids as outlined above also allowed further inclusion and participation, allowing differing and alternate forms of communication to be embraced.

The participant survey was created with the intention for most, if not all participants to complete through assisted responses with the help of a staff member, family member or caregiver.

This method of data collection allowed participants to use the person assisting them for support and clarification if needed. The assistant was also there to help with technology, reading and providing appropriate response tools such as visual aids when needed to suit the communication style of the individual. This method of response, although labour intensive, was considered favorable over a proxy response as it relied on direct answers from the respondent rather than assumptions made by the proxy.

Proxy responses were not sought after for this survey. All information was obtain through the interviews conducted by Mercy Connect staff and in the participants' own words. In previous studies conducted throughout the industry, self-responding has been considered ideal but not often performed, sighting the nature of intellectual disability and the individual's impairment acting as an insurmountable barrier to self-reporting. For some people with disability, particularly those with severe to profound intellectual disability and those with informal levels of communication, the literature shows that the dominant strategy to include this group is that of a proxy report (Kroll, 2014; Wilson et al., 2013). There are differing perspectives as to whether the use of proxies is deemed better than not obtaining any information at all, as proxies may have different perspectives on the value of the research, as well as the value placed on the underlying concepts being asked compared to the person with a disability and may act as a gatekeeper. Also, a proxy may provide information or skew responses to information based on their own experience rather than the experiences of the person with a disability. In some cases, proxy responses have been the only form of data collection for some participants, it is noted by disability advocates that researches should always assume that the respondent can answer for themselves, even if the assistance of special technology or a translator is required, and that most people with a disability do not want others answering for them (Parsons et al. 2001). For this reason proxy answers were not used throughout this study.

Results and Findings

Results

The 2019 Mercy Connect Participant Survey involved the collection of data returned by 50 participants with the assistance of Mercy Connect staff. The below information is separated into the 6 sections of the survey:

- About where you live
- About your relationships
- About your weekends and spare time
- About your choices
- About the day program you attend
- About the staff who come to your house

Each section consisted of questions relating to how the persons felt about a certain topic and an overall open ended question where the participant was able to elaborate on their feelings, add additional information to the topic surrounding their feelings on particular subjects or provide feedback on the topic as a whole. These open ended questions are presented below in a completely raw data form, in the words direct from the participants who were interviewed. These have been included in this manner to capture the direct words and voices of the participants who completed the survey. The information below are the results of the total data collected for each question asked, additional filtered information which has been analysed in the discussion section below and can be found in the appendix shows the breakdown of answers for:

- Participants who live in a Mercy Connect group home.
- Participants who are not living in a group home, but receive drop-in support.

By applying a filter and separating each section into focus groups, an overall picture of individuals in variable accommodation settings is able to be seen and analysed.

About where you live



Question: Overall how do you feel about where you live?

ANSWER CHOICES	RESPONSES	
Great	48.94%	23
ок	23.40%	11
Bad	23.40%	11
No answer	4.26%	2
TOTAL		47



Question: How do you feel about the location of your house?

ANSWER CHOICES	RESPONSES	
Great	50.00%	22
ОК	40.91%	18
Bad	6.82%	3
No answer	2.27%	1
TOTAL		44

Question: How safe do you feel in your home?



ANSWER CHOICES	RESPONSES	
Great	57.45%	27
ок	25.53%	12
Bad	12.77%	6
No answer	4.26%	2
TOTAL		47



Question: How do you feel about the people you live with?

ANSWER CHOICES	RESPONSES	
Great	34.04%	16
ок	36.17%	17
Bad	8.51%	4
No answer	21.28%	10
TOTAL		47



Question: How do you feel about the number of people you live with?

ANSWER CHOICES	RESPONSES	
Great	33.33%	15
ок	28.89%	13
Bad	13.33%	6
No answer	24.44%	11
TOTAL		45

Question: Would you like to live with:



ANSWER CHOICES	RESPONSES	
More people	13.04%	6
Less people	26.09%	12
The same amount	41.30%	19
No answer	19.57%	9
TOTAL		46



Question: How do you feel about the meals you eat at your home?

ANSWER CHOICES	RESPONSES	
Great	67.39%	31
ок	19.57%	9
Bad	6.52%	3
No answer	6.52%	3
TOTAL		46



Question: How do you feel about the privacy you have in your home?

ANSWER CHOICES	RESPONSES	
Great	48.94%	23
ок	29.79%	14
Bad	6.38%	3
No answer	14.89%	7
TOTAL		47

Question: If you could live in your dream home, what would be important to you?

La	aptop or ipad
A	garden
Fe	eeling safe
Li	ve with Daniel quinn in 2021
۱v	vant to live near the shops
Ha	ave my own room and space. I want a pet Live with my mum in my own house.
S	ome girlfriends in my house. I want to live in Wattle House
Ne	etflix Air conditioning and heating Get on well with staff and residents.
A	dam to fish in
۱v	vould like a dog.
Sa	afety
24	4 Hour support to help me
	ice house with a pool, spa and a sauna. Nice bed, a water bed. Veggie Garden. Internet. arm House.
Bi	gger shed with air conditioning and more stuff.
cit	pet, a dog that I could take for a walk. A big backyard with a shed in it. My own home in th ty. I would clean my own home if I had one and invite my friends over. I would like support go on a holiday, do my own shopping and catch the train.
A	pool a bike A big backyard Live with less people
Sa	afety continuous
т	be safe, have fun and have my music playing.
N	ot to much clutter
A	room to do my craft in.
	vould like to live in a 4 bedroom house. I would like to have a study, a store room, visitors ind for me to be able to sleep in.
	vould like to live in my own home. I want to have a pet (Cat) and a pool. A quiet room to lax in. I want to live in a unit in the city. I also want support to go on a holiday.
Bi	gger house. swimming pool. Bigger yard with shady BBQ area.
sv	vimming pool and a spa
То	have a home with a small yard that I could mow myself. Have a pool and a tennis court.
	vant as swimming pool out the back of my house and a drinks machine with soft drinks. A It house with no steps.
Li	ving near my family
	ed, kitchen, lounge, bathroom, garage/workshop/ easy access to the house, lots of privacy ts of space and access for a wheelchair.
lv	vant a farm, with a cat and dog.
A	dream come true
lv	vould like to have animals like the farm at coolamon
ij	ust had my house renovated and I love it. I especially love my new bathroom.
Be	etter furniture, but I love where I live. I live in my dream home.
۱v	vould have a pool.
Bi	gger house, more space to have an animal that I can take care of, take for a walk or feed
th	em. A house closer to town or right out of town. Anywhere but where I live now.
	ew curtains and more outings to the markets and coffee. Really loves where she lives, ready living in the perfect home for her.

Question: How can Mercy Connect improve where you live?

More Devon
Garden program
Choice of program
Live on my own with staff (Shyla) in 2020
I want my own place to live on my won with support staff in my own unit.
Move to a house with less people A house that is quieter
Its to noisy in my house. I want more staff
A dam or river
I don't want my morning staff.
Get a bigger house. Want to live on a farm with chickens and horses. 70 chickens. Veggie Garden Acreage (about 90 acres).
No Grant Jones
A shade cloth over the swing area. (Narrabri)
Listen to me more. I would like easier access to the bathtub.
I would love a bath.
Its good here.
Can't think of anything
I want support to go on a holiday.
more storage/shelving/cupboards space. built in pantry for food and a bath.
Find me a unit with a small yard.
I want a flat house. I want a new house. I want to change where I live because I don't like where I live. I want a flat house with no steps.
Renovations on my house
Other participants being noisy.
The back step of my house needs to be fixed. It is dangerous.
I love where I live.
Wants to live in Lavi, Albury or right out of town. My house now is like a jail, I don't feel safe here and things have been going missing. I need a better door and security.

Already likes living in her home.

About your relationships



Question: How do you feel about how much contact you have with your family?

ANSWER CHOICES	RESPONSES	
Great	50.00%	23
ок	26.09%	12
Bad	13.04%	6
No answer	10.87%	5
TOTAL		46



Question: Would you like:

ANSWER CHOICES	RESPONSES	
More contact with your family	42.22%	19
Less contact with your family	0.00%	0
The same amount of contact with family	37.78%	17
No answer	20.00%	9
TOTAL		45

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Question: How do you feel about how much contact you have with your friends?

ANSWER CHOICES	RESPONSES	
Great	34.78%	16
ок	39.13%	18
Bad	8.70%	4
No answer	17.39%	8
TOTAL		46

Question: How do you feel about sharing more of your experiences with your family?



ANSWER CHOICES	RESPONSES	
Great	42.22%	19
ОК	31.11%	14
Bad	4.44%	2
No answer	22.22%	10
TOTAL		45

Question: How can Mercy Connect improve the contact you have with your friends and family?

More support to see friends, to go out to dinner and coffee. Don't have much staff support so can'y get out to see friends.
Play Mario party 4 with friends Hang out with friends having pizza
Go out to dinner with friends
Going to see my friends for dinner. Visiting my friends house I want to go get some girlfriends and another house
To see real dad and brothers and sisters
Visit them more often.
I am in contact with my family sometimes.
I want more support to see my family and have day visits from them or me travel to them. I want to see them more but it is hard with my disability.
I want more contact with my family but it is getting better.
More trips to see mum, glen and the kids.
I can call my mum and dad whenever I like. I don't need help.
send more photos of what I do.
I would like phone access. Assistance with letter writing and to use Skype.
I have lots of contact with my family.
I have a lot of contact with my family.
Sometimes I would like to go and see my brother, my mother and my aunties.
No answer
More visits with family per year.
No way, I am happy.
I want to see my parents and my sister more. I want to connect more with my friends kevin, Bev, mate, and Susan. I want to meet my parents in my home town. I want to go to the swimming pool and meet my friends more.
More communication with myself and staff
Help with access to family and friends - phone calls, emails, visits.
I would like to see my cousins. Visits to Canberra. I would like help to go on a date with other another participant.
I would like more outings organised with my friends.
I would like help to see my family. I would like them to come and visit me.
Lucent to be supported to second enous time with family. Lales want to share more with

I want to be supported to spend more time with family. I also want to share more with behaviour about my personal things and with my doctor.

About your weekends and spare time



Question: How do you feel about the activities you do in your spare time?

ANSWER CHOICES	RESPONSES	
Great	44.68%	21
ок	38.30%	18
Bad	8.51%	4
No answer	8.51%	4
TOTAL		47

Question: How do you feel about the choice in activities you have?



ANSWER CHOICES	RESPONSES	
Great	48.94%	23
ок	29.79%	14
Bad	14.89%	7
No answer	6.38%	3
TOTAL		47

Question: How would you like to spend your spare time?

Go to Big W to buy games.
I want to go down to the shops. I want to go away or on a holiday.
Play with my ipad
Play with my radio
Spend time playing Mario Party number 9 Gold class movies
Smoking more
Go to the shops bowling swimming
I want to watch videos in private and quiet
Fishing
To get out more.
I would like to clean the kitchen on a Sunday.
Play computers, play music and house activities.
Doing more things on weekends with staff
I cant to play pool
I get lots of choice but want to spend more time with people, spend time with my sister and go out for dinner more.
I want to go on holidays
Want Drink
In the shed.
More fishing when the weather is cooler.
Collecting cans Spending time with mates.
I like spending time with my friend Bonny and doing puzzles. I like to listen to music.
With family. Doing what I like. Water activities.
Dancing, singing, cooking, socialisation with staff and other residents.
I would like to do more worthwhile activities. Sensory activities.
Going to bands, shopping, RSL doing my crafts.
I would like to do some pottery, sewing and some more outings that some other people do. Eg Wagga
I would like more choices. I want to go for drives. Take remote control car out. Go swimming.
Go fishing, camping and swimming. Go on road trips. see the V8 supercars. Football games.
Riding my bike to keep fit
I would rather be in a different house. I would like to go swimming, for tree drives and nature walks. I want to go swimming.
Bowling
Reading, listening to music, having a coffee.
I would like to go to the club and see my friends, go out for dinner and spend time with another participant with the help of staff.
Shopping, going to the movies, going for walks and/or drives. Going for coffee with my friend Dawn.
I want some staff on the weekend to help me go out. I cannot do this on my own. I also want to go on a holiday.
I would like to go away for the weekend with my friends but I don't have any staff to help me. I also want to go out on the weekend to the shops.
I do lots of fun activities my family organises for me in my spare time.
Wants more choice about where he can go out for dinner with friends. Wants to spend more time with friends but has a good amount of choice in his life.

Going to the movies and going to the markets.

About your choices



Question: Overall how do you feel about how much choice you have?

ANSWER CHOICES	RESPONSES	
Great	50.00%	23
ок	34.78%	16
Bad	8.70%	4
No answer	6.52%	3
TOTAL		46

Question: In what areas would you like more choice?

Swimming Go to the movies.
Mealtime
Meal time Choice of program
Choice in supermario 64 Mariocart DS
More spare time
Money
All is good
I want to go on a holiday.
Choice about where I go out. The commercial club and algens
Transport. Day services.
Day programs
Have some spare time
I would like to have a massage.
Weekend activities. Going out for dinner.
Weekend and day activities. Staff
I have got everything that I want
I would like more choice. I want drinks (Soft drinks) and choice where I go. (Swimming).
More choice in my menu and not having to do housework.
I want more weekend outings
I would choose to go on a holiday. I don't have anyone to take me though.
Wants more choice to do more trips away to the V8's, footy and sport. I want greater choice about where I live.

Feels as though she has a lot of choice already.

About the day program you attend

Question: Overall how do you feel about the day program activities you attend?



ANSWER CHOICES	RESPONSES	
Great	40.91%	18
ОК	40.91%	18
Bad	2.27%	1
No answer	15.91%	7
TOTAL		44

Question: How do you feel about the staff at your day program?



ANSWER CHOICES	RESPONSES	
Great	50.00%	22
ок	31.82%	14
Bad	2.27%	1
No answer	15.91%	7
TOTAL		44



Question: How do you feel about the setting your day program is run from?

ANSWER CHOICES	RESPONSES	
Great	45.45%	20
ок	22.73%	10
Bad	9.09%	4
No answer	22.73%	10
TOTAL		44

Question: How do you feel about the choice of day program activities that are available?



ANSWER CHOICES	RESPONSES	
Great	36.36%	16
ОК	40.91%	18
Bad	9.09%	4
No answer	13.64%	6
TOTAL		44

Question: How can Mercy Connect improve the day program activities you attend?

More painting. Catch cartoons
I want to go to the op-shops Window shopping
Cooking Program Play the wee I like st Johns too
I feel I don't get a choice.
More cups of tea
Go fishing more
More options for programs.
O'Brian Centre
Richard is good but some of the other workers and participants are sometimes not so good. I like to stay and work on the gardens at Mercy, I don't like having to go out to the morning, but I won't get payed if I don't. I don't get to choose my activities. I want more animals to look after like cows and sheep.
Playing golf
More rest time during program.
I want to do different activities. I have some troubles with some of the other participants so I want to change programs but I can't. I want to collect cans and I want the money I earn to be payed in my hand.
Should set up mercy day program.
I don't like the outside day program I attend
Im not happy with the outside activities I attend.
I go to an outside service sometimes but I want more choice in activities and services.
They are all great.
Mare drives
I don't want to go to rose house due to the other participants.
More ideas for more programs. I want to teach people to do dot art and have an aboriginal culture day. I want to have someone come and talk about aboriginal culture.
I don't understand these questions.
I go to tafe independently
Talk with me and hopefully together we will find a way to make it happen.
I would like to do more craft. I would like to do exercise.
I want more choice, not just doing craft all the time.
The rec room at coolock court is to hot to go into. We can't do our day program there.
Everyone should be pulling their weight in day program work crew. Sometimes people don't.

About the staff who come to your home

Question: How do you feel about the way staff support you to live as independently as possible?



ANSWER CHOICES	RESPONSES	
Great	70.45%	31
ОК	18.18%	8
Bad	4.55%	2
No answer	6.82%	3
TOTAL		44

Question: How do you feel about the way staff support you to make choices relevant to your life?



ANSWER CHOICES	RESPONSES		
Great	58.14%	25	
ОК	30.23%	13	
Bad	9.30%	4	33
No answer	2.33%	1	
TOTAL		43	



Question: Do you feel staff are well trained to support you?

ANSWER CHOICES	RESPONSES	
Great	72.09%	31
ок	20.93%	9
Bad	4.65%	2
No answer	2.33%	1
TOTAL		43

Question: How can Mercy Connect improve how staff support you in your home?

Staff don't listen to me. They should listen to people. They shouldn't swear and play more games. I would like more staff support. Doing a good Job Help me when my hips hurt. My staff help me well now Exercising Mostly the staff support me to make choices I like, some staff want me to do what they like and I want to do what I want to do. They are well trained to help me. They are good More behaviour training to assist me better when I am having a behaviour. To know my triggers Training. Being available I think you are all doing a fantastic Job. Reading my BSP so they know how to better deal with me when im in a bad mood. I could give them a cup of tea every now and then. Help with more cleaning. More help, more time with me. More attached, talking to me and respect me more. * Participant stated staff hurt her, when asked what she means all she says is they hurt her. Support decisions made. The staff are the best they can be. Dawn and my other staff are the best. Staff need to be trained better, I am not happy with a few things with my staff. I want better support and behaviour support to come to my house everyday to help me with the things I am thinking. I want a better house so that my family can come and stay with me.

More outing and support to go out for lunch

Question: Is there anything else you would like to add about your life at Mercy Connect?

I like living at mercy connect but would like more time with staff. I like doing craft activities.

I want Daniel Quin and me to live in Mate St in 2021

Can I have my own unit now? I have been waiting long enough.

I am happy with everything

I really liked the Disco and being with my friends. I like living at mercy but I want to live with less people in a quieter house.

I like Antoinette she is a good worker I want to watch the TV at my friends house. They will need to take my medication with me.

More contact with distant family?

Help staff out in day program do office work like spend time with staff in Mercy Connect.

I would like to have staff and their families to come to visit me on the farm where I can live and have my own animals, a dog (Kelpie), a horse I can rise, cows, sheep and have swings for the kids to play on and I can have a bonfire with my staff and enjoy their company.

Having KFC

NO

I love mercy connect. I feel safe and secure.

I like living here because I can participate in community social events. I am close to shops, I can go to day program, I like living with the other people in my home.

I am happy that I can live in my own home town, so that I can have access to my family on a regular basis.

I like living here because I am an adult living outside my own home. I can make my decisions on my own.

Everything is fine.

More female staff to work with me. More camping trips. Im lonely. Staff not fun. New female house manager.

Everything now is fine.

Im very happy living here at the moment.

I love living here. I have good friends. I want to go away for the weekend but I don't have any help.

I love living here

I want a new Job, there is not enough money of enough skills provided by this one. I want staff to work together with me and the other participants. I also want help to find a girlfriend and a bigger house so my family can come and stay over so that I feel safe and I can have an animal.

Everything is good living at mercy. Very happy where she lives and her life here.

Results in Context

The 2019 Participant Satisfaction Survey has given the participants who receive services through the organisation a voice. This has been the first time that a survey has been conducted completely from the point of view and in the words of the participant. Bigby and Beadle-Brown (2018) explain that previous research does not often address multiple QOL outcomes, but rather focuses on one aspect of a person's life such as accommodation, material wellbeing, emotional wellbeing or social relationships. Most of these studies have relied on informant based objective measures to assess peoples lived experiences arguing that observational measures of engagement in meaningful activities and relationships are good proxy measures for many quality of life domains. This project however has not collected any proxy information or used objective measures of activities to base its data collection or conclusions. This study conducted by Mercy Connect has used the voices and opinions of its participants without proxy's collected directly to draw conclusions relative to their lives. This is however not without its limitations and complexities.

As this was the first time a study like this has been conducted by the organisation, with little research of this nature in the field to guide frameworks, this study should serve as a first step requiring further development, not only into participant lead research, but also regular consumer testing by the organisation. This project sampled the views of 50 of its participants which represented 41.67% of the people who receive services with the organisation. The main reasoning that this was not greater was due to time restraints, the timing of the study over the holiday period and the availability of team leaders to participate in training around the objectives of the study and the communication aids that were used. Additional time to complete further consumer testing on communication tools and the ability to train and upskill staff members around their use as well as collecting advice on any further tools that could be adapted and used for the collection of data could have increased the amount of people who accessed the survey, or who were possibly not offered the opportunity to complete it due to staff theorising that the participants they work with may not have the abilities to understand or communicate their ideas around the topics presented.

The generalised nature of intellectual disability must also be noted. The results of this survey are the thoughts and opinions of the participants receiving services from Mercy Connect on the particular day that they were interviewed. What this study demonstrates is that factors such as accommodation, social relationships, choice and control and staffing interactions shape a person's life; however it does not reveal the changing nature of intellectual disability. While someone may be content or dissatisfied in the situation they are in (for example at day program) at that particular moment, which may influence the answers given, this response may not be a true reflection of the satisfaction of their life, or that facet of their life, as a whole. This is not to discount the feelings and

emotions of the person at that time, but highlights the need for future research, testing and education about the methods and reliability of questioning techniques for participants who have an intellectual disability.

Discussion

The findings of this report highlights the experiences of participants covering a range of subjects relevant to the lives of the people the organisation services. As is the nature of intellectual disability, and with this project being the first attempt at complete control being handed over to the participants of Mercy Connect in regards to the answers they give and the information being presented, some of the answers and themes coming from the survey results and responses could be considered ambiguous at times. However they do provide an inclusive picture of the satisfaction levels currently being experienced by the participants receiving different and varying levels of services.

When considering at these results, references are made to the separate filtered answer sets which have been included in the Appendix. These include the data collected and filtered by those who live in group homes and those who receive 'drop-in' support only. Also included is input collected from the survey sent out to parents; however the insights gained from participants form the majority of this discussion. Several themes were highlighted throughout the collection process and subsequent analysis. The most consistent being that people who have an intellectual disability want to live a similar existence with access to the same rights and opportunities as people who live without a disability. Simple tasks such as mowing their own lawn, going out to dinner with or spending time with friends in a social capacity, going on a holiday, owning a pet, living in their own house, a swimming pool and being better supported to reach their goals were the most consistently indicated improvements that could be made to the lives of the people supported by Mercy Connect, in their own opinion. For Mercy Connect participants' answers such as these were consistent through each of the open-ended questions asked throughout the survey with 37 answers being given to the question "If you could live in your dream home, what would be important to you?", where 8 people indicated that they specifically wanted a pet, 8 wished they had a pool, several requested to live in their own house and many desired to have space for a private garden for activities such as growing vegetables, relaxation, and working in the workshops/sheds. This was echoed in the question "How can Mercy Connect improve where you live", where participants, mainly those who lived in group homes, expressed a desire to live in houses with less people with the support of staff. For this question, when filtered down to participants who live in group homes

only, a theme of these houses being noisy, and a desire to live in their own space was evident. When asked how they felt about the number of people you live with, 31.25% of people living in a group home setting indicated that they felt 'great' about this, and 18.75% of the people interviewed indicated that this was 'bad', while no one indicated a 'bad' response of those interviewed who lived on their own with drop in support. During interviews it was noted that the people who expressed that the houses were noisy, unsuitable, and who were not necessarily happy with their current living arrangements in group homes were those who had higher capacities, either physically or cognitively, who were residing in houses with other participants who may have higher levels of support needs. This could be due to the a balance swing of services towards the needs of individuals who have higher support levels, or an unintentional group orientated or block treatment of the house residence rather than individualised support systems. Clement and Bigby (2010) noted that people with disabilities in group homes can sometimes find themselves not only sharing the same space with their fellow residents, but also sharing the same lives. Compatibility when placing people in supported accommodation is understandably complex when taking into account suitability in regards to support needs, individual personalities and funding arrangements. This study presents the possibility to look further into the level of choice participants who live in group homes have over the type and suitability of the accommodation they live in, and how they would like this to look in the future. While this was explored through the completion of this survey, an in-depth longitudinal study on how people with an intellectual disability would like their accommodation and personal support needs met would allow a truly person centered approach to housing and accommodation planning in the future.

Choice was explored through this study over several different subjects. The overall results from this study indicate that participants are satisfied with the level of choice they have in their lives. When asked the question, "Overall how do you feel about how much choice you have?" only 4 (8.7%) people replied with an answer of 'bad', while, 'great' received a score of 50% or 23 responses in total. When filtered to group home accommodation and outreach participants, 76.92% of people who lived on their own with outreach support indicated that they felt 'great' about the overall amount of choice they had in their lives, while only 37.5% of people who lived in group home supported accommodation indicated that they felt 'great' about their choices with 46.88% giving an answer of 'OK'. These results were similarly replicated in the questions "How do you feel about the choice in activities you have" under the section heading "About your weekends and spare time". 46.67% of people who live in group homes expressing a feeling of 'OK' with their choice in day program activities as opposed to 30.77% of people from outreach accommodation feeling 'OK', and 53.85% feeling 'great' about their choices in that area. Again, a higher percentage of people receiving outreach services

(61.54%) felt 'great' about their choices in activity during their spare time and weekends than those residing in group homes with 42.42% returning an answer of 'great' and 18.18% feeling 'bad' about their choices in weekend activities. These answers, while indicating that overall people are happy or satisfied with the level of choice they have in their lives, are skewed towards people who live in a more independent setting having greater levels, or the appearance of greater levels of choice over their lives. Clement and Bigby (2010) deduce that the reality for some people with moderate to profound intellectual disabilities is that the concept and ability to choose their own lifestyle, where and how they live, how they spend their money or who supports them is unrealistic and at times unsuitable to their needs. Clement and Bigby (2010) outline that by using a high degree of inference, other people may, with effort and reflection, do a reasonable job in deciding solutions to these issues, based on what they think they know about the person. They may for example organize housing and supports in a way that enables a good 'quality of life' according to an objective measure. However 'choice and control' of that person's lifestyle remains in the hands of that person's immediate social network. Schwartz (2003) however in a study of self-appraised lifestyle satisfaction of persons with intellectual disability finds that living in an independent apartment or residence is not a significant predictor of high lifestyle satisfaction but was superior to living in a group home.

Schwartz (2003), however, found that living in semi-independent residential arrangements, those of fewer residents in a single dwelling, reduced satisfaction levels and poses the question of whether this may be due to the differences in staffing presence relating to a sense of personal control. Previous studies indicated that in residences with full-time supervision, the presence of staff may have served as an unintentional barrier to exercising choice freely, by offering an easy alternative to it; whereas residences with only part-time supervision, were obliged to make most of their decisions affecting their lives for themselves. This absence of staff facilitates not only independence of choice but also independence of performance in many other areas, such as participation in community activities. However, when looking at the responses from the participants who completed this survey, those in an outreach residential setting which typically have far lower staffing levels, particularly on the weekend commented on the question "How would you like to spend your spare time?" with answers relating to specifically needing help and support from staff to partake in a particular activity such as visit with friends, go to the shops or away for the weekend, and wishing for greater levels of support, as opposed to simply requests for activities that would be enjoyable. This idea of staff in a group home residential setting making choices for the people they work with as an easy alternative to them making their own choices in life for many different reasons and the satisfaction that may come with this idea is indicated by the responses to the question " How do you feel about the way staff support you to make choices relevant to your life?", where

participants living in a group home setting indicated that they generally felt 'great' about this question with 63.33% returning an answer of 'great' as opposed to people in outreach returning values of 46.15% feeling 'great' and 53.85% feeling 'OK'. This poses the question, do people in group homes have less choice which they are unaware of and therefore happy with the way staff help them to make more simple choices in their lives? As opposed to people living in an outreach setting where people are asked or expected to make more complex decisions about their lives with lower levels of staff supporting them to do so? A follow up study of this using a more qualitative approach could help to gain insight into whether the ideas of choice and control are understood an exercised in different residential settings and what this looks like for people who receive services as well as what they would like this to look like in the future.

As part of this discussion it is important to consider the responses received from the parent survey and any trends that have appeared from this. For the parents of our participants a high level of satisfaction with the housing arrangements of their family members was expressed with the exception of one respondent consistently returning a reply of dissatisfied over numerous domains. For family members the most consistent theme around housing arrangements to arise was knowing that their family members were safe and well cared for, "safety and wellbeing" was mentioned multiple times in qualitative responses rather than the provision of material or objective measures. The knowledge that their family member was being cared for in an appropriate and suitable manner with their needs being met was of utmost importance. The idea that staff would "genuinely care for" their family member and support them in all facets of their life including daily living, emotional support, decision making and the navigation of systems they engage with such as the NDIS and other social services, was the basis for the majority of feedback given throughout the survey. When asked "Would you recommend Mercy Connect to others looking for services provided by us?" 95% of family members responded with 'yes'.

In conclusion, it is apparent that overall the majority of people who receive services from Mercy Connect are happy and satisfied with the level of care they receive and with the lives they live. This was reflected in the question "Is there anything else you would like to add about your life at Mercy Connect?" where many expressions of happiness around lives and love for where they live were given in responses. This project has not followed the same patterns as previous studies into the area of disability and supported accommodation where research has previously relied on informant completed objective measures (for example how often a person took part in an activity in the community), or on some observational method of assessing peoples lived experiences (Bigby & Beadle-Brown, 2018). This study has undertaken the direct attainment of subjective lived experiences of people with an intellectual disability, around their lives, how they are lived, and how

they would like to see service provision changed or adapted in the future in a truly person centered approach to practice.

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Appendix

List of Appendices:

- 2019 Participant Survey Results Total Data
- 2019 Participant Survey Results Group Home Data
- 2019 Participant Survey Results Outreach Data
- 2019 Family Satisfaction Survey Results Data