

Peter Scott Project (P.S. Project)

Final Report

June 2020 – June 2022






P.S.

Connecting with people who
lived in institutions in Victoria

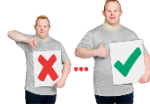
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1. Executive Summary

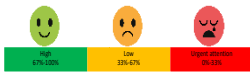
Aim of the P.S. project



The aim of the P.S. project was to check how people who used to live in Victorian Government institutions are going, and to see if there is anything that could be improved.



VALID asked these people and their staff lots of questions, by using a survey and interviewing people online about the things they do and have in their life.



We talked about things in peoples' lives, called the eight 'Good Life Domains', this is how we measure if people are having a good life, each of the answers got a score.



The score told us if people were having a good life or if they needed some help to have a better life.



Good Life Domains are about things like; health, community, learning things, speaking up and relationships.

What People told us



In the surveys and interviews people told us about their life, and most of the answers people told us, scored low against the eight 'Good Life Domains'.

For example, we found out that most people only have:

- paid staff in their lives
- no one was volunteering

or

- had learnt about self-advocacy (speaking up)

So, lots of things need to be done to bring peoples score up.

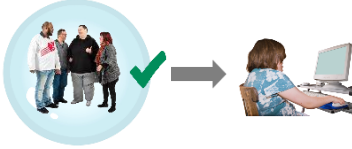




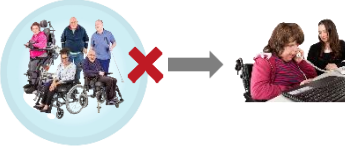
- Most people said that they felt unsafe sometimes and some people said that they felt sad sometimes (Data Set B Q13)



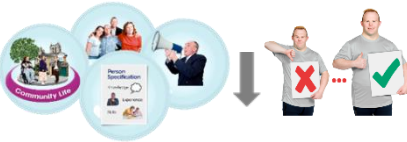
- Half of the people said they did not have friends, other than paid staff or family while a few people said that they had some friends



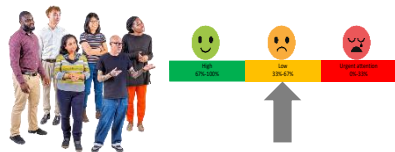
- Only 4 people said that they get to learn new things



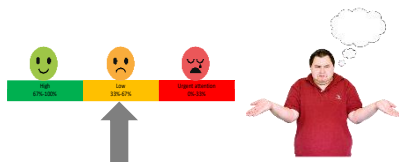
- It was very disappointing to see that none of the 20 residents who were interviewed had an opportunity to work or volunteer



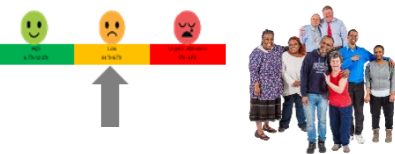
- All of the 20 residents scored low in the 'Good Life Index', meaning that all are in need of supports to improve their quality of life



- All of the 20 key staff who supported the resident in the interview scored them in the 'low' range of 'Good Life' Index



- Most people rated low in opportunities to learn area which could mean that people are not given support to get better at things, including in everyday activities. More needs to be done to help people to improve their skills and confidence



- Over half of the people and their staff said they didn't have many relationships or community connections



- Many people need support with communication however, staff said that people hadn't had their communication plans updated and reassessed regularly (Data Set A Q25 Graph B)



- All of the people we interviewed have different types of disabilities and often had other things that they need support for, like, communication, behaviour and sensory needs

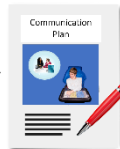
Recommendations for P.S. participants



- A Support Coordinator should be funded in peoples NDIS Plan to help make sure that they get the right paid and unpaid supports



- A Supported Decision-Making agreement (support to make your own decisions) should be funded in peoples NDIS plan to make sure they are having a say about their life



- Each person who needs communication support should have a Complex disability communication assessment every two years to build skills and involvement in choices and decisions, at home, in services, and the community



- A fully independent Person-Centred Plan should be developed (NDIS funded) to make sure that all parts of a persons' life are supported, not just home and day program, but their interests, goals, and connections with their community



- Each person has a plan to build a community circle of support (NDIS funded) or is linked with a volunteer program like, Citizens Advocacy services

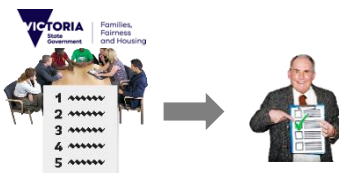


- Each person should have access to individual advocacy when needed. For example, no resident should be moved into aged care without independent support by an advocate or OPA

Given that there is no list of residents, who have formally lived in institutions, VALID would also recommend:



- That a database of all residents from closed Victorian Government institutions be set up using the data collected by the P.S. project



- That DFFH work with other Government bodies and services to check that the residents who used to live in institutions have good supports in place, particularly as people get older and their support networks decrease



- That DFFH sets up a process to make sure that supports for individual residents are maintained following institutions being closed or houses being transferred to non-government service providers

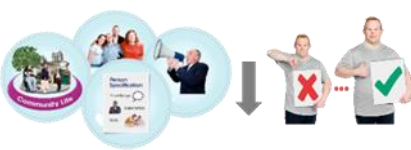
Conclusion



We looked at the survey and interview answers, given by people (who used to live in Victorian Government institutions) and their staff, and we could see that people are not having as good a life as they could.



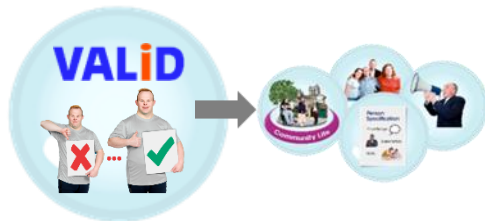
We saw lots of low scores in the 'Good Life Domains' which tells us peoples supports need to be improved.



People and staff told us that they are not getting the support they need, with things like: empowerment (speaking up), learning new things, having relationships or friendships, working, volunteering and being part of the community.



There is still a lot more work to do. VALID believes that everyone needs to work together to make sure people get the things that they need, deserve and should have.

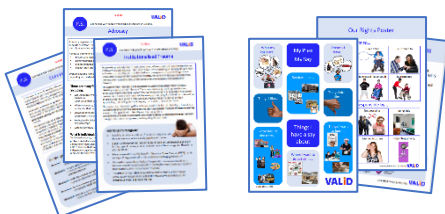


VALID will keep speaking up to make sure people who are part of the P.S. Project, their service providers and DFFH, get people with disability the things they need, deserve and should have.



VALID feels that the NDIS need to be included in the work too, so that people get the right funding for the supports they need, like:

- Support coordination
- Supported Decision-Making agreements
- Person-Centred plans
- Community Circles of Support plans
- Advocacy



In-line with the recommendations VALID has developed a range of tip sheets and easy and plain English posters to support and build on residents' skills. These are free for services to use.

2. Project Overview

2.1 Project Background

VALID has had contact with many people prior to the closure of institutions and transition of services to non-government providers. This has occurred over the last twenty-five years; through programs, such as Self-Advocacy Networks, individual advocacy, Transition to the NDIS project, working with Disability Accommodation Services (DAS) to support the empowerment processes within residential services. This involvement has included establishing resident meetings, 'Speaking Up For Yourself' (SUFY) groups, independent client quality audits and creation of easy English resources and posters.

On the 7 April 2020, Peter James Scott passed away. Peter had lived in an institution for many years and later moved into a group home. However, he had no family or unpaid people in his life to speak up for him. So, when he became unwell and was admitted to hospital and then moved into a nursing home no one was sticking up for his needs in these decisions. Subsequently a support coordinator sought VALID involvement and it was discovered that he had adequate funds to purchase appropriate supports. His death soon after had a significant impact on the VALID community. Peter is one of hundreds of people with intellectual disability who have been separated from their families and largely forgotten in institutions, residential services, and aged care.

The Peter Scott project is affectionately known as the P.S. project in honour of Peter Scott and to take advantage of the function of postscript, and the importance of not forgetting people.

As we move towards new ways of supporting people with disability in Australia, we can't forget the people who were impacted by the 'old ways' of locking people in institutions. It is also evident that many of the support workers and providers have little knowledge of the background of many residents as information has been lost. Knowing that a resident lived in an institution assists services and staff understand their needs better. So, their stories are not yet finished. We have a responsibility to make sure each person is connected to people that care about them and supported to make decisions about how they want their life to be. VALID will work with this group of people to identify the support they need so that they can live as the valued, empowered and entitled members of our community that they all have a right to be.

2.2 Aims

The overall aim of the P.S Project is for VALID to connect with people who lived in institutional care in Victoria, have minimal or no active family support, to take a snapshot of their supports and needs in order to identify gaps and ways to improve their quality of life.

The specific aims of the PS Project include:

- Record information about people that will help the P.S. Project team to map where people are and what supports they have and need
- To connect with as many people as possible who previously lived in Victorian institutions, have no family, and rely solely on paid services for support
- Work with the targeted agencies to share ideas about how people can have better lives and improved community connections
- Identify gaps in supports and make recommendations to DFFH
- Develop a resource package including tip sheets based on discussion topics at Community of Practice (CoP) meetings and other complementary plain English posters

- Highlight the stories of residents and help others to understand impact of institutions

2.3 Objectives of the Project

- Contact targeted agencies to identify which residents previously lived in institutions in Victoria
- Creation of a Customer Relationship Management (CRM) to hold data on people identified as P.S. participants
- Establish and facilitate monthly (CoP) meetings, attended by representatives from the TARGET agencies
- Development of an administration, baseline and review questionnaire that supports the gathering of information about individual P.S. participants and gaps in their support
- Provide residents and supporters with relevant and accessible information outside of their paid support about:
 - Support for decision making
 - Independent advocacy
 - Person-centred approaches to plans
 - Relationships and friendships
- Help secure resources to provide ongoing advocacy for people in such situations (Victorians with disability, particularly those who previously lived in residential institutions)
- Provide a foundation / evidence base for systemic advocacy – provide data to help improve advocacy for people
- make people feel valued – including by someone reaching out and asking how they are going and listening to their story

3. Project Phases

Phase 1: Project Set Up

3.1 Recruitment of project staff

VALID was able to recruit staff with appropriate skills and experience from within its current staff, as they had completed other projects.

3.2 CRM/Database

Investigated options of a database that could be used to record all the participants in the project. Met with Athena software to discuss what support they already provide VALID through its current CRM. We Eventually settled on using 'Penelope' which is a CRM (Client Records Management) database used widely by disability agencies and advocacy services. We chose 'Penelope' as it was already being used in VALID's Individual Advocacy team. It was cost effective for the project as we were able to use in house expertise. 'Penelope' also allows for individual services/programs to be created, such as the P.S. Project, with full functionality of the CRM program as well as individual secure access.

3.3 ORIMA

VALID worked with ORIMA to create a project evaluation framework to assist VALID in collecting the right data throughout the project and enabling robust evaluation at the project conclusion. This required many meetings over the first 16 months to support the collaboration of the data analysis tools and how to use them.

To reduce costs and strengthen security of participants private information VALID purchased the Qualtrics program. This also allowed VALID to use the data captured for our own analysis and evaluation and also to support the security of participants' private information collected through the questionnaires.

3.4 Information to be gathered

It was agreed that we would endeavour through the questionnaires to obtain information to better understand:

- what happened since being moved out of institutions;
- peoples current living arrangements;
- access to decision-making;
- connection to community and supports; and,
- opportunities to maximise their plan to support them to live a 'good life'.

3.5 Information on the Project

In the initial stages project staff were invited to attend the Stakeholders Engagement Group facilitated by DFFH and attended by CEOs of the targeted agencies to give an overview and introduce the project. As part of setting up the project an outline of the project aims, and objectives was put into Easy English in the form of letters to participants and support staff. Letters from DFFH and VALID

were also sent to the five transfer agencies to provide additional information and invite them to nominate a representative to participate in the project community of practice.

3.6 Steering Group establishment

A Steering Group was established comprising of VALID staff and DFFH representatives. This group meets monthly and oversees all aspects of the project. The main aim of the Steering Group was for VALID to report regularly to DFFH about the progress and issues encountered with the project.

- **DFFH**
 - Carley Northcott (current)
 - Nathan Lillee (current)
- **VALID**
 - Kevin Stone (until Sept 2021)
 - Sarah Forbes (until Oct 2021)
 - Liz Collier (until July 2021)
 - Zoe Broadway (current)
 - Heather Forsyth (current)
 - Christine Scott (from June 2021 to current)

4. Questionnaires

Phase 2: Questionnaires

4.1 Aims of Questionnaires

- Identify the basic current living situations of ex-institution residents involved
- Understand what a good life looks like to participants (e.g. lifestyle and goals)
- To identify systemic gaps and needs specific to the ex-institution resident cohort
- Increase focus among providers to how they can support the ex-institution residents to live a good life

4.2 Questionnaire Format rationale

The rationale for the format of the questionnaires was developed through examining the domain indicators from the following sources:

- The NDIS outcomes evaluation framework
- The VALID Theory of Change model
- The VALID8 audit tool

Other evaluation frameworks used and/or considered covered the 'good life' measures for people with intellectual disability, including:

- The Personal Wellbeing Index (PWI), Australian Centre on Quality of Life (Deakin University)
- The Good Group Homes Guide, Centre for Applied Disability Research (Latrobe University)
- The World Health Organisation Quality of Life Disabilities Module
- The draft framework for Improving Outcomes for People with Disability under the National Disability Strategy and the NDIS, Department of Social Services

VALID contracted ORIMA to create a 'concordance' to identify common domains/outcome measures and gaps/differences between these models, focusing on areas of most relevance to the project.

The final framework selected was based on an adapted version of the NDIS framework, and some elements of other models listed above. The final framework includes the **eight domains** outlined below:

- Empowerment
- Daily living
- Relationships
- Home
- Health and Wellbeing
- Lifelong learning
- Work and volunteering
- Social, community and civic participation

A series of specific indicators were mapped against each of the outcome domains to create questionnaires for completion by the person with disability (or someone* who can assist the person/answer on their behalf, where needed) and by a staff member from their disability service.

4.3 Format of Questionnaires

The questionnaire is in two parts: Part 1 (completed by a staff member) **objective/factual questions**; and Part 2 (completed by the person) **ratings of their life**.

The questionnaires were originally designed to be completed in **two stages** for each program participant:

- at commencement of their involvement in the program (**baseline**)
- at conclusion of their involvement in the program (**review**)

NOTE: However, please note that the design of the questionnaires was completed before the COVID outbreak, which then impacted greatly on this project. The issues faced by the project led to the baseline questionnaire being conducted later than expected, which left inadequate time to then do a twelve month **review** questionnaire, therefore the review stage has not yet been completed. Delays are outlined in detail in the **Issues** section on page 17.

4.4 Qualtrics

The Qualtrics application was chosen due to its security specifications/provisions around storage and privacy of information, as well as at the recommendation of ORIMA's research consultants' team, who supported the project to create its evaluation framework and resources that needed to be compatible.

The application also provided user friendly training videos and group sessions to learn about how to use it. The functionality of Qualtrics allowed VALID to create and store the different questionnaires we needed to capture information. We were also able to generate personalised links for each of the questionnaires created which allowed us to monitor who we had and had not sent the questionnaires to.

4.5 Administrative Questionnaire (see Data Set A, page 31)

Overview

The project team received a list of names from DFFH identifying 249 people as possible eligible participants. A Plain English invitation along with a link to the Administration Questionnaire was sent to agencies to support people to complete.

(See Data Set A on page 31)

We received 174 completed questionnaires, 132 of these were from people identified in the list from DFFH and an additional 117 were identified within their services, that is, they were not on the original DFFH list. Some people did not fit in the target group i.e. had significant family involvement, so they didn't complete a questionnaire. In addition there were residents not on our original list but services identified them as ex-institution residents, however, they opted out so were not followed up or added to the database.

All participants had the option to choose not to be part of the project by opting out and not providing their information in the questionnaire. The questionnaire also gave the option to participants to remain anonymous. An opt out form was created in easy English for participants to complete.

(See appendix 4 on page 30)

Demographics

- 174 participants completed a whole questionnaire, and this included: 103 males, 70 females and 1 person who identified as 'other'.
- Most of the participants live with four to five other people with disability
- There were residents from ten of Victoria's closed institutions amongst the respondents
- A majority of the residents were aged over 56 years which was to be expected as minimal new admissions to institutions have occurred since the policy of closing institutions was announced in the 2000's
- Data from the Admin Questionnaire can be found on (see Data Set A page 31)

4.6 Baseline Questionnaires (see Data Set B, page 52, and Data Set C, page 67)

Aims

The aims of the Baseline Questionnaire were to:

- better understand people's living situation
- identify the support people receive to live a good life
- share information with people who might need more support

The Baseline Questionnaire consisted of twenty (20) interviews with selected residents (see Data Set B page 67) , followed by twenty (20) questionnaires (see Data Set C page 67) completed by key staff that supported each of these residents.

Information collected in the Phase 2 Baseline Questionnaires was used by the P.S. team to further document the connections and supports of ex-institution residents without family support. It has also informed our recommendations to DFFH around the gaps in peoples' supports, and ways to continue to support ex-institution residents to have a good life.

Baseline Questionnaire spread

- Service A. – 2 residents and 2 staff questionnaires completed
- Service B. – 6 resident and 6 staff questionnaires completed
- Service C. – 3 residents 3 staff questionnaires completed
- Service D. – 2 residents and 2 staff questionnaires completed
- Service E. – 7 residents and 7 staff questionnaires completed

= 40 total (20 participants and 20 staff)

Sample group selection for interviews

Based on data collected from the administration questionnaires a sample group of 20 residents was selected for the baseline interviews. **VALID selected** the twenty participants to be involved in the baseline questionnaire interviews and their key staff person. The selection criteria **ensured a mix of people** using the following criteria:

- resident has no significant family support/contact

- balancing a spread of residents across the target agencies
- the number of completed administration questionnaires received from each of the target agencies, that is, some agencies had small numbers and others large numbers of respondents
- an even split of gender, that is, ten males and ten females
- While this evaluation will *not* provide a representative assessment of all those who have left large residential institutions, it will provide data and case studies that are likely to be relevant to people from this group and could be considered as a pilot for a future representative questionnaire should the project be continued.

Interviews (see Data Set B, page 52)

The Baseline Questionnaire was conducted during a period where Victoria was in lockdown (people not able to move around the community normally), so interviews had to be arranged and conducted online. This was a challenge for many residents who are not used to having meetings online, but we were very grateful for great support that house staff provided from all five agencies. Staff were very helpful in highlighting the right staff person who was very familiar with the resident and could support them in their interview effectively. Especially as numerous interviews had to be rescheduled due to COVID-19 outbreaks and staff being off with COVID-19 within the residential houses.

Difficulties with Interviews

The other factor that impacted the interviews was we not being able to conduct face-to-face interviews. This made it more difficult to connect with people, both to keep their attention and understand what they were trying to get across, given that many had communication impairments. Staff were very helpful with supporting people to communicate, but the online format did mean that potentially we missed some of the richness of information that face-to-face interactions provide.

We were also disappointed that due to being online we missed the opportunity to interact with the residents and staff and gain more of their stories so we could document these later.

Baseline Questionnaire Data

While the Administration Questionnaire collected some basic information, the Baseline and interviews were able to provide us with a more detailed picture for each individual's current life situation.

Following the staff baseline questionnaires and participant interviews, data was compiled into a series of 'index scores' this provided a summary measure of the person's ratings against each of the eight domains. Each index combines the answers for relevant questions to generate a score from 0 to 100 for each domain area, with higher scores representing more positive ratings.

Index scores were calculated for each person involved in the evaluation. Index scores were calculated based on the person's answers, the staff member's answers and a combination of both. An overall index score was also generated across all eight domains.

As well as providing a single number summary of multiple questionnaire responses for individual participants, the index scores:

- Help to quickly identify people who have more and less positive ratings to allow targeting of support

- Are designed to allow 'drill down' to trace the underlying reasons for lower / higher index scores by examining the component questions that make up the index
- Can be tracked over time to show changes between the baseline and a follow up review questionnaire
- Allow an average rating across all people to identify domains that may require systemic intervention and to highlight where average scores against which individual results can be compared

The Baseline Questionnaires and interviews were designed to collect additional information based on 8 'Good Life' Domains:

1. Empowerment
2. Daily Living
3. Relationships
4. Home
5. Health and Wellbeing
6. Lifelong Learning
7. Work and Volunteering
8. Social, Community and Civic Participation

(see Appendix 2 page 27)

Good Life Index individual participant data examples:

P.S. Project Individual Participant Report

P. S. Project Evaluation
Individual Participant Report

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Overall Good Life Index

	Baseline Assessment	Review Assessment
Overall Good Life Index	39%	39%

Empowerment	0%	0%
Daily Living	62%	62%
Relationships	70%	70%
Home	0%	0%
Health and wellbeing	70%	70%
Lifelong learning	0%	0%
Work and volunteering	100%	100%
Social, community and civic participation	50%	50%

Participant Ratings

	Baseline Assessment	Review Assessment
Date of assessment	26/06/2021	10/12/2021
Participant Good Life Index	39%	39%

Empowerment	0%	0%
Daily Living	62%	62%
Relationships	70%	70%
Home	0%	0%
Health and wellbeing	70%	70%
Lifelong learning	-	-
Work and volunteering	-	-
Social, community and civic participation	50%	50%

Staff Ratings

	First Questionnaire	Second Questionnaire
Date of assessment	26/06/2021	10/12/2021
Staff Good Life Index	47%	50%

Empowerment	0%	0%
Daily Living	62%	62%
Relationships	70%	70%
Home	-	-
Health and wellbeing	43%	67%
Lifelong learning	0%	0%
Work and volunteering	100%	0%
Social, community and civic participation	50%	94%

Date: 20/07/2021

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P.S. Project Individual Participant Report

Detailed Participant Results

Overall rating	Happy	Happy
How happy are you with your life?	Happy	Happy

Empowerment

What do you think of / how do you like: how staff treat you?	Don't know / Can't answer	Don't know / Can't answer
Do you get to choose what you do each day?	No	Don't know / Can't answer
Are you able to choose the things you buy?	No	Sometimes
Do you know who to talk to if you have a problem?	Don't know / Can't answer	Yes
Do you feel able to speak up (for yourself) if there is a problem?	No	Yes

Daily Living

What do you think of / how do you like: the things you get to do each day?	Good / Like	Good / Like
Do staff support you to do things for yourself?	Sometimes	No

Relationships

Do you have friends other than family or paid staff?	Yes	No
What do you think of how often you see your friends?	Good	
Do you have any family who are not currently living with you?	Don't know / Can't answer	Yes
What do you think of how often you see your family?		OK
Do you feel lonely?	Yes	Don't know / Can't answer

Home

What do you think of / how do you like: your home?	Bad / Don't like	Don't know / Can't answer
What do you think of / how do you like: the other people you live with?	Bad / Don't like	Good / Like

Health and wellbeing

Do you feel safe?	Sometimes	No
(In general) / On most days do you feel healthy?	Yes	Yes
Do you ever feel unsafe or scared?	Yes	Sometimes
Can you tell me more about why you (sometimes) feel safe?	Tellus pretium odio vestibulum sed eros natoque morbi fermentum tempus at nulla dui sapien.	
Can you tell me more about why you are (sometimes) not feeling healthy?		
Can you tell me more about why you (sometimes) feel unsafe or scared?	Mi. Ultricies elit accumsan euismod natoque per facilis tempus arcu egestas magna posuere phasellus portitor.	Rutrum bibendum suspendisse nunc fringilla et? Blendi. Maecenas natoque. Veneratis? Lacus! Partitur curabitur.

Date: 20/07/2021

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P.S. Project Individual Participant Report

Detailed Staff Results

Empowerment	0%	0%
Has the person completed a self-advocacy course?	No	Yes
In your opinion, how often would the person speak up about things they are not happy about?	Never	Usually
Has the person ever made a formal complaint about the services they receive?	No	No
To the best of your knowledge, what was the outcome of this complaint? (Please select all that apply)		

Daily Living

Does the person need support with any of the following?	62%	62%
Domestic tasks	Yes	Yes
Personal care (e.g. washing themselves, dressing)	No (They can do it themselves)	No (They can do it themselves)
Problem solving	Yes	Yes
Travel and transport	Yes	Yes
Getting out of the house	Yes	No (They can do it themselves)
Dealing with finances and money	No (They can do it themselves)	Yes
Communicating with others (i.e. expressing themselves)	No (They can do it themselves)	Yes
Receiving and understanding information	No (They can do it themselves)	No (They can do it themselves)
Using technology (i.e. mobile, smart phone, internet)	No (They can do it themselves)	No (They can do it themselves)
Do they receive support with this activity?	No	No
Domestic tasks	No	No
Personal care (e.g. washing themselves, dressing)	Yes	Yes
Problem solving	Yes	Yes
Travel and transport	No	No
Getting out of the house	No	No
Dealing with finances and money	Yes	Yes
Communicating with others (i.e. expressing themselves)	No	No
Receiving and understanding information	No	No
Using technology (i.e. mobile, smart phone, internet)	No	No
To what extent does this support enable them to do these activities independently (as much as they can)?		
Domestic tasks		
Personal care (e.g. washing themselves, dressing)	Not as much as they could be	To a small extent
Problem solving		
Travel and transport		
Getting out of the house		
Dealing with finances and money		Not applicable
Communicating with others (i.e. expressing themselves)		
Receiving and understanding information		

Date: 20/07/2021

Page: 4

Good Life Index Overall Ratings Graph

Colour coding key

High 67%-100%	Low 33%-67%	Urgent attention 0%-33%
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PS Project Good Life Index data

Participant	Overall Good Life index	Participant Good Life index	Staff Good Life index
PSP 1	48%	54%	42%
PSP 2	48%	43%	54%
PSP 3	53%	60%	46%
PSP 4	43%	37%	49%
PSP 5	42%	48%	37%
PSP 6	49%	57%	40%
PSP 7	62%	71%	54%
PSP 8	54%	61%	48%
PSP 9	63%	63%	62%
PSP 10	53%	73%	32%
PSP 11	44%	52%	35%
PSP 12	47%	59%	34%
PSP 13	41%	48%	34%
PSP 14	53%	47%	59%
PSP 15	59%	61%	56%
PSP 16	60%	69%	50%
PSP 17	40%	39%	41%
PSP 18	54%	59%	49%
PSP 19	52%	69%	34%
PSP 20	56%	55%	57%
Average Index	Average Good Life Index 51%	Participant average 56%	Staff average 46%

KEY

Overall Good Life Index – this is a combined rating using both Participant and Staff Good Life Index ratings

Participant Index – is the average rating across all eight of the Good Life Domains

Staff Index – is the average rating across all eight of the Good Life Domains

PSP# – deidentified code given to each of the 20 participants

Participant rating by Domain

Good Life Domains	Average participant rating	Average Staff rating	Average overall domain ratings
Empowerment	68%	23%	45.5%
Daily Living	68%	77%	72.5%
Relationships	43%	12%	48.5%
Home	86%	86%	86%
Health & Wellbeing	58%	84%	71%
Lifelong Learning	38%	48%	43%
Work & Volunteering	3%	0%	1.5%
Social, Community & Civic Participation	78%	35%	56.5%

(Refer to Appendix 2 on page 31. For a list of the Good Life Domain areas)

5. Project Activities

Other project activities were conducted across all phases of the project including the Community of Practice, Steering Group, and resource development

5.1 Community of Practice (CoP)

The Community of Practice (CoP) was established in May 2021 and has met eleven times since. The CoP comprises of representatives from the target agencies, DFFH, STAR advocacy and VALID. The CoP was consulted about topics they would like to see discussed during CoP meetings, that would be relevant to their role in supporting residents.

Aims of CoP

- Meet monthly using Microsoft Teams or Zoom
- Provide information on the project activities and progress
- Support the implementation of the project e.g. identify people within their service who were entitled to be part of the project
- Give advice to the project team
- Come up with ideas to help the project team and other CoP members
- Share opinions and ideas
- Support decisions about the project
- Be honest, open and respectful to other group members

Topics covered at the monthly meetings

Topics discussed and titles of Tip Sheets

- | | |
|---|--|
| 1 | Supported Decision Making |
| 2 | Advocacy |
| 3 | Person Centred Practice |
| 4 | NDIS Review Planning |
| 5 | Institutionalised Trauma |
| - | Disability Support for Older Australians Program (DSOA) - No tip sheet |
| 6 | Community Inclusion |
| 7 | Staying Safe |
| 8 | Complaints |
| 9 | Communication |

Throughout the project we have provided resources to the CoP agencies including:

- presentations from CoP meetings (see list of topics in previous section)
- links to other resources and agencies relevant to the topics

5.2 Resource Package

The resource package was created to capture topics and information discussed at the monthly CoP's meetings. This includes eight tip sheets and fifteen Plain English posters. These will be made available on VALID's website and to the participating agencies.

Tip Sheets created

- Supported Decision Making
- Advocacy
- Person Centred Practice
- NDIS Review Planning
- Institutionalised Trauma
- Community Inclusion
- Staying Safe
- Complaints
- Communication

Posters Created – Plain English versions

Planning

- My Plan My Say

Standards

- National Standards for Disability Services
- NDIS Practice Standards

Speaking up about problems

- Someone you trust
- Speaking up about problems – NDIS QSC
- Staying Safe

Complaints

- How Can an Advocate help?
- Where to find an Advocate
- Speaking up about problems – NDIS QSC
- Who you can complain to?
- Community Visitors
- You have the right to complain

Rights and Responsibilities

- Our Rights poster
- My Home
- Relationships

6. Issues

6.1 Delays affecting the Project

Ethics approval

The development and sending out of the Administration questionnaires was delayed due to the providers questioning the need for ethics approval for the project. It took a significant amount of time to ensure all areas were considered and that participants information was secure and safe.

Issues with cooperation of services

Considerations were raised around consent in the CoP and after we had sent out the initial admin questionnaire it was raised again. This was due to staff not understanding that the residents they were supporting, were entitled to be part of the project. We discussed within the steering group the need for DFFH to write a letter to the CEO's of the 'target' agencies confirming this. A letter was requested from DFFH, supplied and then circulated by DFFH to the CEO's and VALID. We were then able to diffuse this concern with representatives of the CoP and staff within their services by showing them a copy, along with additional correspondence from the project team in Plain English for participants.

Consent issues during questionnaire process

To counteract the concern around residents needing to give consent to participate in the P.S. project we had to do a significant amount of work to support staff and services to recognize the project as an entitlement for the target group. We created a 'Opt-out' option. Due to some staff within the agencies it took a while to establish that the P.S. project is an 'entitlement'.

Request for extensions to complete admin questionnaires

It was requested by the target agencies that a two week extension would be needed to complete the Administration Questionnaires. This was due to unfortunate timing with the transfer questionnaire that all agencies were required to do for the Department of Families Fairness and Housing. One agency required a one-month extension, which further delayed the completion of this stage of the project.

Budget issues

Initially VALID wasn't aware that the funding amount outlined in the letter of offer was GST inclusive. So planned the staffing and other project needs, such as, the utilisation of ORIMA to do analysis. We outlined with ORIMA our specifications and requirements and they verbally agreed to this on numerous occasions. We then found after requesting multiple times a written confirmation, that the price was more than double what was verbally agreed to.

This impacted staff time significantly as project staff had to be trained in using Qualtrics, and then convert Qualtrics data into reports and undertake the relevant analysis. All of which was planned to be conducted by ORIMA.

6.2 COVID-19 Impacts

We do know that COVID-19 impacted the results of the questionnaires especially because the residents were in lockdown when the baseline interviews were conducted. We feel that the fact that residents were not going out as usual and Day Programs were closed, could have influenced and increased the levels of dissatisfaction. So, we are unable to get an accurate picture on issues such as satisfaction with the type and amount of community activities and on satisfaction with the things that residents do during the day.

Some residents also commented about COVID-19 related issues in response to Question 17, “What would make your life better?”, these included:

- “Getting out of lockdown”
- “Getting back to SCOPE day program where there is more to do.”
- “COVID-19 is impacting greatly”

Impacts of COVID-19 on Project Delivery

The project has had significant delays due to COVID-19 lockdowns. We received numerous requests from the targeted agencies to push back the timeline for the Administration questionnaires to be completed. The Baseline questionnaire interview process was impacted on due to staff and residents having positive COVID-19 cases. This impacted on staff being able to support residents to participate.

The other factor that impacted the interviews was that they were able to be conducted face to face. This made it more difficult to connect with people, both to keep their attention and understand what they were trying to get across, given that many had communication impairments. Staff were very helpful with supporting people to communicate, but the online format did mean that potentially we missed some of the richness of information that face-to-face interactions provide.

7. Recommendations

7.1 What the Data Revealed

We have completed the analysis of the data from the baseline interviews and questionnaires, along with looking at the links with the issues and gaps that were noted in the administration questionnaire.

Concerning findings from the baseline questionnaire data include:

- 60% felt unsafe sometimes and 40% said that they felt sad sometimes (Data Set B Q13)
- None, that is, 100% of the residents reported not having a job, but three said in the comments that they wanted other choices during the day (Data Set B Q2)
- While 60% said that they liked the things they did in the community, there were a range of responses indicating residents wanted to be able to do other things, including the desire to go out for a meal, a comment that there isn't much choice of Day Programs and several wanting to go on specific outings
- 100% were unable to tell us or did not know what they thought of how often they got to see their friends
- 30% said they had friends and 50% said they did not have friends other than paid staff or family
- 90% of people in the sample group do not volunteer
- 20% or 4 people reported that they get to learn new things
- 40% said they feel lonely sometimes and one person said 'yes', they felt lonely. In addition 20% did not know or could not answer if they felt lonely
- It was concerning that when asked "if they ever feel unsafe or scared" only 20% of people said "No", and 60% of residents said that they sometimes feel scared or unsafe
- 55% of people said that they sometimes get to choose what they do each day and when asked "are you able to choose the things you do?" 65% said sometimes. Some comments in Question 18 about what would make life better were about things residents wanted to do including:
 - Spending time with animals. "I'd like to have a pet".
 - Joining an art class.
 - Gets' bored at home.
 - Being able to go on holidays - funding is really difficult to organise.
 - Getting out to the pub for a meal or a coke.

Positive responses included:

- It was good 70% of people liked their home
- 60% of people said staff support them to do things for themselves and 45% said that they choose what they do themselves
- 70% or 14 people said they get to learn new things sometimes

7.2 Good Life Index Ratings

Concerning issues related to the Good Life Index ratings:

- All of the 20 residents interviewed had an overall low score in the Good Life Index, meaning all are in need of supports to improve their quality of life
- Overall the 'Good Life Index' was 51% which is well below a good standard across all domains
- All of the 20 key staff (who supported individual residents in the interview) scored them in the 'low' range and the average Good Life Index was 46% when completing the survey about the resident
- Four of the twenty residents interviewed scored in the acceptable range (high) but none scored above 71%. The highest possible score was 100% in the Good Life Index
- The average participant rating in the Lifelong Learning domain was very low (38%) in all areas, meaning that individual capacity building does not appear to be integrated into everyday activities and/or opportunities are not being provided for learning and skill development
- Participants rated their Health and Wellbeing domain at a concerning 58%, however, staff had a much higher perspective and rated Health and Wellbeing at 84%
- While the overall Good Life Index average rating for Daily Living was 68% for participants this was a result of seven 'low' (38%) scores and five 100% scores, which indicates that the majority of people were experiencing less than average Daily Living supports
- In line with the non-existent self-advocacy opportunities noted in the Admin Questionnaire (appendix A. Q29), the Empowerment domain was rated overall at only 45.5%. This was impacted by the very low (23%) staff rating for this domain
- It should be noted that seven residents scored Social, Community and Civic Participation domain at only 50% which is 'low' range and one resident scored 0% in this domain. However, the overall average for the domain was boosted to 78% by the majority of people scoring it 100%
- Consistent with the lack of relationships and community connections reported in the Admin Questionnaire, the Relationships domain rated overall at only 48.5%. Again this was impacted by an extremely low (12%), staff rating for this domain
- It was very disappointing to see that none of the 20 residents are currently working or volunteering, however 2 residents had volunteered in the past
- Contradictory scores were noted between the resident 'high' (78%) rating for the Social, Community and Civic Participation domain, and the staff score that was 'low' (35%)
- It should be noted that we feel that the Index rating has been skewed by COVID impacts as these interviews and questionnaires were conducted during COVID lockdowns, and The interviewers got the impression that people said they were happy because they were being upbeat during COVID

Positive things noted in the Good Life Index ratings:

- It was positive to see that the overall average rating was 'high' (72.5%) in the Daily Living domain, showing both the 20 residents score at 68%, and their key staff score at 77%. However, this average was only attained through five residents scoring this domain at 100%. Note: seven residents rated Daily Living at only 38%
- It was pleasing to see a consistent 'high' score of 86% was noted across the 'Home' domain
- It was consistent with the Admin Questionnaire that a majority of residents were happy with their social and community participation (12 scored it 100%)

Reasons for these recommendations:

At this point in the project all the data is supporting these recommendations:

- Residents have no significant unpaid person supporting them with decisions and NDIS planning (Data Set A Q30)
- The high level of need for support with decision-making (Data Set A Q24)
- As part of VALID's liaison with OPA, both organisations have noted the significant increase in requests for guardianship as agencies are unable to provide the support that is needed for people, as well as the conflict of interest this brings up when they are put in the position of being the residents only significant other
- Skills for many residents were not necessarily being identified and/or improved, such as:
 - Only one person has previously had the opportunity to volunteer but 20% indicated that they wanted to do volunteering (Data Set B Q4)
 - None of the residents had undertaken self-advocacy training e.g., at Day Program (Data Set A Q29)
 - In addition, 40% didn't get support to do things for themselves and 65% reported only being able to buy things for themselves sometimes (Data Set B Q3)
- Low numbers of communication plans and even lower figures regarding updating these plans through communication assessments (Data Set A Q25 Graph B?)
- The high level of complex needs e.g., behaviours of concern, multiple disability (Data Set A Q12 & Q25)
- In Question 18 of the baseline questionnaire residents were asked about what would make their life better. There were many comments about the goals they had that were not realised, the need for advocacy and the need for support to plan things in their life. This supports the recommendations around the need for independent person-centred plans to map out life goals and the supports needed to achieve them. It also substantiates the need for good Support Coordination to implement goals that require funding and assistance for residents to explore other options:
 - "Having someone to advocate on their behalf"
 - "Having a bigger bedroom"
 - "Having more support"
 - "Trauma counselling"
 - "Consistent staff and the time needed for individual support"

- “Advocacy support for decision making”
- “More socialising”
- “Going on outings in general”
- “Go out for coffee at a café”
- “Go on a holiday to France”
- “Planning around aging, moving forward to maintain skills”
- “To be able to age at home with the people he knows and to have enough funding to support this”
- “Holidays after COVID-19”
- “Getting back to 1:1 support, shopping, restaurants, movies, swimming”
- “Being able to live in their current home until the end. Being able to reconnect with family”
- “Maintain cultural history”
- “Have a party”

7.3 Recommendations

After the conclusion of the administration questionnaire, VALID presented the results of the questionnaire to the Community of Practice with some preliminary recommendations.

These recommendations included that all residents (in the PS target group) have:

- Support Coordinator funded in the NDIS Plan to support getting the most from their Plan and connecting both relevant supports and unpaid supports
- Supported Decision Making funding in their NDIS plan, so that a person-centred (not legal) Supported Decision Making Agreement can be developed and connected to their main ‘support plan’ or Person-Centred Plan (PCP)
- Regular complex communication assessments to build capacity and maximize their involvement in choices and decisions in all environments – home, services, and community
- A full independent Person-Centred Plan developed (NDIS funded) for them to provide a broader plan for all aspects of their life, not just home and day program, but their interests, goals in life and connections with community
- That residents without regular family support be linked with volunteer program such as Citizens Advocacy services or NDIS funding is sought to build a community circle of support
- Access to individual advocacy when appropriate due to the lack of unpaid people in their lives to support them with problems, complaints, or transitions. For example, no resident should be moved into aged care without independent scrutiny of the issues by an advocate or OPA

Given the lack of awareness in DFFH, services and NDIS of which residents have previously lived in institutions, VALID also recommends that:

- A database of all residents from closed Victorian institutions be set up using the data collected by the P.S. project

- DFFH liaise with other Government bodies and service providers to keep track of residents who lived in institutions so that proactive supports can be put in place for people as their support networks decrease due to ageing and dwindling family support
- DFFH sets up a process to check that supports for individual residents are maintained as needed and deserved

7.4 Implementation of Recommendations

Given the issues VALID has found and the lack of empowerment and support for decisions we would recommend the following activities be done to implement these recommendations.

A. Stories

While interviewing residents and staff for the project, there were many valuable stories shared but our capacity to document was limited. It would be beneficial for both historic purposes and to provide new staff coming into the sector with documentation of stories of residents who lived in institutions, and/or their support staff, so that their experience while living/working in an institution is not lost forever. There is a high risk of these stories never being told as most of the residents involved are over 56 years of age and many of the original institution staff who continued working with residents when they left the institutions are retiring. These stories would contribute to the overall story of why we closed institutions in Victoria, so they are never opened again.

B. Review Questionnaire

Conduct the Review Questionnaire with the same twenty residents and their key staff who completed the Baseline Questionnaire.

We hope to find that community involvement and unpaid connections have improved since they were surveyed in October 2021, especially given the impacts of COVID-19 where people were in lockdown from both day programs and community. VALID is aware that some residents are still not able to return to Day Programs even in May 2022. Conducting the Review Questionnaire would hopefully provide insight into whether residents are getting back into the community after COVID-19 restrictions, and that existing connections have been strengthened and not lost due to the isolation of restrictions and lockdowns.

C. Training and Information for Staff

Provide training to the staff of the 20 residents surveyed in October 2021. The key focus would be on recognition and support of people who have limited communication and/or who have experienced institutionalized trauma.

In addition, other training/information sessions to be provided to support best practice around areas identified in the original project;

- Person centred approaches, including how to apply for NDIS funding to get a full PCP completed for residents
- Promoting self-advocacy skills within houses
- Supported Decision Making agreements and how to get funding for this
- Circles of Support – building connections in community, including applying for NDIS funding for a facilitator to assist to develop the circle

The five targeted agencies involved in the P.S. Project Community of Practice were keen on further information and training around these areas.

D. Database

In an ideal world, we would like to see the Department (DFFH) set up a database of residents who previously lived in Victorian institutions. However, if this is not possible then effort should be put into ensuring that the NDIS/other funding bodies are aware of and record the fact that the person is from a closed institution and therefore has different needs related to that experience. For example, NDIS could be approached about adding this fact to their electronic client files and/or encourage planners to note this fact in the 'My Profile' section of participants NDIS plans.

This tracking is all the more important as residents' families' support changes or dwindles, i.e. many more people will be in the position that instigated the project in the first place, but no follow-up will occur for them and their history will potentially be lost as we have found for many already.

In addition, given what is happening in the system currently which is beyond DFFH's control, it is especially important for ex-institution residents to be easily identified as their needs are often different to other residents.

Summary

VALID believes that there is great scope to undertake further work based on the data gathered in the P.S. Project. This could be done by addressing issues raised by residents, staff and organisations (Section 7.1 & 7.2) and in implementing the recommendations of the project (refer to Section 7.3 page 26).

8. Conclusion

Overall, the questionnaires and interviews highlight that residents who previously lived in institutions in Victoria and who now have little regular family (or unpaid people) supporting them, are experiencing a poorer quality of life than they should be. There are major gaps in supports, especially in empowerment, learning, relationships, community participation, work and volunteering areas. This when measured in 'life domains' (refer to Good Life Domains ratings – page 12-14) represents the majority of life where supports are inadequate and need to be improved.

VALID is aware that there is still more to do beyond this project to address the project findings, whether by VALID or by another agency. VALID is committed as we have been over the past 33 years, to supporting the P.S. Project participants, their service providers and DFFH to achieve the outcomes that people need, deserve, and are entitled to.

We feel that to do this there needs to be a committed approach by all stakeholders. This would involve an ongoing commitment from the Department (DFFH) to monitor service provision to ensure that services are continuing to deliver at a good level of quality. This includes transport, low rental, ongoing placement in current housing, continence products and appropriate staff training.

To achieve a good quality of life for residents DFFH would need to work with the NDIS to assist them to note residents who lived in institutions and ensure that appropriate supports are both funded and provided, such as the development of supported decision-making agreements, whole of life person-centred plans and community Circles of Support for each resident. This would address many of the gaps that were highlighted by residents and staff during the project.

9. Appendices

Appendix 1 - Acronyms

Acronyms used in this report include:

CoP	Community of Practice
CRM	Client Records Management
DSOA	Disability Support for Older Australians Program
ID	Intellectual Disability
NDIS	National Disability Insurance Scheme
OPA	Office Public Advocate
PCP	Person Centred Plan/Planning
PS	Peter Scott/Post Script (name of project)
QSC	NDIS Quality & Safeguards Commission
SDM	Supported Decision Making
SUFY	Speaking Up For Yourself

Appendix 2 - Good Life Domains

1. Empowerment

- Choice and control in life and supports
- Opportunity to try new things
- Service policies include input from people with disabilities
- Rights and protections
- Self-advocacy skills and confidence

2. Daily living

- Satisfaction with daily activities /routine
- Whether service practices 'active support' – facilitates person to do things themselves wherever possible

3. Relationships

- Spending time with friends, family, others outside their home
- Satisfaction with relationships / level of contact

4. Home

- Suitability of living arrangements
- Satisfaction with living arrangements

5. Health and Wellbeing

- Physical wellbeing and health
- Emotional wellbeing and mental health
- Feeling safe

6. Lifelong learning

- Access to learning and skills development
- Support to achieve full potential

7. Work and volunteering

- Employment – participation and opportunities
- Volunteering - participation and opportunities

8. Social, community and civic participation

- Support to do things / attend events in the community
- Support to do things outside the home

Appendix 3 - Plain English invitation for P.S. participants



Connecting with people who
lived in institutions in Victoria

VALID
M 0439619785
E zoe@valid.org.au



Zoe and Heather from the P.S. team at VALID
got your completed 'Admin questionnaire' - Thank you!
You have helped us complete Phase 1 of the P.S. project.

We are now working on Phase 2.



About Phase 2

The Department of Family Fairness and Housing (DFFH) and VALID
want to know more about your life and the supports you get.

We will be asking you and your support staff some more questions
to understand what your life is like in the following 8 areas:



- Speaking up (Empowerment)
- What you do and the support you need (Daily Living)
- Who are important people in your life (Relationships)
- How you feel about where and who you live with (Home)
- How you feel (Health and Wellbeing)
- Things you like to learn about (Life long learning)
- Making money and giving back (Work and volunteering)
- How you spend your time (Social & Community participation)



We will use what you say to help VALID, DFFH and your Service
understand things, keep things how you like them or make things
better for you and other people in the P.S. project.

Connecting with people who lived in institutions in Victoria

VALID
M 0439619785
E zoe@valid.org.au



Your role in Phase 2

We would like you to answer some more important questions about you and the support you have now. We will send you a copy of the questions so you can be prepared.



(Due to COVID we cannot meet face to face and have a cuppa and cake like we wanted to so, we will have to meet online or over the phone (The meeting will be for 1 hour or less).



The P.S. team will

We will send an email to your support staff to help us organise a time to meet with you so we can write down your answers.

We will meet on the computer (so we can see each other)

or

On the phone.



The final report

A final **confidential** report will be written about what the P.S. team have learnt from all the people who answered the questions.

Confidential means we won't share your name with other organisations.

The report will help VALID and DFFH look at ways to continue to help you and others to have a good life.

Contact P.S. team

If you would like to speak to the P.S. team you can call or email Zoe.

Mob: 0439 619 785 Email: zoe@valid.org.au



Appendix 4 - Plain English Opt-out form for P.S. participants



Connecting with people who
lived in institutions in Victoria.

VALID
Mob: 0439619785
Email: zoe@valid.org.au

P.S. Project Opt Out Form

Important Information

Support staff cannot decide on any person's behalf that they will not be a part of the project. This is a choice that can only be made by the person after they have understood all information about the project.

Dear P.S. project team,

I (insert name) _____ have read and understood the P.S. project plain English letter myself.

I understand that I am entitled to be part of the P.S. project. I am choosing not to be part of the P.S. project.

Please tick box ☐

-----OR-----

My support (insert name) _____ who is my (relationship to this person) _____ read and explained the P.S. project plain English letter to me.

I understand that I am entitled to be part of the P.S. project. I am choosing not to be part of the P.S. project.

Please tick box ☐

Signature _____ Date _____

Witness (Support) _____ Date _____

(Please fill out the form and email back to the P.S. team zoe@valid.org.au)

Data Sets (This data cannot be quoted or used without the permission of VALID)

Data Set A - Administration Questionnaire and Graphs

Who completed this questionnaire?

The questionnaire was designed to be completed with the participant by a staff member at the service that provides supports to the person with disability. Ideally you will work through the questions together with the person.

Key staff contact details - Q 1-7 (Data provided and kept confidential)

Q 1. What is your name?

Q 2. What is the name of your service

Q 3. What type of service(s) does your service provide for the person?

Q 4. How long has the person been receiving services from your organisation?

Q 5. What is your position?

Q 6. How long have you worked closely with the person with intellectual disability (had regular contact, provided direct support)?

Q 7. What are your contact details? (Person filling in the questionnaire)

Email: _____

Work Telephone: _____

Mobile Telephone: _____

Participant/resident demographics – Q 8-11

Q 8. What is the name of the person with intellectual disability?

Q 9 What is the gender of the person?

Q 10. What is the person's date of birth?

Q 11. What is the persons cultural background?

1. An Aboriginal and/or Torres Strait Islander
2. From a culturally or linguistically diverse background
3. Neither of the above

Participant/resident basic diagnosis and communication supports – Q 12-15ii

Q 12. In addition to intellectual disability, what other impairments does this person have?

Q 13. How does this person generally communicate with others?

Q 14. Does the person require any aids or equipment in the home?

Q14i. Outline what supports this person needs

Q 15i. Are these supports provided and do they meet the person's needs?

Q 15ii. Outline what supports are *not* provided and/or why they do not fully meet the person's needs:

Accommodation – Q 16-23

Q16 Where does the person live?

Q17 What is the address of their accommodation?

Q18 How long ago did they enter their current accommodation arrangements?

Q19 How many people do they currently live with?

Q20 What is the name of the service that provides the person's accommodation?

Q21 What is the name of the large institution where they used to live?

Q22 Did they move to their current accommodation with other people from the institution?

Q23 How long ago did they transition from the institution?

Support needs and plans – Q 24-29

Q24 How much support does this person need to make decisions?

Q25 What support plans does the person have?

Q26 How long ago was the person-centered plan last reviewed/updated?

Q27 Was the person with disabilities involved in developing the content of the person-centered plan when it was developed/last reviewed (whichever was most recent)?

Q28 To what extent have the activities and content of the plan changed over the last 3 years?

Q29 Has the person done self-advocacy or empowerment training?

Q29.2 If yes - Please specify?

People involved in the person's life – Q 30

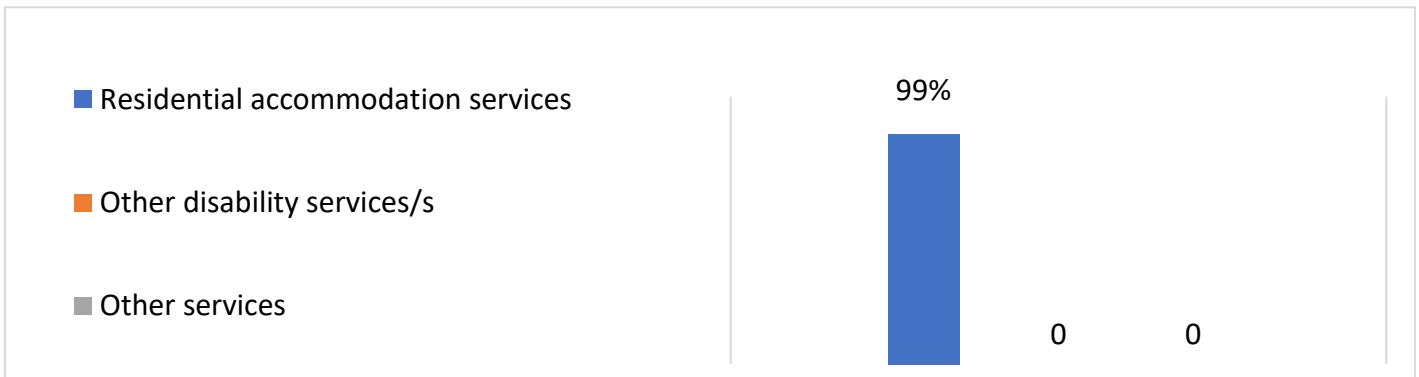
Q30 Which of these people does this person have in their lives?

Key staff contact details - Questions 1-7

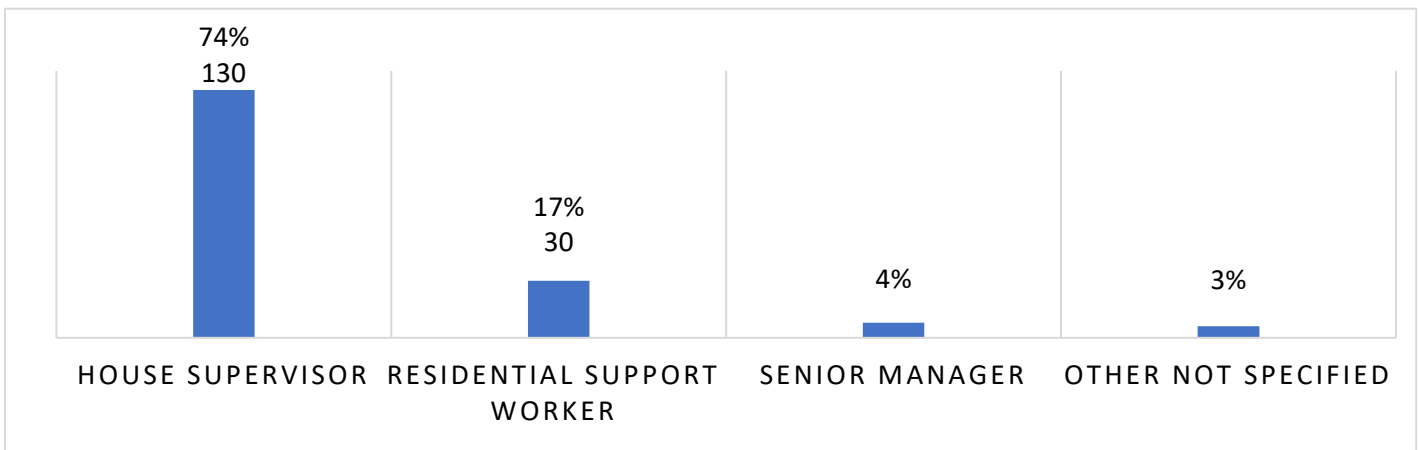
Q1 What is your name? – (Data provided and kept confidential)

Q2 What is the name of your service (Data provided and kept confidential)

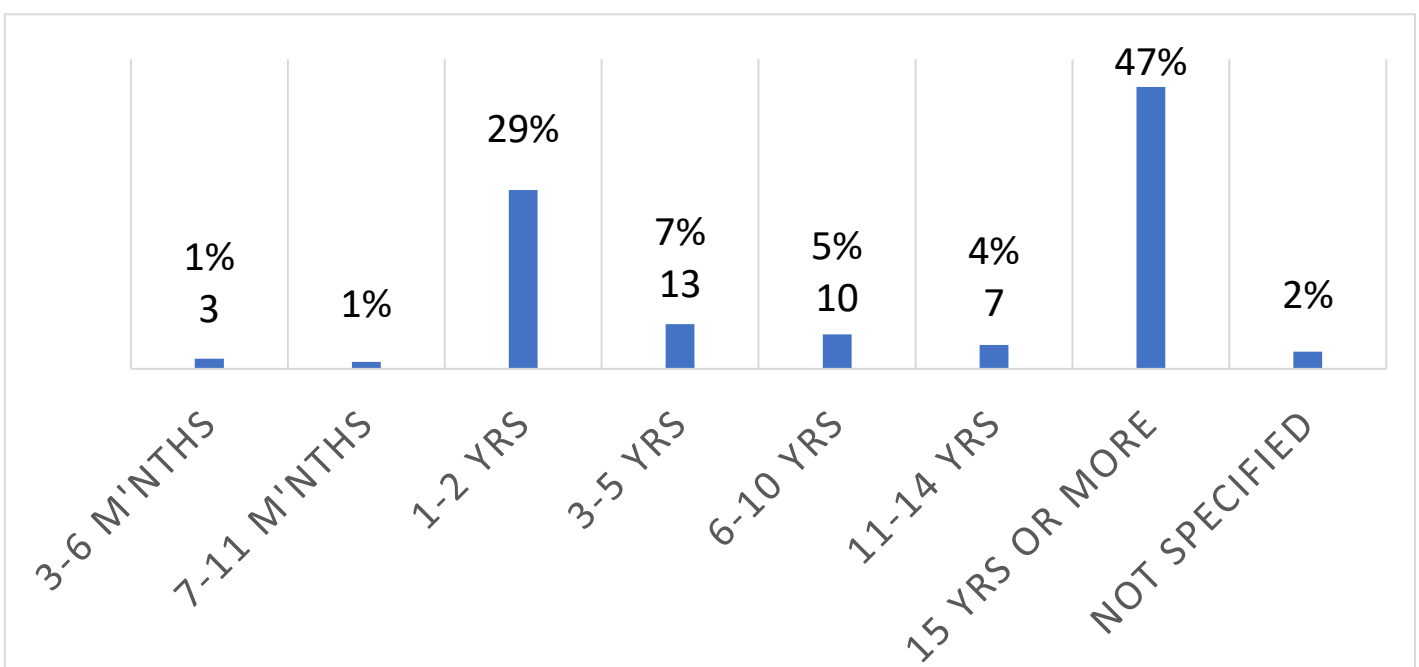
Q3 What type of service(s) does your service provide for the person?



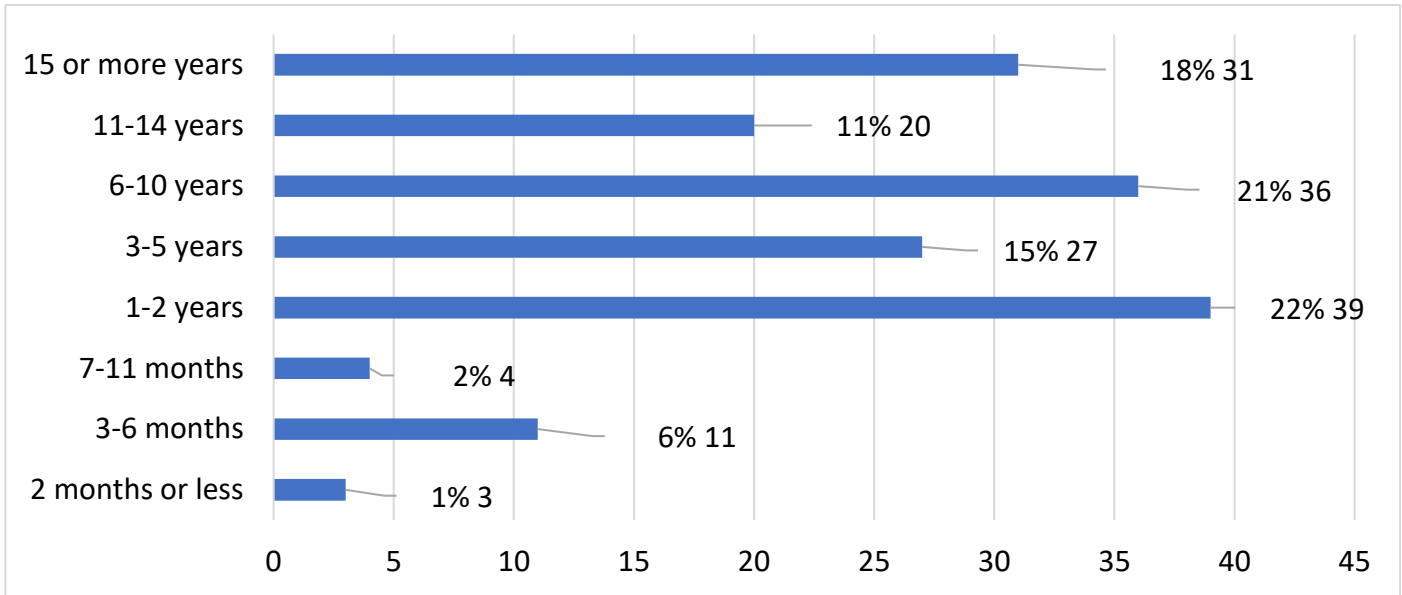
Q4 How long has the person been receiving services from your organisation?



Q5 What is your position?



Q6 How long have you worked closely with the person with intellectual disability (had regular contact, provided direct support)?



Q7. What are your contact details? (Person filling in the questionnaire)

Email: _____

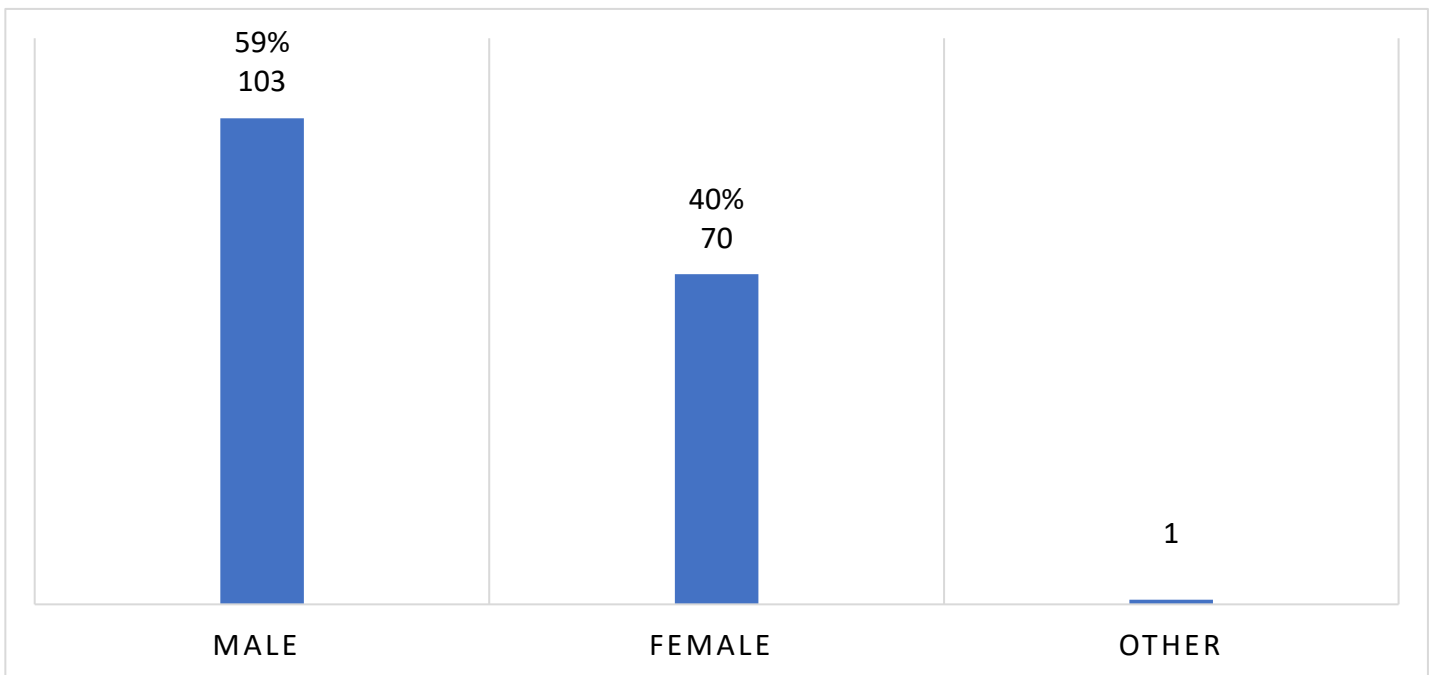
Work Telephone: _____

Mobile Telephone: _____

Participant/resident Demographics Questions 8-11

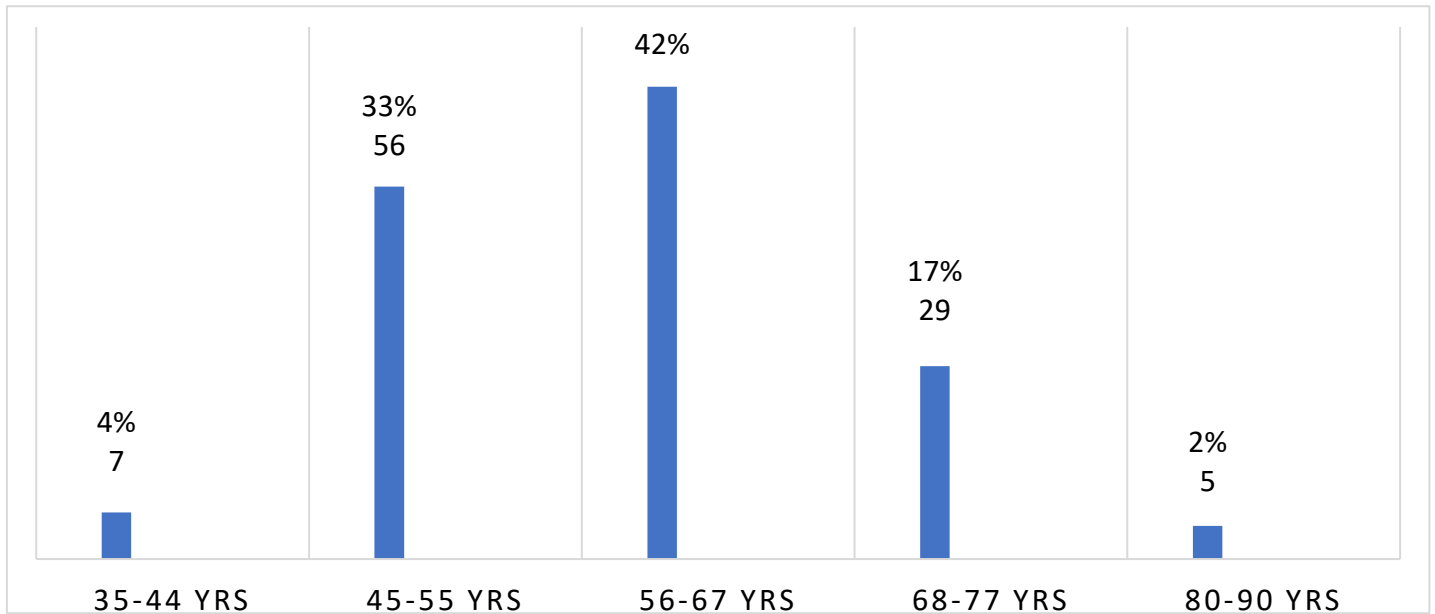
Q8. What is the name of the person with intellectual disability? (Data provided and kept confidential)

Q9 What is the gender of the person?



- 174 participants -103 are male, 70 females and 1 identified as other.

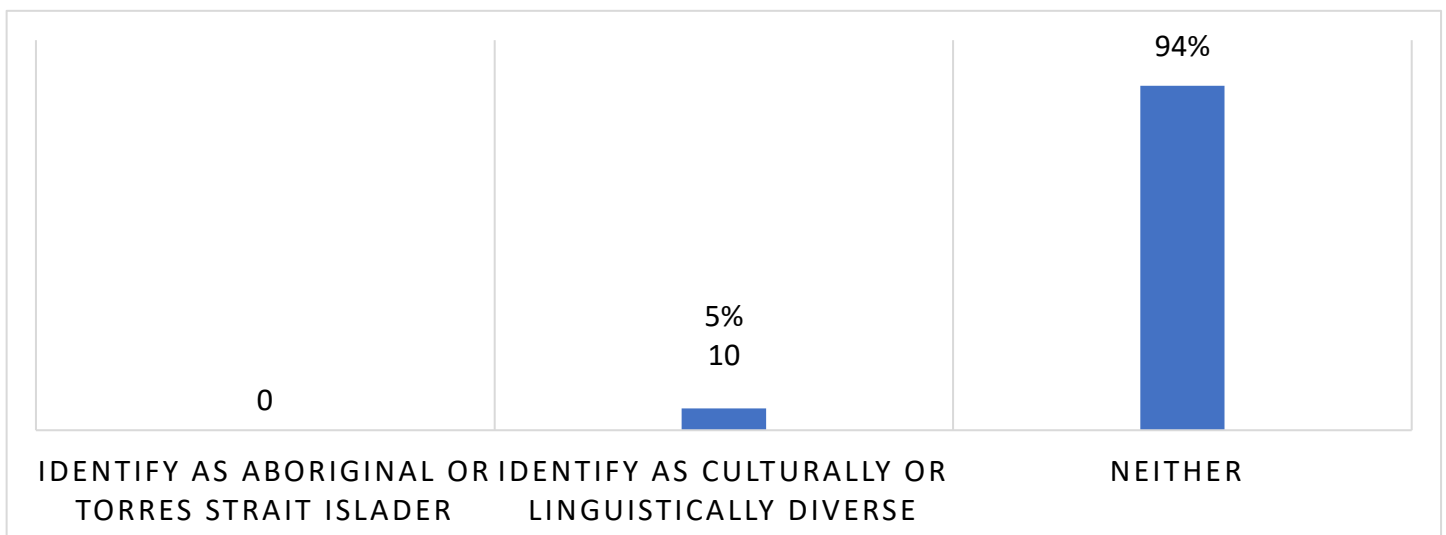
Q10 What is the person's date of birth?



- The vast majority of the residents were aged over 56 years which was to be expected as minimal new admissions to institutions have occurred since the policy of closing institutions was announced in the 2000's

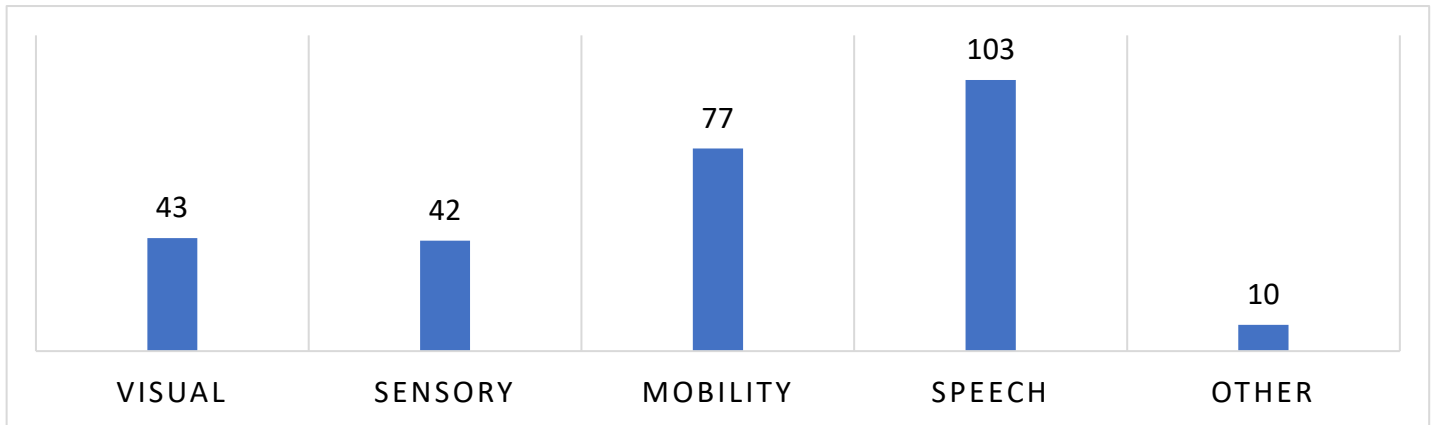
Q11 What is the persons cultural background?

1. An Aboriginal and/or Torres Strait Islander
2. From a culturally or linguistically diverse background
3. Neither of the above



Participant/resident basic diagnosis and communication supports – Q 12-15ii

Q12 In addition to intellectual disability, what other impairments does this person have?

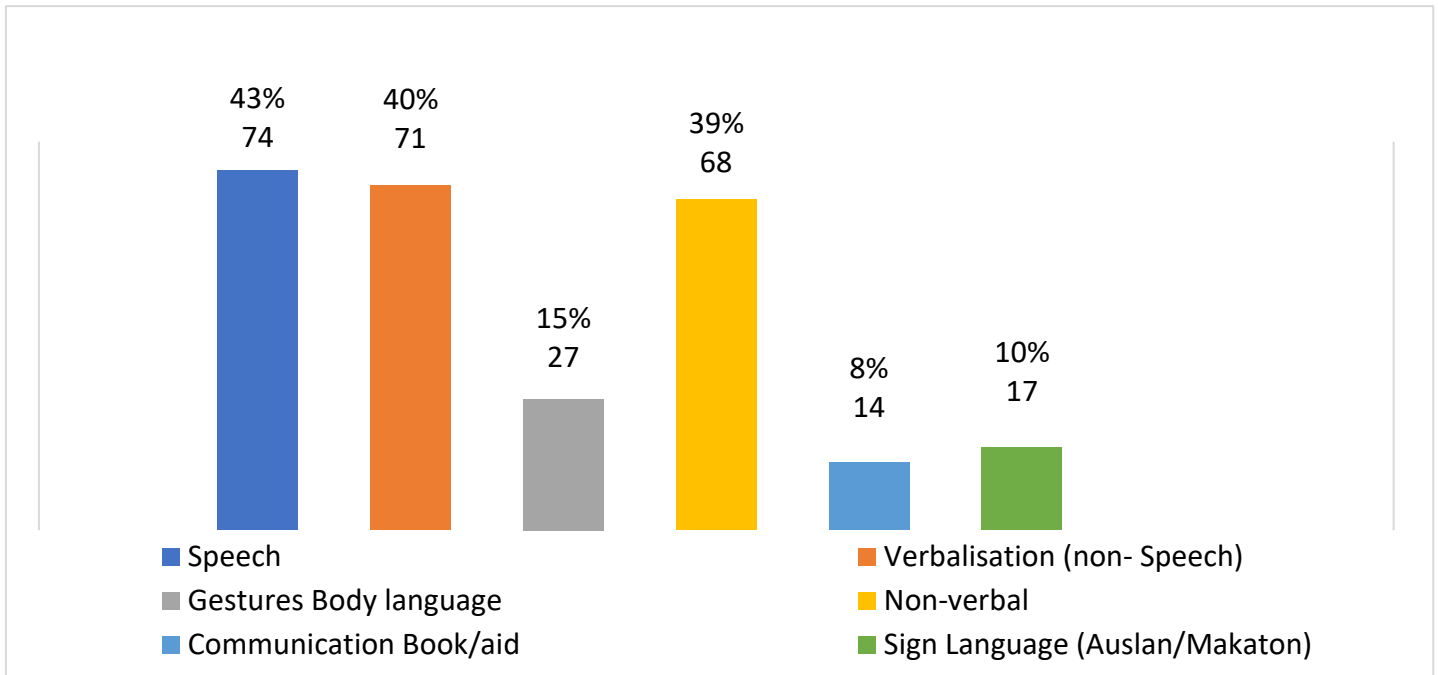


169 answered 5 didn't

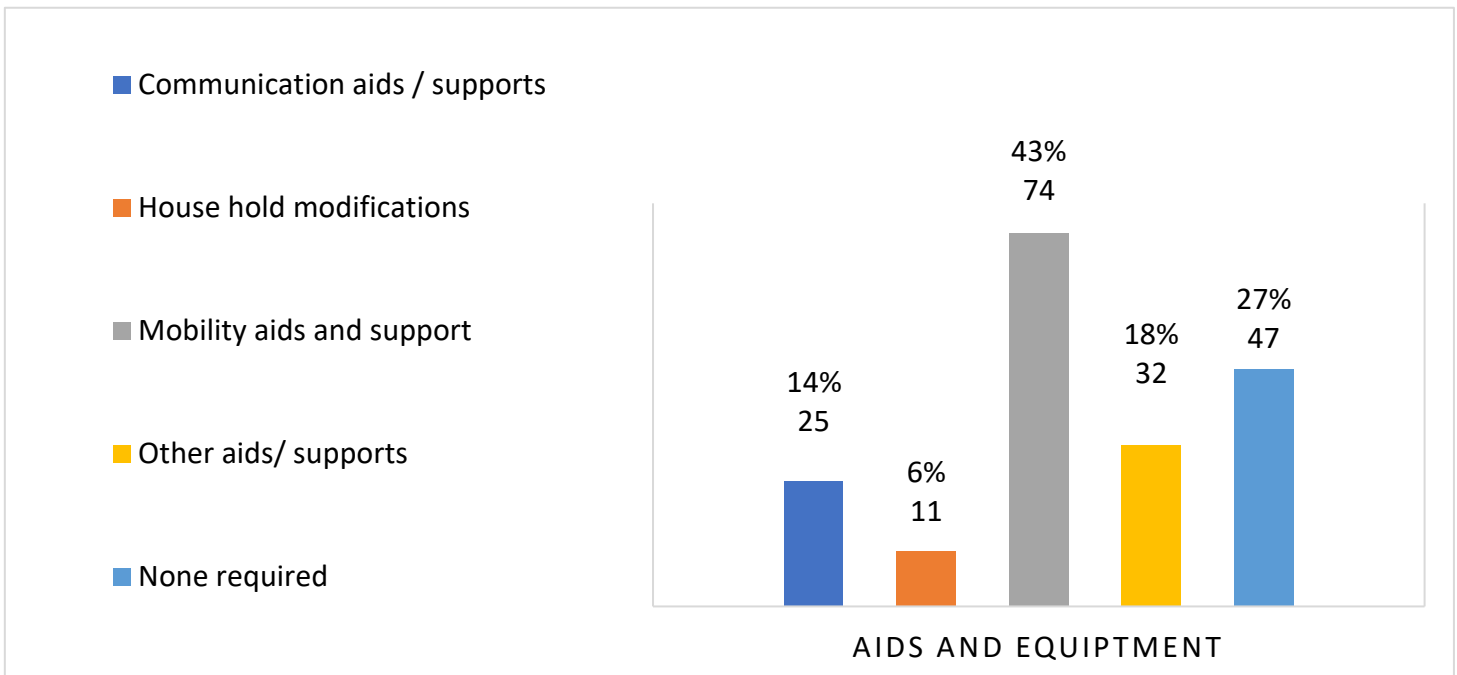
Note: one person did not have an ID

ID & Communication	-	61%	ID & Sensory	-	50%
ID & Mobility	-	45%	Multiple disability	-	34%
ID & Dementia	-	2%			

Q13 How does this person generally communicate with others?



Q14 Does the person require any aids or equipment in the home?



Q14i Please outline what supports this person needs:

- Communication board
- Support with day to day living, help with managing Behaviour of concern
- requires supports in all life areas and at different levels
- Full support in all areas of personal care, mealtimes, taking medication, medical decisions, finances, communication
- Positive Behaviour Support - Personal care - Independent Living support
- Personal Care, meal preparation, money management/handling
- complete assistance with personal care. 1:1 support in community

- Communication Strategies
- We have tried sign language and Compic cards. We have sign language boards, who here today and activity boards using Compic and photos.
- Communication board
- shopping list book
- visual aids
- Needs supports in all life areas
- Supports in all life areas
- Supports in all life areas
- Communication cards
- Sensory
- Requires full support in all of his daily living
- Behaviour Support, All independent living skills, personal hygiene, money handling
- Requires support in all daily activities. NDIA plan management support, Advocacy support, Financial management support, Personal hygiene Support, Mealtime Support, Mobility Support, Communication support, Support to Access Community, Health and Allied Health services
- Requires support in all daily activities. NDIA plan management support, Advocacy support, Financial management support, Personal hygiene Support, Mealtime Support, Communication support, Support to Access Community, Health and Allied Health services
- Modified meal (minced and moist), thickened fluids. Stoma care. Full mealtime assistance. Full Personal Care. 1:1 support community (wheelchair).
- grab rails in bathrooms, modified dining chair
- Support in the home with cooking, support with some personal hygiene regimes, support making phone calls and using a telephone, support cleaning his glasses. Support with cleaning of their bedroom, bathroom, washing of clothes and linen. Support to order and arrange taxi services. Requires support during COVID lockdowns' to be advised of what he can and can't do due to restrictions. Requires support to manage any health appointments and issues.
- Requires full support with personal care showering brushing teeth shaving.
- full support with medication and accessing the community
- Handrails in toilet and shower area
- 24/7 support for all daily living and personal needs. Cannot be left unsupervised as he eats inedible objects.
- Communication, everyday tasks, mobility support
- Shower chair
- Requires a wheelchair when out in the community, sensory programs, sensory toys, slings when they decide not to stand.
- Mealtime Preparation (soft & bite sized Level 6)
- All Personal Care & Hygiene Support
- Dressing
- Medication Administration
- Community Support 1:1
- Fall prevention support
- wheelchair, hoist, slings, hi lo bed, hi lo bath. Two staff at all times to assist with transfers.
- 24/7 care for all aspects of his life including all personal care.
- Need 2 staff member support for all ADLs including meal times.
- Physical support at home and full support in the community.
- physical and emotional support

- Wheelie walker, grab rails in bathroom
- full support with all daily living
- Needs physical assistance to walk around the house but can ambulate on their own. Has frequent falls. Has been assessed as needing a wheelchair for community access. Wheelchair has not been purchased as yet.
- support with all daily living activities
- Assistance with his Mobility and Personal Care
- Ageing and non-verbal they crawl around or use a wheelchair and requires full assistance in all areas of life
- Full assistance with daily living and has a wheelchair for long distances when out for walks
- Personal care full assistance meal assistance and mobility assistance

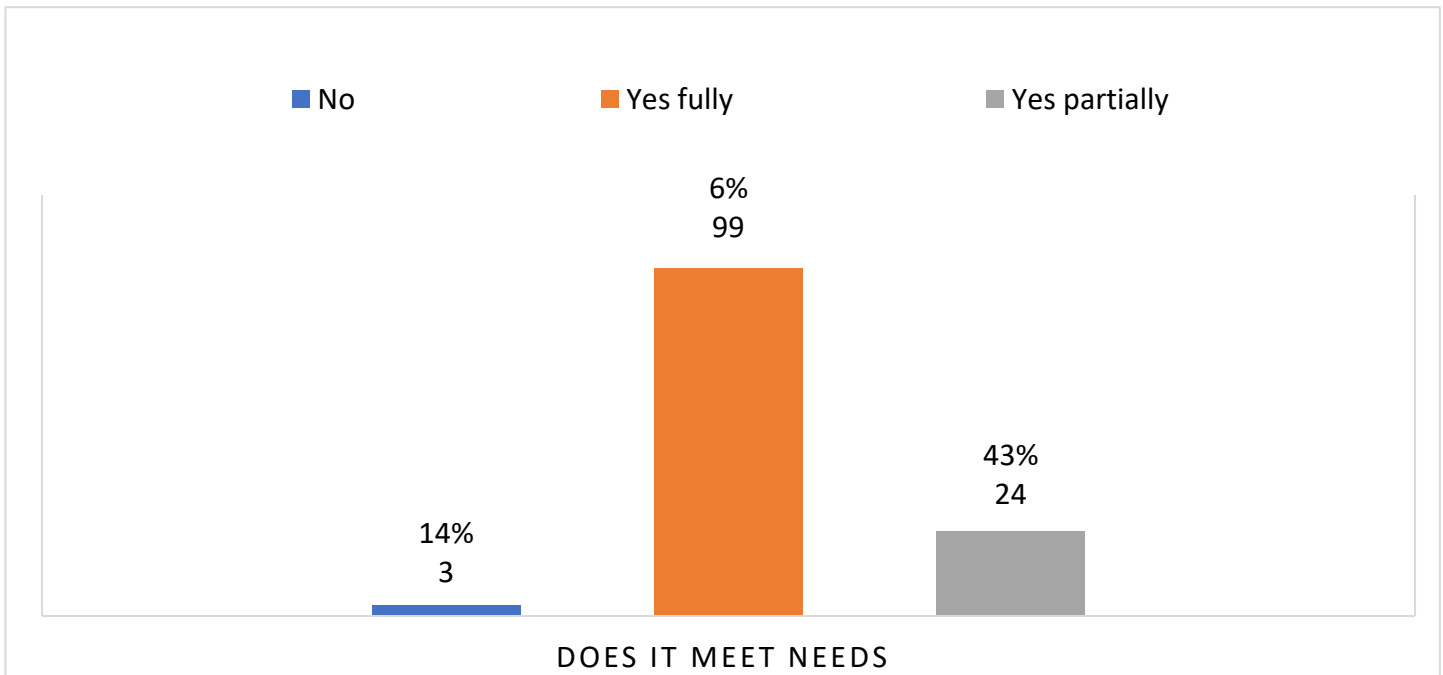
Q 14ii. Please outline what supports this person needs:

- Needs full supports with all daily living supports including all physical care
- wheelchair with tray, shower trolley and iPad also receives 1:1 support in the group home
- Wheelchair and hoists, iPad
- Needs full assistance in all tasks
- Uses a 4 wheel walker in hose and a wheelchair when accessing the community. Support coordinator will attempt to access a speech pathologist through his next NDIS plan.
- Has orthotics in her shoes (AFO)
- Has a communication profile
- Has a wheelchair if she leaves the house
- manual handling, complete assistance with personal care. mealtime assistance
- 24/7 care for all aspects of his life including personal care. Cannot be left unsupervised as he is a falls risk.
- All supports for daily living. Fully dependant on others for every aspect of his life.
- Rails to stand in bathrooms, bedrooms. wheelchair for transport , when out in community and to transfer around home.
- Advocacy support as she has little contact with NOK
- Full Support in all areas
- Requires support in all daily activities. NDIA plan management support, Advocacy support, Financial management support, Personal hygiene Support, Meal time Support, Mobility Support, Communication support, Support to Access Community, Health and Allied Health services
- Requires full supports with all daily living tasks including all physical care
- Requires full support for all daily living tasks including all physical care
- requires total support with all of his daily living
- Requires support in all daily activities. NDIA plan management support, Advocacy support, Financial management support, Personal hygiene Support, Mealtime Support, Mobility Support, Behaviour Management support, Communication support, Support to Access Community, Health and Allied Health services
- Supports in all life areas
- Support with all aspects of daily life: meal preparation and eating/drinking, personal care, mobility/transfers, community assistance, medication administration.
- Wheelchair for community use, commode for showering and toileting, modified mealtime equipment, hi-lo bed, grab rails
- Full assistance with all personal care, mealtime, assistance, assistance with medication, finances, medical decisions

- Manual handling/transfers
- Full personal care support and everyday living support
- Assistance with everyday activities
- Assistance with all medical appointments
- Assistance with transportation and keeping self-safe
- Full personal care support
- Full support in all daily living needs
- Full Personal care support
- Full support in everyday living needs
- Some manual handling, complete support with personal care. meal assistance
- Hoist, wheelchair, shower chair, slide sheet, sling
- Rails in toilet and bathroom shower chair
- Adjustable bed and dining chair
- Callipers
- Hoist, sling modified wheelchair
- Pressure mattress and adjustable bed
- Shower trolley
- Bus with hoist
- Commode adjustable bed
- Wheelchair dining chair on wheels
- Bus with hoist
- Shower chair, rails in bathroom and toilet
- Wheelchair
- Bus with extra handrails
- Adjustable bed
- Swivel dining-chair
- Shower trolley sling and hoist
- Adjustable bed with pressure mattress
- Wheelchair
- Bus with hoist
- ceiling hoist, built up cutlery, sip up. high low bed, air mattress, princess chair and table, electric wheelchair, manual wheelchair
- Walker
- Sliding doors removed in walk-in robe and bathroom to enable wider doorway
- Shower chair
- Furniture moved around to enable sufficient access for walker
- Wheelchair
- Walking frame, shower chair, railings
- Wheelchair (manual and electric) for home and community plus as above
- specialised dining chair, walker for indoor use, wheelchair for community use, commode, specialised lounge chair, specialised spoon, grab rails
- Requires full support with all areas of life. Including but limited to, personal care, continence, walking, eating, food preparation, dressing and undressing, communicating
- Requires full assistance and support with all of his activities of daily living including dressing, continence, eating, transferring, bathing, communication & choice.
- Assistance with meal preparations and eating
- Assistance with all domestic tasks
- Assistance with mobility

- Assistance with personal care (including continence management)
- Assistance with finances, including cash handling
- Assistance with community participation"
- Full Support - Community Access, Personal Care, Financial.
- Full Support - Personal Care, Community Access, Financial support.
- Requires handrails within her home for support as well as a ramp outside of her front door. Is currently being assessed for a walker
- Wheelchair, commode, bath trolley, ramps, hoists
- walker
- Requires support with hygiene, hoisting, mobility, toileting, bathing, dressing, oral hygiene, health appointments, transport and decision making.
- requires full assistance in all of his daily living
- Meal preparations
- Domestic tasks
- Accessing the community safely
- self-regulating Behaviours of Protest
- Assistance with dressing
- Assistance with personal hygiene (including brushing teeth)
- Prompting for maintaining continence
- Requires support for community access, social engagement, social skills, general skill building. Requires an advocate to act on his behalf so that his life can be meaningful, and his future goals can be obtained.
- Wheelchair, shower commode,
- Full support with everyday living aspects, Assistance with wheelchair
- assistance with wheelchair, Full assistance with everyday living aspects,
- Full assistance for everyday tasks. Is dependent for staff to provide all meals and drinks by hand. Full showering and bath assistance. Full continence assistance and support. Full assistance in the community 1:1.
- Wheelchair required in the community.
- hygiene, cooking & preparing meals, transport, accessing community, communication, financial, dietary, health.
- Requires 24/7 full care.
- Is an older very active lady who requires supports with her everyday living needs.
- Requires supports at mealtimes due to Dysphagia.
- Is attending day programs 4 days a week and the other day she stayed home. Likes to lay in bed of a morning but the house does not have additional supports for her to this and she would like to go shopping and would like to access the community more often that she does now. Would benefit from having a variety leisure activity especially due to her age. When home she shares staffing with 2 other residents
- Due to a gradual decline in mobility over a number of years, he uses a shower chair in the bathroom when having a shower and getting dried. There are also handrails in place for to grab a hold of, if in a standing position.
- Requires support in all daily activities. NDIA plan management support, Advocacy support, financial management support, Personal hygiene Support, Mealtime Support, Communication support, Support to Access Community, Health and Allied Health services
- Requires support in all life areas at different levels
- Mealtime assistance - Positive Behaviour Support
- complete support with personal care. positive behaviour support, trauma informed support

Q15i Are these supports provided and do they meet the person's needs?



Q15ii Please outline what supports are *not* provided and/or why they do not fully meet the person's needs:

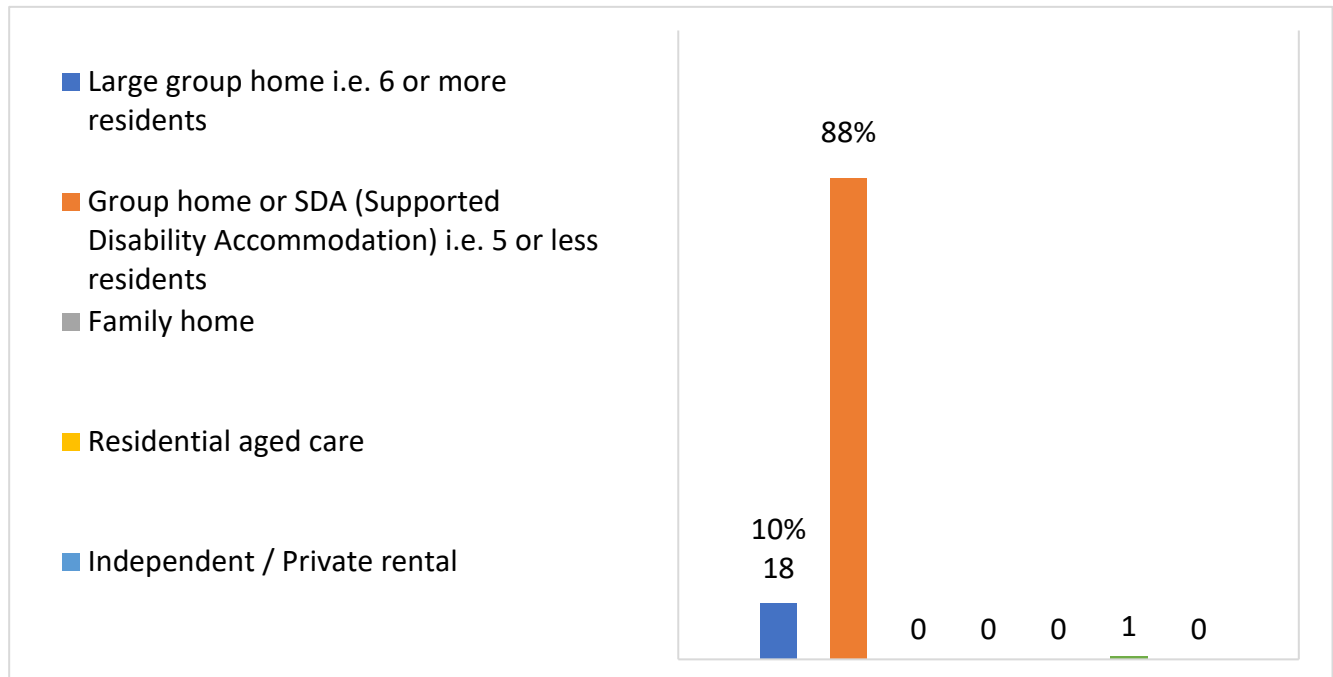
- The person is waiting on a new lifting chair and a new hi-lo bed
- Grab rails for bathroom have not been approved by landlord (DFFH)
- no one to socially engage with him. The support co-coordinator (NDIS) has taken months to facilitate a simple program, whereby communication and social skill development could have been organised. There has been no community participation for a long time. Has only accessed a community program for 36 hours in the last 18 months. Is losing significant skills around socialisation and community inclusion. Requires 2.1 support so that he can be properly supported to achieve his goals. A simple program such as engagement with the neighbourhood, ball catching, being read to, water play, and development of a simple music program would benefit and his mental health.
- It was noted in an Occupational Therapists visit, that requires a Hi-Lo bed, as she has been diagnosed with Alzheimer's disease and her regular bed no longer fulfills her needs. This has yet to be organised through her NDIS Support Co-ordinator.
- Modifications to home identified. In summer likes to stay up late till 11pm-12am (but cannot as the s/o finishes hands on support at 10pm).
- all these items are in progress. Unfortunately, we waited several months for an NDIS review for therapy assessments and equipment when needs changed suddenly because NDIS refused to review without independent advocacy. Eventually it was agreed that House Staff and Support Coordinator could adequately advocate on his behalf and a Plan Review went ahead and now OT and Physio support is underway
- New wheelchair and hi lo bed is required. Has funding for an OT through the my aged care, however as is unable to provide informed consent to access my aged care. An application has

gone to VCAT to have a guardian appointed to provide consent to access my aged care services.

- Could use more support in relation to facilitating her communication. I understand that this is something staff are working with the speech pathologist with.
- Behaviour strategies not effective, currently under review
- Require further development and implementation
- communication aids need to be updated
- 1.1 support for community participation
- To be provided with a variety of services with an independent agency
- Client has limited understanding of verbal communication
- Does not recognise photos or compic and his sign language is very limited. We use physical objects for him to make simple choices.
- Waiting on OT approval/trials for Gel chair. Unable to have noncritical allied health in the home
- Need a communication assessment which would identify his specific needs.
- We are awaiting the arrival of a wheelchair for safer community access.
- Lack of appropriate services / Day supports in the area for people that are nonverbal . Have no family support and significant BOC
- Difficulties with NDIS funding for assistive technology. e.g. replacement Hi Lo Bed
- Day Services in this area cannot provide appropriate support due to significant BOC
- Requires a new manual wheelchair and possibly a new electric wheelchair as what she has is old and in poor condition, also requires some modifications to her bed to accommodate declining muscle condition due to cerebral palsy, waiting on reports, trials and a new NDIS plan to accommodate these things.
- Very little contact with family members
- Wish to move to another SIL house
- Mobility has decreased and house renovations are required (more railings, more accessible bathroom etc). These renovations are yet to take place.

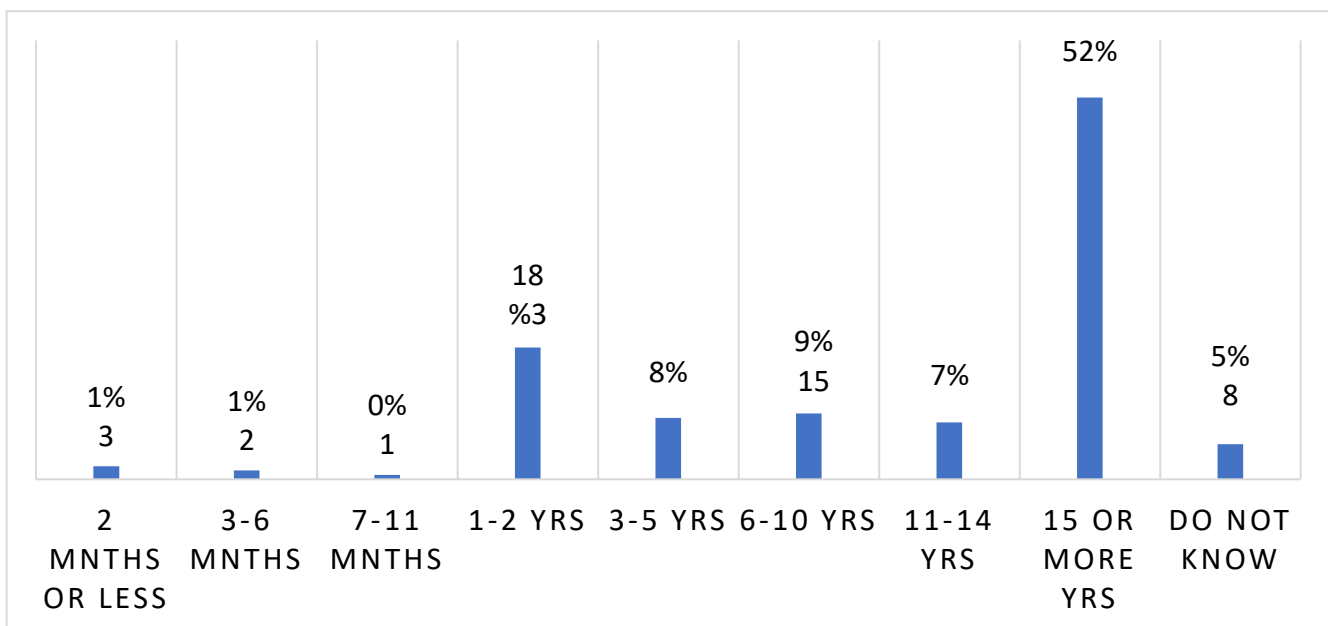
Accommodation – Q 16-23

Q16 Where does the person live?

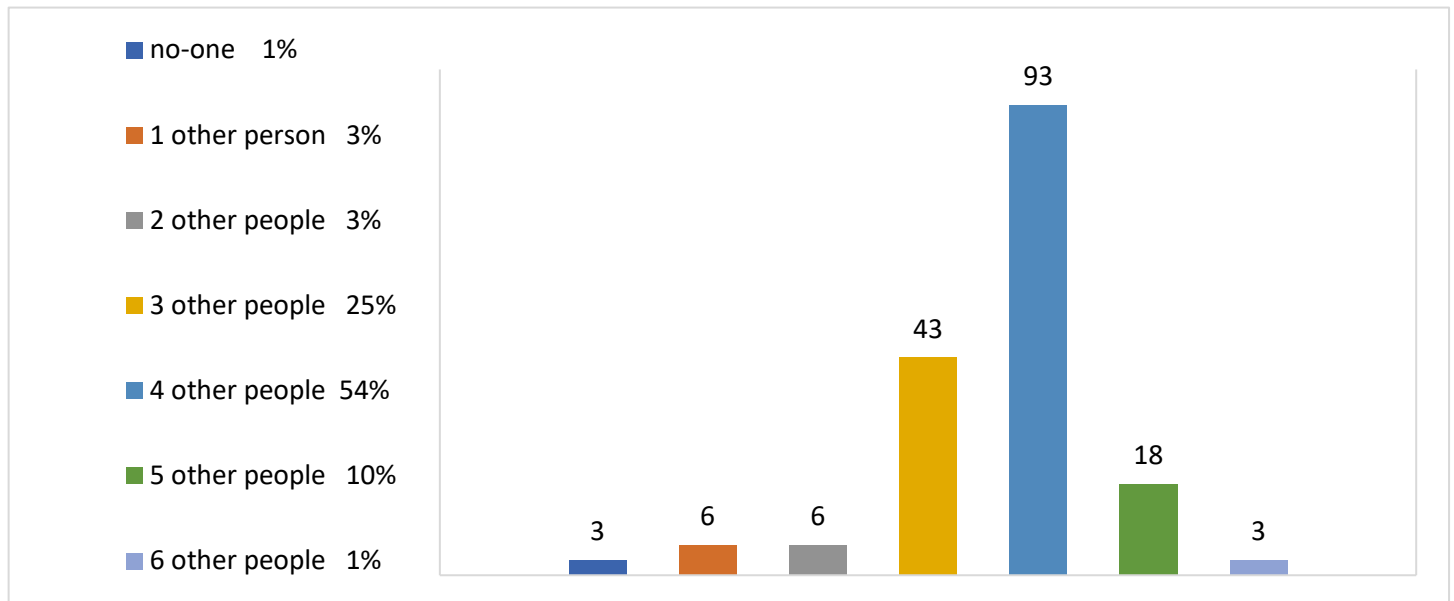


Q17 What is the address of their accommodation? (Data provided and kept confidential)

Q18 How long ago did they enter their current accommodation arrangements?

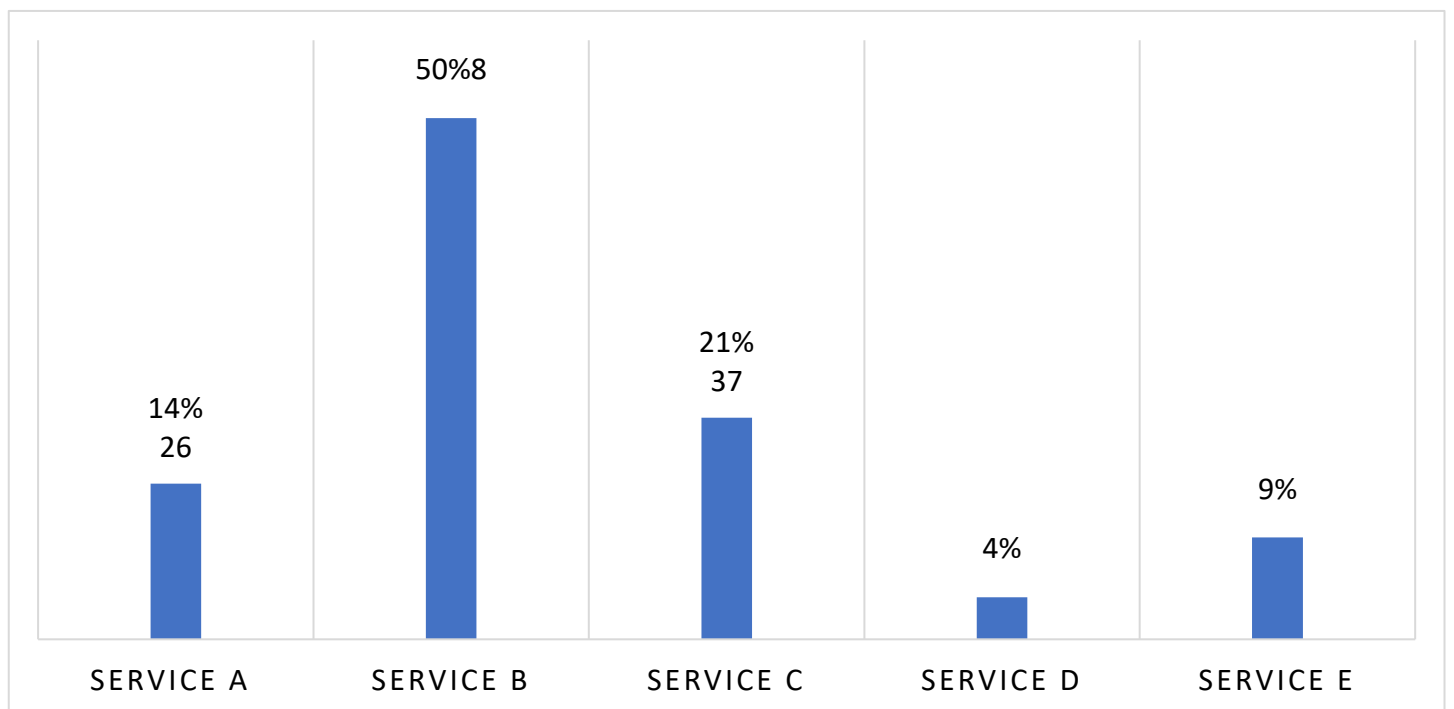


Q19 How many people do they currently live with?

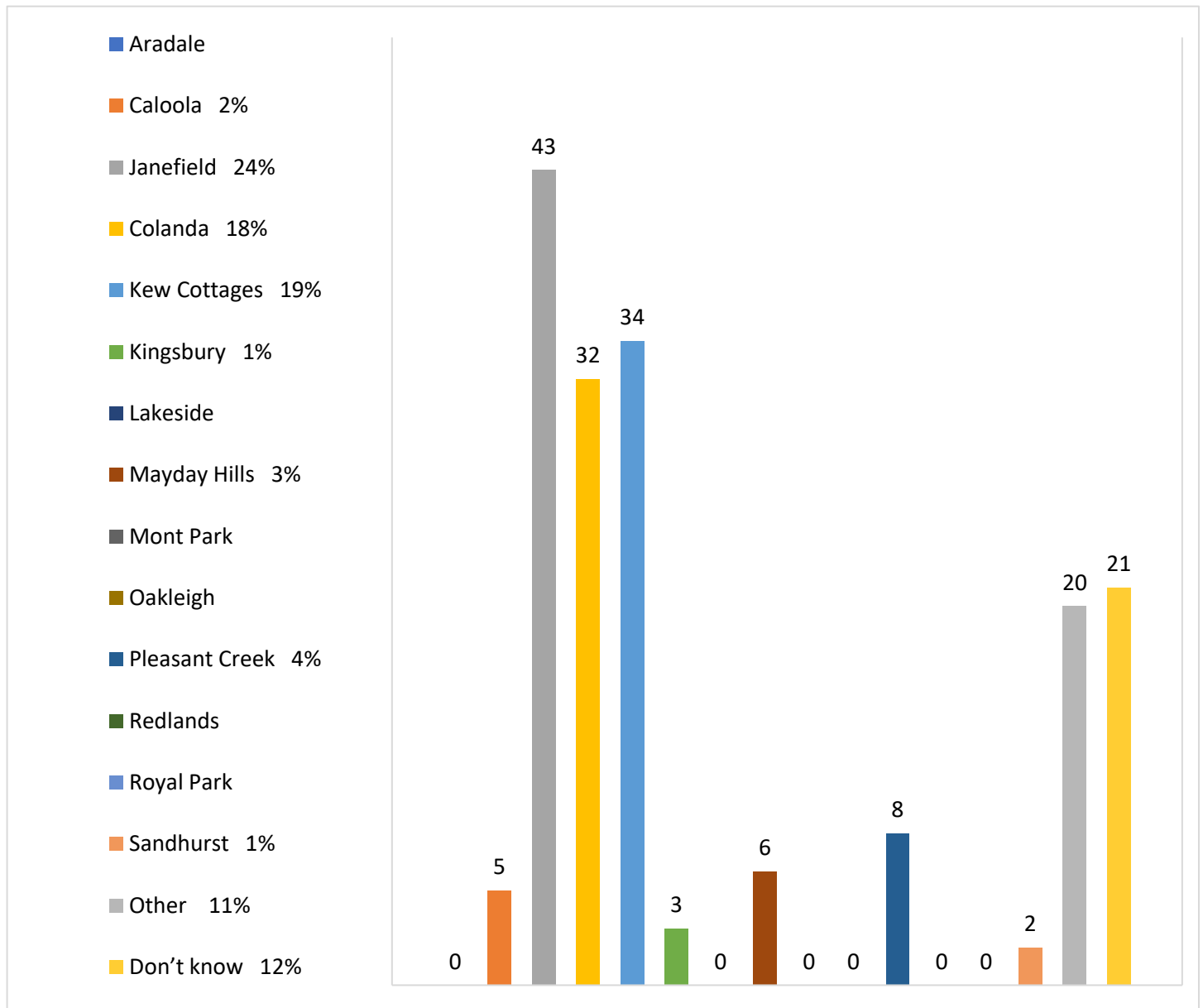


- Most of the participants live with four to five other people with disability

Q20 What is the name of the service that provides the person's accommodation?



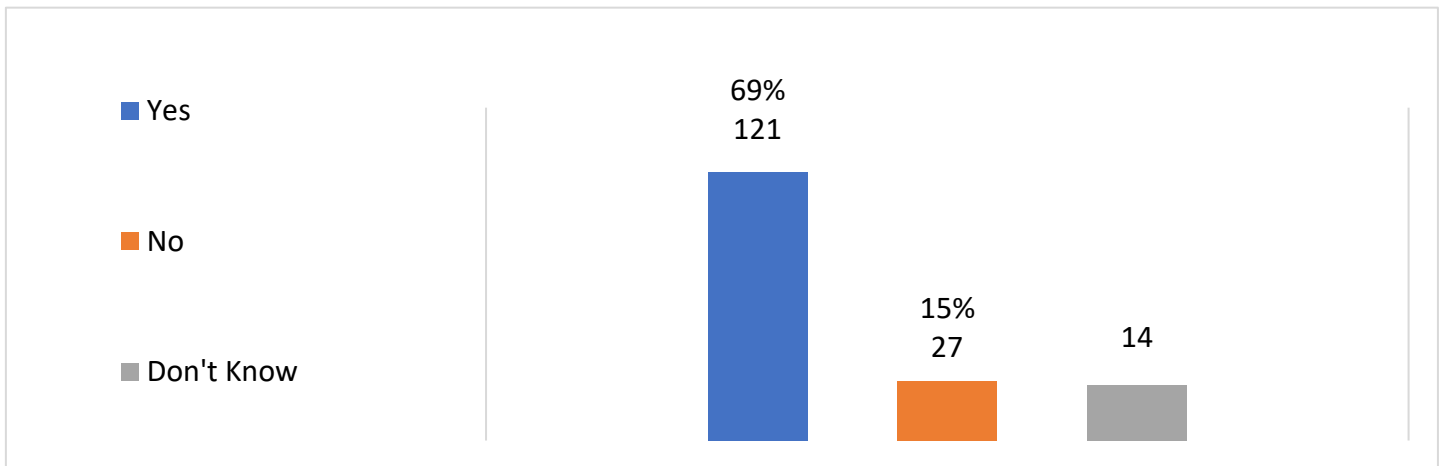
Q21 What is the name of the large institution where they used to live?



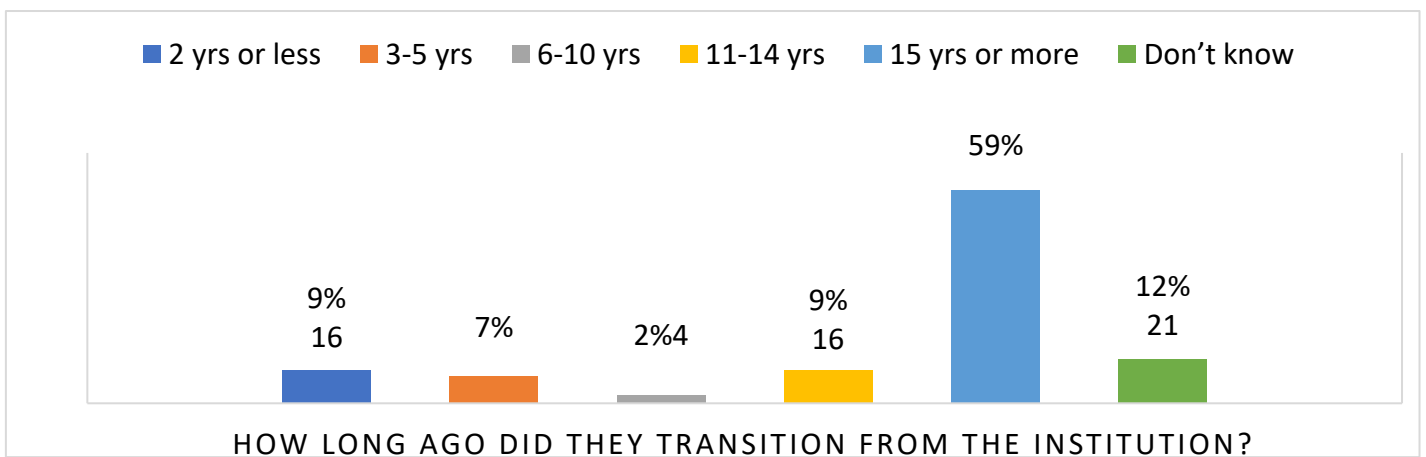
People identified in the 'other category' (Data provided and kept confidential)

- There were residents from ten of Victoria's closed institutions in the respondents

Q22 Did they move to their current accommodation with other people from the institution?

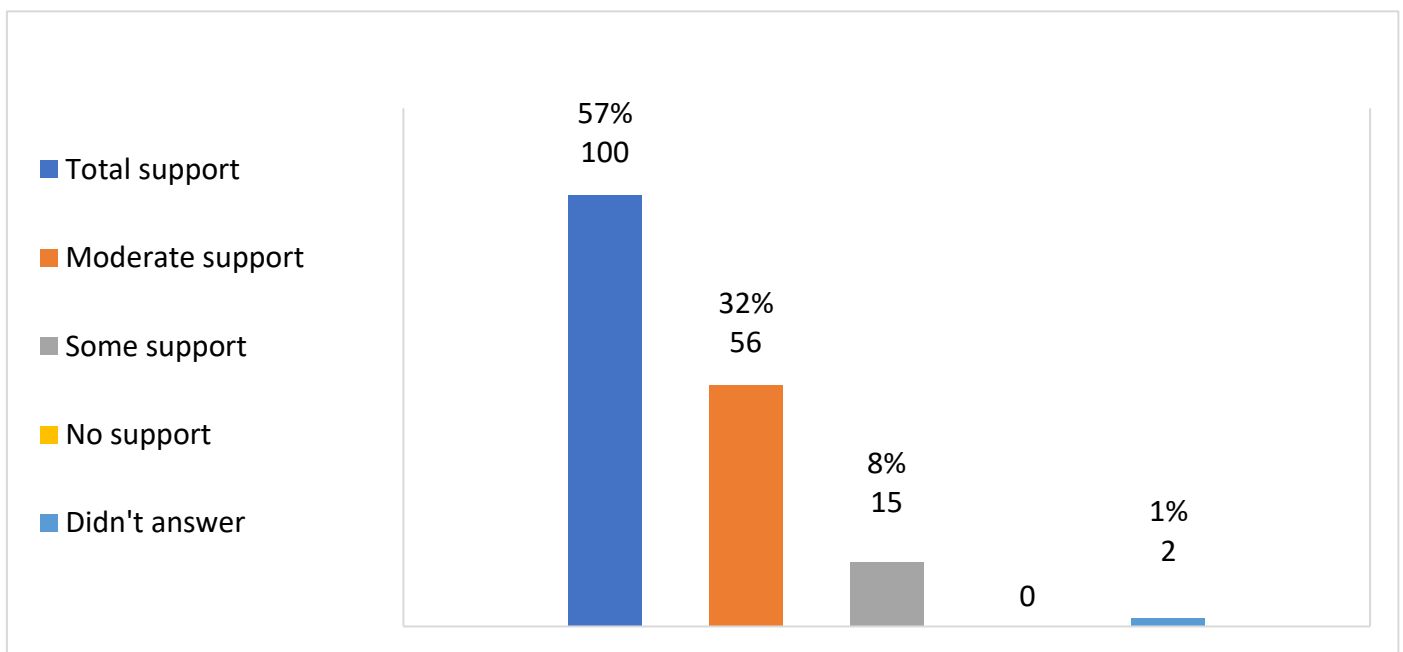


Q23 How long ago did they transition from the institution? 172 answered 174 total

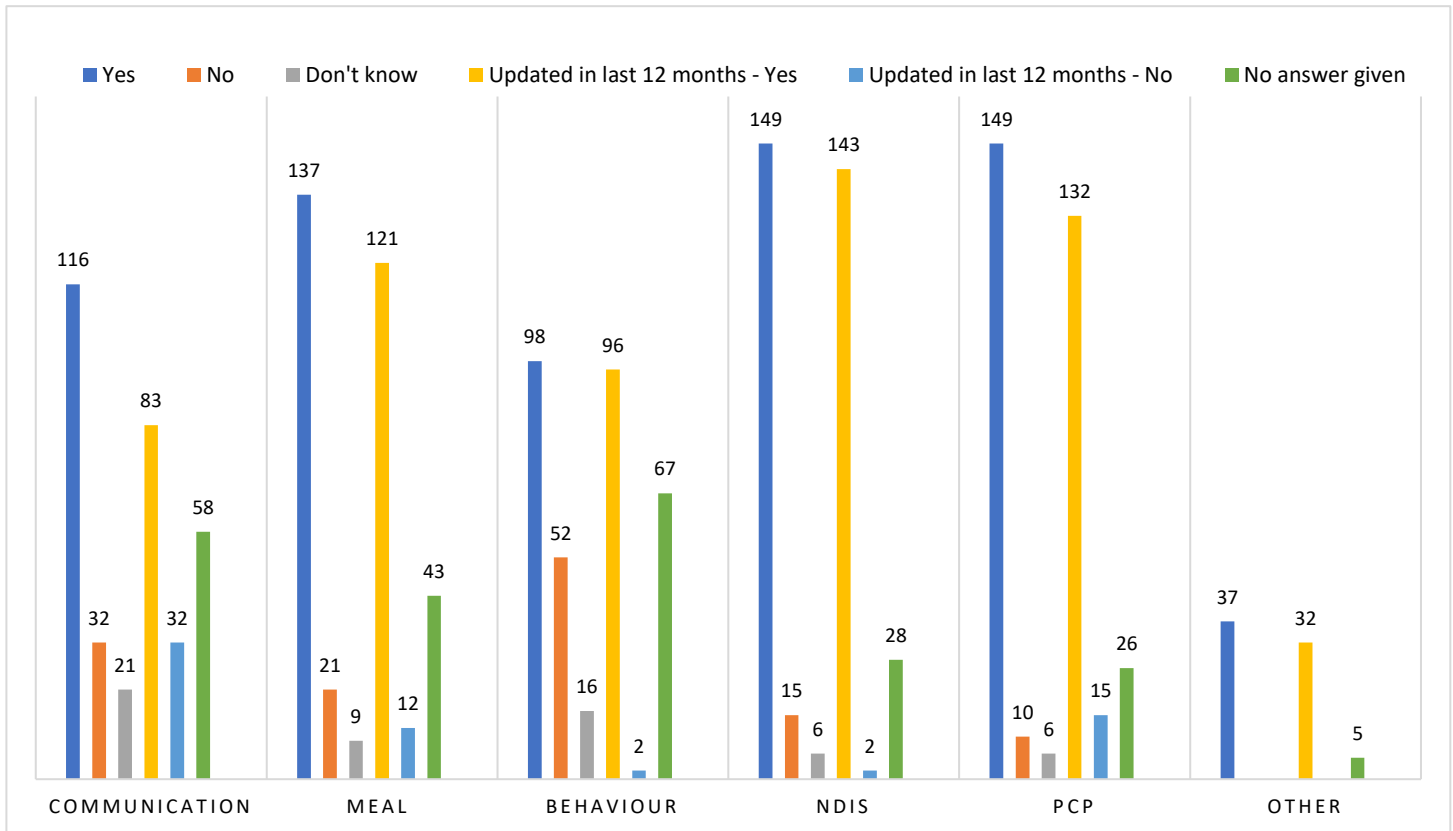


Support needs and plans – Q 24-29

Q24 How much support does this person need to make decisions?



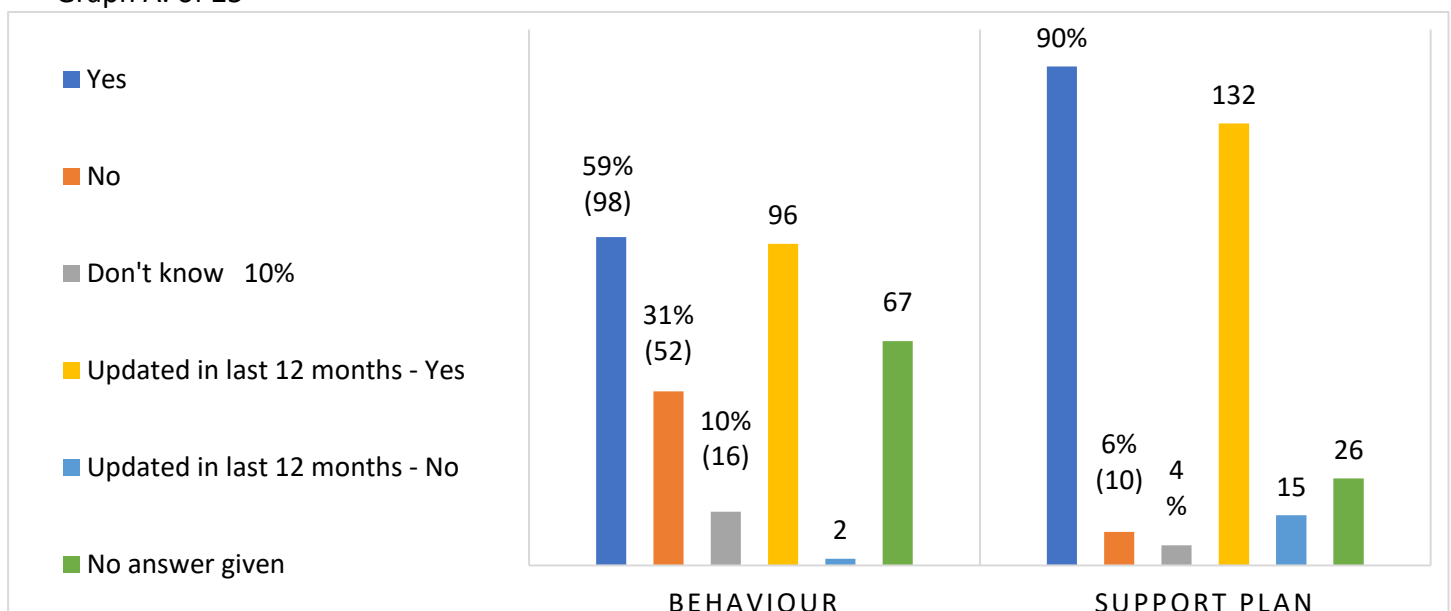
Q25. What Support plans does the person have?



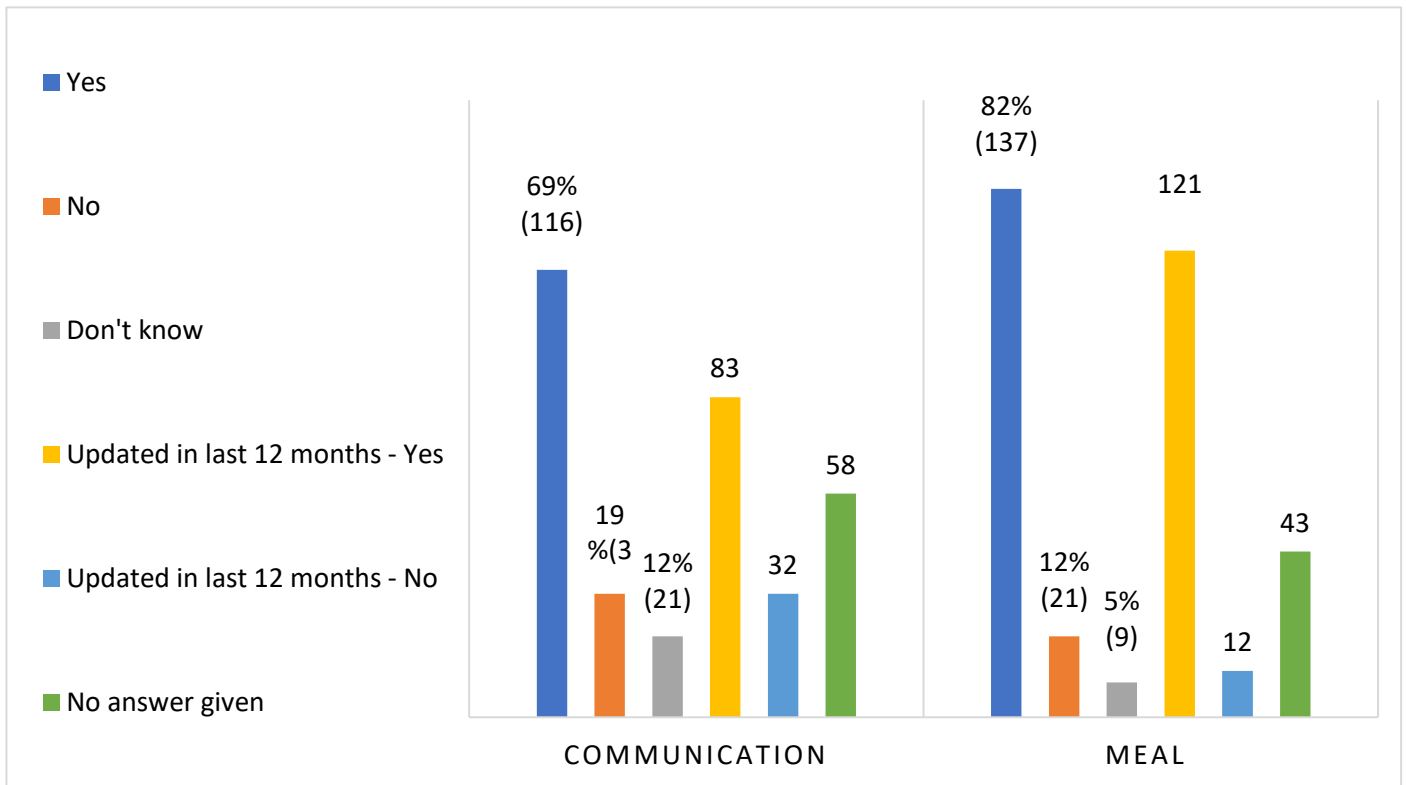
Other:

- Health Management Plans - Epilepsy Management Plan - Mobility/OT Support Plan - medical support plans
- Continence, OT, Functional assessment - Mental Health Plan - Catheter care - Urology health - Incontinence
- Diabetes - Eye health - PRN - PEG feeding plan - Parkinson's - financial plan – ISP - manual handling plan
- Podiatry care plan

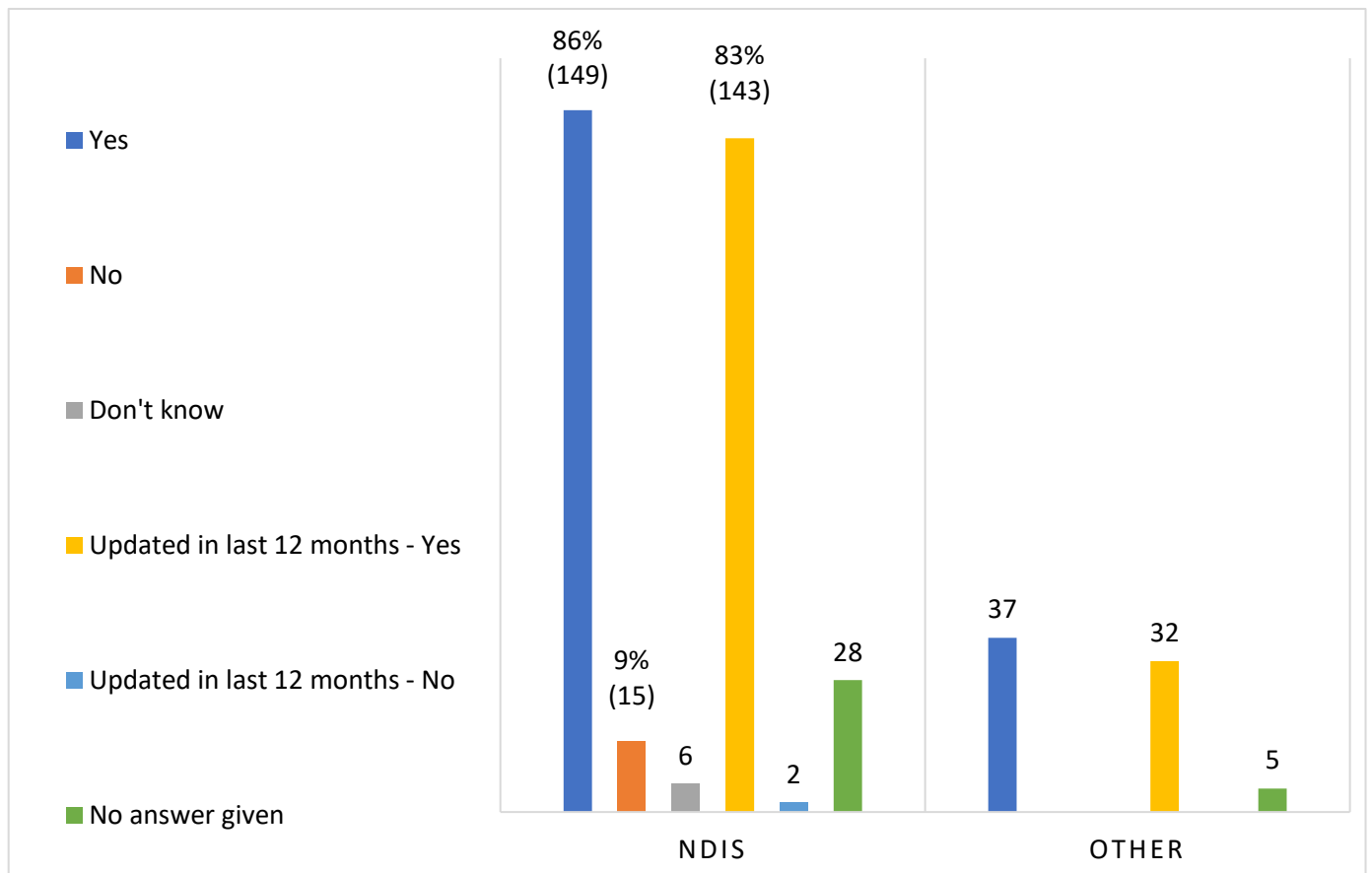
Graph A. of 25



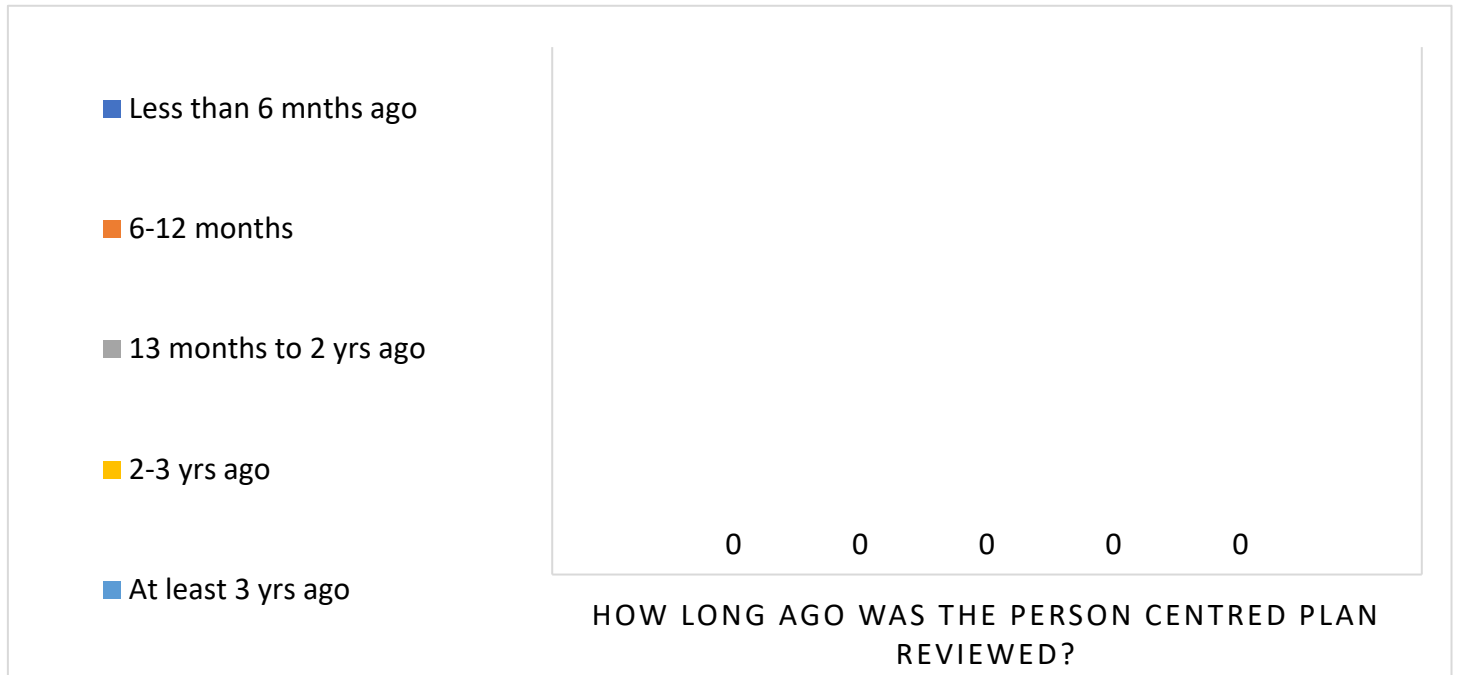
Graph B. of 25



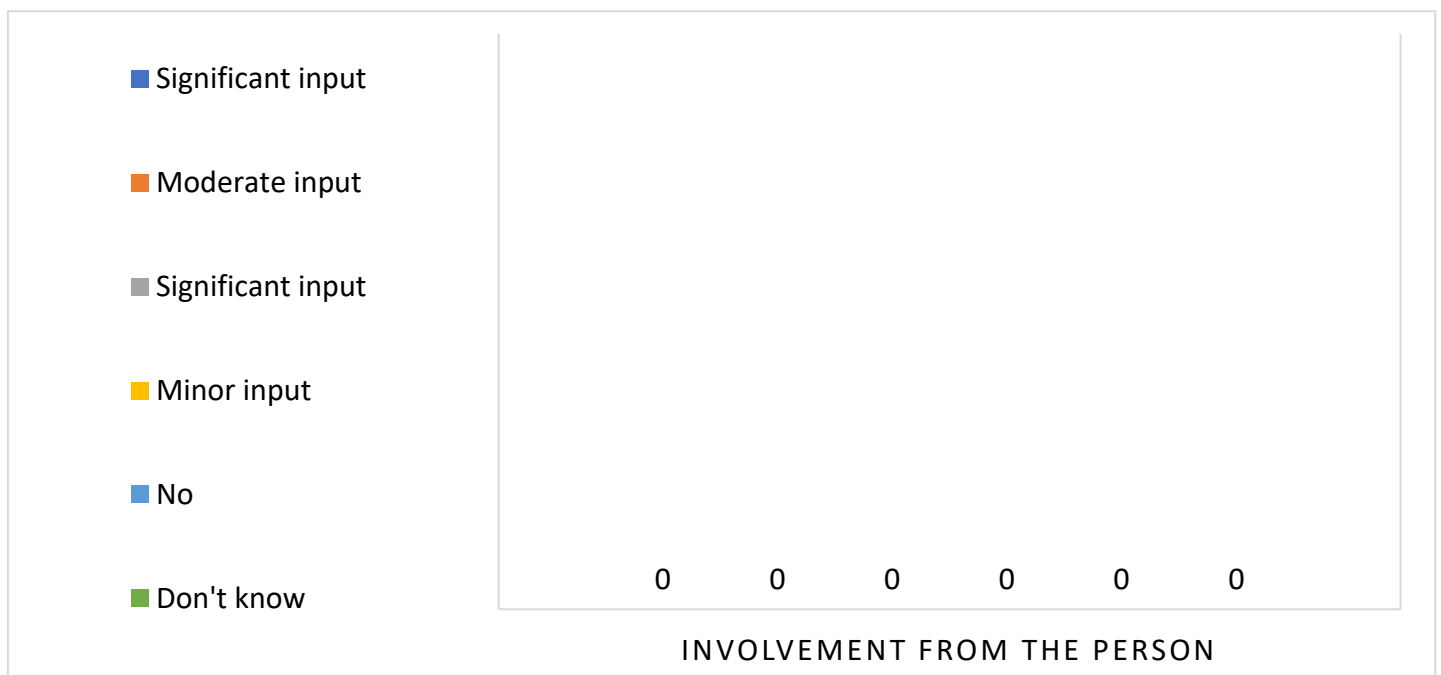
Graph C. of Q25



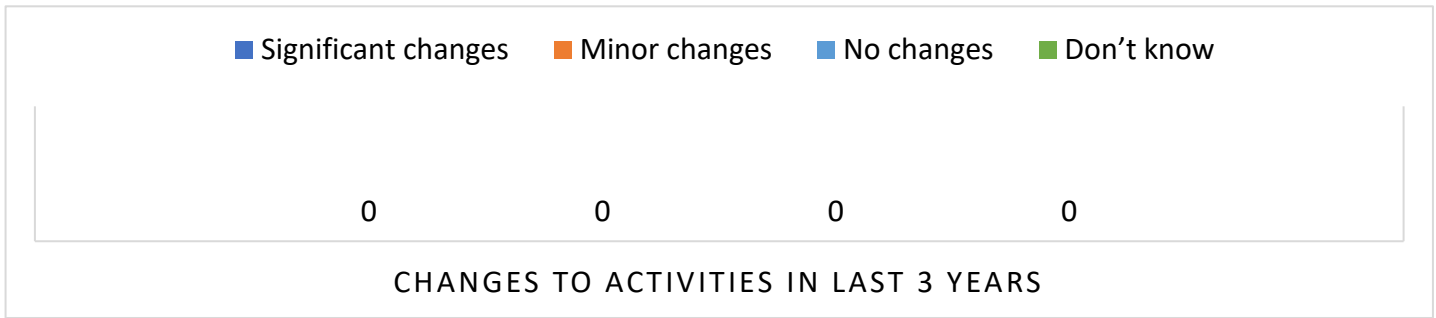
Q26 How long ago was the person-centred plan last reviewed/updated?



Q27 Was the person with disabilities involved in developing the content of the person-centred plan when it was developed/last reviewed (whichever was most recent)?

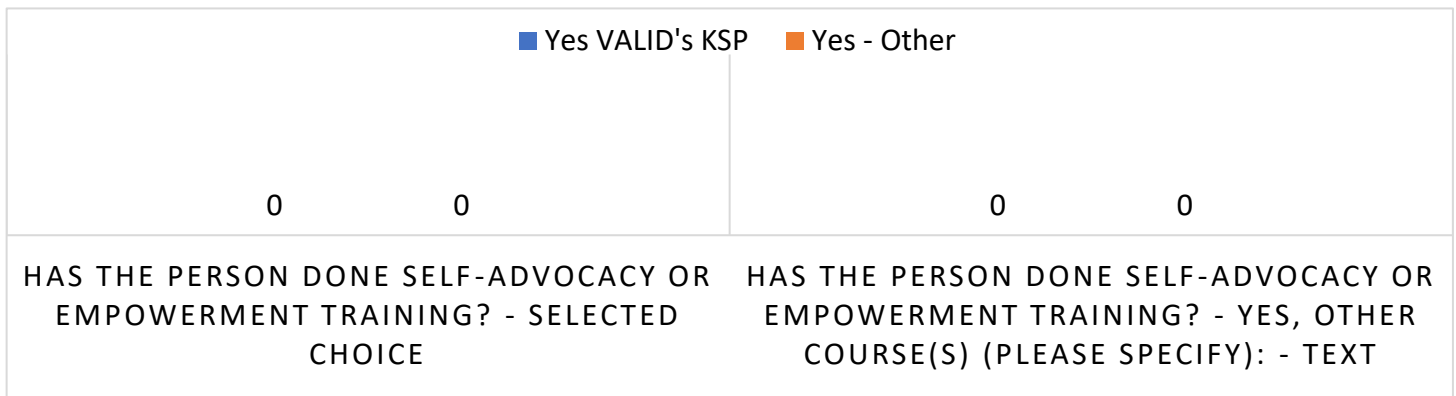


Q28 To what extent have the activities and content of the plan changed over the last 3 years?



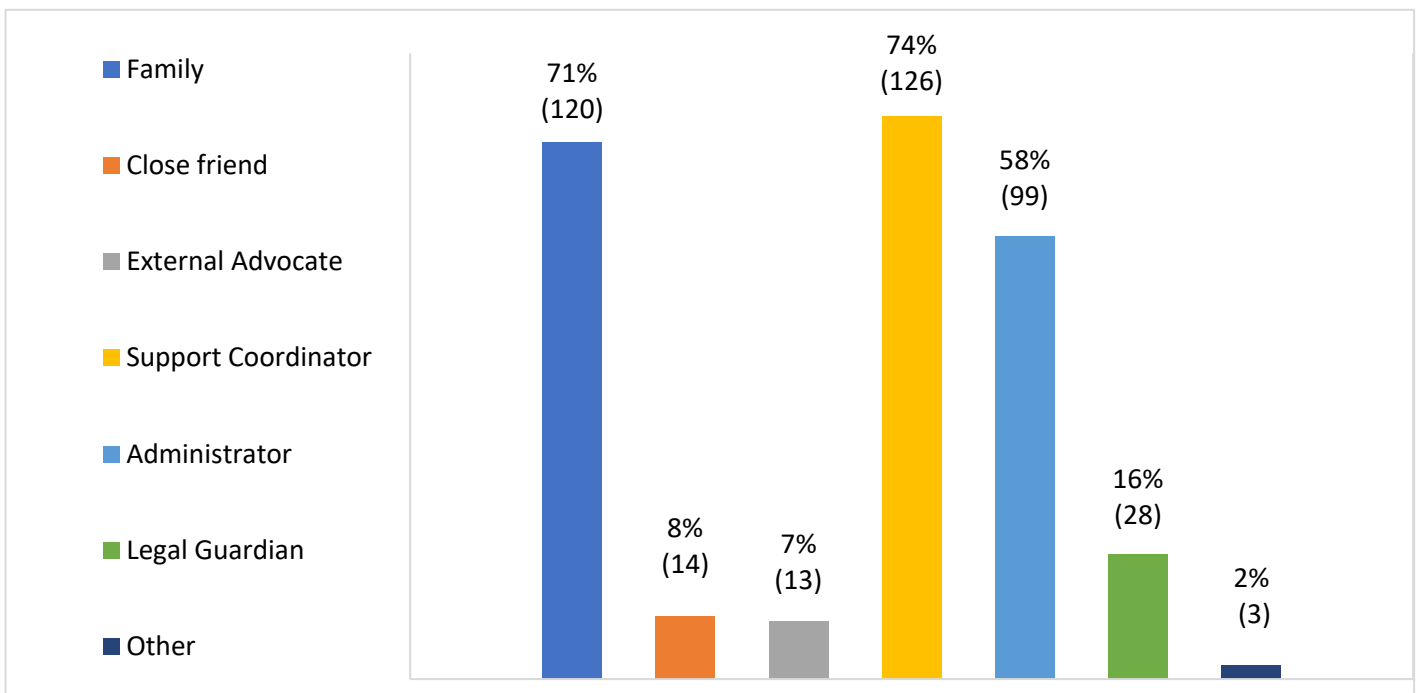
Q29. Has the person done self-advocacy or empowerment training?

Q29.2 If yes - Please specify?



People involved in the person's life – Q 30

Q30 Which of these people does this person have in their lives?



End of Data Set A



Data Set – B (This data cannot be quoted or used without the permission of VALID)

Participant Questionnaire & Graphs (based on ‘Good Life’ Domains)

Who should complete this questionnaire?

This section of the questionnaire is to be completed by interviewing the person with disabilities, where possible. Where required, the person may be assisted to complete the questionnaire or have certain questions answered on their behalf. This assistance should be provided by a staff member of the person who has a good understanding of various aspects of their life and the views and perspectives of the person.

Note: Interviewers can also ask questions in different ways if needed by the person, as long as the concept is the same/similar. For example, if the person struggles with ‘how happy are you with your home’ you could try ‘what do you think of your home’ or ‘do you like living in your home’. If they answer ‘yes’ to the latter version, you can then ask ‘is that a little or a lot’ to allow answers to be recorded on the 3-point happiness scale.

i. What is the name of the person with intellectual disability?

ii. Date of the review: _____

Q 1. The first question is about your life overall.

Q 2. What do you think of / how do you like...

- the things you get to do each day? [DL]
- the things you do in the community? [SCCP]
- your home? [HOM]
- the other people you live with? [HOM]
- how staff treat you? [EMP]

Q 3. Do staff support you to do things for yourself? [DL]

- Do you get to choose what you do each day? [EMP]
- Are you able to choose the things you buy? [EMP]
- Do you get to learn new things? [LL]

Q 4. Do you have a paid job? [WV]

- [If ‘no’] Would you like to get a paid job? [WV]
- Do you do any volunteering? [WV]
- [If ‘no’] Would you like to do volunteering? [WV]

Q 5. Do you have friends other than family or paid staff? [REL]

Q 6. What do you think of how often you get to see them? [REL]

Q 7. Do you have any family who are not currently living with you? [REL]





Q 8. What do you think of how often you see your family? [REL]

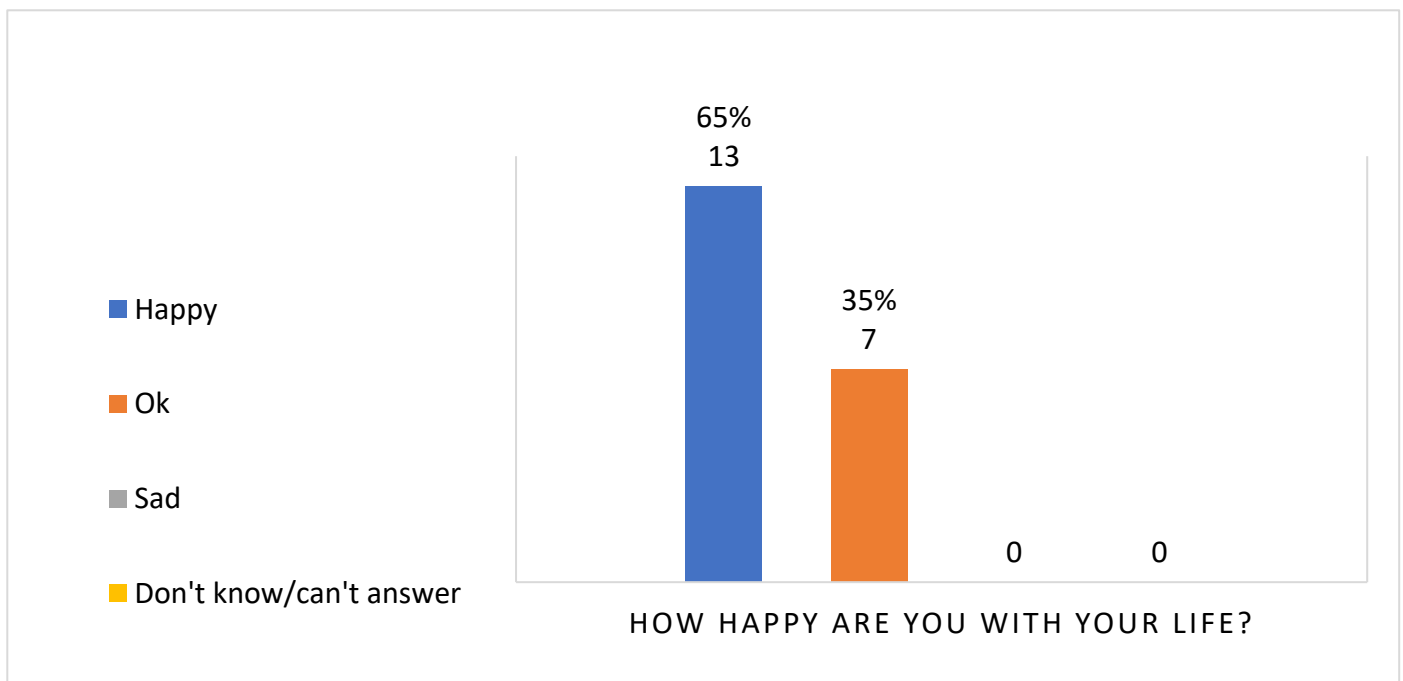
- Q 9. a. Do you feel lonely? [REL]
b. Do you feel sad? [HW]
- Q 10. Can you tell me more about why you [sometimes] feel this way?
- Q 11. In general / On most days, do you feel healthy? [HW]
- Q 12. Can you tell me more about why you are [sometimes] not feeling healthy?
- Q 13. Do you ever feel unsafe or scared? [HW]
- Q 14. Can you tell me more about why you [sometimes] feel unsafe or scared?
- Q 15. What makes you feel unsafe?
- Q 16. Do you know who to talk to if you have a problem?
- Q 17. Do you feel able to speak up (for yourself) if there is a problem? [EMP]
- Q 18. What would make life better for you now? What could we do to make things better?
- Q 19. Is there anything else you'd like to tell us?

Participant Questionnaire





Read out: *I am now going to ask you some questions about different parts of your life. (instructions in green)*

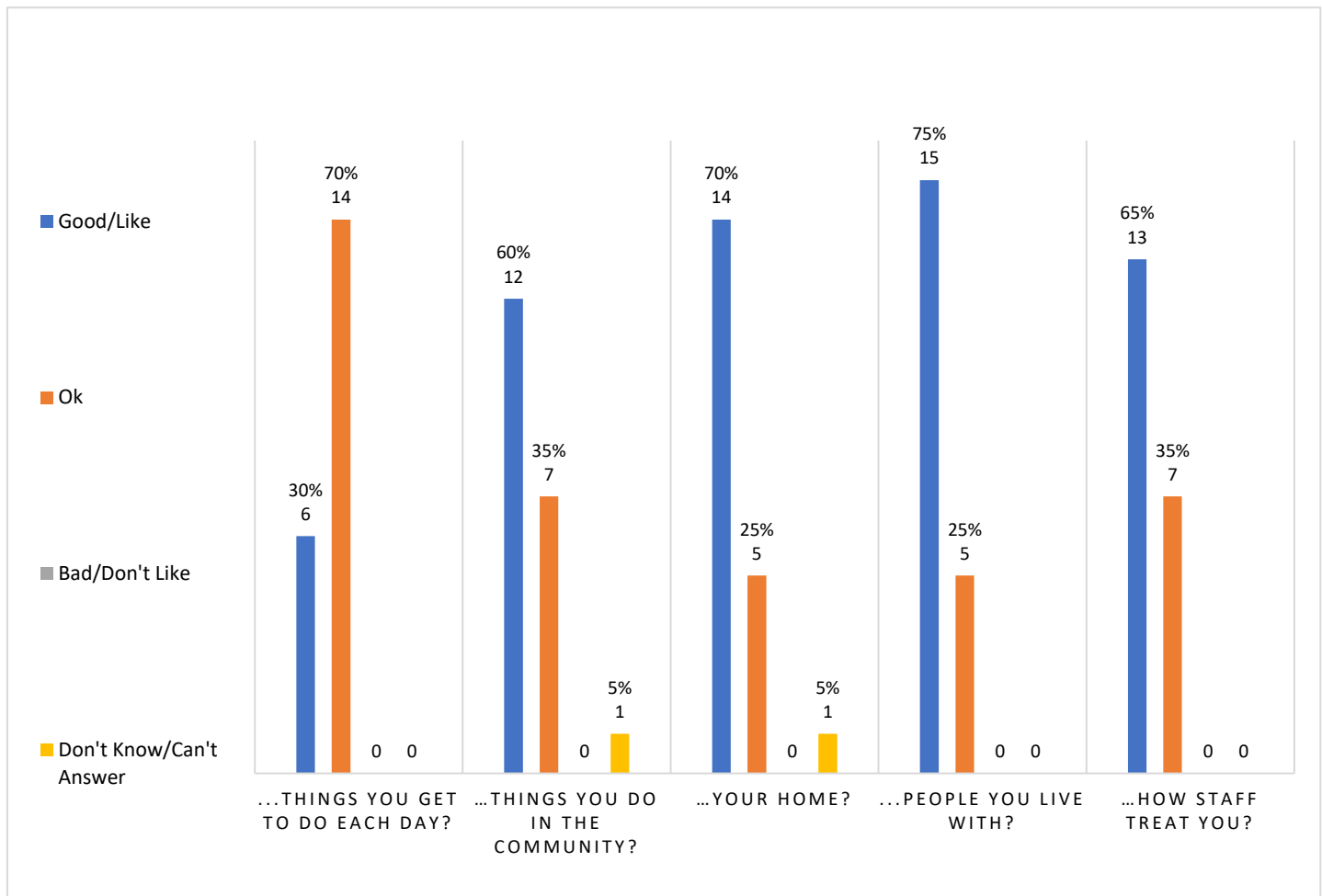
Q 1. The first question is about your life overall.

					
		Happy	OK	Sad	Don't Know/Can't Answer
1.	How happy are you with your life?	1	2	3	4







Read out: The next few questions are about what you think of certain things in your life, like where you live, the things you do and how you are treated.

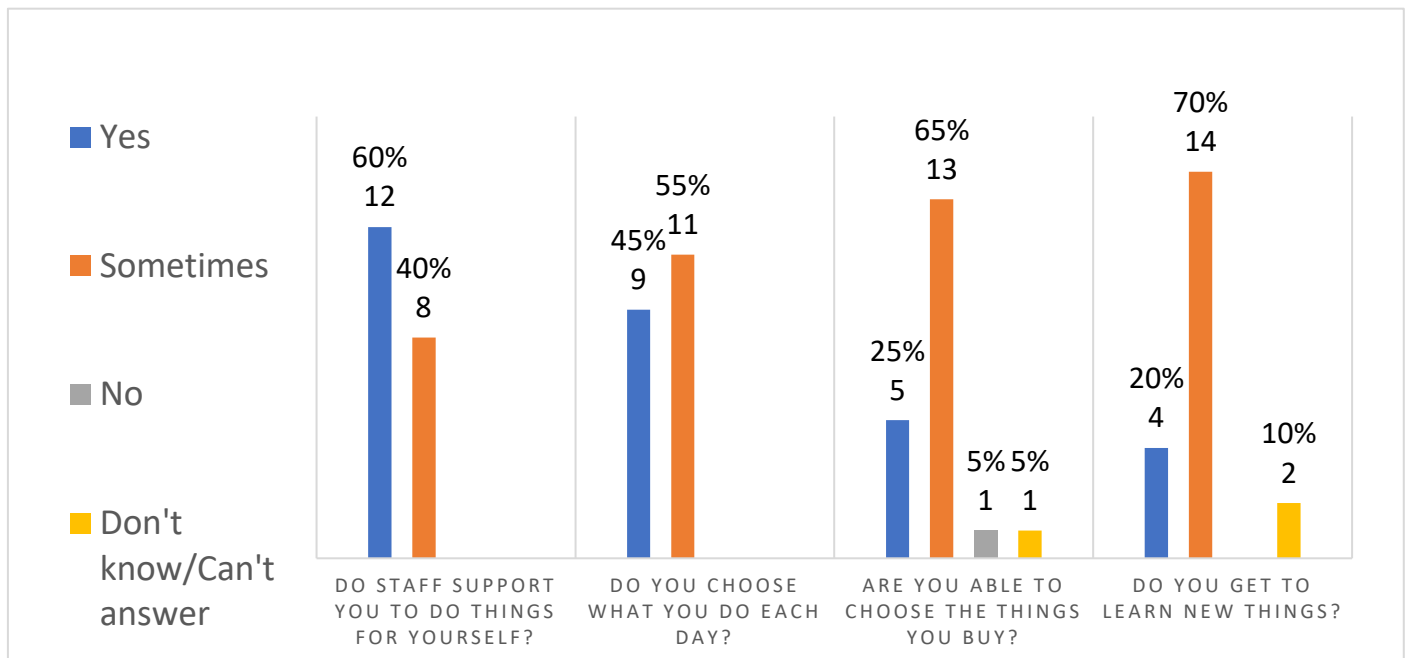
					
		Good / Like	OK	Bad / Don't like	Don't Know/Can't Answer
2.	What do you think of / how do you like...				
	... the things you get to do each day? [DL]	1	2	3	4
	... the things you do in the community? [SCCP]	1	2	3	4
	... your home? [HOM]	1	2	3	4
	... the other people you live with? [HOM]	1	2	3	4
	... how staff treat you? [EMP]	1	2	3	4



- It was good 70% of people liked their home
- 30% didn't like the things they do each day
- Tap into interests' / hobbies and look into support, hence recommendation for Support coordination

Read out: The next questions are about whether or not you get to choose the things you do and whether you get to do certain things.

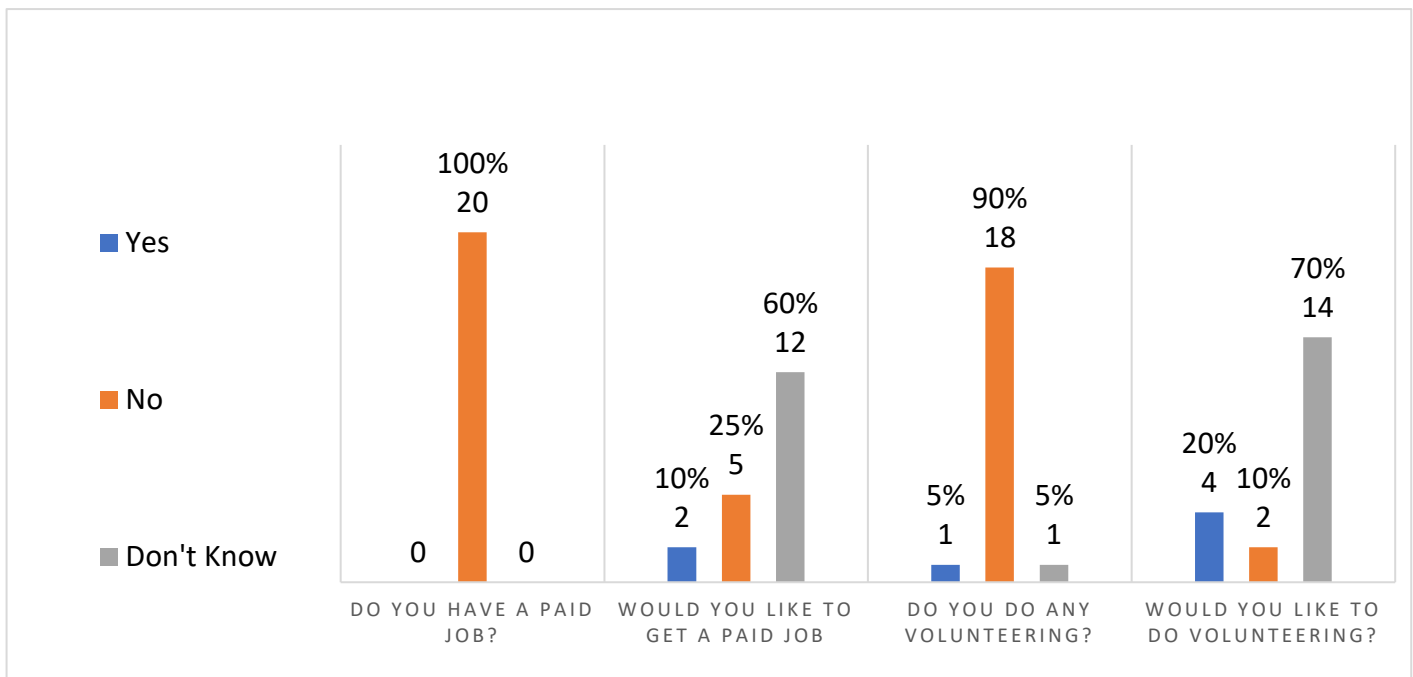
					
3.		Yes	Sometimes	No	Don't know / Can't Answer
	Do staff support you to do things for yourself? [DL]	1	2	3	4
	Do you get to choose what you do each day? [EMP]	1	2	3	4
	Are you able to choose the things you buy? [EMP]	1	2	3	4
	Do you get to learn new things? [LL]	1	2	3	4



- 60% of people said staff support them to do things for themselves
- 40% said that staff sometimes support them to do things for themselves
- 45% they choose what they do each day
- It was concerning to see that 55% of people said that only sometimes they get to choose what they do each day
- When asked are you able to choose the things you do 65% said sometimes
- It was positive to see only 1 person or 5% said no they were not able to choose the things they do
- It was concerning to see only 20% or 4 people get to learn new things
- 70% or 14 people said they get to learn new things sometimes




Read out: The next questions are about whether or not you are currently doing any paid or unpaid work.

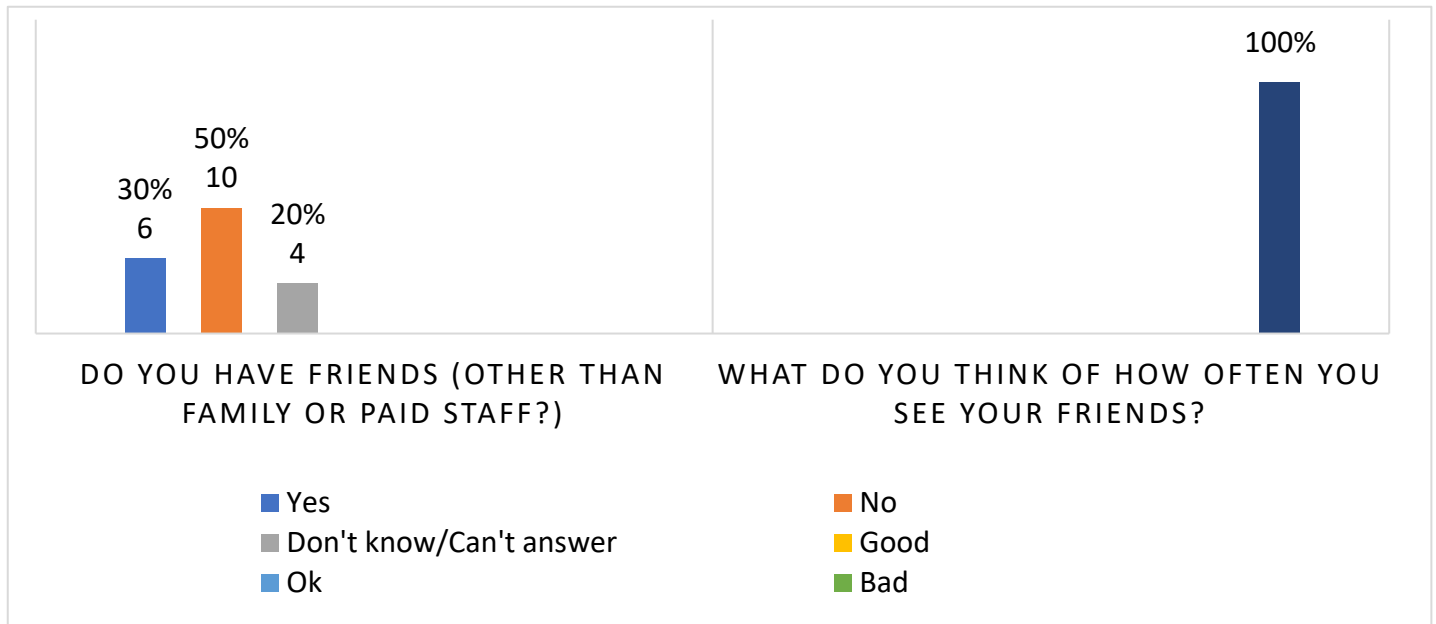
		✓	✗	?
4.		Yes	No	Don't know / Can't Answer
	Do you have a paid job? [WV]	1	2	3
	[If 'no'] Would you like to get a paid job? [WV]	1	2	3
	Do you do any volunteering? [WV]	1	2	3
	[If 'no'] Would you like to do volunteering? [WV]	1	2	3







- none, that is, 100% of the residents reported not having a job, but three in comments wanted other choices during the day
- 90% of people in the sample group are not volunteering (Graph K)
- 10% said they would like a paid job
- 25% No they did not want a paid job
- 60% indicated they didn't know if they wanted a paid job
- 5% said they do volunteer
- 5% said they did not know if they volunteered
- 20% they would you like to Volunteer
- 10% they don't want to volunteering
- 70% said they don't know if they want to volunteer

Read out: The next few questions are about the people you know and how happy you are with your chance to meet your friends and do things with them.

				
		Yes	No	Don't know / Can't Answer
5.	Do you have friends other than family or paid staff? [REL]	1	2	3






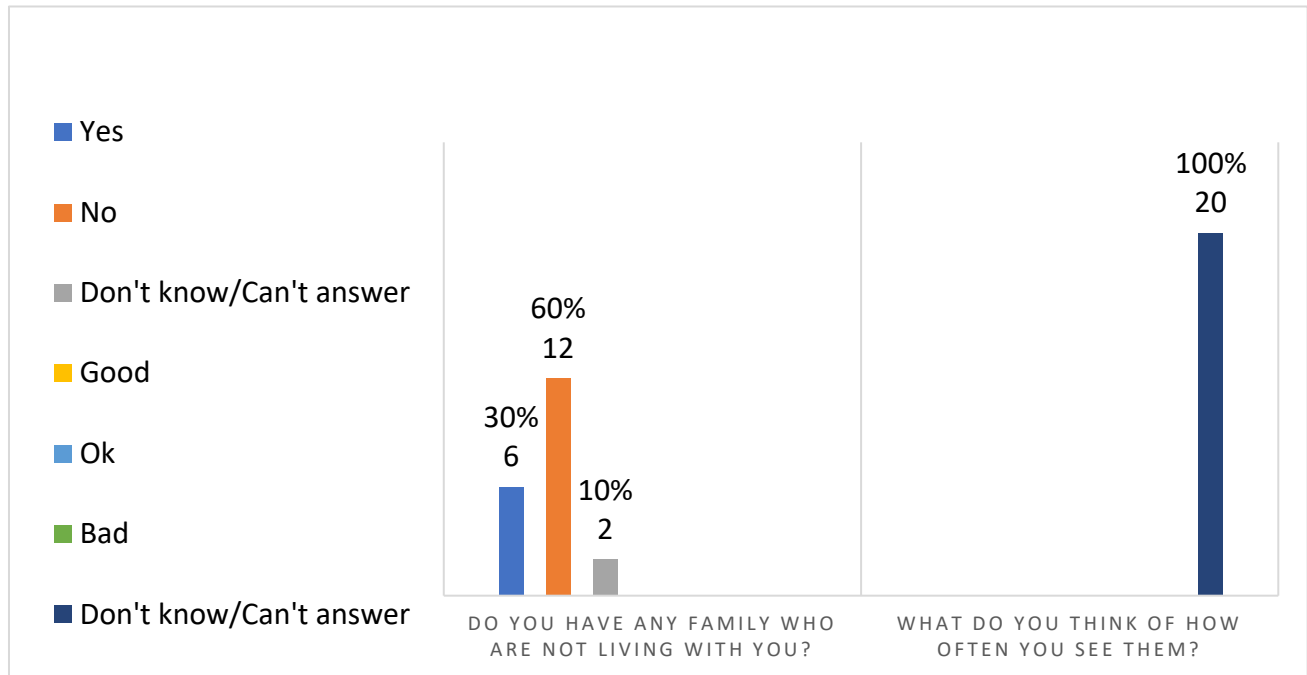
- Only 30% said they had friends
- 50% of people said they did not have friends other than paid staff or family
- 20% said they did not know or couldn't answer
- 100% were unable to tell us or did not know what they thought of how often they got to see their friends

					
		Good	OK	Bad	Don't know/Can't Answer
6.	... [ask this question if the person has friends based on question 0Error! Reference source not found. in Part 1] What do you think of how often you see your friends? [REL]	1	2	3	4





Due to the communication impairments and the impacts of Covid lockdown, all residents have been stuck at home not attending usual programs and/or seeing their friends in social activities. So, we can't make any assumptions about people not being happy with how much they see friends.

Q. 6 results.

					
			Yes	No	Don't know / Can't Answer
7.		Do you have any family who are not currently living with you? [REL]	1	2	3







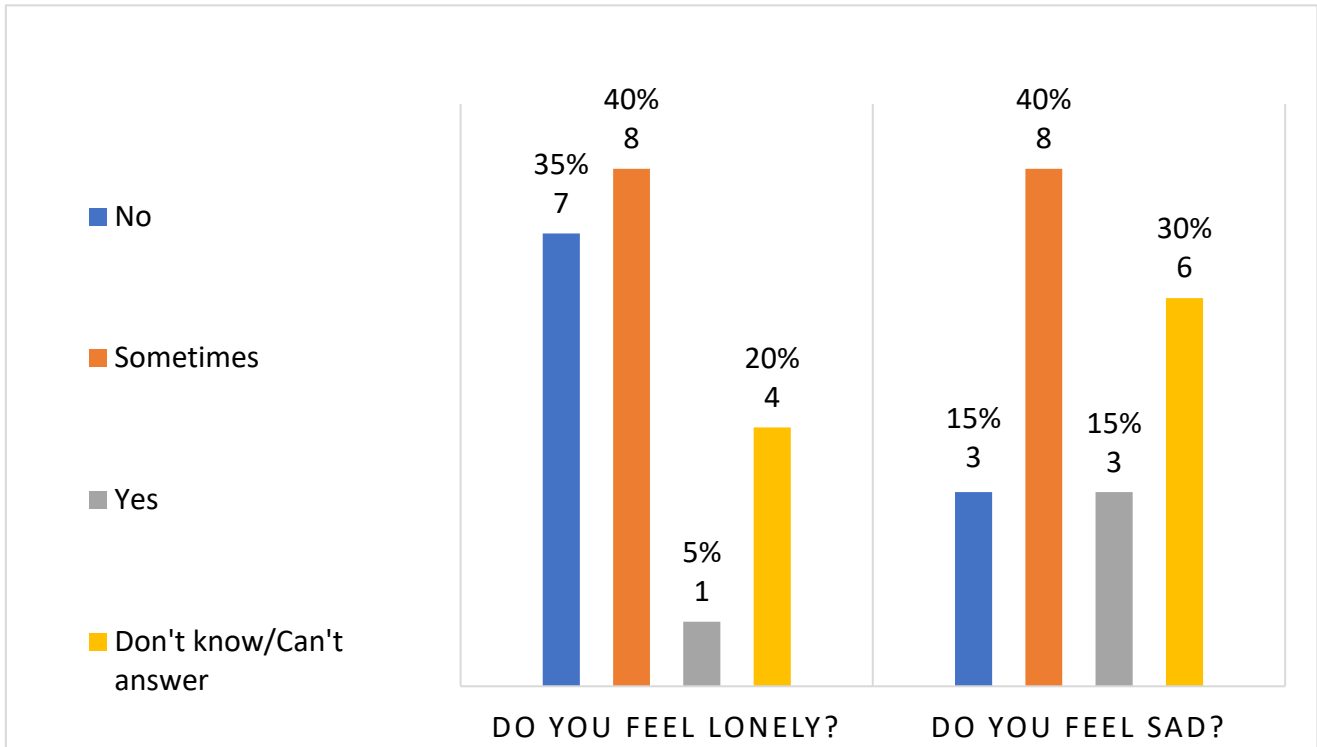
- 100% were unable to tell us or did not know what they thought of how often they got to see their friends (Graph H)
- 30% said they had friends and 50% of people said they did not have friends other than paid staff or family

					
		Good	OK	Bad	Don't know/Can't Answer
8.	[ask this question if the person has family based on question 0b in Part 1]] What do you think of how often you see your family? [REL]	1	2	3	4

No Answers were given

The next few questions are about your health and how you are feeling.

					
9.		No	Sometimes	Yes	Don't know/Can't Answer
	Do you feel lonely? [REL]	1	2	3	4
	Do you feel sad? [HW]	1	2	3	4







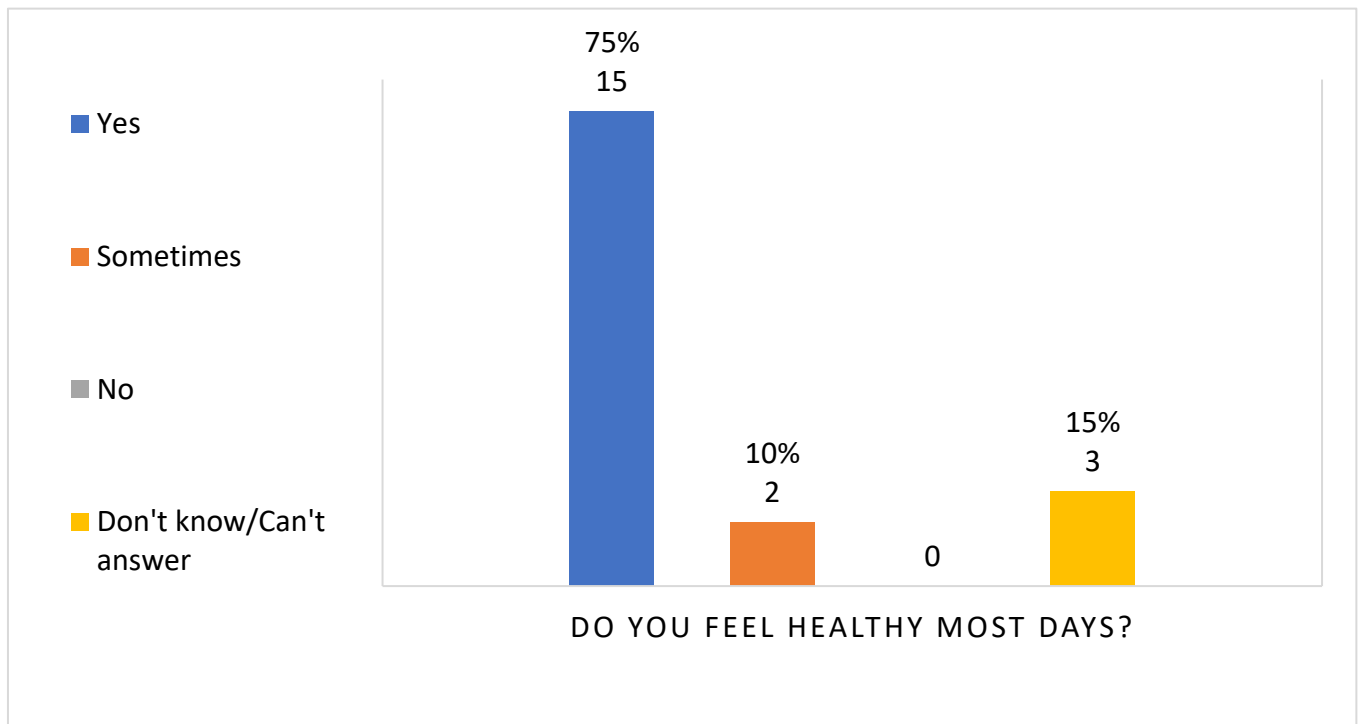
- When asked 'do you ever feel lonely?' 35% said no
- 40% said they feel lonely sometimes
- 1 person said 'yes' they feel lonely
- 20% did not know or could not answer if they felt lonely
- When asked 'do you ever feel sad?' 15% said yes
- 40% said sometimes which reflects the possible 40% who said they also felt lonely
- Only 3 people or 15% said no, they didn't feel say
- 6 people or 30% did not know or could not tell us if they felt sad

10. If 'yes' or 'sometimes' to questions **Error! Reference source not found.** or **Error! Reference source not found.**, ask: Can you tell me more about why you [sometimes] feel this way? [Probe for what makes them lonely sad/when it happens – if needed].

Some answers were based on staff interpretation and observation through historic understanding and knowledge of a person while some answers were from individuals themselves.





(Data provided and kept confidential)

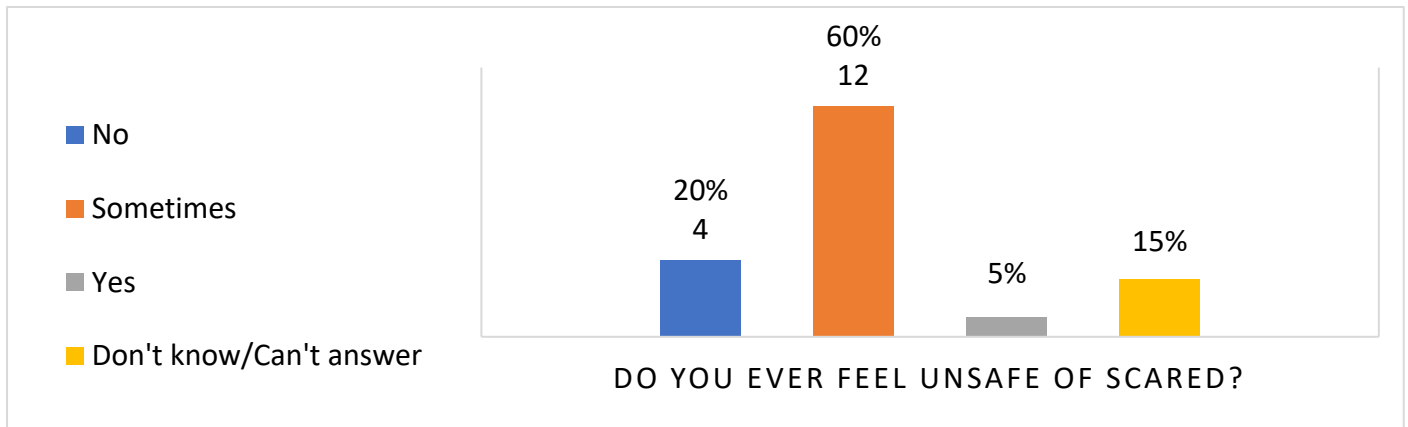
					
		Yes	Sometimes	No	Don't know/Can't Answer
11.	In general / On most days, do you feel healthy? [HW]	1	2	3	4



12. If 'yes' or 'sometimes' to question, ask. Can you tell me more about why you are [sometimes] not feeling healthy? [Probe for what makes them feel unhealthy – if needed].

(Data provided and kept confidential)

					
		No	Sometimes	Yes	Don't know/Can't Answer
13.	Do you ever feel unsafe or scared? [HW]	1	2	3	4



- 60% felt unsafe sometimes and 40% said that they felt sad sometimes
- I was concerning that only 20% of people when asked if they ever feel unsafe or scared said No
- Only one person or 5% yes they do feel unsafe and scared
- 3 people or 15% said they don't know or couldn't answer

If 'yes' or 'sometimes' to question **Error! Reference source not found.**, ask: Can you tell me more about why you [sometimes] feel unsafe or scared? [Probe for what makes them feel unsafe/when it happens – if needed].

Some answers were based on staff interpretation and observation through historic understanding and knowledge of a person while some answers were from individuals themselves.

(Data provided and kept confidential)

14. If 'yes' or 'sometimes' to question **Error! Reference source not found.**, fill out the following question based on answer to question **0** or probe further about: What makes you feel unsafe? [Do not read out options, Select all that apply]

(Data provided and kept confidential for the following questions)

At home

1. Staff in your home
2. Other residents in your home
3. The physical environment of the home [Please specify which aspect:_____]

At work / day programs

4. Staff at your work / day programs
5. Other people at work / day programs
6. Workplace / day program location [Please specify which aspect and location:_____]




In the community

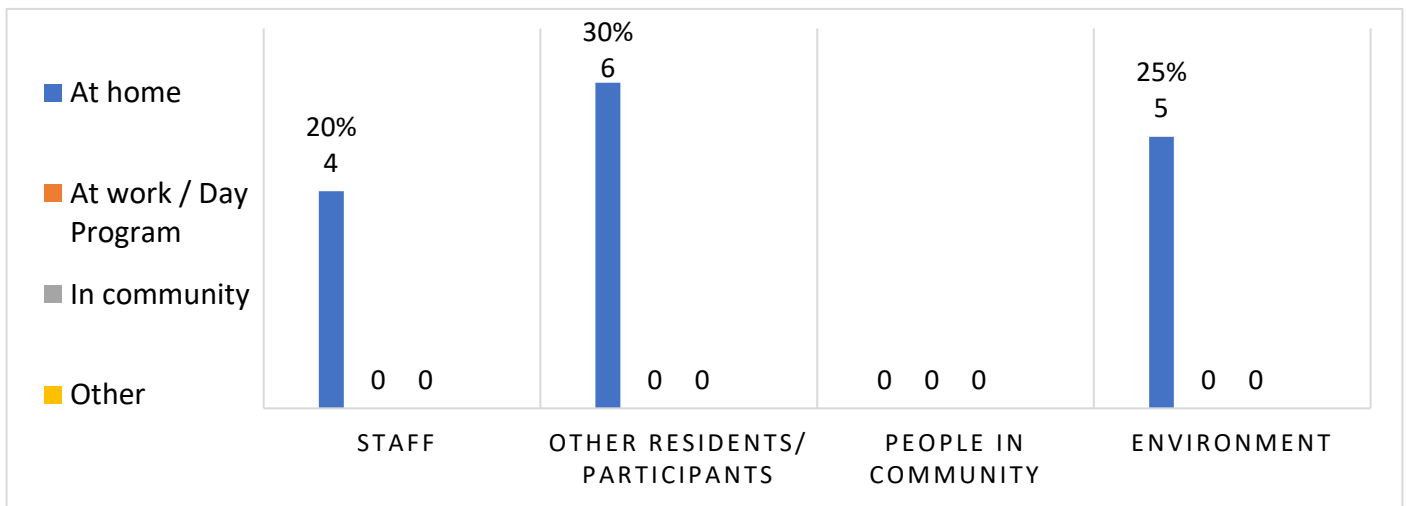
7. People in the community
8. Community location [Please specify which location:_____]





Other

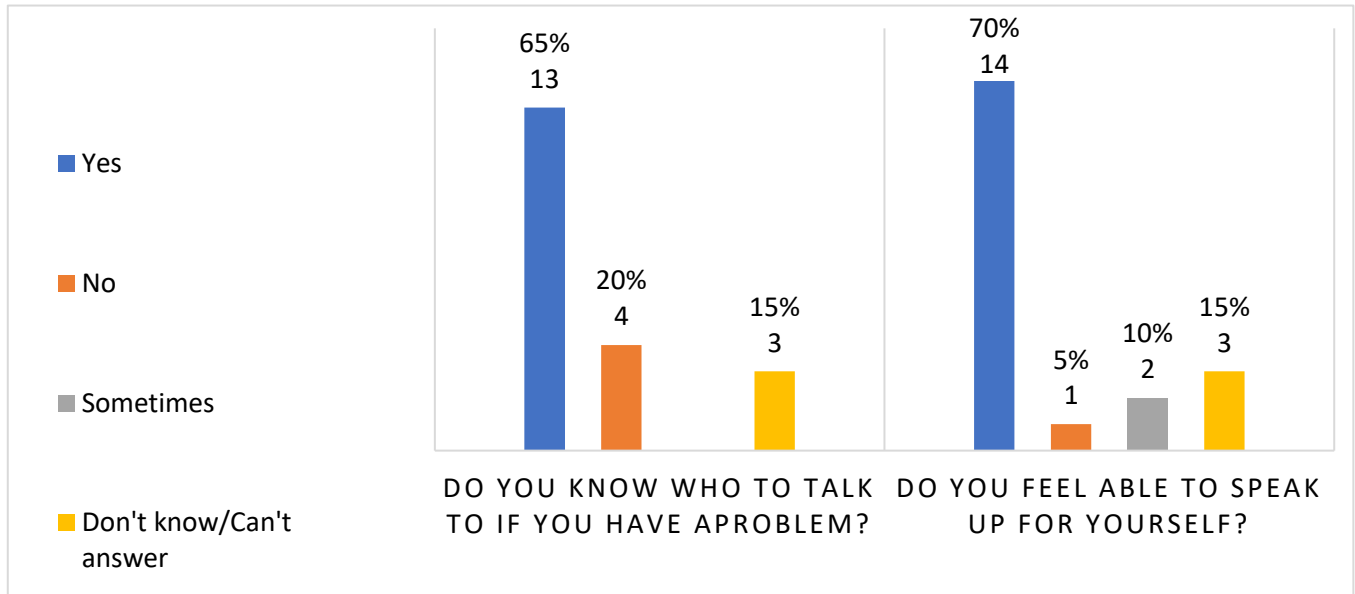
9. Other [please specify]:_____]

Read out: The next questions are about how much support you get to do things yourself and whether you get to have a say in important things in your life.

				
		Yes	No	Don't know / Can't Answer
15.	Do you know who to talk to if you have a problem?	1	2	3



					
		Yes	Sometimes	No	Don't know / Can't Answer
16.	Do you feel able to speak up (for yourself) if there is a problem? [EMP]	1	2	3	4



17. What would make life better for you now? What could we do to make things better?

- while 60% said that they liked the things they did in the community, there were a range of responses indicating residents wanted to be able to do other things including the desire to go out for a meal, a comment that there isn't much choice of Day Programs and several wanting to go on specific outings (Question 18)

(Data provided and kept confidential)

18. Is there anything else you'd like to tell us?

(Data provided and kept confidential)

End of Data Set B

Data Set – C (This data cannot be quoted or used without the permission of VALID)

Staff Questionnaire and Graphs

Who should complete this questionnaire?

This questionnaire is to be completed by a staff member who is best able to comment on the life of the person with intellectual disabilities and give answers based on your experience and knowledge of the person. Ideally, all questions should be completed by a staff member responsible for supporting the person in their current home environment (where possible). to enable a balanced assessment of the person's life situation, wellbeing and views from your perspective as well as to complement the attitudinal questions completed by the person with a disability to provide a more complete assessment of key aspects of the person's life.

About the person (participant/resident) – Q 1-8

Q 1. Did you complete the P.S. Project preliminary administrative questionnaire and/or the initial assessment questionnaire for this person?

Q 2. What is your name? _____

Q 3. What is the name of your service (where you work)? _____

Q 4. What type of service(s) does your service provide for the person with intellectual disability?

- Residential accommodation service
- Other disability service(s) [Please specify]: _____
- Other services [Please specify]: _____

Q 5. Did you complete the P.S. Project preliminary administrative questionnaire and/or the initial assessment questionnaire for this person?

Q 6. What is your position?

Q 7. How long have you worked closely with the person with intellectual disability (had regular contact, provided direct support)?

Home – Q 8-8b

Q 8. Please answer the following questions about the persons' satisfaction with aspects of their current home. In your opinion:

- a. Is the person happy where they live?
- b. Does the person get along with their house mates?

Daily Living – Q 9-11

Q 9. Please answer the following questions about the extent the person's support requirements and ability to conduct daily tasks, including with support.

Q 10. Have there been any significant changes in their support needs in the last 6 months?

Q 11. Please briefly describe which aspects of their support needs have changes and how?



Relationships – Q 12-17

This section includes questions about the personal relationships of the person.

Q 12. Does the person have any of the following relationships?

- a. A close friend(s) who is not family or paid staff
- b. A family member(s) who have had at least some meaningful contact (e.g. more than just birthday/Christmas cards) within the last year

Q 13. How often does this person receive visitors other than paid staff? (For the purpose of this questionnaire, this is someone that comes to the home specifically to visit them).

Q 14. What relation to this person are these visitors?

Q 15. How often does this person visit or spend time outside of the home with people (excluding paid staff or people who live with them) to maintain a relationship or friendship?

Q 16. Which of these people does the person visit or spend time with outside the home?

Q 17. How often does this person have contact with people outside their home using telephone or digital means (e.g. Zoom, Facebook, Email, SMS)?

Health and wellbeing – Q 18-24

This section includes questions about the health and wellbeing of the person.

Q 18. Has this person had a health check-up with a doctor in the last 12 months?

Q 19. Has this person had a check-up with a dentist in the last 12 months?

Q 20. Does this person have access to counselling services where required (whether or not they have used them)?

Q 21. Does this person have a current Behaviour Support Plan?

Q 22. Has the person been subjected to restrictive practices in the last 12 months?

Q 23. To the best of your knowledge, how often does the person feel safe in their home environment with the following people?

- a. Housemates
- b. Staff
- c. Visitors

Q 24. Please describe the circumstances that the person does not feel safe.

Lifelong learning – Q 25-27b

This section includes questions about access to learning for the person.

Q 25. Has this person participated in any education or training courses in the last 12 months?

Q 26. How many courses have they taken part in over this period? _____

Q 27 i. In the last 6 months has this person been supported to:

- a. develop a new skill?
- b. maintain their skills / use the skills learnt on a regular basis?

Work and volunteering – Q 28-30

This section includes questions about the involvement of the person in activities that may provide a sense of achievement or enjoyment for the person.

Q 28. Is the person currently working in a paid job?

Q 29. Is the person currently volunteering?

Q 30. Is the person currently looking for work (paid or unpaid)?

Social, community and civic participation – Q 31-32

This section includes questions about the involvement of the person in the community.

Q 31. Does the person participate in any of the following activities outside the home regularly (at least weekly for routine activities and at least every two months for infrequent events)?

- a. Physical activities, like: sports, dance, physical games, swimming, gym, yoga
- b. Social activities, like: board games, multiplayer video games, catching up with friends, movies
- c. Creative activities, like: music lessons, art groups
- d. Religious/spiritual activities, like Church
- e. Attending cafes, restaurants, pubs
- f. Attending events, like: theatre, football, live music, galleries
- g. Other [please specify]____

Q 32 a: Has this person been a member of any community groups in the last 6 months (e.g. ParkRun, football, knitting/craft, train spotting, car club etc)?

Empowerment – Q 33-36

This section includes questions about the extent to which the person has choice and control over their activities and services and are able to exercise their rights.

Q 33. Has the person completed a self-advocacy course?

Q 34. In your opinion, how often would the person speak up about things they are not happy about (e.g. things they don't want to do, things they don't want to eat, issues with people they live with)?

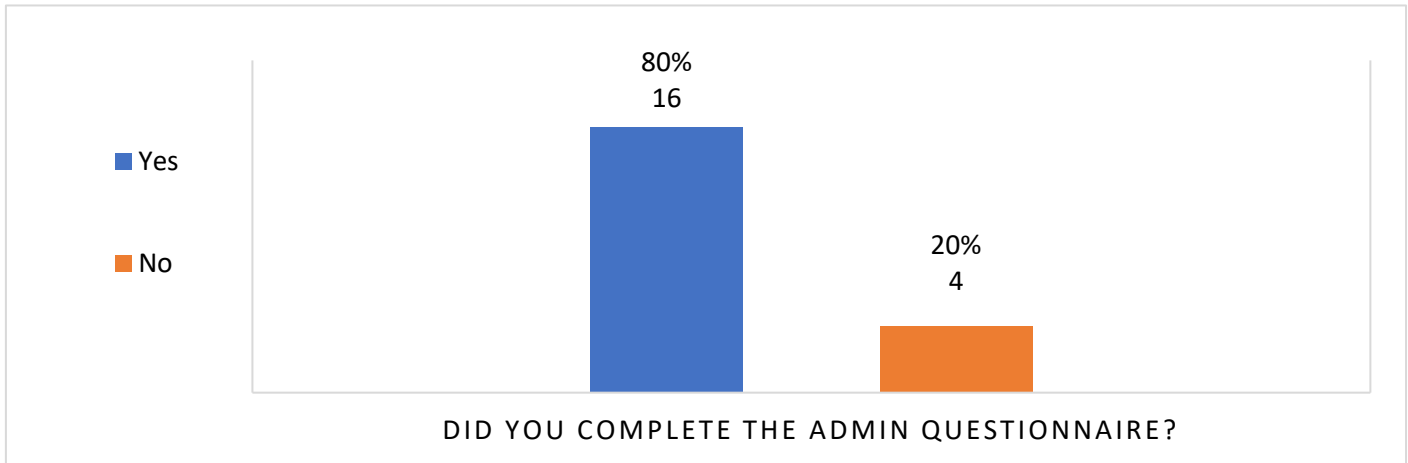
Q 35. Has the person ever made a formal complaint about the services they receive?

Q 36. To the best of your knowledge, what was the outcome of this complaint?

About the person – Q 1-8

1. Did you complete the P.S. Project preliminary administrative questionnaire and/or the initial assessment questionnaire for this person?

(The next few questions were included in the preliminary questionnaire and the initial assessment questionnaire do not need to be answered if you have done so already.)



- 80% of staff who completed the Baseline Questionnaire also completed the Admin questionnaire. Leaving 20% or 4 staff who only completed the Baseline questionnaire.

Q 2. What is your name? _____

(Data provided and kept confidential for the following questions)

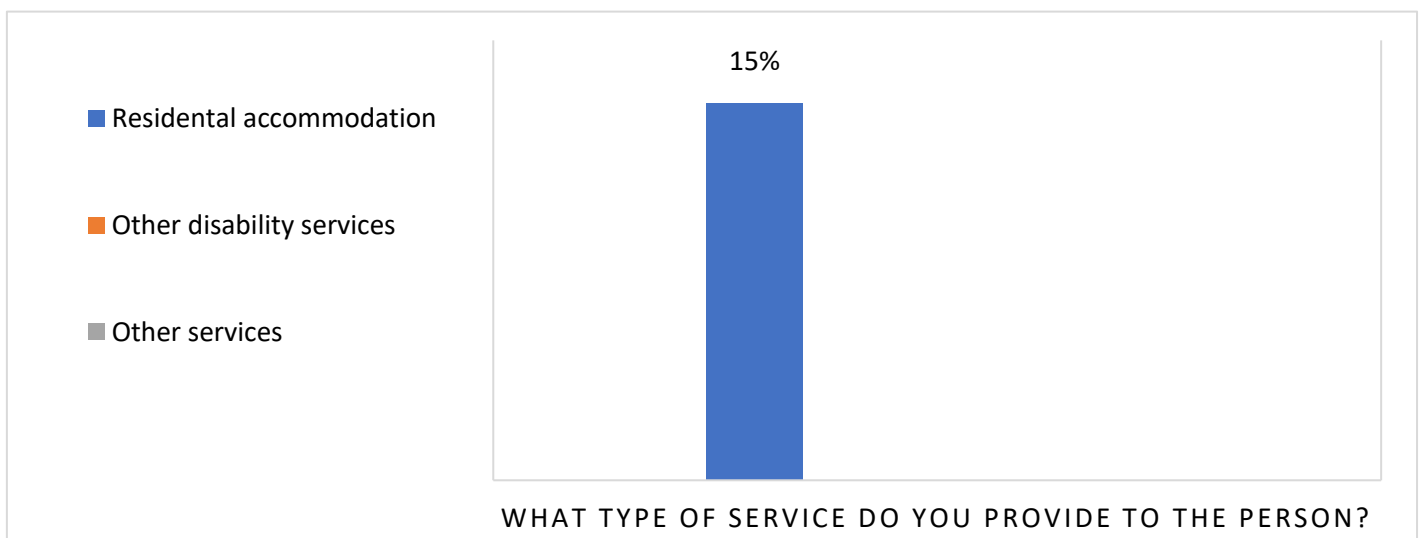
Q 3. What is the name of your service (where you work)? _____

Note: Only 4 people answered Q3

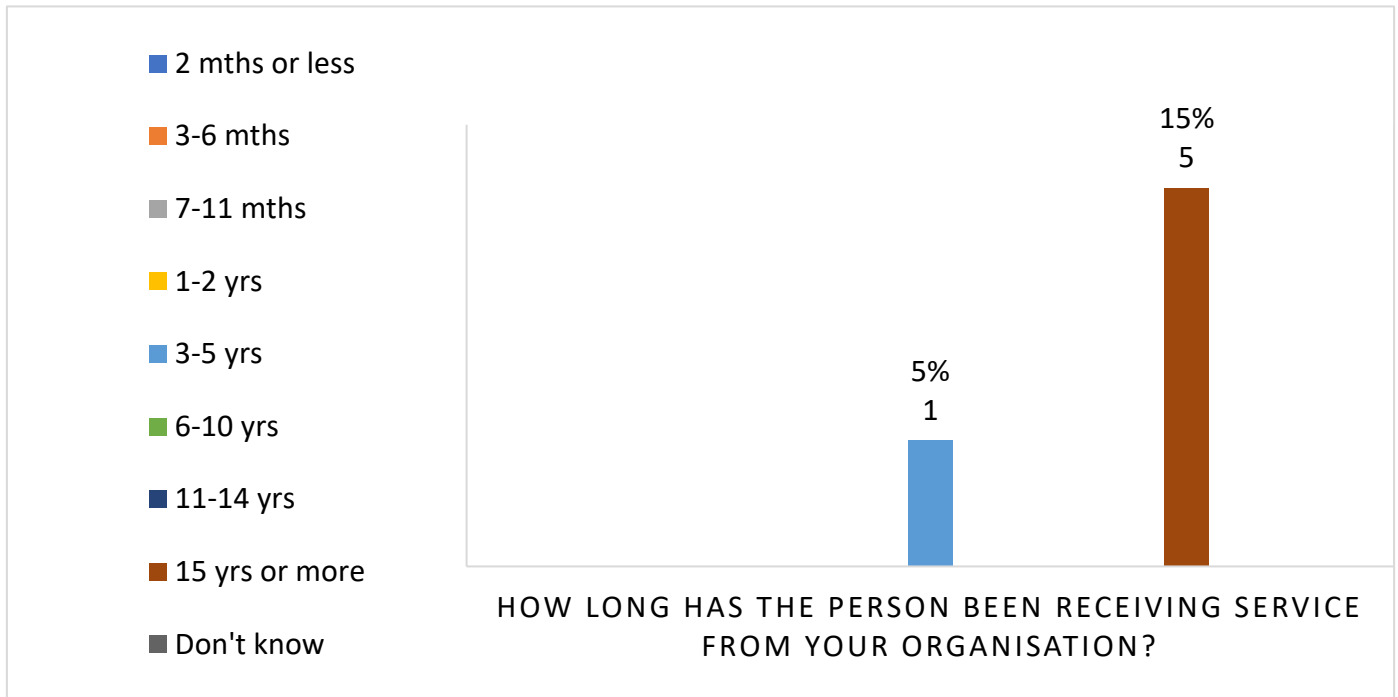
(Data provided and kept confidential for the following questions)

Q 4. What type of service(s) does your service provide for the person with intellectual disability?

Note: Only 3 people answered Q4

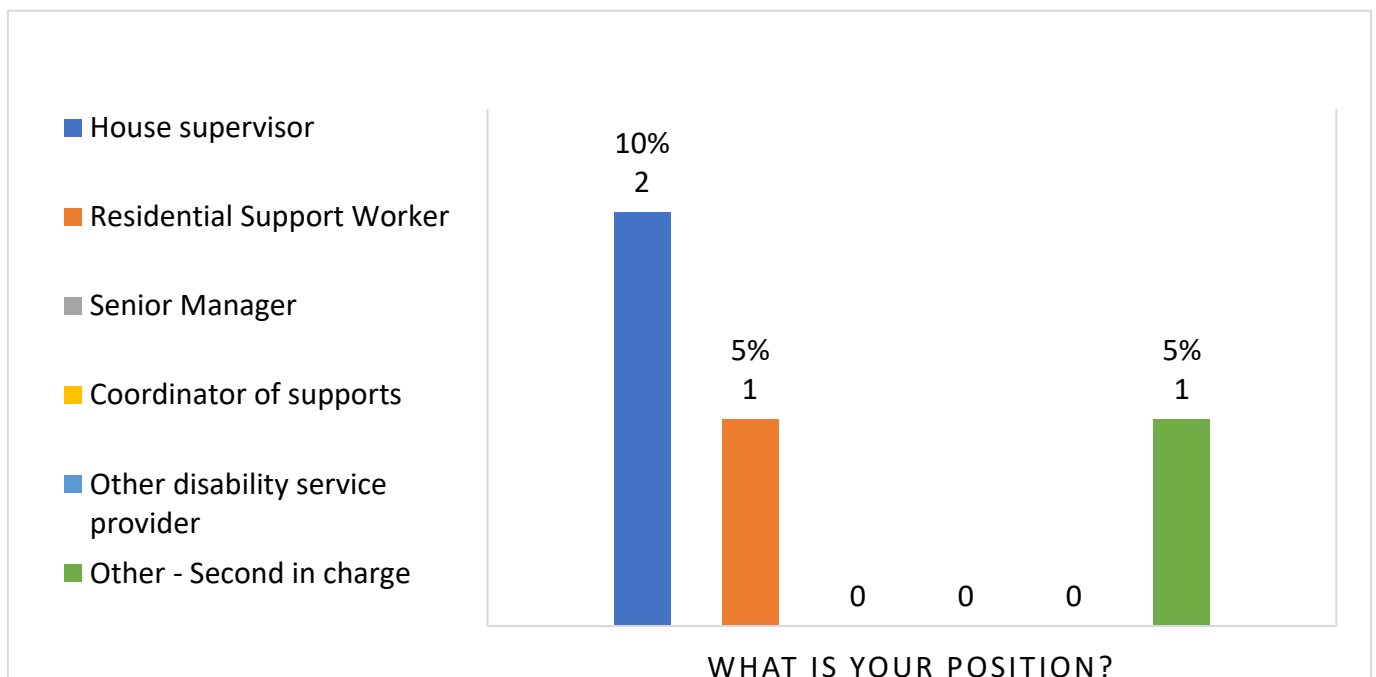


Q 5. How long has the person been receiving services from your organisation?

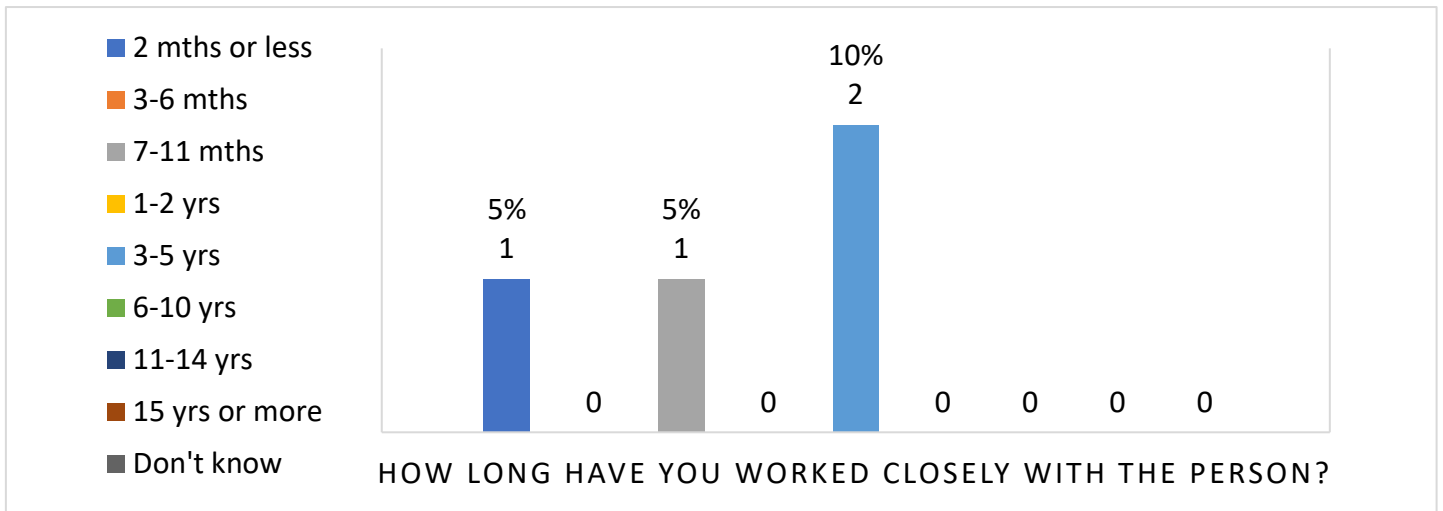


- 1 person or 5% of the sample group have received services for 3-5 years.
- 15% or 5 people have received services from the organisation for 15 years or more.
- 80% of staff did not answer the question, we presume because they did not know how long the resident had lived in the house

Q 6. What is your position?



Q 7. How long have you worked closely with the person with intellectual disability (had regular contact, provided direct support)?



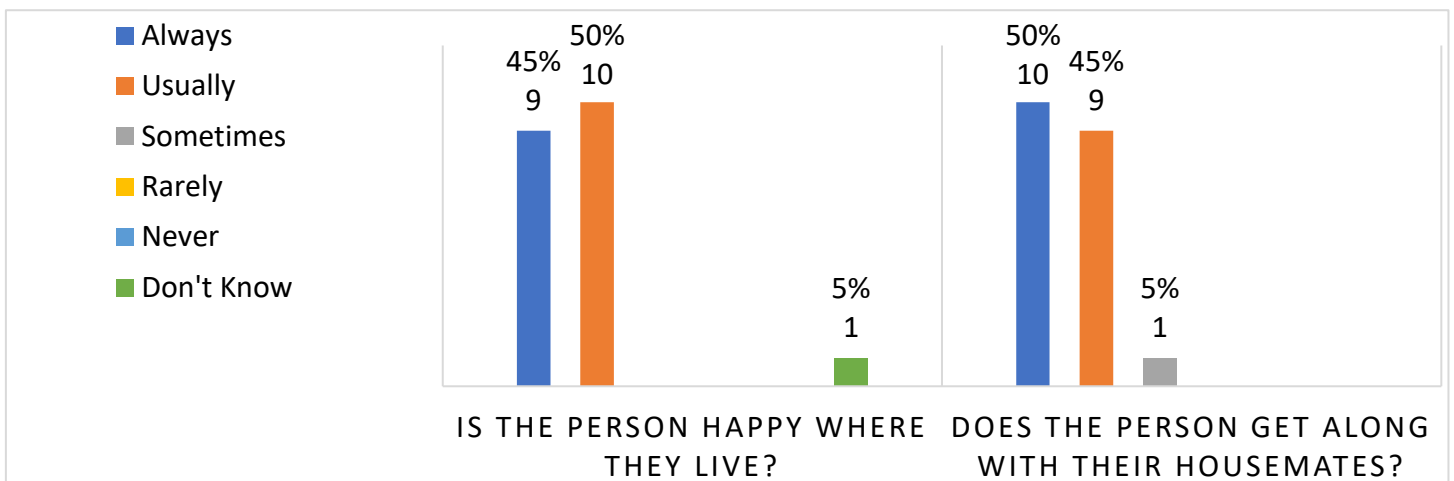
- 10% or 2 staff persons have worked closely with individuals for 3-5 years
- 1 staff person who completed the questionnaire has worked closely with the person for 2 months or less
- 1 staff person who completed the questionnaire has worked closely with the person for 7-11 months
- 80% of staff did not respond to the question

Home – Q 8-8b

Q 8. Please answer the following questions about the persons' satisfaction with aspects of their current home.

In your opinion

- Is the person happy where they live?
- Does the person get along with their house mates?



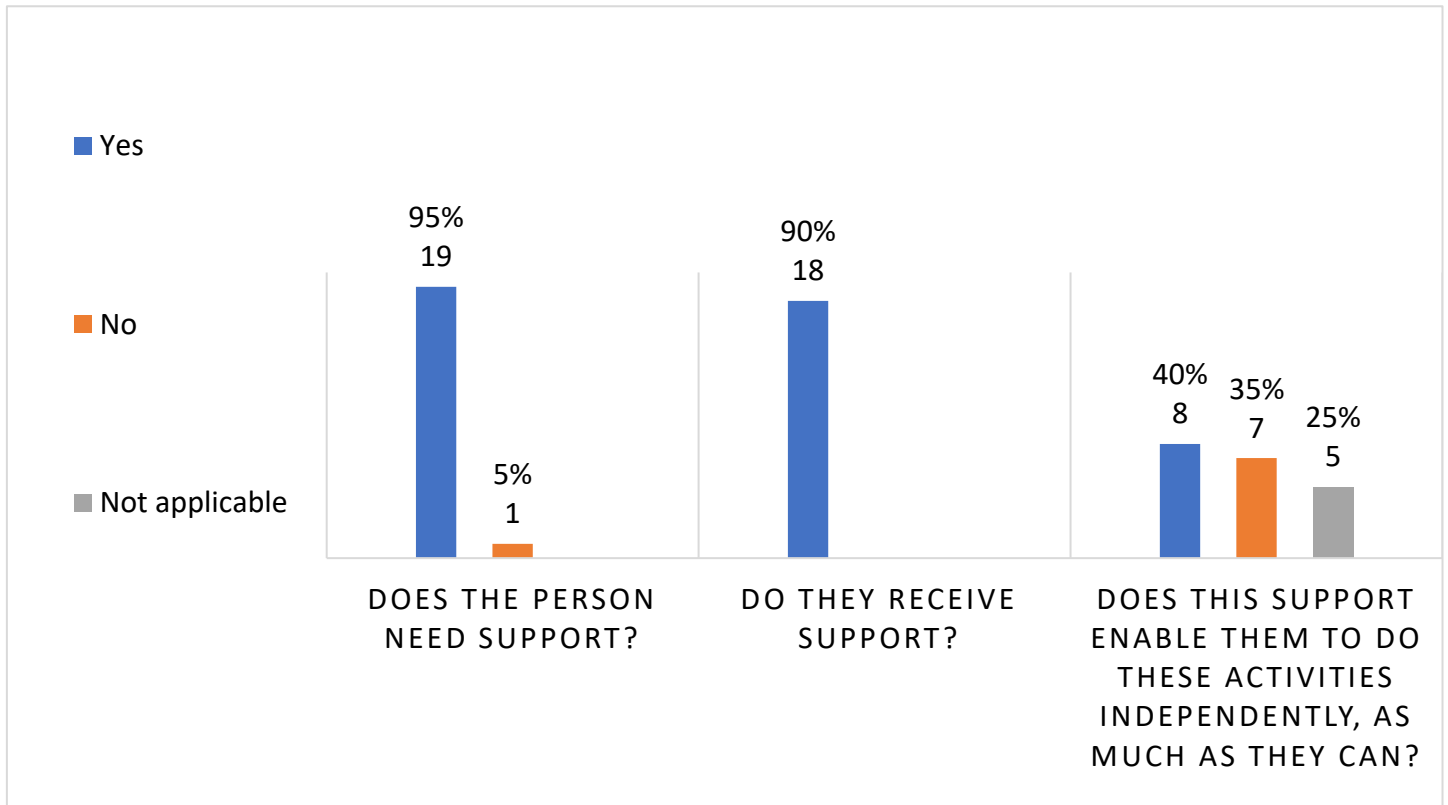
- Staff said 45% or 9 people were always happy with where they live and that 50% always got along with their house mates.
- 50% of people were identified as being usually happy with where they live and 45% were identified as getting along with their house mates
- 1 person was identified as only sometimes getting along with house mates
- 5% or 1 person was unable to tell us if the person was happy/unhappy with where they live

Daily Living – Q9-11

Q 9. Please answer the following questions about the extent the person's support requirements and ability to conduct daily tasks, including with support.

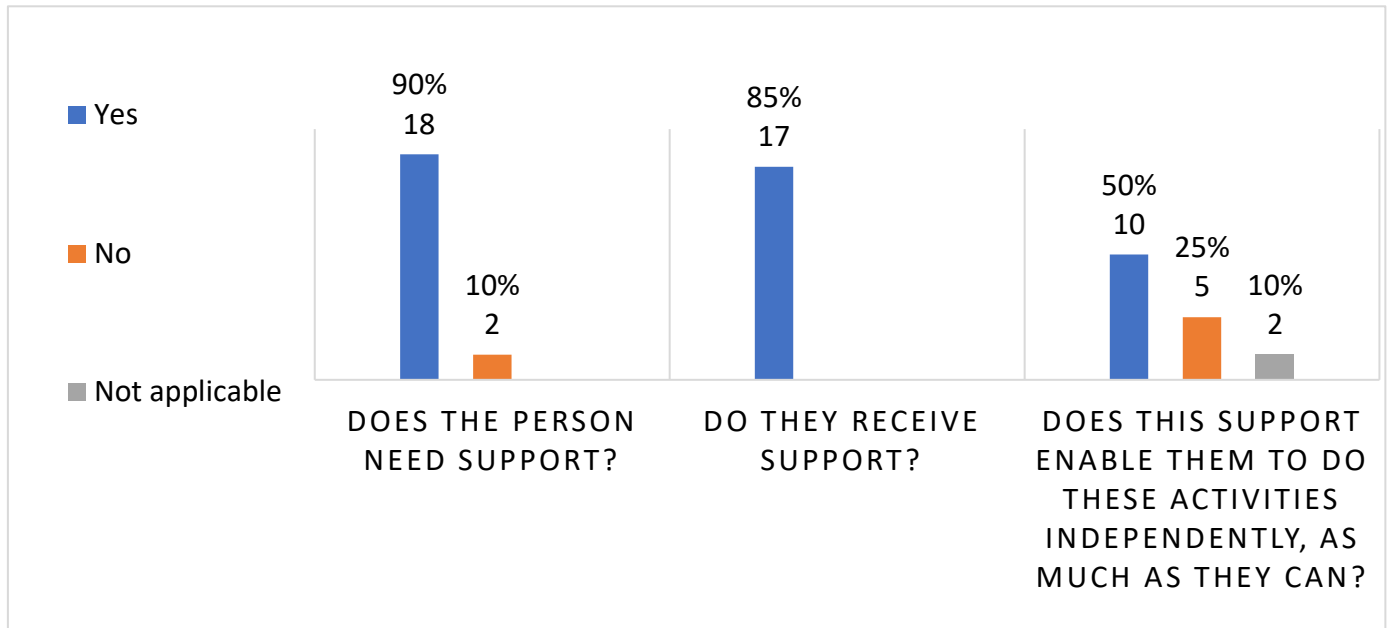
- i. Does the person need support with any of the following?
- ii. [If 'yes' to part i] Do they receive support with this activity?
- iii. [If 'yes' to part ii] Does this support enable them to do these activities independently, as much as they can?

A. Domestic tasks



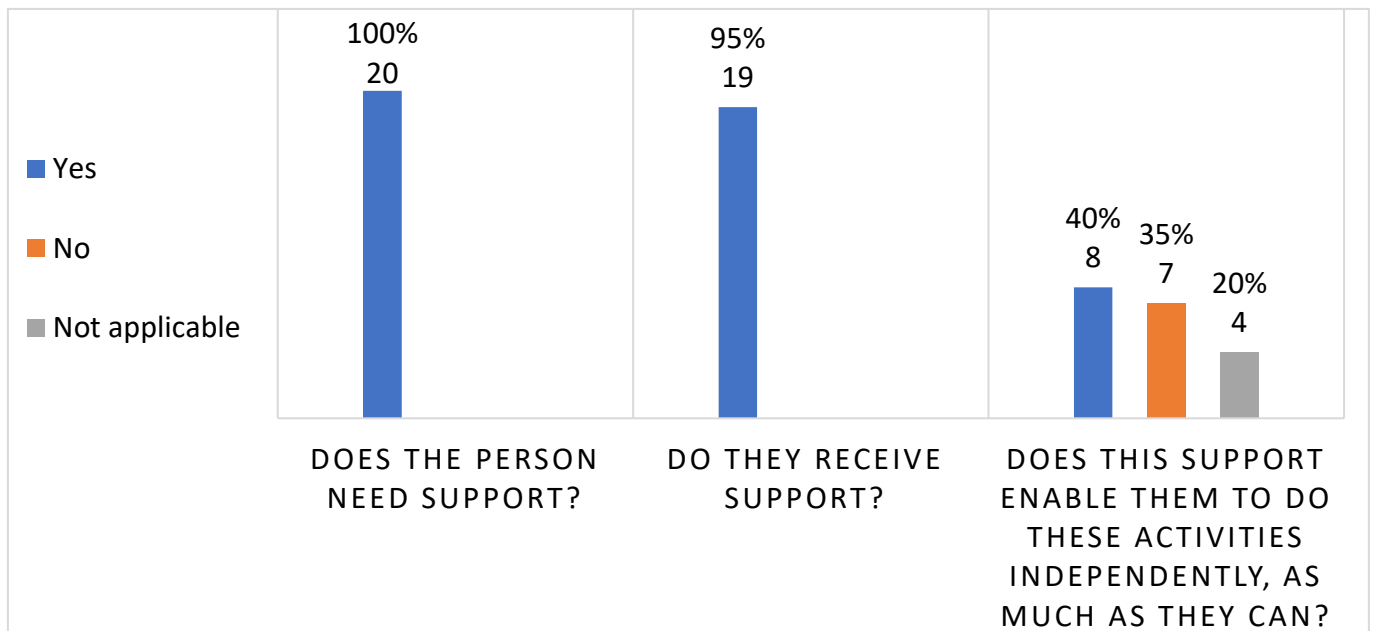
- 19 of the 20 people need support with domestic tasks 18 receive support
- 8 people or 40% of people were reported as being able to do their domestic tasks on their own as much as they can due to the support they received
- 7 people were noted as still needing support or not being able to do domestic tasks even with the support they received

B. Personal care (e.g. washing themselves, dressing)



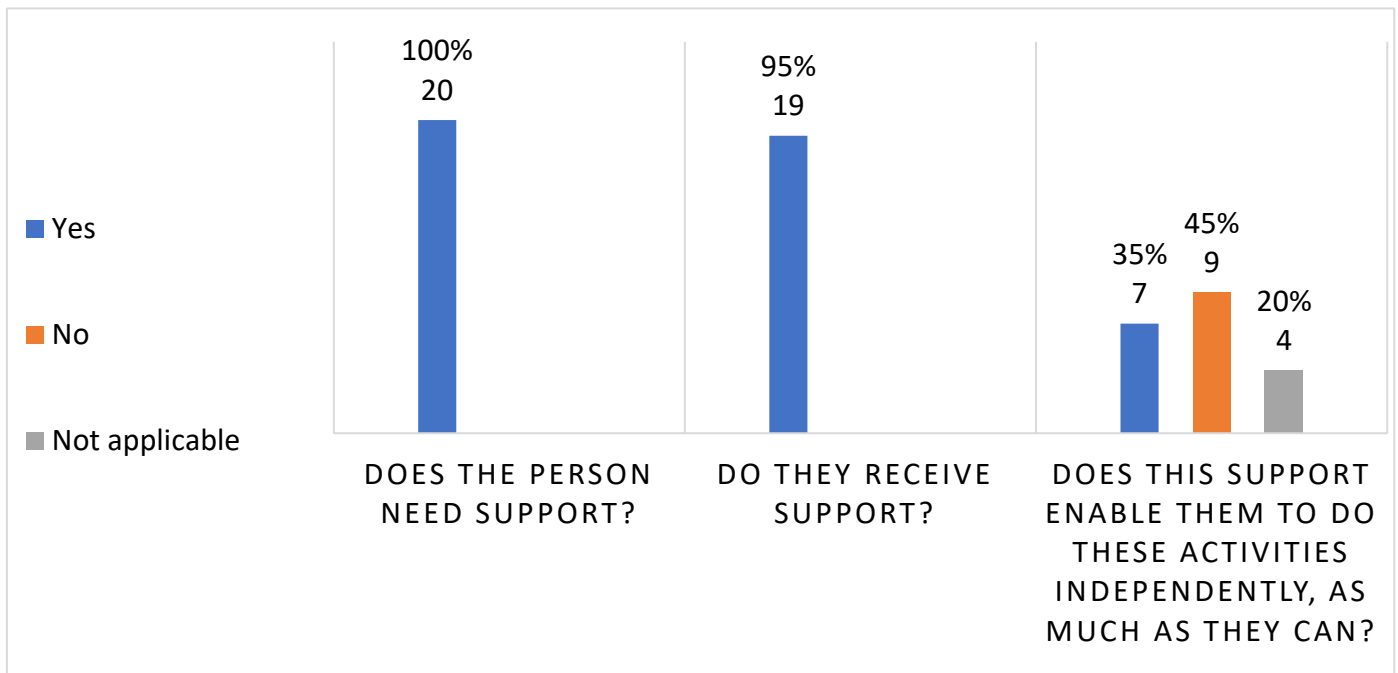
- Staff say 90% of people in the sample group need support with their personal care and 10% do not need support with their personal care
- 85% of people are receiving support with their personal care, 50% of these people are identified as being more independent with their personal care due to the support they receive
- 25% out of the 85% of people who receive support do not demonstrate more independence to do these tasks, even with this support

C. Problem solving



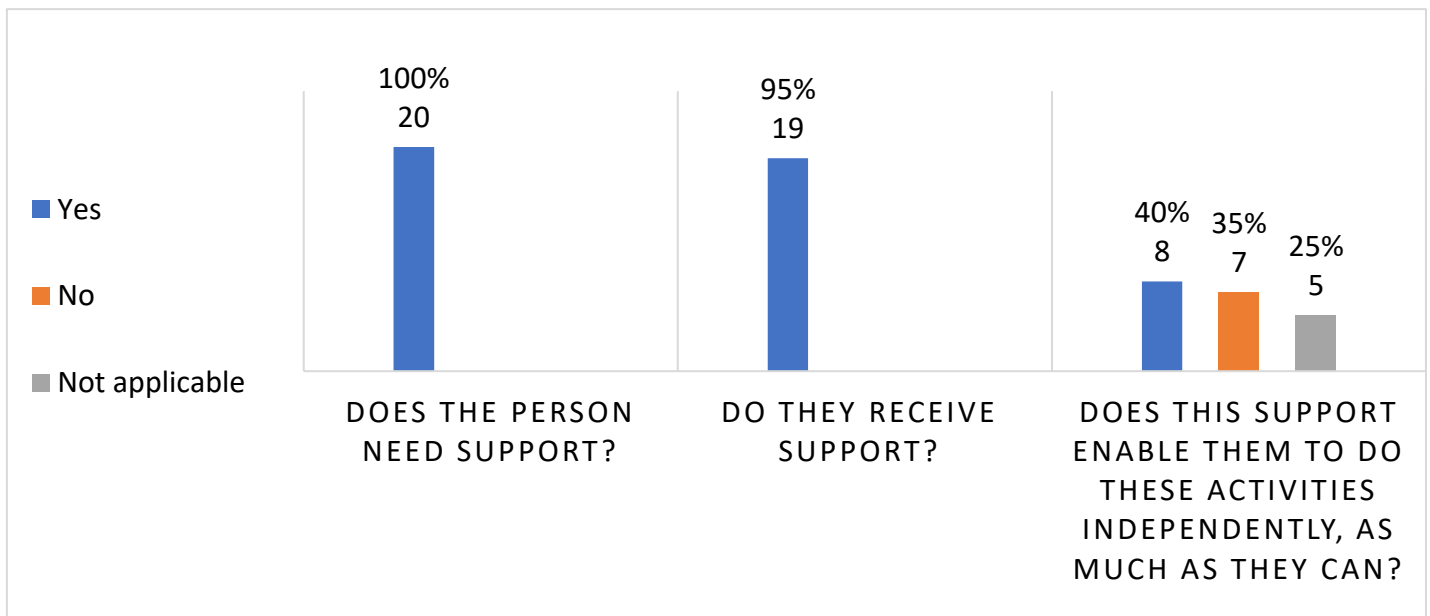
- 100% of the sample group need support with problem solving 95% receive support 40% show that they are more independent when they are supported with their problem solving 35% do not

D. Travel and transport



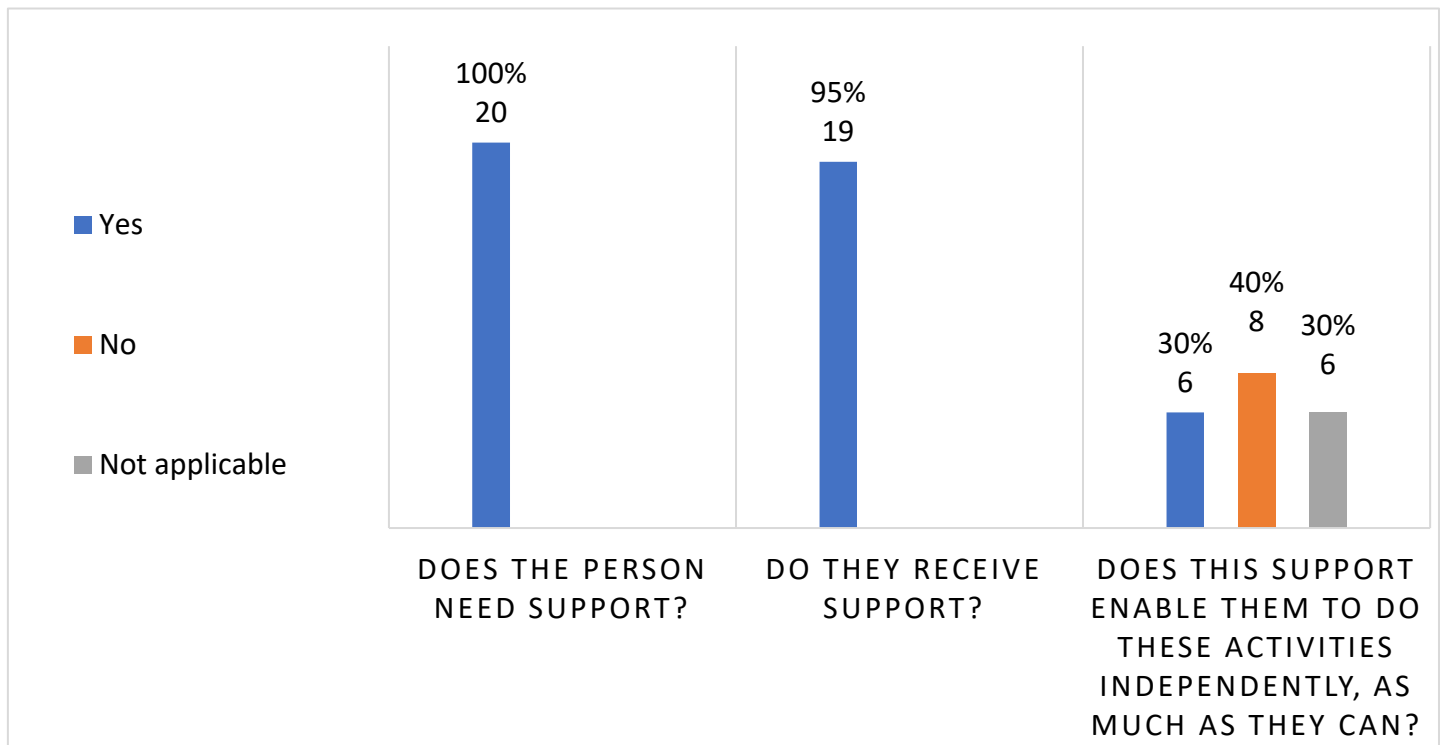
- 100% of sample group of 20 people need support to travel or use transport, 19 were currently receiving support at the time that the questionnaire was completed.
- 9 people who receive support do not show any independence in travel or using transport due to the support they receive, whereas 7 people out of 20 do show independence due to the support they receive

F. Dealing with finances and F money



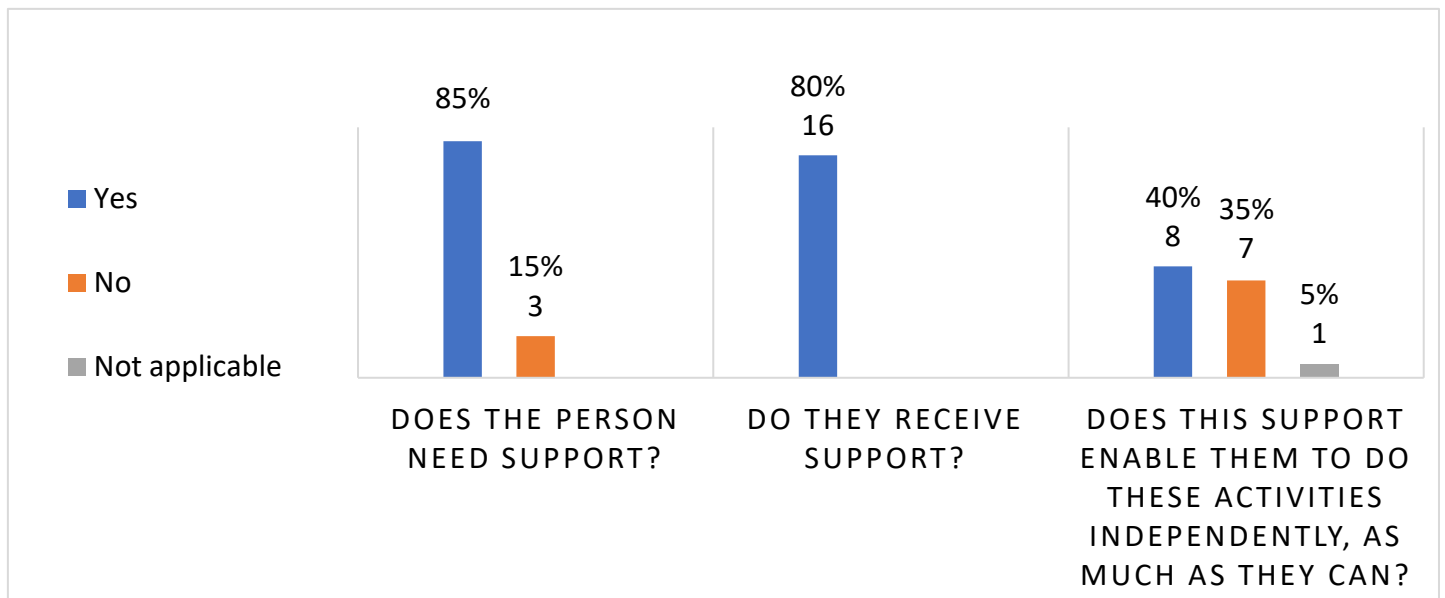
- 100% of the sample group need support to get out of their house, 1% is not supported to do this
- 8 people are more independent with the support they receive 7 still need significant support

E. Getting out of the house



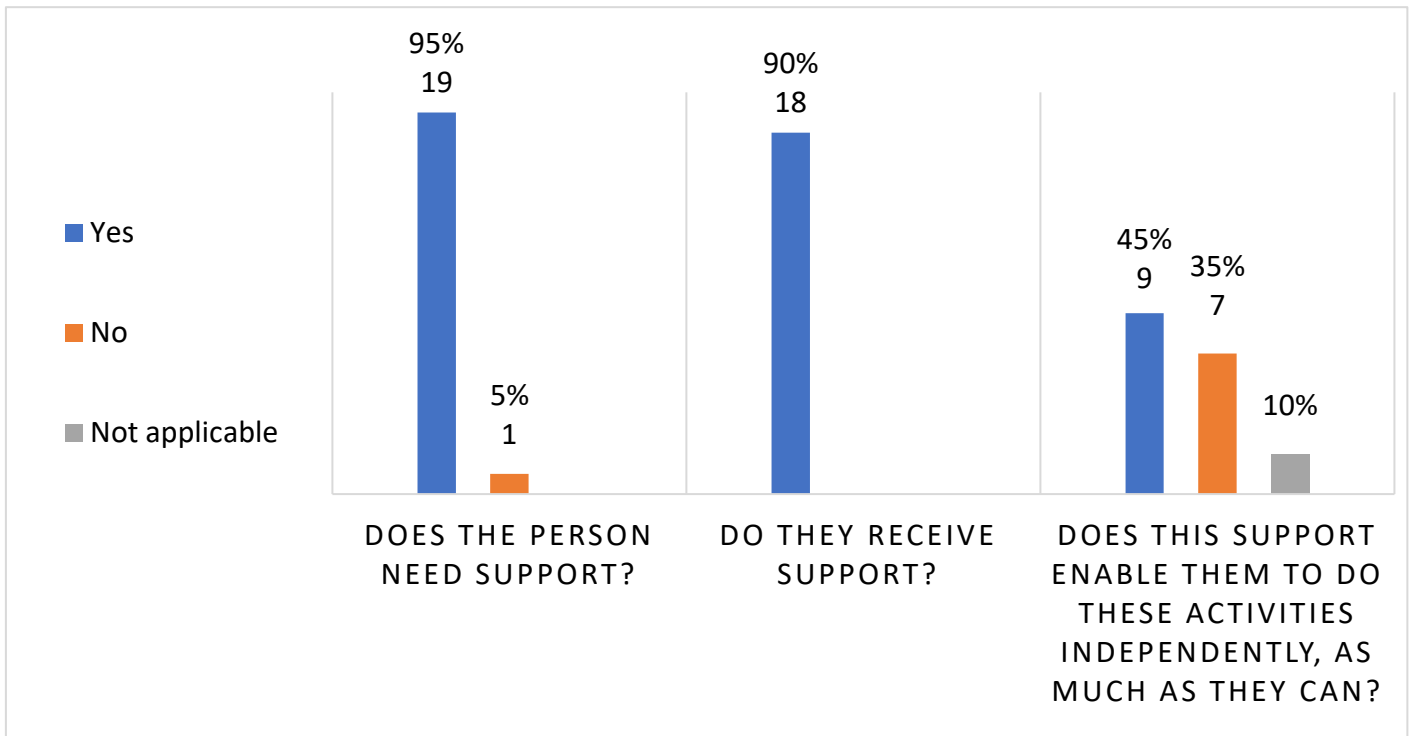
- 6 people or 30% of the sample group who receive support with their finances and money are more independent due to this support, 40% are not
- From the 100% of people only 95% receive support with their finances and money

G. Communicating with others i.e. expressing themselves



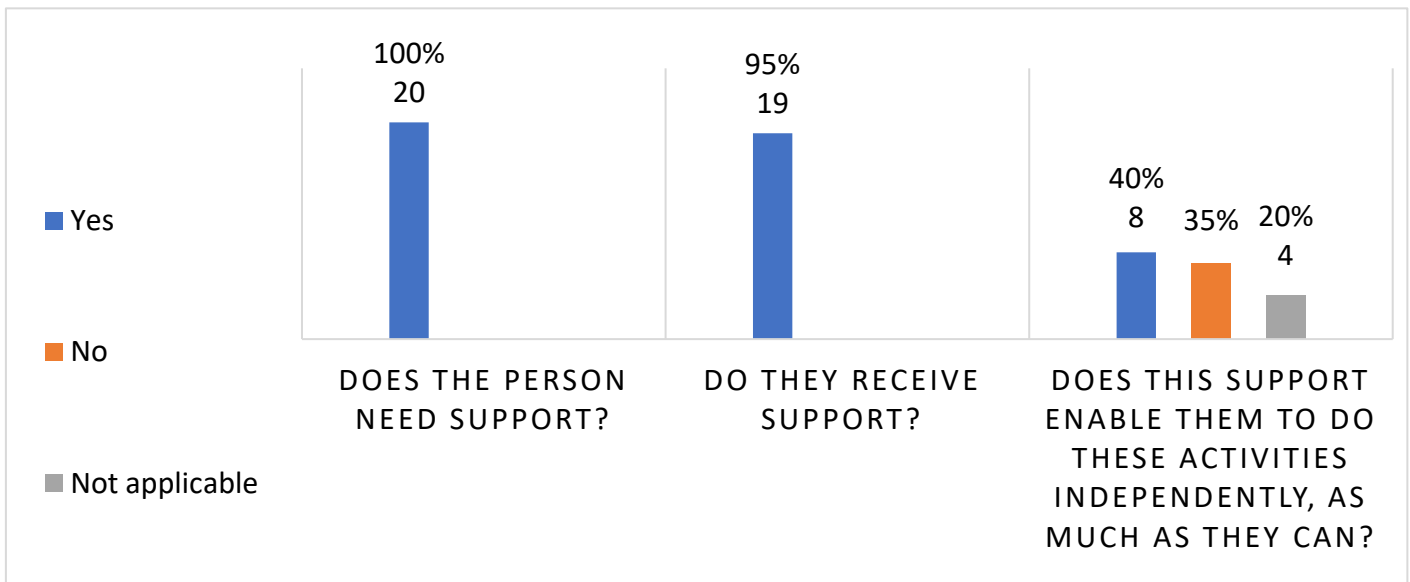
- 8 out of the 16 people who receive support to communicate are more independent due to this support
- 1 person who is identified as needing support to communicate is not receiving it

H. Receiving and understanding information



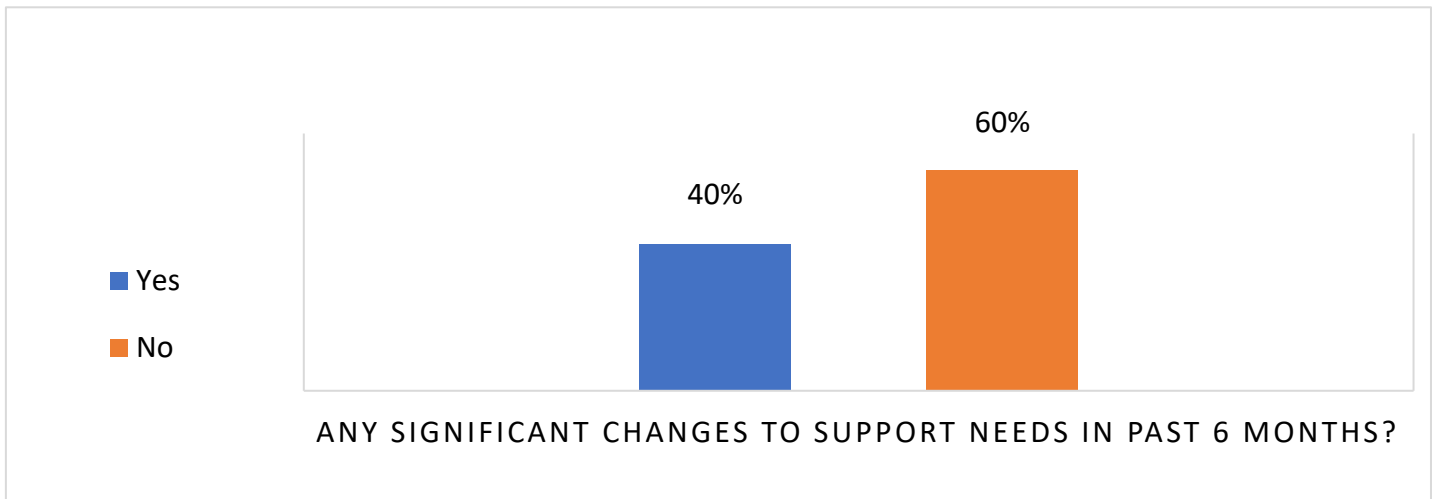
- 90% out of the 95% who need support to understand information receive it.
- 9 of the people who receive support to understand information are seen to be more independent, leaving 7 out of the 18 still needing significant support to understand information

I. Using technology i.e. mobile phone, iPad or computer etc.



- 19 out of the 20 people in the sample group receive support to use technology
- 40% or 8 people show independence when they are supported. A further 35% or 7 people do not show more independence with support

Q 10. Have there been any significant changes in their support needs in the last 6 months?



- Almost half of the sample group at 40% have had significant changes to their support needs in the past six months
- 60% of peoples needs have not changed significantly or at all

Q 11. Please briefly describe which aspects of their support needs have changes and how?

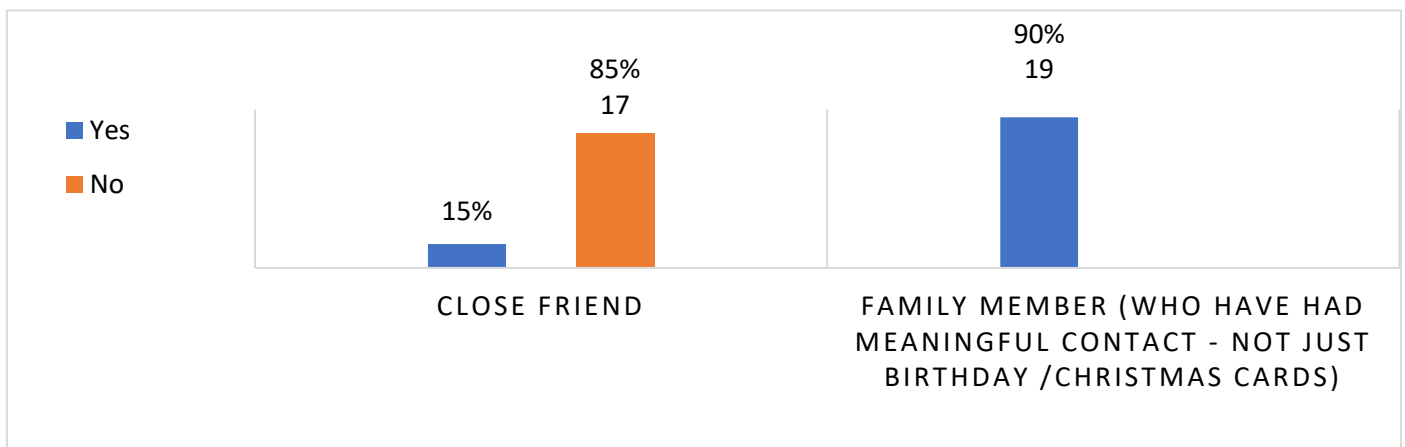
(Data provided and kept confidential)

Relationships – Q 12-17

This section includes questions about the personal relationships of the person.

Q 12. Does the person have any of the following relationships?

- A close friend(s) who is not family or paid staff
- A family member(s) who have had at least some meaningful contact (e.g. more than just birthday/Christmas cards) within the last year



- 85% or 17/20 people have no close friends
- 90% of the sample group do have contact with a family member contradictory to the admin questionnaire that stated all the sample group had no family contact.

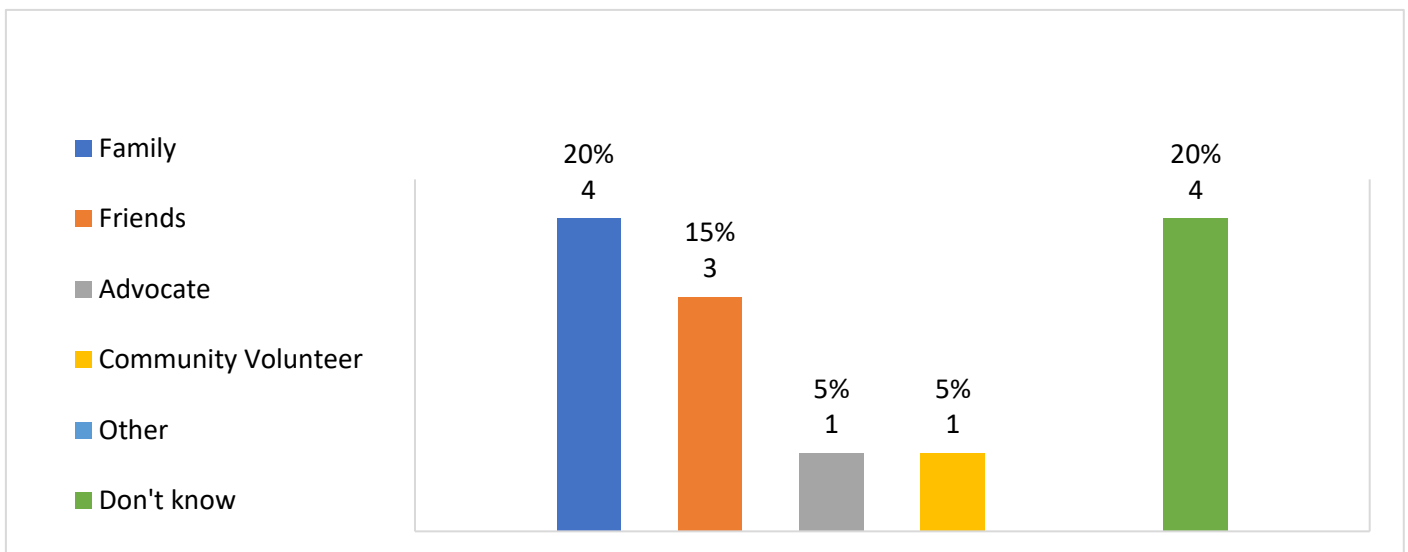


Q 13. How often does this person receive visitors other than paid staff? (For the purpose of this questionnaire, this is someone that comes to the home specifically to visit them).



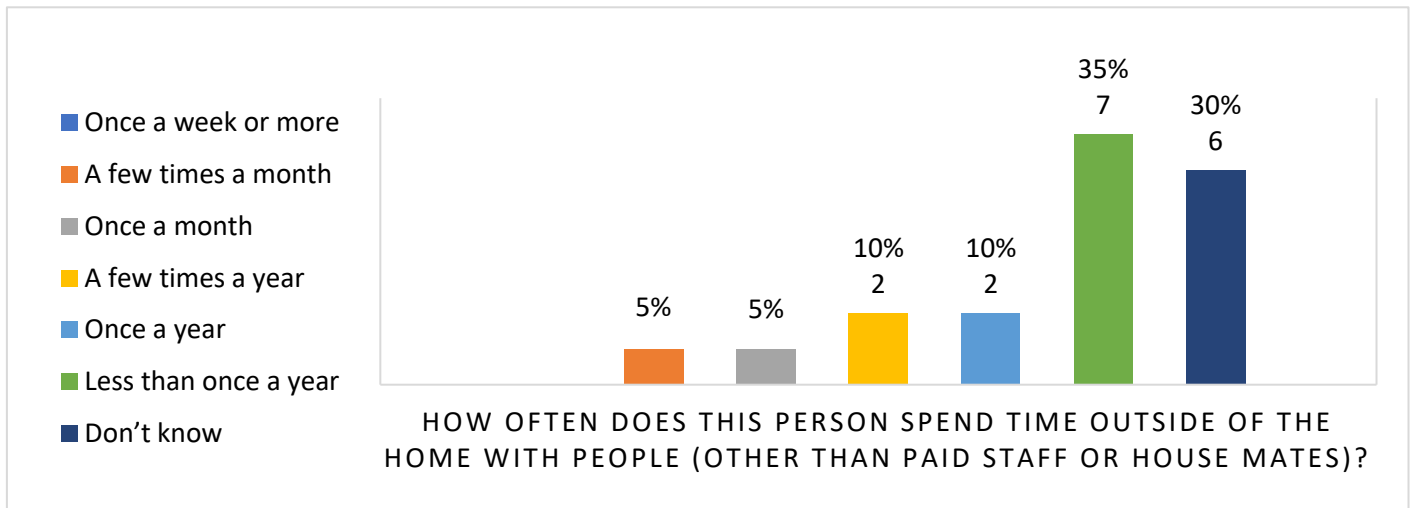
- 25% of the sample group have a visit from someone specifically to see them a few times a year
- 30% of the sample group or 6 people have a visit from someone specifically to see them, less than once a year
- 40% of the sample group were identified as, staff not knowing how many often they receive a visitor which is worrying when we know that 85% need support to communicate with others and 90% need support to receive and understand information

Q 14. What relation to this person are these visitors?



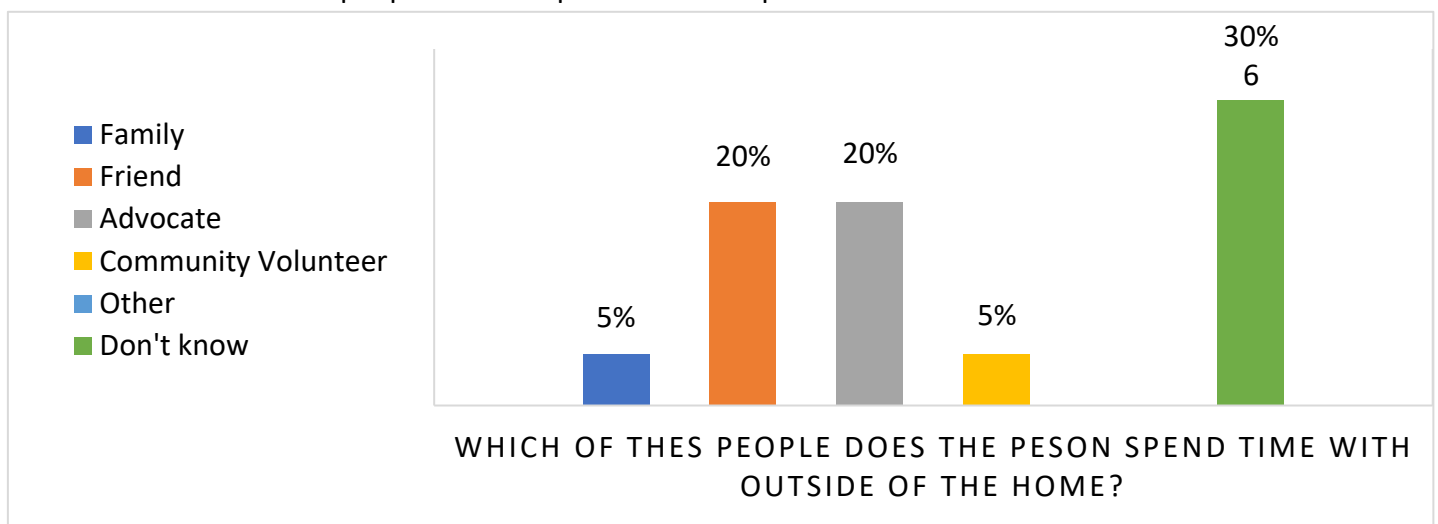
- 20% of the visits are from family while 15% are from friends which reflects the 15% identified as having friends in Q12
- 20% or 4 people who receive visitors, it is unknown what relationship to the person these visitors are
- One person has received a visit from a Community Visitor and one other person has been visited by their Advocate

Q 15. How often does this person visit or spend time outside of the home with people (excluding paid staff or people who live with them) to maintain a relationship or friendship?



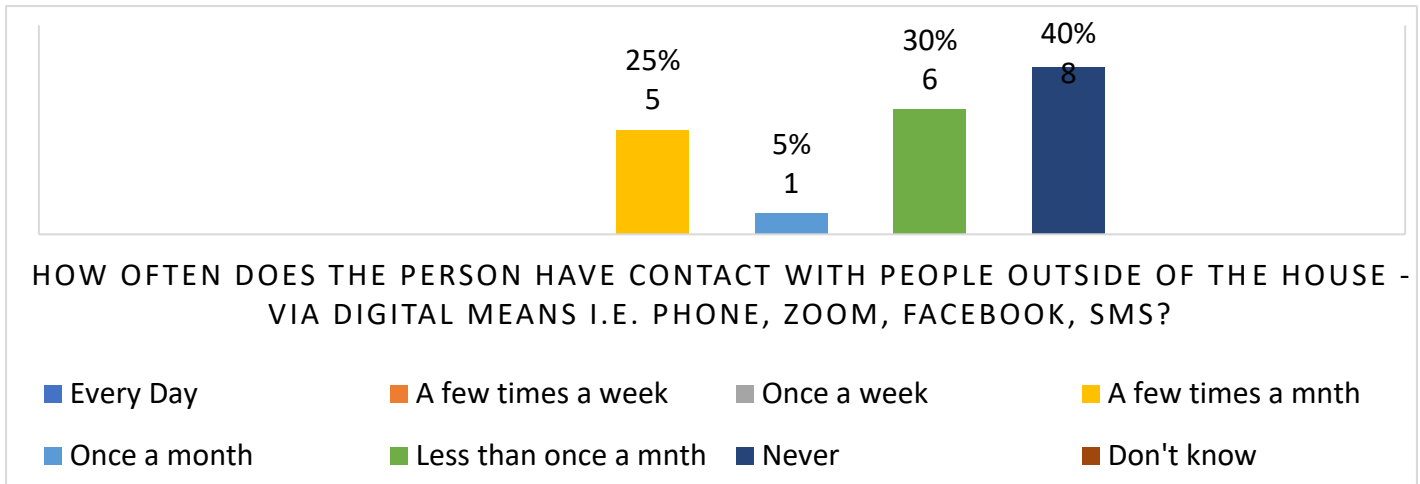
- 35% or 7 people spend time outside of their home less than once a year, to maintain a friendship or relationship with someone. This is extremely alarming!!
- It is unknown how often 30% or another 6 people from the sample group, spend time maintaining relationships or friendships outside of their home. Again, this is extremely alarming due to people needing support to use transport or travel as well as support to communicate. This is raising concerns around people's opportunities to live an ordinary life and maintain relationships.
- It is sad and concerning that only 5% or 1 person in the sample group gets to maintain their relationships outside their home a few times a month. Leaving 95% or 19 people of the sample group maintain relationships once a month or less outside of their home

Q 16. Which of these people does the person visit or spend time with outside the home?



- It is not known who 30% or 6 of the sample group spend time with outside of their home
- We can see that 1 person spends time with their family and 1 person spends time with a community volunteer
- 4 people are seeing a friend and 4 people are seeing an advocate. We can assume by the results in Q15 graph that the amount of time spent with someone outside of their home is minimal

Q 17. How often does this person have contact with people outside their home using telephone or digital means (e.g. Zoom, Facebook, Email, SMS)?



- Staff say that 8 people out of the sample group never use technology. 6 people are using technology less than once a month to have contact with people outside of their home
- 5 people are connecting with people via technology a few times a month and 1 person once a month

Health and wellbeing – Q 18-24

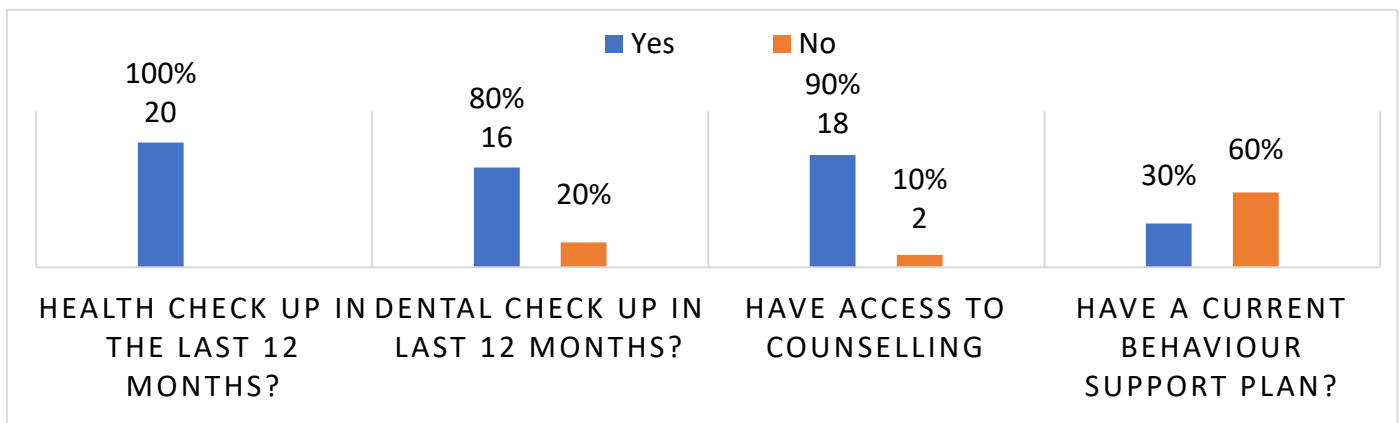
This section includes questions about the health and wellbeing of the person.

Q 18. Has this person had a health check-up with a doctor in the last 12 months?

Q 19. Has this person had a check-up with a dentist in the last 12 months?

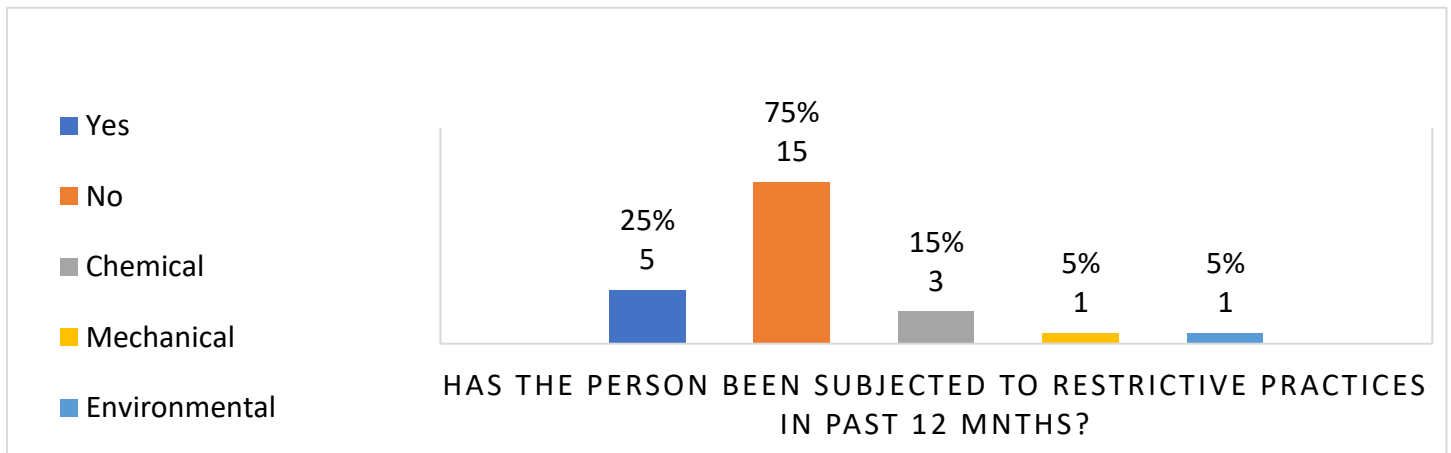
Q 20. Does this person have access to counselling services where required (whether they have used them)?

Q 21. Does this person have a current Behaviour Support Plan?



- 100% of the sample group have had a health check in the last 12 months. 80% have had a dental check-up, leaving 20% without an annual dental check up
- 90% have access to counselling but we don't know if they have used it
- 7/20 people have a current behaviour support plan which is quite a lot considering this is almost half of the sample group
- 60% of the sample group do not have a current behaviour support plan, it is not confirmed if this is due to them not needing one or it is not updated.

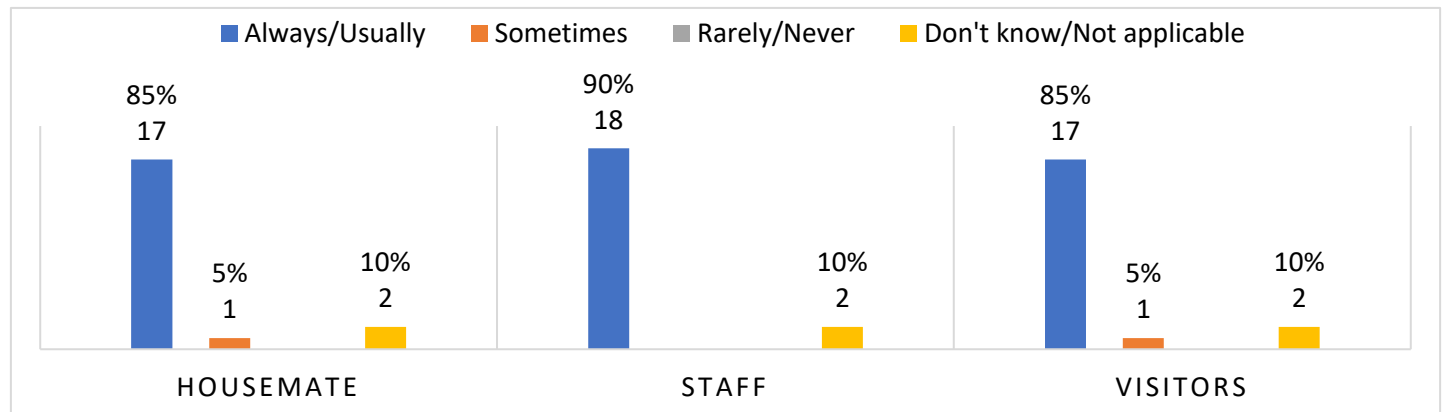
Q 22. Has the person been subjected to restrictive practices in the last 12 months?



- 25% of people or 5 people have been subjected to a restrictive practice such as chemical, mechanical and/or environmental
- It would be interesting to know if the 25% of people who currently are subject to restrictive practices are identified in the 30% of people having a behaviour support plan (see Q21)

Q 23. To the best of your knowledge, how often does the person feel safe in their home environment with the following people?

- Housemates
- Staff
- Visitors



- When we asked staff if residents felt safe they said 85-90% of the residents interviewed felt safe always/usually.
- This is contradicted in the answers given by residents when they were interviewed in the participant questionnaire, stating 60% felt unsafe or scared sometimes. Only 4% stating that they didn't feel scared or unsafe.

Q 24. [If answered Question 22 as 'sometimes' or 'rarely/never'] Please describe the circumstances that the person does not feel safe.

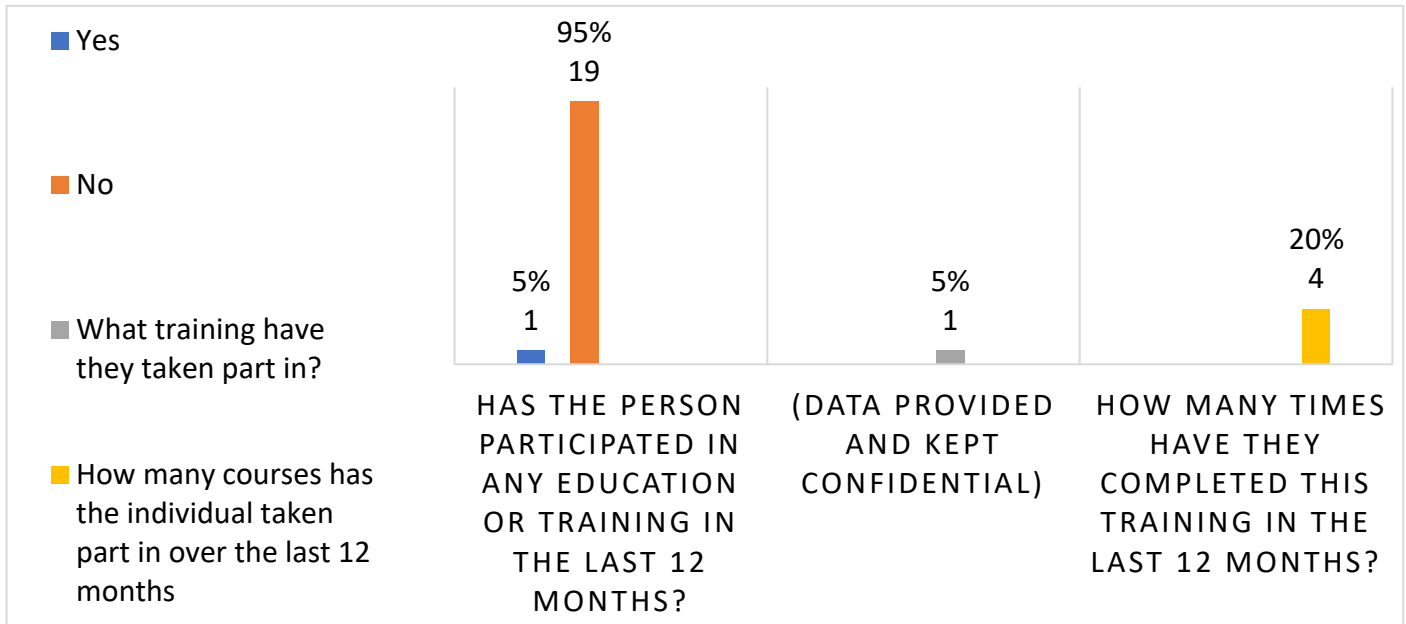
(Data provided and kept confidential)

Lifelong learning – Q 25-27b

This section includes questions about access to learning for the person.

Q 25. Has this person participated in any education or training courses in the last 12 months?

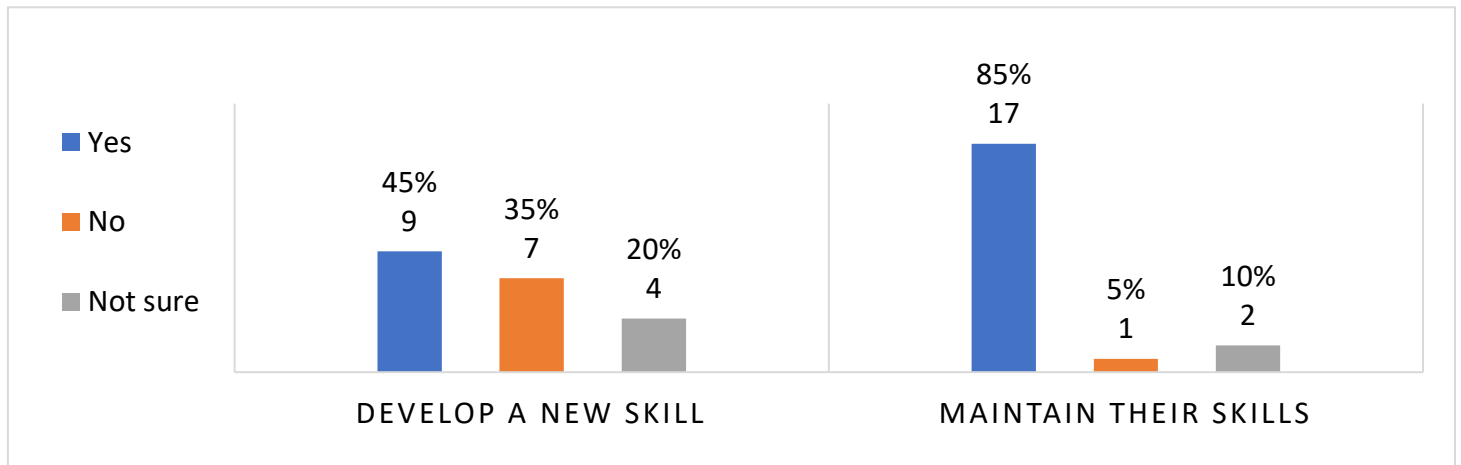
Q 26. How many courses have they taken part in over this period?



- 19/20 have not participated in any education or training in the last 12 months. 1 person has done the same course four times in the last 12 months

Q 27i. In the last 6 months has this person been supported to:

- develop a new skill?
- maintain their skills / use the skills learnt on a regular basis?



- 9/20 people have been supported to develop new skills 7/20 have not
- 85% of the sample group have been supported to maintain their skills

[If part a and b are both 'no' or 'not sure', Go to question 0]

ii. Please explain what skill(s) have been developed and/or maintained and how this has been supported:

(Data provided and kept confidential)

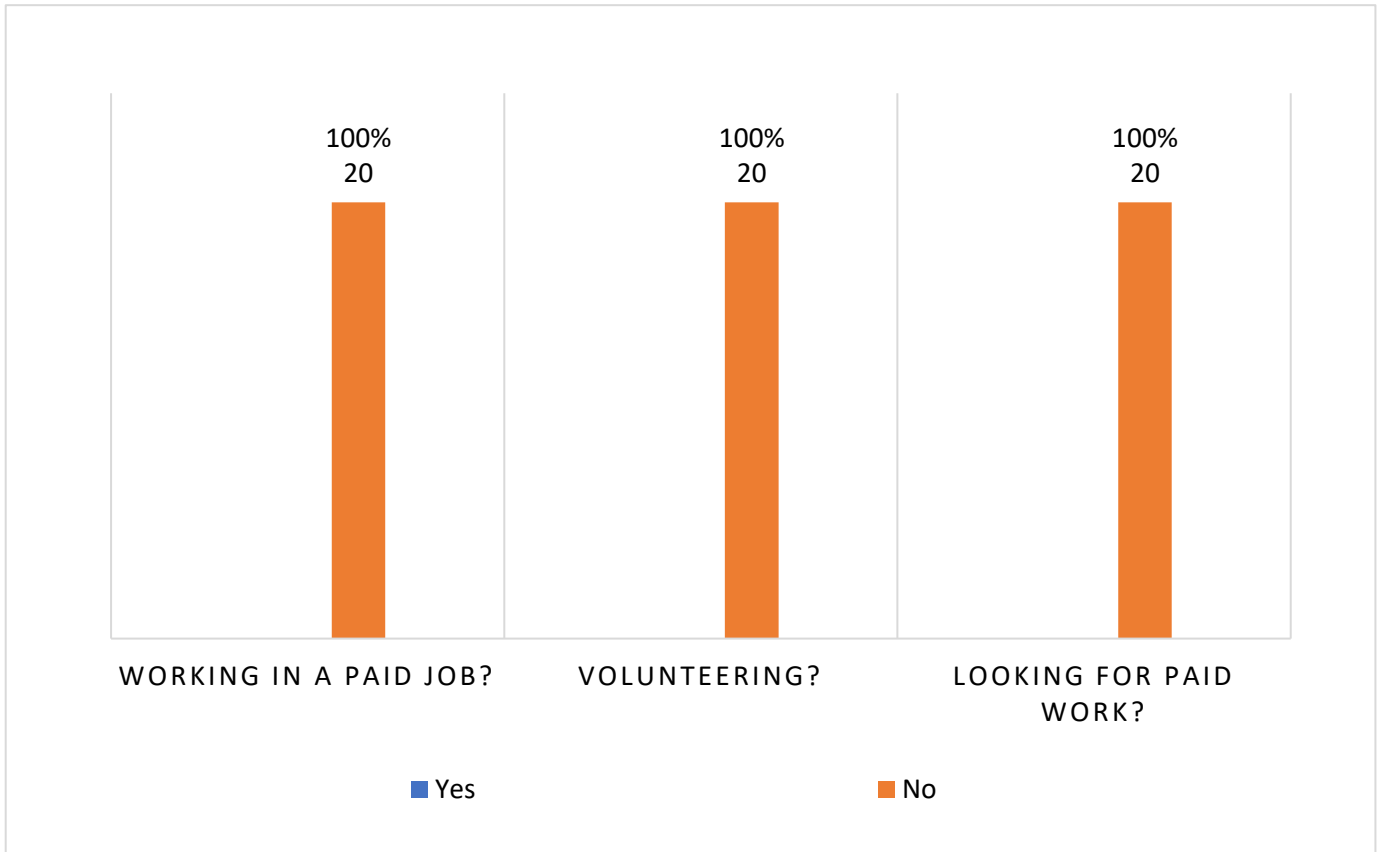
Work and volunteering – Q 28-30

This section includes questions about the involvement of the person in activities that may provide a sense of achievement or enjoyment for the person.

Q 28. Is the person currently working in a paid job?

Q 29. Is the person currently volunteering?

Q 30. Is the person currently looking for work (paid or unpaid)?



- 100% of the sample group are not currently in paid work or volunteering or are they looking for paid or volunteer work.
- Staff could be assuming that people don't want a paid job or to volunteer. We can see a conflict in the results from the participants questionnaire that 2 people said they would like paid work, but staff are recording different results. This could be due to staff not asking people or providing the opportunity to people to explore.

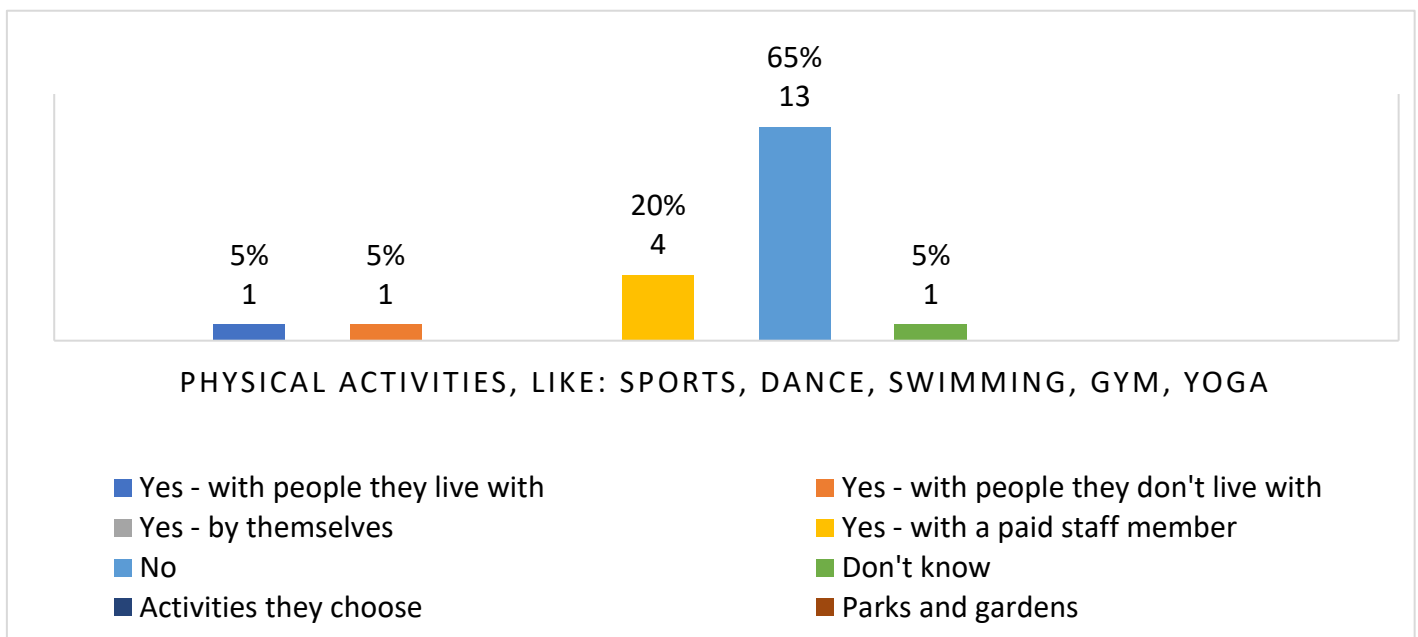
Social, community and civic participation – Q 31-32

This section includes questions about the involvement of the person in the community.

Q 31. Does the person participate in any of the following activities outside the home regularly (at least weekly for routine activities and at least every two months for infrequent events)? [Please select all that apply]

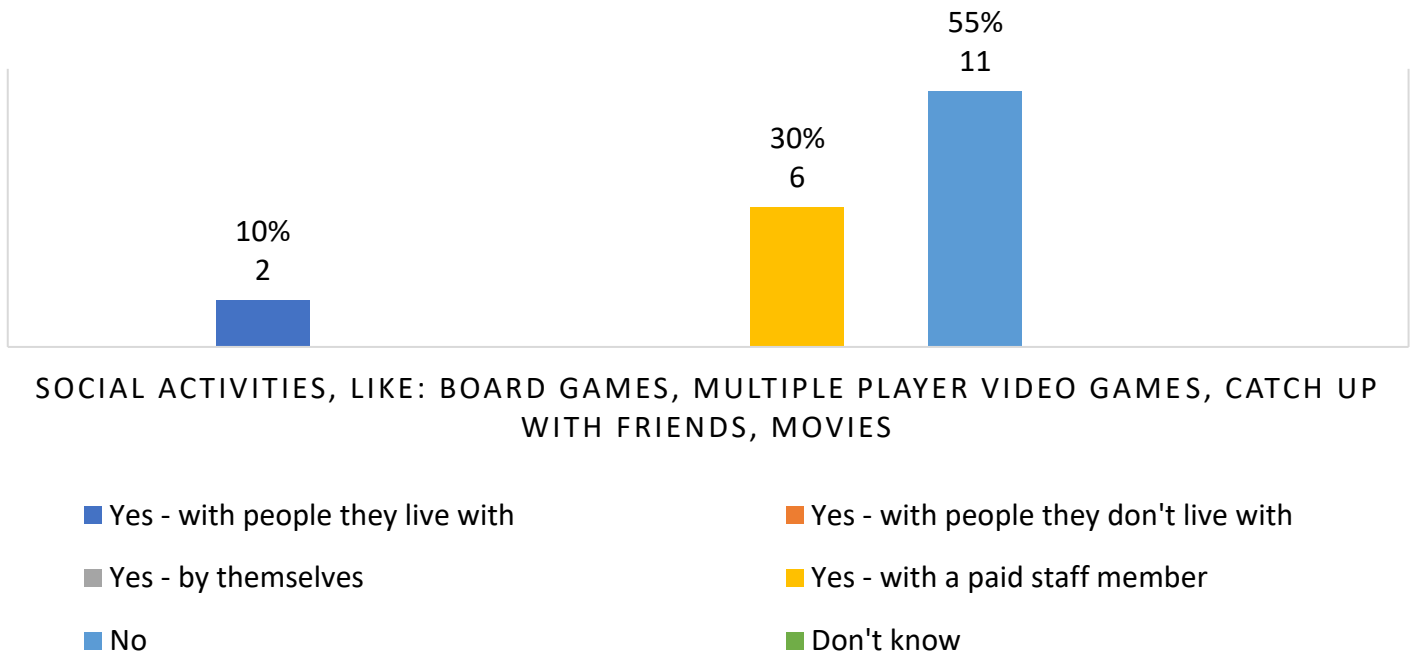
- Physical activities, like: sports, dance, physical games, swimming, gym, yoga
- Social activities, like: board games, multiplayer video games, catching up with friends, movies
- Creative activities, like: music lessons, art groups
- Religious/spiritual activities, like Church
- Attending cafes, restaurants, pubs
- Attending events, like: theatre, football, live music, galleries
- Other [please specify]____

Q 31a.



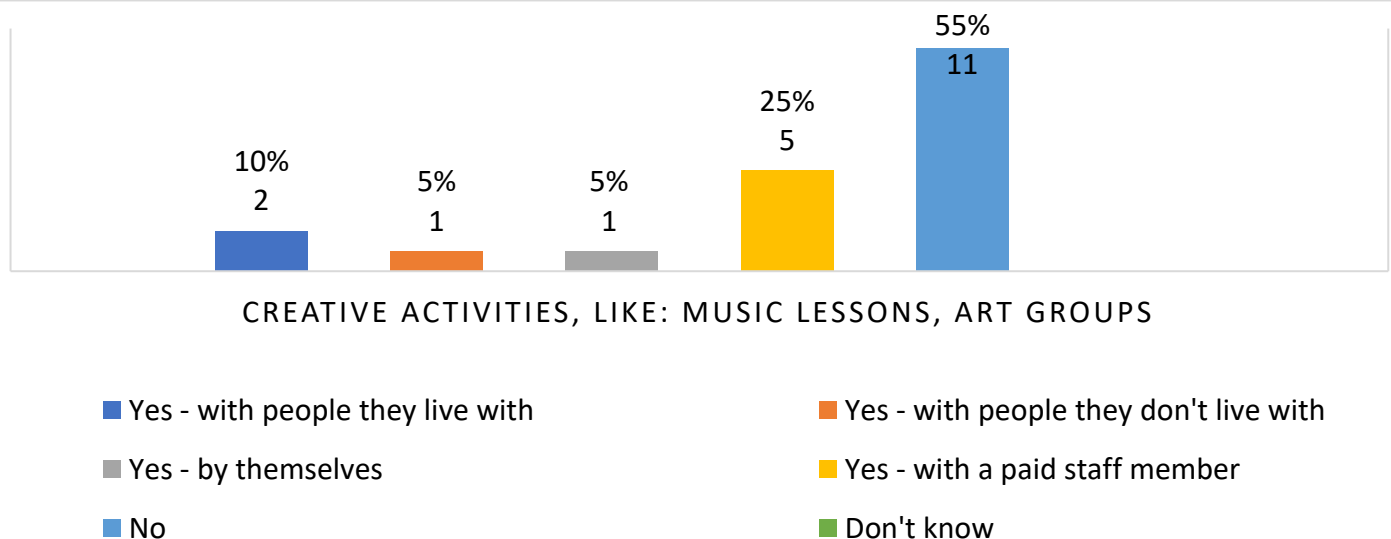
- 1 person does physical activities outside of the house with people they live with
- 1 person does physical activities outside of the house with people they don't live with. 4 people are identified as doing physical activity outside their house with a staff member
- No-one is identified as doing a physical activity outside of their house by themselves
- 13/20 people do not do any physical activities outside of their house at all

Q 31b.



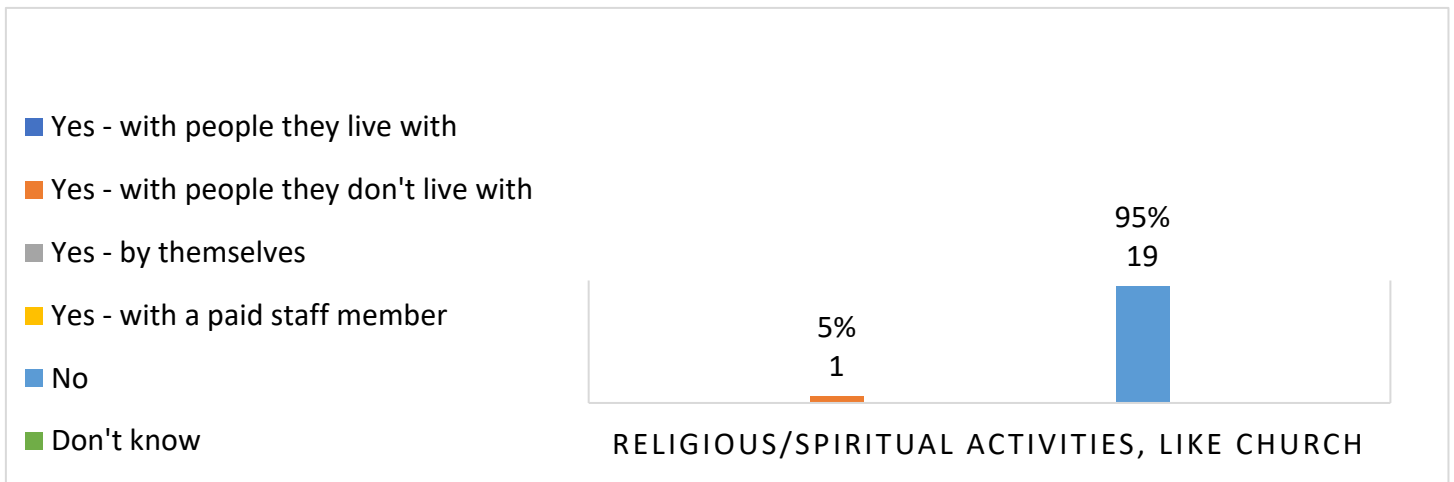
- 2 people participate in social activities with people they live with. 11 people do not participate at all
- 6 interact in social activities with paid staff

Q 31c.



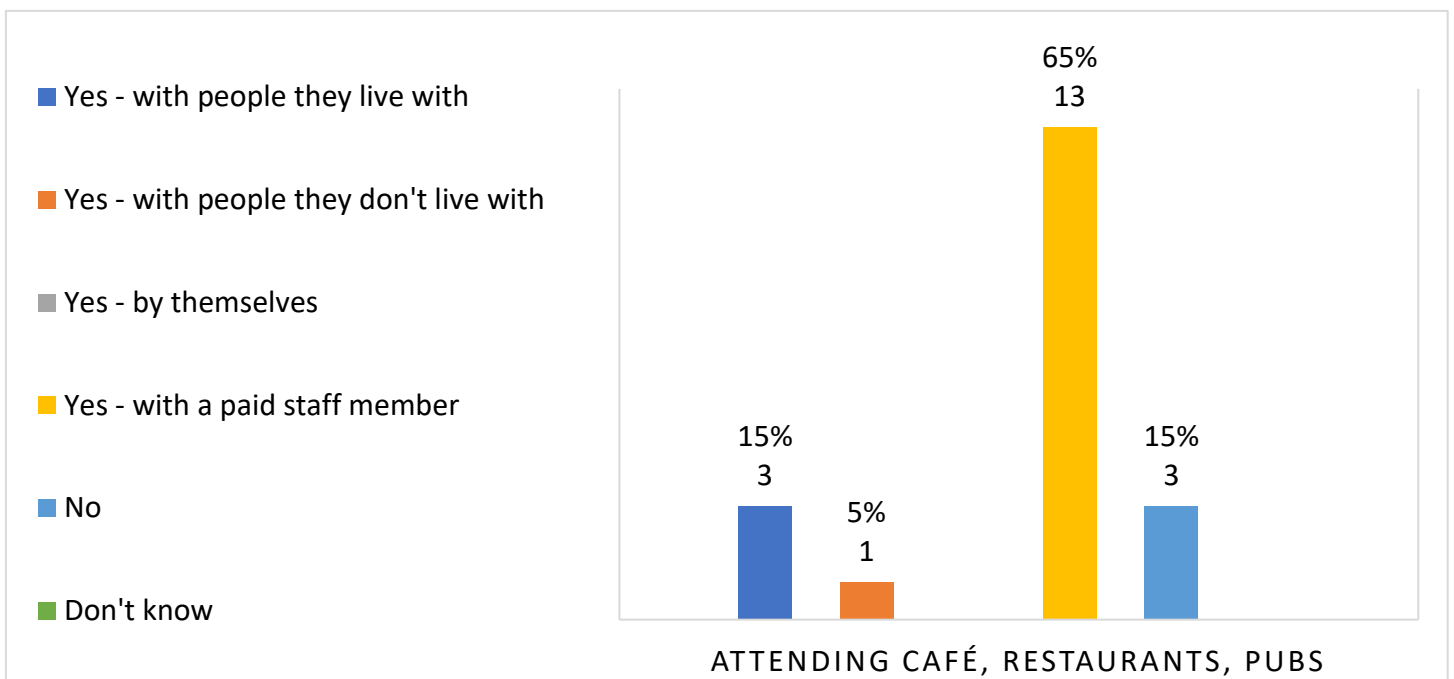
- 55% or 11/20 people do not participate in creative activities
- 25% or 5/20 people do creative activities with their paid staff
- 2 people participate in creative activities with people they live with and 1 person with people they don't live with, and 1 person does creative activities by themselves

Q 31d.



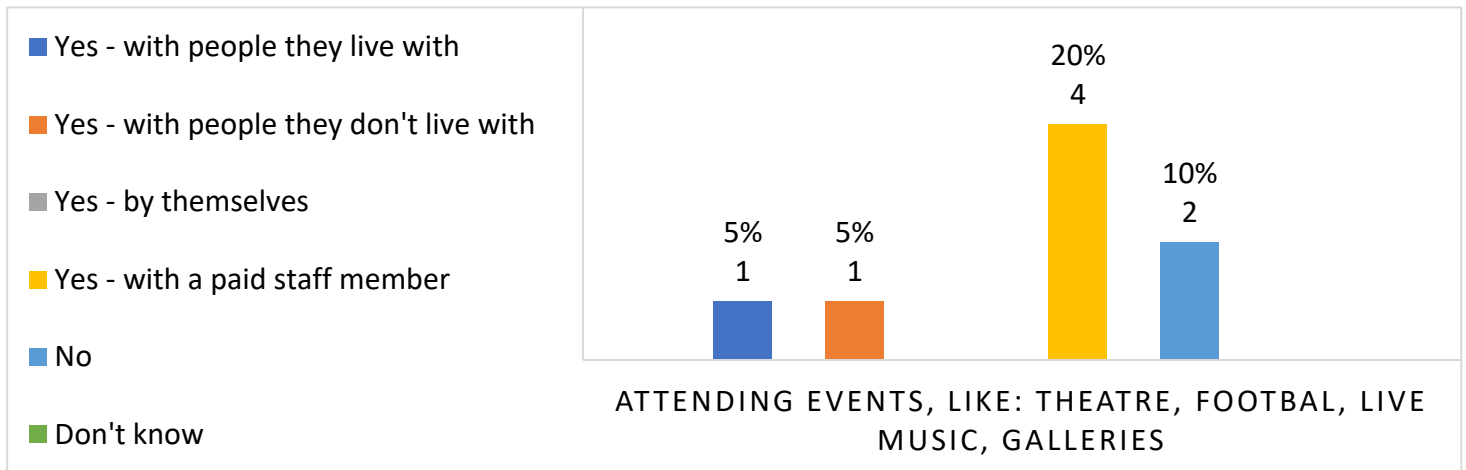
- 19/20 people do not participate in any form of spiritual or religious activities

Q 31e.



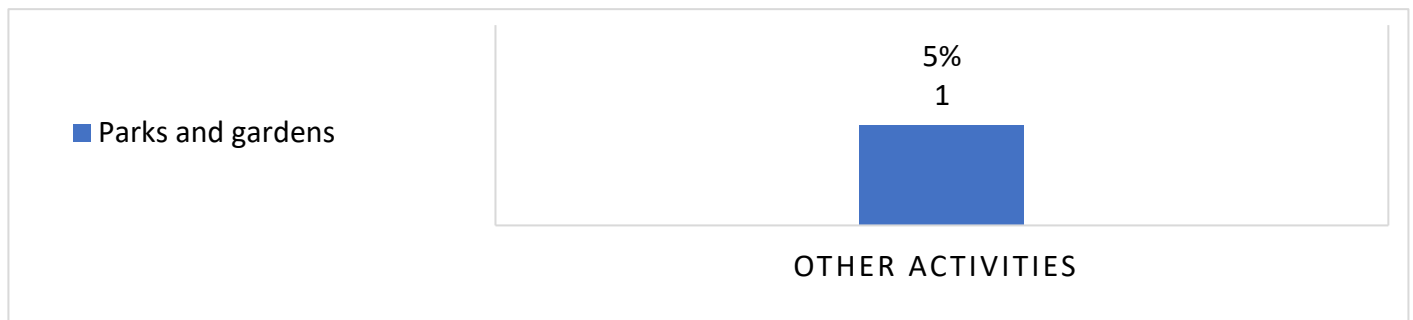
- 13/20 people or 65% attend café's restaurants and Pubs with their paid staff. 3 people with people they live with and 1 person with people they don't live with.
- 3/20 people in the sample group were identified by staff as not attending café's restaurants and pubs at all

Q31f.



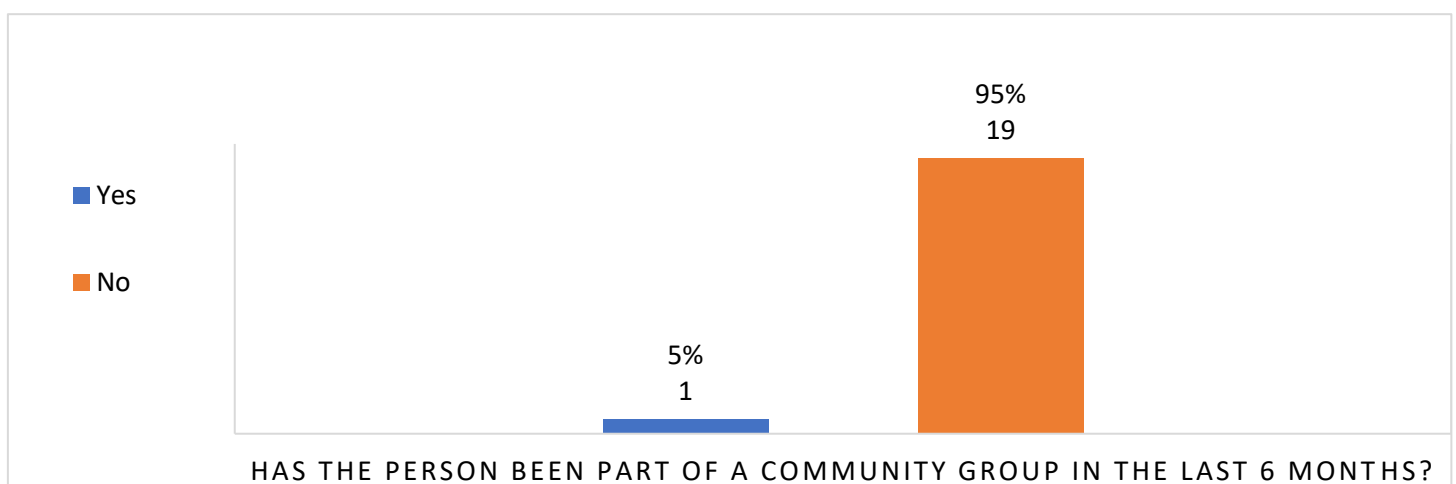
- 4 people attend events with a paid staff member, 1 person attend events with people they live with, and 1 person attends events with people they don't live with.
- 2 people don't attend events at all

Q31g.



(Data provided and kept confidential for the following questions)

Q 32 a: Has this person been a member of any community groups in the last 6 months (e.g. ParkRun, football, knitting/craft, train spotting, car club etc)?

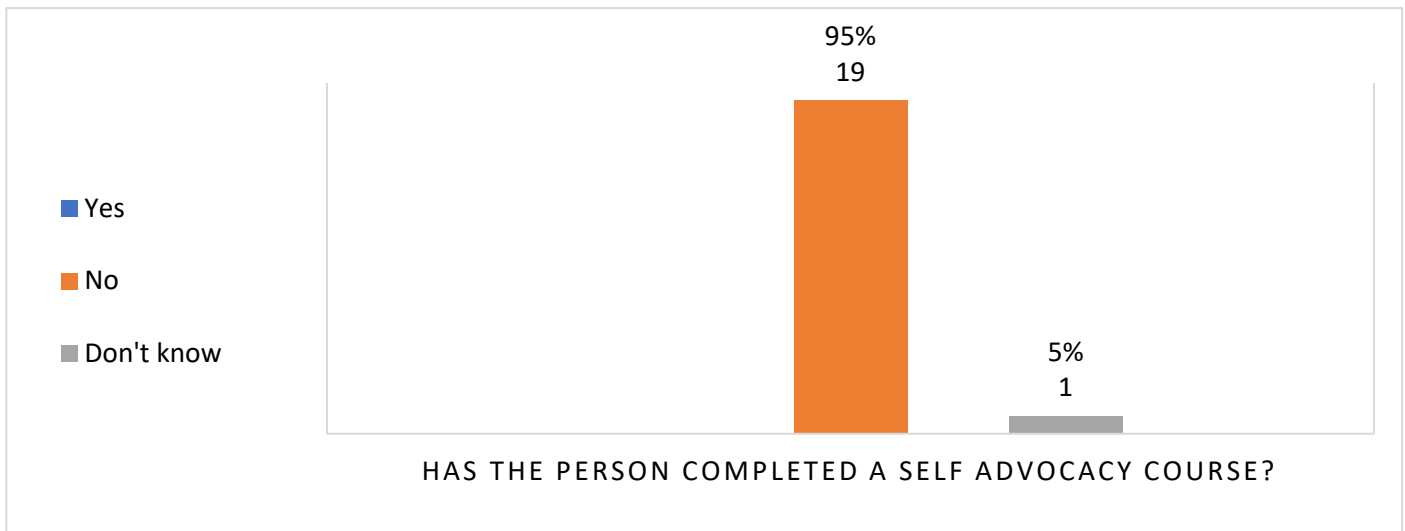


- Very concerning that people haven't been able to connect with the community on a different platform e.g. zoom, teams, Facebook

Empowerment – Q 31-36a

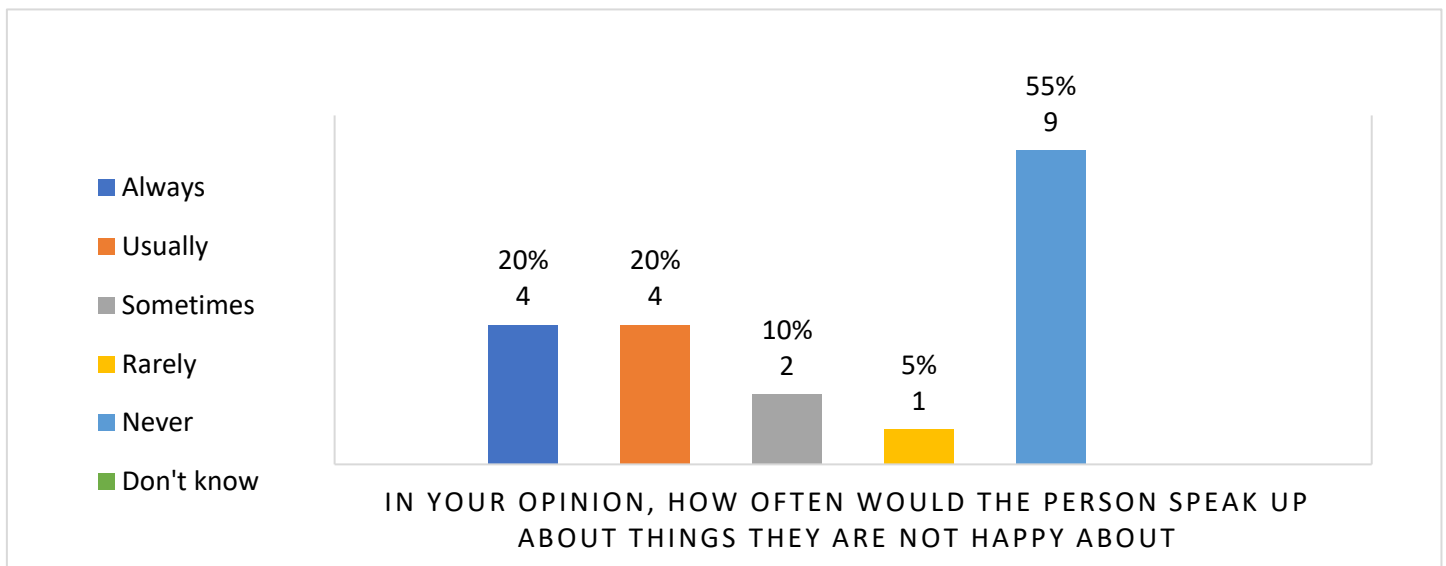
This section includes questions about the extent to which the person has choice and control over their activities and services and are able to exercise their rights.

Q 33. Has the person completed a self-advocacy course?



- 19 out of 20 people have confirmed not to have done empowerment training
- This is very concerning as it is reinforcing the high number of people who would never speak up in the graph below

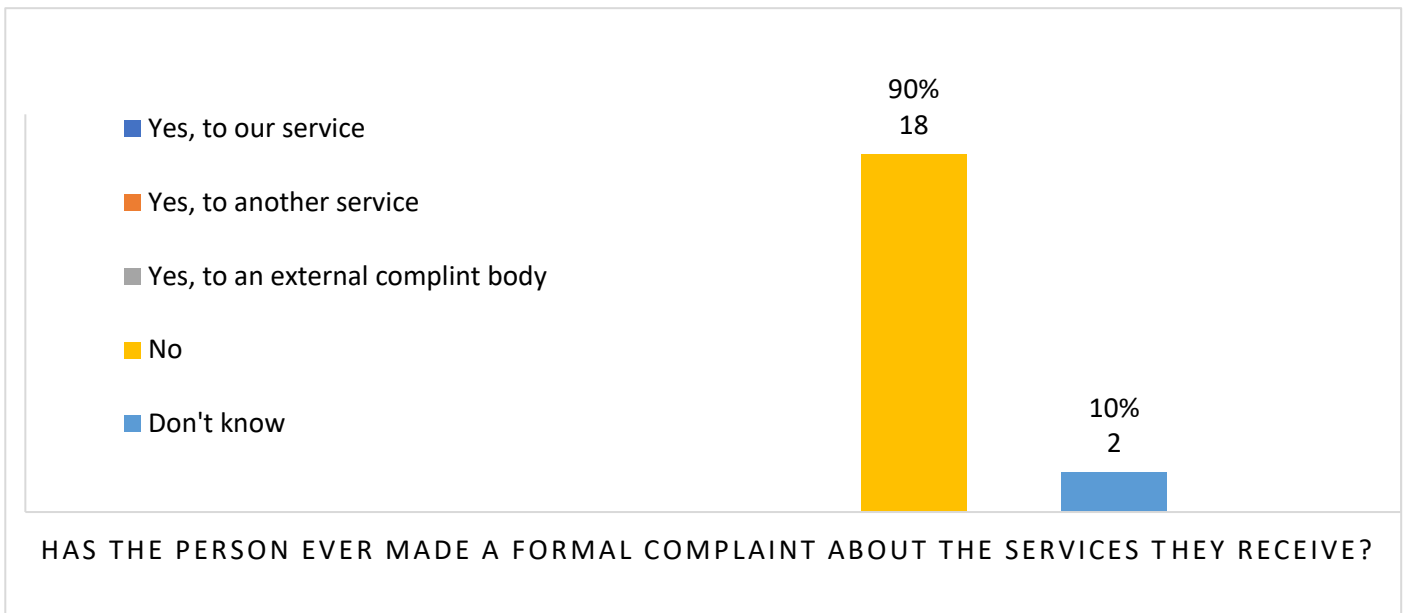
Q 34. In your opinion, how often would the person speak up about things they are not happy about (e.g. things they don't want to do, things they don't want to eat, issues with people they live with)?



Staff identified the following:

- 9/20 people or 55% as never speaking up about things they are not happy about
- 4 people or 20% will always speak up about things they are not happy about
- 2 people or 10% will sometimes speak up about things they are not happy about
- 1 person or 5% will rarely speak up about things they are not happy about

Q 35. Has the person ever made a formal complaint about the services they receive?



- 90% of people have not made a complaint about the service they have received but when we look at how often people will speak it is 55% (See Q 34)
- Do people know how to make a complaint? Or are they too scared to speak up?
- It was not identified in the answers from staff as to knowing if any of the sample group have made a formal complaint to another service or to an external complaint body

Q 36. To the best of your knowledge, what was the outcome of this complaint?

Q 36a. To the best of your knowledge, what was the outcome of this complaint?

- No complaints recorded in Q35 so Q36 is not relevant to chart/graph

End of Data Set C