From presence to belonging: Experiences and outcomes of living independently for adults with intellectual disability

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Plain English Executive Summary

The United Nations Convention on the Rights of Persons with Disabilities is clear that people with disability should be able to choose how and where they live. Recent disability policy in New Zealand aims to support people so that they can make their own choices. However, some people have been concerned that people with intellectual disability who are living independently might be at risk of poor health or of being socially isolated.

The "Presence to Belonging study" was developed to explore what people with intellectual disability themselves thought about living independently.

Twenty people who were living independently within the community and who had less than ten hours of support per week from disability services were interviewed. They were asked about their lives, the things that were important to them and how they managed from day-to-day. They also completed a brief questionnaire about their health.

We also held one focus group and four individual (key informant) interviews with family members and disability support staff, where they told us what they thought led to successful independent living for people with intellectual disability.

We used a qualitative approach to compare and contrast the information from the participants with intellectual disability. Through that process we were able to develop themes that related to the research question.

A practical approach was taken to the analysis of the information from the focus group and interviews with key informants. We learnt about the issues that the focus group and the key informants thought were most important by noting everything they raised and then asking them to rate them.

Results from interviews with people with intellectual disability

Most of the people with intellectual disability who took part in the study were happy with how and where they were living. The best thing about living independently was having choices in how they lived, where they lived, who they lived with, what they did within their day, and who they had relationships with.

Independent living helped people to feel good about themselves. The things that contributed to feeling good were, moving out of their family home and learning how to complete the tasks necessary to be independent and being accepted within their community. For a small number of people it was also in how they managed symptoms of mental illness or previous alcohol addiction. Living independently meant these people could stay away from the people and places that they knew were unhealthy and unsafe for them.

Most people were settled in their homes and liked where they lived. People had different standards for their housing and the way that they made their home their own. Being independent meant that they could choose their home. Having some support when making

decisions about their housing was helpful but they still wanted it to be their choice. Most had help with buying houses or taking on rental agreements either from their disability support service or from family.

For the few men in the study who had a history of drinking to excess and criminal behaviour, cluster housing had not been helpful. These types of housing arrangements led to them socialising with others with similar histories and made it difficult for them to move on. For that reason they had found housing that kept them away from these other people and knew that was an important part of them being able to stop drinking or committing criminal offenses.

Relationships with family and friends were important to most people. Closeness to family was different for everyone, but family was part of most peoples' lives in some way. Family relationships stayed constant where other relationships were more likely to come and go. Family included their birth family, foster family or the family that they had made through setting up home with their partner.

People often focused on a few strong friendships rather than lots of friends. Friendships that were associated with disability support services seemed to be more common when the person had been connected to disability services for a number of years.

Living independently meant learning how to get along with other people and what friendships would be best for them. Overall, people seemed to be careful about who became their friend, including on Facebook. Disability service support staff were not usually seen as friends but as people who were there to assist them. They felt it was important that they had a good relationship with their support person but they did not expect them to be their friend.

Everybody had to budget carefully to cover their cost of living. Some people used budget services to help them manage their money. Direct payments from their bank accounts were used by everyone to pay for rent and utilities. For those who used a budget service, or where they had a family member assisting them, other income was often split between an account that they could access for everyday living and a savings account. The few who managed their money independently preferred to be able to make their own choices about how they spent it.

Any extras, such as dental or medical bills, were difficult to pay out of weekly allowances and usually resulted in the person being in debt. Lack of money also meant that people walked in preference to spending on bus fares. Driving was limited to a few people. Low incomes affected both completion of the three stage driving licence and the ability to buy a vehicle. Most people could not afford holidays and those that did go on holiday usually relied on family or friends to assist them.

Getting and keeping paid employment was very difficult. For the few who had employment, their jobs were important to them. They enjoyed their jobs. Paid work meant that people had a little more money to pay for the things they needed or wanted.

Most of the younger people did volunteer work. Some of that work was to assess their strengths and help them find paid work. A number of the older people had tried various work programmes but were not currently working in paid positions. They generally felt that their disability prevented them from either getting or staying in a job. This opinion was shared by those with no school or tertiary qualifications as well as with those who had some qualifications. When they thought they were unlikely to get paid work, people often settled on volunteer work as a way to have something meaningful to do.

While completing the health questionnaire people also told us about their current and past health. Most people felt that their health was good. However, a number also had either physical or mental health conditions. Most of those people took medication for their health conditions. Although people were living reasonably active lives, pain and other health problems meant some were limited in what they did. More than half of the people had times in the past month when they had felt anxious or downhearted but most knew ways to make themselves feel better.

Some people had found it difficult to get support in the past, especially those with autism, anxiety and who reported troubled childhoods. At times this lack of support led to mental illness and/or coping through drinking alcohol. Getting a diagnosis and/or finding the right support had meant that they were in control and living more satisfactory lives.

A number of the participants went to their general practitioner regularly. The person did not always tell us why they often saw their doctor but as they were usually three monthly visits it is likely that they were for prescriptions for their medication. They had to budget to afford doctor's appointments.

Most people had healthy diets and regular exercise from walking or cycling. Even if they did not eat healthy food, people knew about healthy and unhealthy options. Some people choose to eat what they preferred and what they thought was easiest to prepare.

Results from the focus group and key informant interviews

There were different opinions about what contributed to a good life for people with intellectual disability who were living independently. Parents interviewed as key informants thought that having choices was very important, however the focus group participants thought that having good health and nutrition, and networks of support were the most important. Structure and routine in people's daily lives were also seen as important by the focus group members, while all the key informants considered flexibility to enable choice and being able to develop a sense of self-worth was important.

Everybody agreed that the right support was important. That support should adapt to what the person needed and wanted. Family members in the focus groups were concerned that people might be expected to cope independently too soon. This was not a concern for any of the key informants or the disability support staff in the focus group. They felt that services were careful to assess that the person was ready to cope and made sure that any risks were managed.

People with intellectual disability having meaningful activity in their day was also seen as important by the focus group members. Families supported people having voluntary jobs when they were not able to get paid employment. For the families concerned, these jobs gave their male family members access to other men to talk with and learn from. The focus group identified day-base activities as being better than no job.

All participants agreed that finding employment that was paid was difficult. They thought that stigma and prejudice were the main problems for people with intellectual disability. These beliefs stopped people from getting jobs, joining community groups and being accepted.

Lack of money, including the cost of transport and housing restricted what people could do. Like many of the people with intellectual disability, the key informants and the focus group participants thought that managing budgets was a challenge for people living independently. Budget services were only available in some regions.

In summary

The research identified important points for supporting people with intellectual disability to live independently.

1. People are achieving a good life based on their own definition of what a good life is.
2. People want to have choices and to be in control of how and where they live.
3. For most people, family relationships are important throughout their lives and family have an important role in supporting people to live independently.
4. Informal support also comes from friends, partners and neighbours. Relationships help to sustain the person's chosen lifestyle and provide opportunity for them to be seen as contributing within their community.
5. Formal support was important but needed to be directed to what was most helpful to the person.
6. Although health issues were identified, people with intellectual disability did not focus on these as a major issue in terms of them living an independent life.

Recommendations for policy and practice

1. People with intellectual disability should be supported to make their own choices independently. When they need help to make a decision they should be able to choose who helps them. It is the person with intellectual disability's right to make the final decision.
2. Adults with intellectual disability want family to be involved in a way that is respectful, help when needed but can also let them develop skills for independent living.
3. Family need to be recognised for the major role they often have in helping with decision-making through protecting the person with intellectual disability's right to choose.

4. Education and training is needed to help people with intellectual disability, family members and disability support service staff to understand and use supported decision-making.
5. Service provision should fit with the individual. Support staff need to be respectful and creative in how they work with the person to meet their goals.
6. Funding for budgeting services needs to be reviewed and a service available across New Zealand.
7. Health services, especially primary health care and dental treatment need to be more affordable and consistent across New Zealand.

We need to do more research about:

1. People with intellectual disability from other cultures and/or who are not using disability support services.
2. How to improve health and employment outcomes.
3. Children with intellectual disability who are growing up in New Zealand.
4. Financial management and budgeting support for people with intellectual disability.
5. How family and others can best assist with supported decision-making.

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Chapter One: Background

Introduction

Independent living is an accepted goal for most young people, however many people with intellectual disability[1], regardless of their age, encounter numerous challenges to realising this common life goal. This report details the findings of a study on the experiences and outcomes of independent living for a small group of adults with intellectual disability. Adults with intellectual disability, and support staff and families contributed data to the study, however the research retained a primary focus on the perspectives of people with intellectual disability themselves. This focus on the perspectives of people with intellectual disability was seen as central to the development of an emerging understanding of their realities, both positive and negative, of living with very low levels of formal support. The research was commissioned by IHC Advocacy, and funded by the IHC Foundation.

This report provides a comprehensive overview of the research findings. It comprises four chapters. The background chapter outlines the assumptions that have underpinned the movement from residential support to independent living and in doing so questions whether a more appropriate focus would be that of interdependence. Relevant research is drawn upon to illustrate the perspectives of both people with intellectual disability who are living independently, and those of family and professionals who are close to them. Finally a justification for the current research is presented. Chapter Two details the methodology underpinning this research, and the methods used to conduct it. Chapter Three presents findings generated through analysis of the qualitative interview data contributed by people wiht intellectual disability who were living independently, and the findings derived from data contributed by family members and disability support staff via focus groups and individual qualitative interviews. Chapter Four delivers a discussion of the key findings, along with concluding comments about the implications of the findings, with reference to the current policy and practice context in New Zealand.

The movement to (supported) independent living

People with intellectual disability have been demanding greater independence in their daily lives for some time. While dominant models of support through most of the twentieth century emphasised control and congregate living, current models demonstrate a purposeful shift toward greater personal autonomy in all aspects of life (Williams, 2013). In the New Zealand context disability policy, and consequently disability support funding models such as Supported Independent Living (SIL), Choice in Community Living (CiCL), Enabling Good Lives

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[1]   The term intellectual disability is used in this document to reflect the language commonly used in law and policy within New Zealand. The self advocacy group People First New Zealand Ngā Tāngata Tuatahi prefer the term learning disability.

(EGL)[2], and Individualised Funding (IF) have increasingly given expression to the rights held by disabled people, including those with intellectual disability. Most notably, the right to live in a place of their choosing with people of their choice as required by Article 19 of the United Nations Convention on the Rights of Persons with Disability (UNCRPD) (United Nations, 2006) has been prioritised.

Relatedly, in their 2012 report on living, Inclusion International (Inclusion International, 2012) identified three main issues for self-advocates and families: choice in where to live; support in order to succeed; and inclusion within their local community. In the report Inclusion International made the point that successful inclusion of people within their community is often based upon natural supports, which are necessary but often invisible. If independence is understood as not simply being able to do everything for oneself but as about being able to make self-determined choices, including about who might support you to enact your choice (Northway, 2015), independent living means more than how many hours of formal support a person receives. Instead, such an understanding highlights that what we might be considering is not independence per se, but rather interdependence (Northway, 2015). The notion of interdependence was again highlighted in a recent Australian study which, evaluated models of individual supported living arrangements. In this research the authors noted that participants commonly had informal supports, for example, friends, family, neighbours, regardless of whether or not they had formal supports, and these contributed to the success of their living arrangements (Cocks et al., 2016).

Further reiterating the need to see independent living as about having choice, rather than a need to prove oneself capable of certain functions, Williams and Porter (2017, p.106) suggest that "the right to be oneself will never be fulfilled as long as people consider they have to continually improve their skills in order to be capable of managing their lives." Duffy (2017) suggests such an approach is compatible with a notion of citizenship, which acknowledges the freedom to pursue goals while accepting help from others when it is needed. This understanding is consistent with notions of interdependence as outlined above (Northway, 2015). Citizenship, according to Duffy, also means having the opportunity to participate in political life, and to contribute to decision-making. When applied equally for all people it means that people with intellectual disabilities' perspectives are included in the social contract.

Björnsdóttir, Stefánsdóttir, & Stefánsdóttir (2014) have noted that Icelandic men and women with intellectual disability have struggled to achieve their independence and to make choices about where and with whom they live. Amongst the barriers they encountered were attitudes of family members, lack of information to help them choose where to live, no control over their finances and no assistance to learn how to manage their finances. Analysing data from the National Core Indicator programme in the United Stated of America, Stancliffe et al. (2011) found that those living with less support, such as in their own homes or apartments, were more likely to have chosen where and with whom they lived. However, although they appeared to have more input into their living situation than those who lived in residential or

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[2]   (Further information about these funding models can be found at http://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/new-model-supporting-disabled-people/choice-community-living).

other settings, it was more commonly the case that someone else chose, or, was involved in making the decision. Although focused on individuals with complex support needs, research in the New Zealand context on Article 19 of the United Nations Convention on the Rights of Persons with Disabilities identified similar barriers to those outlined above (Milner & Mirfin-Veitch, 2012). Unsurprisingly, these individuals faced even more entrenched attitudes about their perceived capacity to live in a place of their choosing with people of their choice. Whether or not a person is perceived by family and disability support services to be able to live independently has a strong impact on whether they are encouraged or assisted to do so. Influencing perceptions are the fear that the person might not be safe or does not have the requisite household skills.

Although there is significant commitment to people with intellectual disability achieving greater choice and control over their living contexts, level of support, and personal decisions, some authors have suggested that there is concomitant concern that greater autonomy may also have contributed to some people experiencing greater health or social disadvantage (Emerson & Hatton, 2014; Gravell, 2012). Recent research indicates that people in independent living situations can be disadvantaged by current systems and may subsequently "fall through the cracks" on matters of health and wellbeing (see for example Mirfin-Veitch, Conder, Payne, & Channon's (2017) research on access to women's health screenings in New Zealand). Determinants of health and health inequality are well-recognised as being experienced to greater extents by people of lower socio-economic status; a status that is frequently experienced by people with intellectual disability who live more independently. This exposes them to the material and social hazards of poor nutrition, poor/unsafe neighbourhoods, discrimination and community violence, and social exclusion (Emerson & Hatton, 2014). The extent to which these factors are affecting the individual's health can be difficult to ascertain, including through standard quality of life surveys, which typically focus on subjective wellbeing.

While health is often a prioritised element, wellbeing is comprised of a number of parts that remain under-explored for people living independently. For example, when informing the "To Have An Ordinary Life" Project" fifteen years ago, Bray and Gates (2003) highlighted a large gap in research on the topic of people's experiences of community participation, a key aspect of having a sense of belonging and social wellbeing. Today, belonging is increasingly recognised as a critical safeguard to the wellbeing of all people, particularly in relation to mental health of people with intellectual disability (Foley et al., 2012; Palis, Marchand & Oviedo-Joekes, 2018; Wilson, Jacques, Johnson & Brotherton, 2017). Studies that extend our understanding of the concept of belonging for people with intellectual disability are particularly important, given that they are acknowledged as being at higher risk for depression and anxiety (Conder, Mirfin-Veitch, Gates, 2015; Helps, 2015).

As was made apparent via "The Great Life Project", self-reported wellbeing was inter-related with quality of life (Conder, Milner, Mirfin-Veitch & Schumayer, 2009) with markers of community participation being as important to the participants as those of health status. Bigby, Bould & Beadle-Brown (2017) similarly found that people living more independently in Australia were positive about their connections with their family and community, however they also reported being lonely much of the time. With many reliant on benefits, their limited incomes affected their ability to fully participate in leisure activities or to take holidays. While

they recognised these limitations, being able to be independent and make their own decisions outweighed the alternative of living with more supervised support.

Social exclusion and limited incomes can be related to unemployment and the long-term effects of employment or unemployment have been noted in various studies. For example, Daly and Delaney (2013) found that when they controlled for a number of variables, the data from the longitudinal British National Child Development study demonstrated that unemployment was "likely to have long-run societal effects", with it being "predictive of psychological distress in mid-life"(p.22). To explore the benefit of gaining satisfactory employment to young adults, Winefield, Delfabbro, Winefield, Duong, and Malvaso (2017) conducted a 10 year longitudinal study in South Australia. When compared to those who were unsatisfactorily employed or unemployed, virtually all measures were markedly better for the satisfactorily employed group, including their growth in self-esteem, score on mood, and mental wellbeing. Earlier studies that have focused on quality of life and compared those in paid employment with those in sheltered employment have suggested that paid employment provides a better quality of life (Kober, 2010). A limitation of the studies reviewed by Kober, was that they were unable to identify whether the better quality of life was a result of the type of work or being paid for work.

In New Zealand, the most recent Disability Survey (Statistics New Zealand, 2014) noted that 74% of the people who identified within the study as either intellectually or learning impaired reported that they would like to work. There is a suggestion that supporting people to have an orientation towards the future and developing self-efficacy might assist people with intellectual disability to move into and sustain employment (Santilli, Nota, Ginevra, & Soresi, 2014). These skills might also benefit their wellbeing and decrease their social isolation.

Measuring outcomes for people who are living independently

Commonly, people with intellectual disability are not included in research conducted with the wider population, or, if they are, their disability is not defined. By nature, these wider studies are generally epidemiological in nature and predominantly rely on quantitative measures. These factors do make it difficult to evaluate outcomes for people with intellectual disability who are living independently in comparison to other population groups. In one study where a comparison was attempted Chaplin et al. (2010) analysed mental health referrals to a specialist clinic in London, they found that people with intellectual disability who were living independently were more likely to receive a psychiatric diagnosis than those living with family or in supported accommodation. These diagnoses included schizophrenia syndrome, personality disorder and depressive disorder. Looking to broader studies possibly provides a better way to measure outcomes for people with intellectual disability, however it does require that their disability is clearly identified in the data collected.

Acknowledging that measuring outcomes for people with intellectual disability is one way to influence policy and improve the quality and appropriateness of support for people living independently, Emerson & Hatton (2014) explored health disparities and in doing so identified two categories of people with intellectual disability that might be relevant to what is known about their health outcomes. The two categories are the 'hidden majority' and the

'visible minority' (Emerson & Hatton, 2014). The 'hidden majority' (Emerson, 2011, p.161) refers to the group of adults with mild intellectual disability, who, because they are independent of services, are invisible in administrative statistics. Comparatively, the 'visible minority' (Emerson, 2011, p.162) refers to adults with predominantly severe or profound intellectual disability who use specialised disability services where administrative statistics record some outcomes and there is an identifiable participant group for research. In other words, it is important that the health status of one group of people with intellectual disability is not generalised to another. In particular, this might be seen in quality of life and health screening rates, where fit-for purpose tools are being used to assess the wellbeing of people utilising high levels of formal support.

The approach taken by Emerson, Hatton, Robertson and Baines (2016) to measure the effect of a range of issues on people with intellectual disability, relied on assumptions which they calculated to be the most useful for measuring what they wanted to measure. For this research, they compared nationally-collected data within a UK study that explored the life experiences of its citizens, demonstrating that those who they identified as being likely to have an intellectual disability tended to be less involved in their community, have greater levels of social disadvantage, including fewer friends and fewer hours of employment, and were more concerned with their safety. They then sought to see if there was a relationship between these issues and how the person rated their health and found significant associations, in that they were more likely to report poor health. While this study might provide some insight into how the 'hidden majority' are living, it does depend on accepting the researchers' assumption that educational attainment is a good indicator of intellectual ability. Because only those people living in households (not living in institutions or residential support services) were able to take part, it is likely people with more significant intellectual impairment would not have been included in the study as neither the consenting process nor interviews made adjustments designed to increase accessibility for this group.

A similar attempt at interpreting national survey information in order to compare people with intellectual disability with others receiving benefits within the United States, found those with an intellectual disability were likely to have less high school education and be less likely to be married (although about 20% of both groups had children under age 18) (Livermore, Bardos, & Katz, 2017). While those with intellectual disability reported better health, aspects of daily living, such as shopping and meal preparation were more difficult for them and they reported more problems with mental and emotional tasks than their disabled peers without intellectual disability. Although people with intellectual disability had the same rate of employment as their disabled peers without an intellectual impairment, they received much lower salaries, suggesting that their employment was more likely to be in sheltered or supported settings. Furthermore, their lack of experience with employment meant that they were less able to identify the barriers there might be to them accessing paid employment in the future. For the few that had previous paid employment, barriers included their lack of qualifications and employers being unwilling to give them the opportunity.

One New Zealand study has reported on health indicators and service use by comparing data for people with and without intellectual disability (Ministry of Health, 2011). When compared to the general population, the conclusion was that people with intellectual disability were more disadvantaged than all other New Zealanders across all of the health status indicators

explored. Using a range of centrally held data, from a cross section of health and disability funding steams that linked people to their National Health Index number, meant that this study was limited to those people who could be made visible and, for that reason, possibly missed health issues for people with a mild intellectual disability, in the same way that Emerson (2011) identified that studies in the United Kingdom have done so. A further study conducted within New Zealand found that where people lived emerged as a statistically significantly predictor of the likelihood participants would be prescribed medication, have a BMI in the obese range, have an unhealthy diet, and report using tobacco products (Milner, Mirfin Veitch, & Conder, 2013). This study, which utilised data generated through health screening conducted as part of the Special Olympics Healthy Athletes Programme (HAP's), was the first time that participant living situation had been included as an information field in HAP's screening.

Studies such as Emerson et al. (2016) and the Ministry of Health (2011) provide quantitative data from which we can draw some correlations that suggest cause/s of poorer health, however, they also risk people with intellectual disability appearing oblivious to how they might live healthy lives. To explore their knowledge, Kuijken, Naaldenberg, Nijhuis-van der Sanden, & Schrojenstein-Lantman de Valk (2016) held focus groups with people with mild to moderate disability. They found that people were, on the whole, well informed about contributors to healthy living but low motivation, travel distances that made it difficult to walk between places they wanted to go, lack of support to make a healthy choice, reliance on others to provide information (such as healthy food options) influenced what they actually did to be healthy. Their findings indicate a need for a multifactorial approach when considering how to improve the health and wellbeing of people with intellectual disability who are living independently. That is, while quantitative data is useful, to more fully understand the lives of people with intellectual disability who are living independently both qualitative and quantitative approaches should be considered.

Research about independent living

The experience of independent living for individuals with intellectual disability is an area in which very little specific research has been conducted. Although researchers within the field have frequently collected data from people who are living independently, their focus has not been on how they were living but rather other topics, such as parenting or employment. The research has predominantly been with people who are using disability support services. The knowledge these researchers have gained has, however, led to the concerns expressed above by Emerson and Hatton (2014), in terms that it might be missing the reality for those who are not involved with services. While development of policy is beginning to encourage services to change their mode of support and, as part of that process, provides opportunity for exploratory and evaluation research with people living more independently, such research will continue to miss the "hidden majority" (Emerson & Hatton, 2014).

The small body of research that is available suggests that independence – both general independence and living independently – is an attribute that most people with intellectual disability highly value. Living independently brings a sense of freedom that allows the individual to make choices and to control various aspects of their life (Bigby, Bould, & Beadle-

Brown, 2017; Bond & Hurst, 2010; Karban, Paley, & Willcock, 2013; Sheerin, Griffiths, de Vries, & Keenan, 2015). As well as the benefits of independent living, these studies identify both actual and potential risks to the person exercising their freedom. As outlined below, some of these studies include both people with intellectual disability and family or support people and in doing so highlight the different opinions and concerns of each group.

Bond & Hurst (2010) studied nine adults with mild intellectual disability who lived independently. They identified several themes that demonstrated the complexities of independent living. Such themes included choice and control; vulnerability; health issues; practical support issues, and feelings associated with living alone (Bond & Hurst, 2010). Their study illustrated that living independently as an individual with intellectual disability was not without its issues, but more importantly, those with intellectual disability wanted service providers to understand that while their support needs might be minimal, they had the right to make their own choices within their support relationship.

A study by Weafer (2010) assessed the views of those with disabilities, their families and the frontline staff. The information was elicited from multiple focus groups over a one month period. The aim of the study was to gather the views from the various groups of people in relation to independent living, community participation, and quality of life options (Weafer, 2010). The opinions and views of the different people illustrate how their experience and relational position influences their expectations. Those with intellectual disability had mixed views on whether or not they aspired to independent living depending on their current living situation. Those already living independently were generally satisfied with doing so, while those who lived in group homes or with their families had mixed views on living independently (Weafer, 2010). Many associated an increase in issues or difficulties with independent living and questioned why they would leave the comfort of their current type of supported living or living with family to live independently (Weafer, 2010), reflecting an anxiety that might be expected in the face of a major change.

The parents who took part had mixed views on independent living. Reflecting the age of their young child, numerous parents viewed it as a transition in which they would no longer be able to care for, or look after their children (Weafer, 2010). These parents believed independent living had to mean more than meeting personal needs and selecting accommodation. Rather it should also include quality of life, such as meeting with friends and pursuing their goals. In common with Björnsdóttir et al. (2014) and Stancliffe et al. (2011) who identified safety as a concern of parents, Weafer's study included worries about what would happen to their children once they moved out and if the parents passed away. The parents' anxieties were picked up by some of the frontline staff, who felt that the parent's involvement in decision-making led to restricted growth opportunities for the person with an intellectual disability. To that end they praised the independent advocates who were helping service users access their rights and challenged the traditional practices of the services. Subsequently, frontline staff believed that services had improved significantly as the years progressed but still felt there was more work to be done. They believed that for people with disabilities, independent living should be fluid and accommodate each individual's specific needs.

The shift from hostels to purpose-built independent living units provided one area of the UK with the opportunity to study the process (Karban et al., 2013). While this research included

people with intellectual disability as well as those with mental health concerns, reporting identified to which group participants belonged. For those with intellectual disability the move had been positive in terms of their satisfaction with the quality of their new home and their new-found sense of freedom. Some people reported that they were not able to access sufficient support in specific areas, including IT and meal preparation. The authors drew on comments from the participants to note that adjustments to providing support did not always follow the intention of the policy of independent living. For example, people being told to leave their door unlocked so that staff could gain access when they wanted, or being told to clean their home. Staff also struggled with choices people made that they saw as putting them at risk, for example with their money, or with health behaviours such as food and exercise. A key point made by these authors is the need to prepare the people who support those living independently, so that they understand their role is to be responsive to the type of support the person requests.

As noted above, Bigby et al. (2017) reported on supported living experiences for Australians with intellectual disability who were living either on their own or with one other person, and where their housing arrangements were separated from their support arrangements. Data came from focus groups and six individual interviews. Participants who were interviewed had less than eight hours of formal support a week. While all agreed that living independently provided greater freedoms, they also commented on the areas of their life where others were in control, such as with their finances. The lack of money was a problem that affected daily choices and opportunities for leisure activities, impacting on overall wellbeing. Apparently lack of money also impacted on their ability to make full use of the internet; while all had a mobile phone, few had internet connections at home, despite many using technology at other places when it was available to them. Support workers were generally appreciated, along with informal supports, as a source of help that was available if needed. Despite these positive comments, formal support was also noted to be inconsistent, changeable and frustrating at times. Neighbourhood safety was an issue for many and restricted their evening activities, as well as making them fearful when dealing with people that they did not know or those who were rude to them.

A request from a service led to Sheerin et al. (2015) interviewing five older adults and family members following their move from a residential setting into self-contained units. Although these units were within a cluster that was supervised, the mode of support changed along with the setting. Participants identified benefits of their move as having more space, privacy and being able to make their own decisions regarding what and when they ate, how they shopped and so on. For some of the older adults, having staff readily available was reassuring but also had the potential to make it more difficult for them to develop self-confidence and self-sufficiency in that they expected there would be someone checking on them. The authors noted that the participants had long term experience of living in institutions and some had health concerns typical of an aging group. While the history of institutional living might differ amongst those people with intellectual disability who are living independently, it needs to be remembered that aging is likely to raise similar concerns to those expressed by people without intellectual disability, with support needs changing throughout the lifespan.

In summary, while these qualitative studies generally have included small numbers of participants, independence is consistently rated highly by people who live independently.

Although family and support people often have some concerns, they are generally supportive of moves towards people with intellectual disability choosing to live independently.

Justification for the current research

As a signatory to the UNCRPD the NZ government has to report on progress towards meeting all of the rights expressed in the Articles of the Convention. Research that explores the lives of disabled people can provide valuable information about such progress, including pointing to areas where further work is needed to meet the expressed goals. Article 19 identifies "the equal right of all persons with disabilities to live in the community, with choices equal to others …" (p.13). The right is supported by other Articles, including 12, which relates to equal recognition before the law, thus establishing a right to the assumption of legal capacity. An interpretation of Article 12 identifies that any person who is not fully able to make an autonomous decision should be supported on the basis of establishing their will and preference (Mirfin-Veitch, 2016). As noted above, concerns have been expressed about both the standard of living that people have and the constraints that there are on their choices. Article 28 requires States to ensure that people have access to the supports that they require in order to have an adequate standard of living.

Recent NZ research has been conducted in relation to people living in residential services (Malatest International, 2016), mirroring the focus of the earlier important report "To Have an Ordinary Life" (National Health Committee, 2003). However, in general, there continues to be an absence of research that has engaged with people with intellectual disability who are living independently under the new service models in New Zealand. Thus, a deep understanding of wellbeing as experienced by people living more independently has yet to be achieved. This lack of understanding is problematic for ongoing policy and practice[3].

Quantitative studies, such as the Ministry of Health's (2011) analysis of data have not been able to link living status with other findings. Studies that utilise surveys, such as the Special Olympics Healthy Athletes Programme, do enable a link to living situation but lack facility to explore issues in any depth. A point noted when analysing focus group data in the Great Life Project (Conder, Milner, Mirfin-Veitch, & Schumayer, 2009) was that what people did not say could be as revealing as factors that they did say. That is, in the absence of experience (or expectation) people are not always able to identify what is missing from their lives. This observation highlights the importance of conducting qualitative research with people themselves, whereby a greater array of questions can be posed, and a deeper understanding of people's life contexts can be developed.

Additionally, while major national health surveys contribute important data that provides an oversight of population health, they tend to be periodical and within New Zealand do not specify a category for people with intellectual disability. To explore whether a comparatively simple tool would provide a way to capture the actual health and wellbeing status of

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[3] Of note, the New Zealand Treasury is moving towards providing measurements of living standards within New Zealand for future reports on the NZ economy (see https://treasury.govt.nz/information-and-services/nz-economy/living-standards/our-living-standards-framework)

individual people in order to identify trends or patterns across this group, the SF20 has been included within this study as a health data collection tool.

The current research was designed as a preliminary study with the potential to contribute to inform more comprehensive research in this area in the future. As policy and practice relating to disability support increasingly moves toward self-directed models, it is critical that such models are informed by the lived experience of those people already living independently. In particular, it is important to determine whether people living independently with little formal support consider that they are living a good life, including the benefits and limitations they may have experienced in relation to citizenship (Duffy, 2017) and how this influences independent living.

Chapter Two: Method

Introduction

This chapter sets out the methodology that guided our approach to the research, and describes the method that we implemented. The research was the culmination of discussions between the Donald Beasley Institute and IHC Advocacy about the need to explore whether or not people with intellectual disability who were living comparatively independent lives within Aotearoa New Zealand were achieving a good life, according to their own personal assessment. Based on this perceived need and the literature outlined in the previous section, the aim of the research was identified as being:

To explore the experiences and outcomes of independent living from the perspectives of adults with intellectual disability in Aotearoa New Zealand.

This broad aim was to be achieved through:
- An exploration of the daily lives of adults with intellectual disability through interview and observation;
- Identifying the factors that adults with intellectual disability perceive as facilitating or enabling a good life;
- Ascertaining the impacts and outcomes of independent living on health and wellbeing using a validated measure, the SF20 (Rand Health, n.d.);
- Identifying the views and experiences of families and service providers through focus groups;
- Integrating the three strands of data to provide a more comprehensive understanding of independent living and the factors that are integral to a good life for adults with intellectual disability.

Methodology

A constructivist approach (Lincoln, Lynham and Guba, 2011) was utilised to explore the topic. Constructivism recognises that realities are co-constructed and situational, and was therefore considered to align with the aim and objectives of the research. Constructivism enabled a better understanding of what is important in the lives of people with intellectual disability from their perspective rather than being imposed by others' pre-determined values. Within this study the constructivist position was relevant to understanding both how individuals with intellectual disability positioned their lives as good, or otherwise, as well as how their lives were constructed by others (family members of people with intellectual disability and staff of disability support services).

Relational ethics fits comfortably with constructivist approaches (Lahman, Geist, Rodriguez, Graglia & De Roche, 2011). Lahman et al., (2011), in summarising the work of others, identify trust, respect, reciprocity, being attuned to the participant and their ongoing willingness to proceed with interviews, among the important components of research relationships. Appropriately responding to cues from the participant demonstrates respect. Throughout the interviews, the researchers were careful to acknowledge when a person looked

uncomfortable with a question and responded by reiterating that they had control over the process when this happened. Specifically, people were reminded that they could make choices about what they chose to answer and/or disclose during the interview.

Reflexivity was important throughout the research process of analysis, writing and dissemination and was aided by carefully recording each step. As soon as possible after interviews we met to discuss the process and content, reflecting on what that information might mean for how we conducted future interviews and beginning the process of analysis. Further information about analysis is contained later in this chapter.

Prior to commencing the research, a reference group was established to guide each stage of the project, from planning through to dissemination. The reference group included two people with learning disability (one female and one male) and two people from organisations that support people with learning disability[4]. Initial input from members of the reference group was influential in the final versions of the semi-structured interview guide and the participant information sheets and consent forms. In particular the people with a learning disability identified a number of additions to the interview guide, including the suggestion to begin the interview by asking about the person's interests and what they liked about living independently (see appendix 1).

The research was approved by the Health and Disability Ethics Committee (HDEC) Northern Region Committee reference: 17/NTA/207/AM02

Method

The predominant method for the study was qualitative, however the utilisation of the SF20 survey provided data that could be quantitatively reported.

Participants

The research included two participant groupings. Group One was made up of twenty adults with intellectual disability who were recruited through Disability Support Services and People First Aotearoa New Zealand, Ngā Tangata Tutahi. Four regions of New Zealand were represented, two in the South Island and two in the North Island. Participants ranged in age from 22 to approximately 65 years of age. The 12 men and eight women who chose to take part, identified as New Zealand European. All participants lived independently with 10 hours per week or less formal support from a disability service. They most commonly lived by themselves or with flatmates, one young participant was living with a parent who was frequently absent due to work that took them out of the country. Most rented their home but four were home owners. Participants involvement with disability support services ranged from being recently accepted to having been supported for many years. Group Two were family and disability support staff who participated in a focus group (n=7) or in individual key informant interviews (n=4).

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4 The term learning disability is used in this context as it is the preferred term of the people involved.

Data collection – Group One: participants with intellectual disability

In keeping with the Aotearoa New Zealand government's holistic model of wellbeing, which incorporates Te Whare Tapa Whā's dimensions of physical, mental and emotional, social, and spiritual wellbeing (Mental Health Foundation, 2015) and the World Health Organisation's broad definition of health, the research was designed with the aim to collect a range of relevant information.

Prior to the interview the researchers made contact with each potential participant to establish a relationship, discuss the study and answers their questions. At this point, people were able to choose where they wanted to be interviewed, with most choosing their own home.

Individual qualitative interviews provided the main source of data from the 20 people with intellectual disability. In addition to the semi-structured question guide and ecomap[5], the SF20 was used to explore their perceptions of their health and well-being. The SF20 includes items relating to physical functioning, role functioning, social functioning, mental health, current health perceptions, and pain (Rand Health, n.d.). Pictorial cues were available to guide the general topics of interest and these were used by some participants. While it was expected that most people would understand the questions in the SF20, alternative cue sheets were prepared and available if participants had difficulty understanding the options. These included a picture-based pain scale and appropriate graphics for the other questions that have five or six options within the scale. As it happened, none of the participants required these visual cues but the researchers did provide verbal prompts to assist the participants to complete the SF20. The intention had been to also collect data from personal plans, however most participants were not able to provide these for us at the time of the interview so this did not occur. Some did, however, identify their goals.

Data collection – Group Two: families and disability support staff

Two approaches were used for data collection from Group Two, focus groups and individual interviews with key informants.

Focus groups

Focus groups were selected as an effective way to engage with family members and staff because they provide an opportunity to hear a range of views and enable discussion in way that the individual interview is not able to do (Braun & Clarke, 2013). These factors were seen as important when it came to gathering the perspectives of disability service providers and

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[5] Ecomaps have been used within a variety of contexts, including as a research tool. They are diagrams that use symbols to illustrate relationships between the individual and those in their social network (Ray & Street, 2005). An inner circle is used to represent the individual. Surrounding this inner circle are the people or groups that the individual identifies having a relationship with. The strength of the relationship can be illustrated by the thickness of the lines between the individual and the others.

families. Two focus groups were planned but difficulty with recruiting participants resulted in one focus group being held. The focus group data, gained through collective discussion amongst the group was collected at the time onto large sheets of paper, with a note-taker collecting additional information and audio-recording to support later analysis. The focus group was structured to first gain the views and perspectives of disability service professionals and families about the positive and negative aspects of independent living, and to identify what they saw as most important features of independent living, that is, what denoted "successful" independent living according to their perspectives Towards the end of the session, we presented preliminary findings generated through our work with adults with intellectual disability to focus group participants. This final element was designed to facilitate understanding and discussion about the similarities and contrasts in the views held by each group, and consequently, where appropriate, to provide some direction about the pathway to address issues identified at a service and system level.

Key informant interviews

To provide balance, once it was clear that there would be just one focus group, additional key informant interviews were arranged. Two parents and two disability support service staff with relevant experience were interviewed using questions that had been prepared for the focus group. These people were recruited through one service following ethical approval for the change in method from the HDEC.

Analysis

Interviews

The data from individual audio-recordings was transcribed. These transcribed audio-recordings were analysed along with field notes and other data that the person agreed to have included to create a representation of their life. Participants received a copy of their "representation". While it is usual to return transcripts of interviews for this purpose they can be difficult to follow. Writing a more fluent account that is also inclusive of the other information that was collected at the time of the interview was expected to assist the participant to make a decision about their information being included in analysis. Utilising the "middle ground" of qualitative analysis (Ellingson, 2011, p.600), the twenty representations, along with the separate components of data, were compared and contrasted, beginning with repeated reading in order to familiarise ourselves with the data, noting emergent trends and patterns to identify significant themes. Themes were reflective of the purpose of the study but generated, as Patton (2002) suggests, through interpretation of the data to uncover meaning and deeper understanding of the lives of the people interviewed. Memos were utilised to track the progress of analysis.

SF20

The SF20 data was entered into SPSS for the purpose of descriptive analysis. The individual results from the SF20 was used to inform the first stage of the above analysis. In this respect, the quantitative component to the research can be seen as one that was concurrent with

respect to data collection and analysis, while the qualitative elements were intended to be dominant within the interpretation (Leech & Onwuegbuzie, 2009).

Focus group

In keeping with the position of Kreuger (1998) focus group analysis was practical and driven by the objectives of the research. The participants' responses to focus group questions were recorded at the time. Analysis utilising these written responses, the audio-recording and notes focused on the process of interaction to identify how participants have constructed their views on the daily lives of people with intellectual disability who are living independently (Silverman, 2011). Through iterative cycles of reading and listening the data sources themes were identified. As with the interview data, memos were used as a way of capturing the analysis process as it occurred.

Key informant interviews

Similarly to the focus group data, analysis of the familiy and disability support worker interviews focused on determining how these individuals understood independent living, and what they saw as critical features of a "positive" independent living experience.

Drawing all the strands together

Research that draws on a number of sources requires integration of the data. In the case of the current study, we acknowledge an emphasis on the qualitative aspect of the work however we have sought to position and explain the SF20 findings in relation to the qualitative findings. The following chapter details the research findings, which are based on all forms of data collected for the purposes of this study.

Chapter Three: Findings

Introduction

The findings from this research demonstrate the variability in the lives of people with intellectual disability who are living independently. In Section One of this chapter the main themes are identified from within the transcripts of the individuals, as well as a collated profile of their background as identified by the individuals. In Section Two, the results of the focus group and key informant interviews are presented.

Section One: The individuals with intellectual disability

Who were the participants?

The 20 people that contributed to this study had a self-reported intellectual disability, with 19 receiving support from a service supporting people with intellectual disability. Many were happy with the support they received, however, the current arrangement had often been negotiated in order to get the people supporting them right and the hours and type of support most helpful. In addition, although many identified no other disability or health-related concern, some participants mentioned mental illness, alcohol addiction, physical disability, epilepsy and medical conditions. Living arrangements included renting flats either alone or with flatmates or partners, renting a room in a boarding-type establishment and home ownership.

Most of the participants had attended school through to secondary. Primary school more commonly meant inclusion in classes with their age-mates, whereas, once they reached secondary school they were more likely to be in special classes. Although some had liked this separation, others thought it had not been to their benefit. School became a place where they were "picked on", "teased" and "bullied" with the consequence for some that they began "acting out". Only one participant achieved NCEA subjects, while another had achieved passes in some School Certificate subjects.

There was some evidence that pointed to the benefit of having a supportive family and school experience in terms of the person adjusting to adulthood and independent living. Opportunites throughout childhood and early adulthood differed widely, a few had travelled overseas for holidays with family or with disability organisations such as Special Olympics. Some had lived throughout various parts of New Zealand, moving with family when younger, or independently when they were older. Among the participants were those who recounted a history of alcohol abuse, violence, criminal convictions and social isolation and these people also commonly talked of troubled early lives, either in relation to their family or school experiences in childhood. Those who were parents had limited to no contact with their children. While people were at different places in their journey, the stories told by individuals provided insight into, and evidence for, their resilience and how they valued their independence.

Living independently means having choices

The one message that participants were most clear about was that living independently gave them choice. Choice was generally seen as positive, contributing to their overall sense of wellbeing. There were many aspects to choice, including where and with whom they lived, how they spent their money, who they had as formal support, as well as the day-to-day decisions such as what to eat or wear.

As the following quotes demonstrate, while what people liked about living independently could be expressed in various ways, it often came back to being able to experience choice. For example:

> "I have my own freedom. …. I can do what I want to do. Choosing what I want to do around here and when I want to do it, like doing housework or watching TV or probably going out and about and that." (105)

In addition to having choice, living independently was also seen as a way to demonstrate ability:

> "For me it means stepping out from my family standing on my own two feet and doing things myself … Basically, spreading my wings is what it means to me.… I get to make up my own mind. I don't have people telling me what to do. So, basically the world is my oyster, and, I've basically blossomed… living independently means you blossom. Where, if you're cooped up in a shell, you can't blossom cause you're not the person you want to be." (113)

Living independently provided the space that some people needed to be happy. For example, 101 commented … "*Gives me my own space …. And I just enjoy it really because it gets me out of people's way.*"

However, having the independence to choose didn't always work out for some people … *"I could do anything I like, how I like it, whenever … But I had no supports. Lack of supports."* (111). The main concern for 101 was the lack of social opportunity that he associated with living alone. This sense of loneliness was also expressed by 118:

> "Living by myself, and when I got kicked out of my family home, um I went to a council flat for 5 years. Um, it was pretty, what would I say, lonely? Um I didn't have any friends. Um, if I was going to go out I would go see my mate at their house. Um every Wednesday night just to get drunk. Get more depressed. But um yeah, it's just it was pretty lonely, um at a council flat, um just playing games, watching TV. Yeah" (118)

This person identified how much happier he was living in a boarding house, as he put it "*More happiness inside me*".

Taking choice about how to live as the major theme, it was possible to draw out what this might mean in more detail. The following subthemes identify what the individuals saw as important to living an independent life where they had choices.

1. "It gives me a bit of self-esteem"

More commonly expressed by the younger participants, and as indicated above, being independent was important for self-esteem. Having got to middle age, 114 eloquently reflected on the importance of achieving independent living, setting it clearly within this subtheme …

> "… it means for me self-esteem … it means to me that you have that you can live your life on your own terms and … you're not treated you don't feel like you're a special case. … I think for me it gives me a bit of self-esteem and a sense of ah you know being well-grounded which I didn't always used to have. … I don't feel like I have to constantly say to people I don't have this particular problem, I don't hear voices I don't you know I'm kind of grounded in reality. … and I've acquired skills I mean like when you know I didn't always know how to look after a flat on my own I didn't always know how to organise a flat and clean and tidy I didn't always know how to do that."

The younger participants related their developing independence to their physical separation from family. Moving out of the family home and beginning life as an independent adult provided the opportunity to develop confidence. As 115 put it:

> "…to show people that I can do things for myself. And that I am independent. And don't always need my Mum around, my family.
> Interviewer: Has mum been surprised?
> Respondent: Yes. Because she never thought I would get this far. She was always worried how I would get on in a flat. But she said you've got along really well."

For 102 achieving greater independence through learning new skills was important … *"To … challenge, and just, and also to prove to others that I am capable of it. It's just that it needs a bit of a push."*

While self-motivated, 102 implies that she also valued the formal support provided by the service for the additional motivation they offered. Most of the younger participants had specific support linked to developing the skills that they needed, such as grocery shopping, cooking and learning how to keep their home clean and tidy. However support hours commonly decreased as they became more confident. For example, 121 noted:

> "… when I first started [with support service], in 2008, and I had … about 24 hours support. But it's now down to four hours. When I first moved out I had …more support to help me with like cooking dinner. Cause I didn't even know how to cook dinner …toasted sandwiches when I started… now I can cook."

As these quotes illustrate, there was pride in what people who were living independently had achieved. That pride, for the most part, seemed to come from within the person and demonstrated a sense of developing self-efficacy.

2. "It's just a lovely home"

Most people were settled within the home they were living. A few owned their home, or their home was family owned and they paid rent or mortgage payments. Suburbs in which they lived were generally low to middle income areas and rental accommodation differed widely from basic three room individual council flats to rental houses that were comparatively roomy. Regardless, most people were happy with their home, aligning it with the overall theme as being the place where they are free to make choices about how they live. They talked about what they liked about their home, including proximity to places that they wanted to go and also that they felt safe there. Most felt that they had a choice in making this their home, they understood they had rental agreements. A few had completed rental agreements for themselves but most had support with this aspect of their housing.

Four participants idenitifed that they were living in homes that they either owned outright or were owned as part of a family trust. There were various agreements in place. For example, when 119 talked about his home ...

"... my sister said that she was looking for houses for rent ... and then stumbled on a different website. Houses for sale ... So we had a look and ... I thought yep sounds good. And then when we met the real estate agent .... We also had to get the rules bent a bit in the body-corp. Because [he was younger than the age accepted by the housing development]. But they were able to negotiate."(119)

In this case, 119 had available the money to buy into the complex. However, another younger participant moved to home ownership by being supported through a family trust, as he explained:

"Here's where things get complicated. I own it, I officially own it when I'm 26. At the moment, the family feels like I own it, in a way of they want me to have control of the rates and the insurance. But legally I've got another two years to wait ... it's very complicated. It doesn't have me, titled to me, because we need to get a rates rebate because it's a trust. But that's fine." (110)

The satisfaction that achieving a goal such as home ownership was expressed by 113 thus:

"It feels homely, it's warm and easy to maintain and easy to keep clean and I like the character of it – it's a lovely character to it. Yeah it's just a lovely home and makes me feel happy that I've bought it coz I've never actually bought a house and it's a dream for me that I had and I feel that's come true now ... so basically my fiancé and I pay off the mortgage to his Mum ... we've bought it off her and we are paying her back so we are basically paying the mortgage"

For the four participants that owned their home, there always appeared to be family involvement at some level. Money to buy the property commonly came from a fund to which the person had access. Such funds included family trusts, bequests and ACC payouts.

The majority of participants were, however, renting their home or room. Most had help from family or services to find and negotiate tenancy. Landlords included parents, support services, City Council and other social housing organisations. Of key importance was that they liked the place, it was well positioned for them to get to where they wanted to go and they felt that they had a choice when entering the rental agreement. For example, 115 expressed why she had chosen to move back to an area in which she had lived before:

> "Oh it's closer to everything. Um I like the area very much. It's a very nice area to be in … I didn't like it where I was before. It was too far away from everything. The buses were not always on time. They weren't the greatest service. Over here I knew the bus times and stuff like that. I know where everything is." (115)

Knowing bus times and having a regular bus service was important for most of the participants. In addition to utilising buses, living in relatively flat towns or parts of town meant that bikes were an alternative for some, including 115 and 103, both of whom had an adult trike. These participants used the footpath when riding and had learnt to ignore comments such as *"… 'get on the road' and stuff*." (103), demonstrating a degree of confidence that they could safely get around their neighbourhood.

While 115 had initiated her move, for 104, who, at the time had no disability service supporting her, the move to her current rental home was driven by her mother. Although she was somewhat resistant to begin with she acknowledged that it had been a good move:

> "I was in x street and it was just one bedroom and a half, and Mum sort of got sick of that place and so she went house hunting while I was at work. … she took me to this one. So, I actually didn't mind it. It had had a lot of work done on it. They had put new carpet down. Did the bathroom, and yeah, everything else. But the one thing it didn't have was a fridge and freezer and a washing machine [which she subsequently bought] ... I have stayed here ever since ... I am actually quite comfy in this place."

In both the above situations, the move was motivated by considerations of convenience, rather than any major deficit in the previous home, however, as 120 explains, getting out of unsuitable accommodation might be more urgent …

> "my old support … got me a counsellor cus I was suicidal and stuff like that and depressed and stuff and … the counsellor and her had a meeting …" The outcome of which was to find him a better place to live, than the one where there was … "little presents in the lift, faeces and stuff like that and my support wouldn't come and visit me because they would think it wasn't safe to come."

For the few men in the study who had a history of drinking to excess and criminal behaviour, there was some evidence that being able to live away from more organised service provision was beneficial. In these cases, as seen also in their relationships, cluster housing arrangements led them into socialising with peers with similar histories and made it difficult for them to move on. 101 explained it …

"But I used to get up, get in naughty stuff over there so I decided to leave … And move into a place where I can actually stop drinking … Because I had a drinking problem … But as soon as I moved in here I stopped that."

Recognising the need to move 101 had found his current rental through Facebook and was then assisted by his support service to make the move. He was typical of the men that had made similar moves in that he had been happily settled since his move.

The data is evidence that people living independently can and do make their homes comfortable and become settled. The quality of the homes was diverse however this did not seem to make a significant difference to how people felt about their home. Although most had needed some help to find and move into their home, even those with relatively few possessions had made it their own.

3.　"Ah, sometimes we like to catch up and do things together."

Participants differed in the emphasis that they put on their relationships with family and friends. While this subtheme focuses upon relationships that were developed face-to-face, Facebook was also an important means of regular social interaction for nearly all the participants, however, for many, the lack of internet at their home meant that access was restricted to visits to their family home or their disability support service. Individuals had learnt how to keep safe on this medium, they varied in the frequency with which they used it and the way that they limited their "friends".

For those with strong social connections, although often living alone, their relationships meant that they were less likely to be lonely. For most participants, their ecomap did not indicate wide social networks, however, more important than the number of people was the strength of relationships. Some, particularly the younger people, were closely connected with their parent/s, for example, about her parents 115 noted … *"They're a big part of my life"*. For those who had parents living close by it was common for them to have at least weekly contact, initiated by either them or their parent. Older participants, on the whole, had less to do with their parent/s, in some cases their parents were no longer alive. However, where they were still alive, even if the contact was less often, parents could be seen to be influential. 116 reported *"occasional"* contact with his father but still saw it as a strong relationship, commenting on whether or not he is a main source of support *"… Ah pretty much, yes"*. The exceptions to these relationships were more common where the person described a childhood or adolescence in which they had been abused, moved out of the family home (for whatever reason), or had episodes of violent behaviour.

Rarely relationships extended to people who had been involved in the person's early life, for example, 102 regularly met with her former nanny, helping her with her children or seeking her company for advice when she went clothes shopping. While 103 continued her association with the family she had lived with during her adolescence … *"… we go out to her husband's sisters for lunch… about every week or so …."*

Typically, like 102 and 103, where entry into disability support services came after adolescence, friendships more commonly originated through their contacts within the wider

community. For 104, friendships seemed easy to accumulate as she explained how she met her best friend:

"I met her through someone. And then, I met her sister [who she now identified as best friend 2] and then [friend 1] and [friend 2], and then that's how you met people through other people."

This group of friends shared special events, such as birthdays, while she had frequent contact with her best friend, either through meeting together, Facebook, or text messaging.

More formal groups, such as clubs, were also mentioned as places where people made friends. These groups included sports clubs and Toastmasters, all of which led to participation in larger events, such as Masters games and national meetings. For one participant, the local sports club was seen as more responsive than Special Olympics, which he saw as being exclusive in terms of expecting people to self-fund for larger events. He commented on how his sport club had ensured his participation through financial support and how he was partnered with another player who could provide the practical support that he required … *"…if you're playing yourself it's hard … I find it hard to read numbers".*

However, for many, friendships more commonly originated in groups such as Special Olympics, or Support Service activities. 107 had recently moved out of the family home and noted that *"Well, two of my friends are now my neighbours … They just live down the road."* He had met these people through Special Olympics and Drama but they also met for other activities that they organised between themselves. As he described it *"Ah, sometimes we like to catch up and do things together."*

While neighbours were identified as friends by a few of the participants it was not always clear whether or not these were friendships that would remain if they moved to different areas, in the way that they had done for 107. What was clear, was the importance such friendships had in their day-to-day lives, particularly as someone that they could seek out when they wanted company.

It was notable that formal support staff from services were not seen by the majority as important in their lives in terms of being a social connection, as 103 commented we … *"Just have a working relationship".* While participants identified the range of support provided by these people, and generally recognised it as helpful and important, they did not see the relationship with individual staff as long-term. Indeed, 112 illustrated an alternative view when she noted …

"… there's another lady that had been interviewed, and [manager] said the other day that she was interviewing her. And I had a choice whether to have her, and just have [current support person] some of the time. Or keep [current support person] the days that she comes and not have the other person. … I think I'll go for a different one … So that I get to meet you know different people which I quite like to do. Meet different people and what their cultures are like …"

Furthermore, they could be critical of who supported them if they did not approach the relationship in a way that the person found acceptable, for example, 120 explained, it was preferable to have people who do not begin by reading the person's file, instead … "… *just when they talk to us not go to the office and read like our goals and stuff just what are they like have a thing at our house and talk to them about what we want to do.*"

One participant did identify their support person as a close friend and one other indicated that support service staff, who make the effort to get to know the person that they support at important times in life, can be influential in a way that impacts of their future …

> … my [support service] manager who looked after me, … he thought 'ooh he's too able to be a client he's going to go flatting' and he buddied up with me, you know took me under his wing showed me how to go flatting and let me when I was in [residential home] he let me come home later than the others.

At the time of the interviews, three people were living with a partner. Previous partnerships were limited to a small group and included being married for two participants. Parenting was rare and no children were living with their parent. This included two separate parents who had children of pre-school age that were not living with them. Contact with their children differed depending on the arrangement that had been made through Oranga Tamariki. It was notable that the first thing one of these parents stated when asked to tell the interviewer about herself was *"I am a mother"*.

For those living with a partner, their social world was predominantly focused on that relationship. For example, 101, when asked about other friends commented … "*Nah not really. I just stick to my partner really.*" While 113 described how they entertained themselves together … "*my fiancé has got a PlayStation – that's the black thing – it's a square thing. And we've got our games in the cabinet … Umm we also like doing puzzles and watching movies and having good laughs together and cracking jokes*" (113)

Learning to negotiate relationships was part of developing their independence for all participants. As 113 illustrated, in discussing how she was setting the boundaries with her future mother-in-law:

> "So basically, I'm learning to be more assertive and not let her walk over me coz sometimes she'll try to walk over me and push my boundaries. Umm as far as I'm concerned, I have boundaries and I don't like it when people try and push them."

And 102 " *… I do stand up for myself. Um, I sometimes stand up to Dad a little bit, sometimes when he just pushes me off the edge.*"

One way that some negotiated relationships was by choosing who they lived with, or who to have as friends. For example, for 105 who she mixed with in the past had not always been to her advantage, so she explained it as *"I've got five friends then I've got associates. ... People that I just bump into and I don't tell them where I live. Just put it that way."* In contrast, as 118 explained, leaving behind a previous life could also mean losing friends:

"when I lived in [named suburb] I used to have maybe four or five friends, or six maybe. And then all those friends disappeared on me … what happened is, when I moved up here [a different suburb in the same city] all my friends just disappeared."

In addition to moving suburbs, 118 had also stopped drinking. Participants who shared such a change in lifestyle commonly reported having few friends, often as a choice that kept them safe from reverting to earlier drinking patterns, which had also been associated with periods of mental illness.

Another reason for having few friends was the degree of comfort that the person felt in relationships. For example, talking about secondary school, 114 commented *"there was this whole thing where people tend to pair off into groups, have groups or crowds they hung out in and I really found that to be pretty hard."* He further noted …

"I still don't really like being in a large crowd of people in a group. It's that thing of even sometimes today, people, [support service] have said to me … 'have you considered joining this particular group who meet and do this?' but I've always found it sort of really hard. Maybe other people do too. Umm yeah but it's just something it just seems to be part of things. I don't know who you are, could be the way you're wired." He currently identified just a couple of friends, noting … "…you could say my friends list isn't very big, not a big dance card."

Interestingly, even for 104, who described a large network of friends, the initial stage of entering new friendships was a challenge …

"Yeah, it's just, that like, um. It's just quite easy to start talking to them and stuff and then you slowly get to know them. But, it's just, sometimes they're quite hard to read. So it's, yeah, body language and you know, it's a wee bit hard. So it's yeah, you don't know until you get to know them better."

As the above quotes illustrate participants made choices about with whom and how they entered or maintained social relationships. Family remained important, whether that was their original birth family or their more recently chosen family, for those who had set up homes with their partners.

4. "You've just got to prioritise your money"

For most people, having choice about how they live relates to the resources that they have available. As 110 put it ...

"I guess, I can sort of flutter off, of where I want to go in my life and do stuff what I want to do. Apart from these things what they call bills. Who invented them?
[about living independently] what I found at the first stage was um, you've just got to prioritise your money. That's the most important thing. It was the most learning experience for me. Ok we've got to prioritise $500 a fortnight. And prioritise the rates and insurance, and some pestering person who wants money [*laughs] f*or something."

Not surprisingly, the participants in this study had to make choices about how they spent their money. Impacting on their choice was their limited discretionary income and their ability to manage a budget. Benefits left little for discretionary spending once utilities, rent and food were covered. Those participants who were employed had more money, but their income still left little extra for saving. For those that achieved it, learning about money management was important to people feeling that they could be independent. A few identified that achieving saving goals provided both the reward of buying what they wanted whilst also demonstrating their financial management skills to others. This sense of achievement was expressed by 106 when he noted that he and his partner were competently budgeting, commenting *"We're not struggling"*.

Budgeting services provided support to a number of participants. Some had started with a budgeting service after getting into difficulty with money in the past. Accepting a budgeting service was often difficult in the first instance but as 109 noted … *"It's good, um cause since I've been with them I've saved a hundred dollars for Christmas"*. Similarly, 119, who was in paid employment, noted about his financial management service … *"Ah yes, I think it's really helped me to be able to save and things, because otherwise I could probably spend the money, or the pay in the weekend or something"*. Whether independent or through budget advice most had rent and utilities paid directly from their accounts. If their money was managed by someone else, they were likely to have access to an everyday account from which they chose what they spent. The other accounts were controlled by family, budget services or other arrangements. When asked about money management, 121 noted *"sometimes I can be good … I suppose I like to spend"*, thus her parents held a joint account with her, while staff helped her with her account for her flat.

Those who managed their own money independently had to be very careful. Managing her own money, 105 recognised the impact of her nicotine addiction, which she was not ready to address … *"Oh I've still got money for food. I always make sure – cause I've got, what, sixty dollars for AP's, my smokes and food. That's every week, I don't buy anything for myself."* For 104, covering the everyday costs was manageable, but extra costs were a problem, commenting on dental treatments … *"Oh, don't even go there … I am still paying off the damn bill"*, the appointment having been a few months previously and at a service that provided lower cost dental care. At the time 104 was working full-time. For 103, earning the maximum amount on top of her benefit, along with careful money management meant that she could get to movies and community activities that she enjoyed.

It was notable that people chose how they spent their money when it came to non necessities, for example priorities ranged from internet access for the serious gamers, to having money to shop for clothes and/or make-up, to 104's tobacco. Few appeared to be able to afford holidays. Although a number of the participants had travelled within New Zealand and overseas, these trips were generally with family or had come about through Special Olympic opportunities or being chosen for Air New Zealand Koru Care holidays as children. However, as 120 noted, even Special Olympics participation relied on people having access to sufficient funds to cover trips to regional and national events.

The responses to questions about how people were moving around within their cities clearly identified the way in which their financial position played out. Few people had their licence

for a motor vehicle, and those that did were in various stages of completing the process to a full licence. The three stage process of achieving a full driving licence appeared to be a barrier, as they had either the first step (allowing them to drive a motor scooter) or the second step, but were unable to afford the driving instruction or cost of the test. Some had let their licence lapse. Where there was any car ownership it was associated with their partner. Some had previously owned cars but were no longer able to afford them. As 116 noted when explaining why he no longer owned a car "...*well I had trouble paying bills once, so I had to sell it.*"

Most of the participants relied on public buses or walking. 109 illustrated how he got about ... "*I'll pay [name] to take me in the car ... give him five bucks*". Like many others, 107 would "*...just walk. Unless it's raining, of course, then I have to catch a bus.*" Often walking meant long distances, such as 118's walk to work that took him "*An hour to get there, an hour and 45 minutes up the hill.*"

For the few participants that had a physical disability, taxi chits provided them with some access to a safer and more practical option, particularly if they wanted to go out at night.

In conclusion, it was clear that the amount of money they had and how they chose to prioritise their spending was a major contributor to how people lived. A number of people were just managing with basic necessities. Choices including whether they went on holiday, how they socialised, their access to transport options and how they weighed up whether or not to seek medical or dental treatments, were limited.

5. "There aren't many jobs out there"

Both getting and keeping paid employment was rare (there were a few exceptions). Commonly people identified their lack of qualifications and/or physical disabilities as preventing them from getting work. Some indicated that they never got beyond an application, however there were also a number who never actually applied for jobs, the reason being unclear. People tended to be either in a workforce programme, or getting some directed support from their service provider. However, overall it seemed that moving into employment was a very slow process, with many trapped in unpaid, voluntary and part-time work that seemed not to progress. For those that did get into work, keeping their job wasn't always easy as one man explained, he had been good at sorting the product for quality but he was too slow, an issue that also arose for 113 ...

"I worked at a motel as a kitchen hand – now that was another fast job that I struggled with. That was actually a paid job but then I lost that because the guy there, the employer said 'she's not fast enough – we're going to have to let her go' and I was devastated – I thought 'wow, well that's not good enough'."

Although she did go on to get another paid job, more recently health concerns have stopped her from working.

For the very few who had paid work, it was usually part-time and could also mean that they worked evenings or nights, for example, 106 was pleased with the 15 hours of work he had each week. He explained "*I start at 10 [pm] and finish about 1:15 in the morning. Five days a*

week". Asked if he enjoyed the work *"It's good fun … Oh yeah. I love it. That's my longest job I've ever kept."* and he then went on to explain that it took him about an hour each way to walk to his work. If it is raining his co-worker will bring him home. Finding positions, such as 120 had, where it was the employer that provided transport home if he worked late was an exception. He further commented on the relationship that he had with his employer and what it meant to him ...

> "...because the person I work for she's proud of me because I want to get off the benefit that's my biggest goal. Cus that's my biggest goal to one day get off the benefit and show that disabled people can do anything what they put their mind to."

An important opening to work were positions within a disability support service. These positions often began as work trials, but if they went well could end up in paid employment. 103 described how she had gradually increased the hours that she worked to be *"... 16 hours a week now"* for the service that employed her. Having tried out a number of jobs and being active in self-advocacy, 119 was also given the opportunity to take on a paid position within a disability support service, which he had held for a number of years. However, others talked of having a trial with their disability support service, but then positions were not open for it to become paid employment. It was important that people could distinguish between opportunities in terms of what had the potential to lead to paid employment and what was always going to be a volunteer position. As 102 explained her week ...

> "… I was doing hospital today [at the SPCA] and I was looking after [guinea pigs], … they had been taking their medication and they had been fed" … then yesterday I was the receptionist [at a disability support service] … I might also take phone calls, written down times or things." Further she explained about her receptionist job "… I will do it for about another 6 weeks and if they decide "oh yes she can be kept" and then I will get paid."

Starting out with volunteer work, or work experience was typical but did not often lead to long-term employment. As 101 commented when noting that it was now 10 years since his earlier work experience ... *"There's not many jobs out there. For people like my age like myself. It's hard to find anything*." Like some others he had various certificates, however Tertiary education was seen to be beyond his financial means ...

> "I was going to do that course but then I got told that it's about two grand or something … I've got the food handling certificate … they just don't hire people with just the food handling certificate anymore, you need other qualifications on top of that, that I don't have".

For 114 there had been years of various paid and unpaid positions, work schemes, courses and such like. He ...

> "never had that sort of luck [where the scheme would end in a job] I would often find myself back to where I was again so you would have to start all over again. You would have to go to the labour office and they would say 'oh well what happened?' And I

would say that I didn't do anything wrong and I completed the training block or whatever it was but I never got cut a break really." At the time of his interview he had "… nothing paid for some time." Further he identified what some others might have been struggling to put into words ...

"When you're wired in a certain way you just don't see things the same way, you don't interpret things and you just don't understand certain things. So that effects your ability to fit into that environment. The fact that people get frustrated and angry with you because you're doing it in a certain way you get that anxiety and lack of confidence on top of it so it's like a double whammy."

Two participants had formal school qualifications, for one this included some School Certificate passes along with Six Form Certificate, while the other had NCEA passes. Despite their school successes employment eluded them and for 110 his success at school was soon dampened when he applied for a tertiary course ... *"Then I wrote down any additional support, I ticked yes. and then we found out where the support room is, so we can't, I wasn't eligible to get the course, what I wanted to do."*

While the previous theme demonstrated that having at least some part-time work made a difference in terms of financial management, the majority of the participants, despite having tried many approaches to gain work, were not employed. To make a meaningful and creative life for themselves, a number had turned to volunteer work or activities that were provided through organisations, such as dance groups, People First and Special Olympics. As 110 stated ...

"… the only reason I don't want to work is because it will be full time, because it will be a disability, will be something I won't enjoy. But if it's part time then I can still have the flexibility to still do this cool People First stuff, I probably will apply for a job, but at the moment I won't."

At the time of the interview 110 participated in various policy and other developmental committees, which was made possible because he did not have paid employment with regular hours that might prevent him from attending meetings. Thus he saw full-time work as having the potential to be a "disability" in terms of the structural barriers imposed by employment agreements. Replacing regular paid employment with other activities that they found meaningful illustrated their resilience in terms of adapting to their reality of limited employment opportunities.

In summary, participants expressed clearly that they enjoyed living independently and preferred being able to make their own decisions day-to-day. While they acknowledged some challenges, these tended to reside outside of their direct control.

Being healthy

An insight into the health and wellbeing of the participants could be taken from the SF20 results. In addition, many shared details about their health during the interviews. This theme draws on both sources of data to illustrate the participants' perspective of their health.

1. Current health

The majority of the participants (n=18) identified their current health as good to excellent (see appendix 2 for the results of the SF20). Most were living active lives within their community, as can be seen by their responses to question 6, their health was not stopping them from engaging in social activities. Even when they had underlying conditions, a number identified treatments they were having that meant these conditions were not affecting their view of their health. For example, as 104 explained in relation to the inhalers that were controlling her asthma ... "*I take my blue one every day and then I take the purple one if I need to.*" For another person, her epilepsy was well controlled with medication ... "*Which I find is really good because it helps also with my behaviour issues that I've got*" (115). Although it might have taken some time to settle on effective anticonvulsants, participants with epilepsy seemed to be satisfied with their health overall once they were seizure free for longer periods of time.

The SF20 scores for activity suggested that more vigorous activity and specific types of activity were affected by participants' health. Potentially relevant to their activity scores was the finding in the SF20 that a number of participants identified that they lived with pain, with many and varied causes of their pain including sore backs, renal stones and non-specific abdominal pain. In addition, data from the interviews included reports of the impact that weight gain had on their fitness. For those that reported weight gain, they commonly associated it with treatment for mental illness.

Current mental health was assessed by a series of questions in the SF20. Mild to moderate anxiety (n=13), being down-hearted or blue for some to all of the time (n=8), while feeling so down-hearted that it was difficult to cheer themselves up (n=2) would suggest that some participants were finding it difficult to maintain mental well-being. However, the interviews demonstrated that many of these participants were able to identify strategies that they used to cope with their anxiety or the times when they felt down-hearted. For example, 116 commented that he "*watched a good comedy*" and 107 ... "*I do stretches, I do breaths, I go for walks and that.*" Furthermore, 15 of the 20 participants identified that they were happy from a good bit to all of the time.

Having had a diagnosis of mental illness was shared by at least six of the participants. For most this was sometime in the past and they were now feeling well. Four participants identified that their mental illness was the path to them being diagnosed with autism or Asperger's syndrome. Having a diagnosis helped them to understand some of the struggles that they had previously experienced and, although some remained on medication, for example to treat mild depression, others were free of medication. A major role that the disability support service had in the lives of a few people was related to monitoring and supporting their mental wellbeing.

2. Influences on health

From the information shared by the participants, some of the influences on their current health could be identified. Amongst those with the longer-term health concerns, congenital or early developmental influences were apparent. These influences included structural problems, such as a kyphosis that has implications for all body systems, through to social deprivation, such as early neglect and abuse, and to inadequate educational assessment, such as experienced by those who were later identified as having autism. For example, 118 described the years both before and after his diagnosis of Asperger's syndrome ...

> I was put mostly, most of my life the back of the class because I had a learning disability. And it causes, all my life it was like, I went right into high school I was diagnosed with depression. And anxiety. And yeah lots of horrible things happened after that ...

Getting support
Although diagnosed at age 10 years, 118 felt that his school did not provide sufficient support, he was bullied and subsequently, when he left school, ended up becoming isolated and alcohol dependent. Similar histories were shared by most of those who identified troubled periods during their youth and early adulthood. While for 118, the damage to his health from alcohol dependence was not likely to be repairable, this was not the case for the majority who had worked out ways to change their risky behaviour. For 114, finding the right service had been an important step to addressing his mental health issues that were associated with autism. After years of schooling and mental health services he commented that ...

> "…people don't know how to help you. They probably try to help you but they can't because they can't help you in the right way … it was not an easy time. So, in a way you know I suppose life in that sense is now is probably a little easier. Because I'm kind of in a place where people kind of know have a better idea of the support I need and the difficulties I have and what I don't need and what I don't have."

For 106, the combination of finding the right service and being supported in his personal life had helped him move on from being … "*in and out of, [Emergency Psychiatric Services]. In and out of hospital with overdoses, and all that.*" While he credited the service for the initial intervention it was his partner and her family that kept him well.

In addition to disability support services, health professionals were evident in the lives of some. A number of participants went to their general practitioner three monthly. It was not always clear why they went this often, however medication, which requires regular prescriptions, were common to those who visited their general practitioner this frequently. Just one person with a regular prescription mentioned being able to get a telephone prescription. These regular medical appointments had an influence on disposable incomes. Most were being charged at least $30 for a visit, while two participants attended clinics where they were not charged. Similarly, dental treatment came with a cost, which influenced whether or not people attended. Most concerning were the few participants who needed major dental work, due to extensive dental caries, but for whom the procedure was not acceptable. In one region, there appeared to be a policy at the local community dental provider, of using local anaesthetic for extractions, even when this meant most of their teeth.

Two participants were clear that they could not tolerate this approach and were, therefore, putting off any treatment, despite the impact that this decision had on their overall health.

Less visible was any mention of counselling or other related services. For 114 the lack of funded long-term counselling was a major limitation for people with intellectual disability and mental illness. However, 113 felt that she had been able to access necessary counselling in her earlier life, after she experienced abuse.

Awareness of healthy choices
Most participants chose to eat foods that were nutritious. While the younger ones had people assisting with meal preparation, a number of the others were planning and cooking meals themselves. The relationship between health and food was commented upon by some participants … "*for breakfast I like muesli, with yoghurt and fruit. Or a smoothie. Nice and healthy*" (113). 120 also commented …

> "Like I eat … very healthily. I rarely go and buy like takeaways. I would cook fish. I would cook salmon. I would cook sausages. I had sausages last night. Um, I, it's really quite healthy and I do it with seasonal, um, vegetables, and I also eat plenty of fruit. I also um, sometimes, um, drink bullets as well. Bullets is like, you know that um fruit stuff?"

Although knowledge of the role that food can have on health was well known amongst the participants, food choices were not always made on this basis. Speaking about what his general practitioner told him in relation to his elevated blood pressure …

> "and he tells me to eat healthy so next year we… gonna start cooking. I have been cooking in the past. I made soup, pumpkin soup, sometimes I made ah, pasta dish. Macaroni cheese and… [then] one day I couldn't be bothered with them. Since then I [have] been living on pies."

Although their budgets no doubt influenced what food choices they had, the sense that buying something readymade was … "*the easier thing*" (111) meant that food choices varied for reasons other than not understanding its relationship with good health.

In addition to knowledge about nutrition, most people recognised that exercise could be of benefit to their health. The most common form of exercise was walking. This was often for necessity, in order to get to work or to other places that they wanted to go. However, some also identified walking as their form of exercise, for example 119 … "*I walk for my exercise and things.*" Commenting further that he had a Fitbit to monitor his steps. Biking was another form of exercise mentioned, although, like with walking, bikes were more commonly used for the purpose of transport from one place to another. Others went to organised exercise groups, such as "*Sit and be fit*", or to swimming pools for aqua jogging and swimming, gymnasiums for indoor rowing, or sports clubs.

In summary, while participants commonly identified as being in good health, there was a small group that did have complex health conditions that had affected their quality of life at various stages. Most of this group felt that they had their health conditions under control. The other larger group of participants had no major health concerns, they were generally living well,

including making opportunities for exercise and predominantly eating nutritious food. While a number of participants did access medical and dental treatment, it was not unusual to hear that people paid for these services through weekly contributions because they had insufficient funds to pay the full amount.

Section Two: The focus group and key informants

Who were the participants?

One focus group and four interviews were held with family members and/or disability service support staff. The focus group of seven participants included two people who identified as family members (siblings), amongst the five other participants was a person who identified both as a family member and disability service support person. Two parents were interviewed as key informants and two disability service support staff. All disability support service staff had direct contact with people with intellectual disability who lived independently. Their experience ranged from more than 10 years to less than five years. Participants were not asked to share their age.

In this section, the results are reported as a combined summary of the data from all participants. The subheadings indicate the lead question that was being answered by the participants.

What did participants see as contributing to a good life for people who live independently?

The responses to this question differed, particularly evident between the focus group and the key informants (both parents and staff). The key informant parents emphasised that people needed to have choices. What they saw as important was having support available in order for the individual to achieve their goals and be offered choice in their day-to-day lives. For key informant disability service staff, choice remained important and they added social dimensions of family and friends and community connections as well as living in a safe, happy and healthy environment. In contrast, the focus group members did not address choice.

The focus group were asked to rate the various points that they had listed as responses to the question, with the result that they identified good nutrition, health and networks as the three most important contributors to a good life for people who live independently. In the process of rating contributors to a good life, it was noted that family didn't prioritise having a good network, this also happened with the family key informant interviews, perhaps suggesting that this was an assumed factor for families who are involved in the lives of their son, daughter or sibling. While both the focus group and the disability service key informants considered family and community connections important, focus group members emphasised the need to be able to trust these other people, while one of the staff key informants identified that it can be important to … *"step back and let people learn for themselves".*

The focus group data in relation to this question was frequently on individual capability, it included such things as physical ability, personal hygiene, ability to make decisions with guidance, ability to manage money. The meaning of capability was, in contrast, expressed from the perspective of what it meant for the person, when one key informant parent noted that achieving independent living was important to the person's sense of self-worth.

In addition to abilities, there was some thought given to what focus group members saw as important in supporting the person, for example, ensuring that they had structure and routine to their day, with some members of the group acknowledging that this should have allowance

for flexibility. Flexibility being a dominant issue for the key informants, who had emphasised it as necessary for the person to have meaningful choices.

What contributes to people achieving a good life?

The role of appropriate disability service support was clearly identified by all participants. There was general agreement that these needed to follow good assessments that explored what people wanted, their goals and aspirations. It was identified that Needs Assessment Services provided "fluffy" assessments that were not necessarily helpful to services when planning support. Ideally, assessments would include the person and would have family and staff available to talk through their goals. When putting into practice the support, it was important, as one key informant put it, "*to get staff to aim higher*". A family member key informant emphasised that any packages of support needed to have the capacity to adapt to the person's needs. To enable this flexibility and innovation, the focus group members mentioned the need to appropriately train support workers and find strategies for supported decision-making, while one of the key informants noted the ongoing need to keep staff people focused in order to respond to the individual's choices.

Participants also addressed aspects such as having employment, whether paid or not. Unpaid employment was not seen as desirable but family members noted that it did provide opportunity for social connections, particularly for men, as it gave them an entry into the more typical working man's world. They felt that these relationships were seen as positively contributing to the quality of life of their family member. If employment wasn't available, the focus group members felt that alternative meaningful activity was important, including day base activities, however alternative options were not mentioned by the key informants.

All participants recognised that living independently might include developing skills, such as cooking. Ensuring that appropriate strategies were used to assist people who did not read, or required alternative means of communication was seen as important when it came to developing such skills. Family within the focus group had safety concerns about the step from supported cooking to independently using cooking appliances, however staff in the focus group thought there were sufficient safe guards and were more concerned that people had the opportunity to be independent. Key informants did not go into detail with skill development support, apart from one identifying the importance this aspect might have in determining who the support person should be. In other words, it was seen to be important to match support need, person able to teach the skill and the person being taught. This approach meant that an individual support package could include two or three support people, each assisting the person with specific goals or needs.

What are the barriers to achieving a good life?

The final question addressed the barriers to achieving a good life. The attitudes of society were considered to be contributors and had a wide influence. Stigma and prejudice was seen to impact on employment opportunities, joining community groups and being accepted within their neighbourhood. Both disability staff key informants mentioned the low expectation of people's ability, potentially from others and the person themselves.

The focus group participants thought that some people were isolated within their community. Transport was an expense people struggled to meet and the specifications for support did not allow services to assist when they often felt that they could make a difference to this aspect. The overall financial burden of living on a limited income and the type of accommodation that they could afford, were also mentioned by the focus group members and staff key informants. Money management was seen as a key skill for successful independent living and the focus group members identified that a lack of services for assistance with budgeting was a significant barrier to people achieving this skill. This was a regional variation, as there were services available in the key informants' region.

In summary, there was general agreement amongst the participants regarding the barriers to people achieving a good life and these reflected some of the aspects that the individuals with intellectual disability had raised as challenging. Within the focus group the emphasis was frequently on what the service did to manage the person and while this did not come from all members of the group, it highlighted the tension between trusting people to make their own choices and being concerned about what those choices might be. All four key informants were clear that choice came first, although the staff key informants recognised that there are risks, they more clearly saw their role as supporting choice. The role of the service in this sense was to educate the support staff as to how they can enable choice, as well as for managers to identify the strengths of individual support staff so that they utilise their skills in developing the person's independence.

Conclusion

From the data collected through the interviews with people with intellectual disability there could be no doubt that the majority enjoyed their independence. Many were living lives that they found satisfying and fulfilling. Although both they and the families and disability support staff were able to identify aspects of their life that were particularly challenging, every indication was that living independently was their preferred option.

Chapter Four: Discussion

Introduction

This study aimed to explore the experiences and perspectives of adults with intellectual disability who were living independently with low or no formal support. While the major focus remained on these individuals, additional information was contributed by family members and disability support staff in order to gain their views. This chapter draws together the key findings of the study, and highlights aspects that have the potential to guide future policy and practice.

The study identified that the majority of the 20 adults who were living independently in the community considered independent living to be unremarkable. It was seen as a natural transition from dependence on parents for the younger participants. This reality contrasts with research where independent living has been studied following deinstitutionalisation. In the current study, the few who had experienced disability support services as residential clients, or mental health services as patients, were clear that independent living provided them with a more fulfilling and self-determined life than the restrictions that they had experienced in these settings.

The title for this project came from a question about whether or not the increased opportunity for independent living for people with intellectual disability has resulted in them having a physical presence within, but not necessarily a concomitant sense of belonging and involvement within their community. However, the findings of this study indicate that the majority of the participants did feel as though they belonged within their community. While there were various definitions of "community" evident, few commented on being seen as different or feeling displaced. Furthermore, what seemed to be particularly important to their sense of belonging were the relationships that they were engaged in and the choice and control they had over these, and other factors.

Choice and control

The emphasis that participants put on having choice as the best thing about living independently should not come as a surprise. Choice about where and how to live has been emphasised through Article 19 of the UNCRPD, and in recent New Zealand policy for disabled people (Office for Disability Issues, 2016). Choice and control was also identified by Inclusion International (2012) as one of their three main issues and reiterated in the literature by various authors (for example, Duffy, 2017; Northway, 2015; Williams & Porter, 2017). While some were able to independently choose how and where they lived, their choices and sense of control were also influenced by the way that informal and formal relationships supported them.

As noted by Inclusion International (2012), natural supports, such as informal relationships, can be a key to successfully being part of the community. In this sense, a number of the participants reflected interdependence (Northway, 2015). While they made many day-to-day decisions independently, they drew on relationships that were meaningful to them when

making larger decisions, such as where to live and signing rental agreements. For some interdependence was also evident in a more formal relationship in the way that they were assisted with making budgeting decisions through a suitable resource, in the form of the budgeting service, that was able to provide assistance so that the person maintained their choice and control. Article 12 on the UNCRPD would suggest that the State should ensure the provision of such services to enable people to live with a decent standard of living.

Relationships with Family

Apart from the few who had difficult early lives, and, where there was a breakdown within family relationships, family provided continuity and were central to people living independent lives. Younger participants were more likely to be in frequent contact with their parents or siblings, while older participants had regular contact and knew they could turn to a parent or sibling for help or advice when they needed. Of significance, both the adults with intellectual disability and family and disability key informants identified families as having specific and ongoing involvement in the lives of adults who were living independently. For example, families were actively involved in helping find suitable accommodation, including assisting people to buy homes, or providing them with a rental home. Thus, they were the primary interdependent relationship for these participants. At times it appeared that decisions were led by family, suggesting a level of control that was tolerated provided it was not intrusive in all aspects of their life. As demonstrated by both 102 and 113, the person with intellectual disability is equally able to take a stand when family become too intrusive and, given the opportunity, will take a stand. This level of interaction is consistent with the concept of interdependence and relational autonomy, the latter of which suggests that no person is truly autonomous as they will always be influenced by, and themselves influence, their social world (Christman, 2014). A key component of relational autonomy is that it holds that the person be recognised as having decision-making capacity and that their perspectives should be valued, in keeping with Article 12 of the UNCRPD.

As Björnsdóttir et al. (2014), found attitudes of families can be a barrier to people living independent lives. She also identified that families were often the leaders in seeing their family member move into independent living, a finding shared with the current study. The key informant parents were particularly clear about what they saw as their role in assisting their adult children to live independent of them, within a context of support that enabled them to choose how they lived. Neither focus group data nor the disability staff key informants' data were as clear about this role for family. Reflecting Björnsdóttir et al. (2014), there remains amongst disability services reticence to see families as able to support their family member from the position of relational autonomy. Family members within the focus group stated an anxiety that providing greater independence might be too risky. These contrasting viewpoints were also reflected in the Weafer (2010) study and point to the need for families to be educated about the rights of their family members and how they can support those rights through a meaningful relationship. A role for disability support services would include welcoming family involvement and providing assistance, if necessary, for family members to adopt a relational autonomy position.

The impact of broken family relationships was significant for a few participants. While this study did not explore early family relationships in depth, those who related the most

challenging periods of transition from childhood to adulthood were less commonly in contact with their family of origin. Their experience points to the importance of supporting young people through these critical periods of their lives. With periods of mental illness, drug or alcohol addiction and criminal offending, these individuals' lives were complex and in the absence of family relationships they had ultimately sought out other support. Finding a better way to support young people in these situations would seem to be crucial. One positive example provided by the person who reported that a manager in his support service had identified him as able to go flatting, providing him with the necessary support when he was an adolescent, resulting in a pathway to independent living.

Personal relationships

Friends and partners tended to be a presence in the lives of those interviewed in terms of day-to-day informal support and were also important in terms of how the person defined their sense of belonging. With friendships built up over time, friends tended to reflect the groups that they had mixed with from childhood through to adulthood. A notable exception was for those who had experienced alcohol dependence and mental illness who tended to enclose themselves within a circle of support that they carefully chose. Their community was defined by the people that were important to them at this time and with whom they felt safe, and who supported their ability to maintain lifestyle changes that they felt were important to make. These individuals had chosen to remove themselves from living in accommodation that put them in close proximity to other people with similar histories, such as disability support cluster housing arrangements. The contrast with others who had much wider circles of support was marked, and, again for this group, they valued these more extensive groups of friends. These findings illustrate the risk that there can be in terms of others defining community integration for any individual. As noted by Williams and Porter (2017) and Duffy (2017) choice in independent living should not be about proving oneself capable, but rather about having support, if needed, to make a choice. The number of friends that a person has is not important and for the participants in this study, this was not a signifier of their community presence. Indeed, for some, having a community presence was not considered to be important and if taken as a measure of successful independent living would misrepresent their will and preference.

Engaging with neighbours and groups

A further way to have community presence is through relationships with neighbours and social, sporting or special interest groups. For some of the people interviewed, neighbours provided a natural support and their relationship was generally considered to be reciprocal. These were the people with whom they shared their day-to-day lives and with whom they had worked out what they wanted the relationship to be. Unlike Bigby et als.' (2017) research, participants expressed few concerns about neighbourhood safety, although some did live in areas of their town or city that were commonly thought to be among the least safe. While a seemingly positive result, specific research would be necessary to establish the reason for their confidence.

 Other evidence of community involvement came from the few who participated in groups, such as Toastmasters, or sports clubs. Those that did attend these groups mentioned natural

supports that had developed around their needs, suggesting a community spirit that is willing to enable rather than disable people and exclude them from participating. Again, the concept of interdependence (Northway, 2015) is useful in thinking about how people are living within their community and these informal supports can be seen as evidence of such a concept functioning within the day-to-day lives of people with intellectual disability who participated in this study.

Formal support

Everyone in this study received 10 hours or less of paid support, meaning that disability support services had little presence in their lives. The presence that they did have was generally expressed in terms of pragmatic help, required at that point in time and subject to change as they developed skills for independent living. This pragmatism was evident in the responses to their relationships with their support people in contrast to other people in their lives, particularly in the way that they accepted that support people would come and go from their lives. In contrast, amongst the key informants there was a sense that support staff played a critical role in supporting independent living, and in some cases needed to manage the person's life to ensure they made what they perceived to be good choices. In light of this perception, it is interesting to note that although requested, few people were able to provide a support plan, and, while they could often identify their current goals for formal support, their responses suggested that plans that had medium to long-term goals were of limited use. These findings, when interpreted through a lens of citizenship (Duffy, 2017) might suggest that disability services are best able to support people when they focus on what the person wants to achieve in the short term. Achievement of these goals is more likely lead to self-efficacy and a raised self-esteem, identified by some participants and key informants as important, as well as by Santilli et al. (2014), who saw it as contributing to the person's potential for employment. From the perspective of quality assurance and audit, however, it does raise issues for policies that are based on people having plans with identifiable goals, their achievement being considered an important measurement of service delivery.

In common with other studies (for example, Bigby et al., 2017), money management was a significant issue for many of the participants. However, in keeping with Bigby et als.' findings, participants valued choice in what they spent their money on after covering the essentials. Over half of the participants were assisted with their budgeting, either by an independent budget service, family or their disability support service. The success of an external budgeting service was evident but confined to one region, indicating the disparities that there are in services available across the country. As noted above, provision of this support was consistent with Article 12 of the UNCRPD. A key finding from the focus group was the frustration that services had when they were not able to access such support due to either not being funded or no budget service being available in their area. Removing disability support services from this responsibility was seen as helpful in that it took any conflict about money decisions out of the support relationship. The different funding support packages that people receive across the country, however, further challenged assumptions about how to best assist people to manage their money, as it was included as part of their key worker's role by some participants. Where wanted and appropriate, provision of support for management of their budget would seem to be one strategy that has the potential to ensure an adequate standard of living of people with intellectual disability who are living independently. While a separate

service might be desirable, recognising relational autonomy within a model of interdependence (Northway, 2015) as the foundation for budgeting decisions would likely have the best outcome in terms of the person feeling that they remain in control and have choices about how they use their money. Although limited incomes and financial pressure are often mentioned, there appears to be little specific focus on the role of community-based budgeting services in the intellectual disability literature.

Health and Wellbeing

This study was motivated in part by interest in exploring whether independent living results in poorer health for adults with intellectual disability. Notably, health was identified by focus group participants as the major determinant of successful independent living. However, health was not a key determinant of successful independent living for the participants with intellectual disability. It was only in their responses to specific questions about their health that it became evident that some people were living with a number of health issues. The SF20 was used to begin the conversation about their health. This tool provided the opportunity to further explore health issues with the participant. Significantly, pain and symptoms suggestive of mental illness (for example, sadness, levels of anxiety) had not been raised by the participants prior to the SF20 questions, suggesting that these areas might need to be directly addressed if their presence and effects on the person are to be explored. That these conditions were present did not mean that they were untreated as these participants appeared to be regular and frequent users of primary health care services. Given the connectedness that these participants had with their primary health care providers, they might be best described as the "visible minority" (Emerson &Hatton, 2014), and their use of health services would have been contained in the report from the Ministry of Health (2011) that identified health outcomes and service use for people with intellectual disability.

Despite what might be seen as some challenging situations, the people in this study were generally positive in terms of how they related their wellbeing. In terms of how they saw a good life, with very few exceptions, they were living it. As with Kuijken et als.' study (2016) it was also evident that people made choices about how they lived, choosing whether or not to put their knowledge of health and healthy living into practise. However, such choice was also influenced by the challenges for all people living on low incomes and who are unemployed. Inevitably these factors influence the health choices that a person has and in turn will influence their wellbeing (Emerson & Hatton, 2014), as we saw in this study.

In terms of wellbeing, employment is considered to provide the opportunity for a larger income as well as contributing to longer term wellness (Daly & Delaney, 2013; Kober, 2010; Winefield et al., 2017). For the few who had employment in this study, these benefits were clear. In addition, having a job contributed to a sense of belonging within their workplace, and widened their community connectedness. However, it was also clear that finding paid employment was not simple, progressed slowly, often meant doing a range of jobs and still ended in no long-term prospect. Some of the older participants, who had a history of anxiety and depression, had reached a point where they no longer applied for work, highlighting the importance of meaningful employment in terms of developing self-esteem (Winefield et al., 2017) and protecting from mental illness (Daly & Delaney, 2013). Furthermore, although

those who chose day service activities and volunteer work might be using an adaptive strategy to support their mental health, that they were able to do so should not excuse the lack of employment opportunities that might have otherwise contributed more meaningfully to their mental health.

Whilst it was evident that people were getting access to some training that might prepare them for employment, as required by Article 27 of the UNCRPD, fulfilment of that Article would see people actively employed, which was not the more usual result for these people. In addition, the training/adult education that was available was limited and too expensive for them to access. Welfare payments that support education for the purpose of work training were not generally available to them for a variety of reasons.

Strengths and limitations

This study has provided insight into the lives of 20 adults with intellectual disability, exploring what they think and feel about their current living situation. As there is not yet a substantial body of literature that has explored independent living from the perspectives of people with intellectual disability themselves, this study makes an important contribution to the literature and can inform NZ's progress in responding to the UNCRPD through policy and practice. The study also signals some useful areas for future research. Both the findings from the interviews with people with intellectual disability and the additional information, about the perspectives of family members or disability support staff that has been captured through the focus group and key informant interviews and can also be drawn on to inform future research and practice.

The SF20 was understood by the participants and demonstrated that a tool, such as this, could be used effectively with people with mild to moderate intellectual disability. The caveat to that is that some people might need assistance to interpret the meaning of questions or the scale being used. The SF12 (similar but with fewer questions than the SF20) is currently used in the National Health Survey. Either tool provides the potential to have data that can be compared to other population groups as well as monitoring across time the same individuals or groups.

The major limitation of the study relates to its small sample size and dependence on participants who retained a connection to disability services. While there was a range of ages and living conditions amongst those interviewed, culturally it was a homogenous sample. The small sample size meant that the SF20 data was insufficiently powered to use a more detailed analysis. The predominant use of disability support services to recruit participants meant that the "hidden majority" identified by Emerson (2011), have yet to tell about their lives.

Future Research

Larger studies that incorporate people with intellectual disability who are not using disability services and people from a range of cultures would provide more detail and, possibly, a broader range of findings. The findings from the current study also identify a need for more detailed exploration of particular aspects of people's lives, including their health and

employment. These could be separate projects and might include collecting data that is both quantitative and qualitative in order to gain a better understanding of the complexity of these issues for people with intellectual disability. Such research would assist the development of policy within NZ in order to better respond to relevant Articles of the UNCRPD.

Research related to financial management and budgeting, including evaluation of budgeting services for people with intellectual disability could inform future direction and the utility of making such services available for all who wish to have them.

The rapidly changing context for children with intellectual disability who are growing up in NZ should be monitored to evaluate the long-term outcomes. The clear association between early experiences of family and school dysfunction and troubled transition to adulthood highlight the need to address early intervention strategies.

Further research with families and disability support service staff to understand their perceptions and experience of enabling supported decision-making with people with intellectual disability would assist with understanding their learning needs and the best ways to provide future education in this area. (related to UNCRPD Article 12).

Recommendations/ implications for policy and practice

1. Facilitate choice: People with intellectual disability should be supported to make their own choice independently. When they require support to make choices that support should be in the context of relational autonomy, acknowledging a place for interdependence and with a person/people of their choosing.
2. Family relationships that were appreciated by the participants were respectful, providing support at times of need but also able to step back and encourage the person to develop into adult roles. To this end, family relationships should be acknowledged within policy and supported by services.
3. Family is the primary and continuous relationship for most people, as such they have a major role in supporting their family member and protecting their personal agency. Interdependence could be seen as the model for this relationship.
4. Education and training for people with intellectual disability, family members and disability support service staff relating to the first three recommendations. Recommendations 1,2 & 3 require all involved to understand their role and how to facilitate supported decision-making that honours will and preference.
5. Service provision needs to be tailored to the individual. Assumptions about community integration and how this is evaluated should be examined in relation to the person's own goals. Staff need to be well prepared for the relationship that they have with the person that they support, encouraged to be flexible and creative in how they provide support. This individual responsiveness has implications for how services are audited.
6. Funding for budget services needs to be reviewed. A consistent approach should be available across NZ.

7. A review of health services, including ways in which primary health care could be more cost effectively available to people with intellectual disability and the cost of Dental Services for both routine and major procedures.

Conclusion

Independent living is now strongly supported by policy. This stands in contrast to years of institutionalisation and other severe restrictions on the degree to which people with intellectual disability have been able to exercise choice in any aspect of their lives. Focusing on the experiences and perspectives of people with intellectual disability who are living independently has provided important insights into the way in which people interpret their lives. Most significantly, independent living was equated with increased choice and enhanced self-esteem, consistent with the direction outlined for system transformation of disability support within New Zealand. For the majority of the participants their relationship with their family remained pivotal, while their relationship with their disability support services were functional and purposeful. In part, this could be due to the few hours of support that they required from these services. In addition, none of the participants had lived in institutions for people with intellectual disability or mental illness for more than a brief period of time.

As noted earlier in this report, the adults with intellectual disability were for the most part getting on with their lives, even though some were managing complex health issues, unemployment and limited incomes. They appeared to feel a sense of belonging within their chosen communities, and clearly expressed how they interacted within their social networks. Small social networks did not necessarily mean impoverished social lives. It is important to acknowledge that there were a small number of exceptions to this general finding. In these cases, participants expressed that they had felt isolated and unsupported when in previous independent living circumstances. What seemed to be common to these previous situations was a lack of support in the areas that the individuals felt they needed, and they were living in environments that were inappropriate for them.

While people generally expressed satisfaction with their lives, the research highlights that a gap remains in opportunities for paid employment. Furthermore, their limited income provides for the basics but only when managed very carefully. People were struggling to afford health care and dental care, particularly if their sole income was from a benefit. Having available and utilising a budget service made a difference to the person's ability to save for the occasional treat or manage repayments.

What was not so easy to capture through this study, were measurable outcomes, highlighting the complexity of identifying meaningful ways to measure life quality when it means different things to different people. This study has illustrated that people hold a range of values that underpin the way in which they choose to live their lives. Therefore, there is a need for caution when seeking to determine what counts as successful independent living, with further consideration of this issue being necessary.

References

Bigby, C., Bould, E., & Beadle-Brown, J. (2017). Conundrums of supported living: The experiences of people with learning disability. *Journal of Learning & Developmental Disability*, 42(4), 309-319.

Björnsdóttir, K., Stefánsdóttir, G. V., & Stefánsdóttir, Á. (2014). "It"s my life' : Autonomy and people with intellectual disabilities. *Journal of Intellectual Disabilities*, *19*(1), 5–21. https://doi.org/10.1177/1744629514564691

Bond, R. J., & Hurst, J. (2010). How adults with learning disabilities view living independently, *British Journal of Learning Disabilities*, *38*(4), 286–292.

Braun, V. & Clarke, V. (2013). *Successful qualitative research: A practical guide for* beginners. London: Sage

Bray, A. & Gates, S. (2003). *Community participation for adults with an intellectual disability.* Wellington: National Health Committee. available from: http://www.moh.govt.nz/notebook/nbbooks.nsf/0/24455C0E1D038844CC257B670009150F/$file/community%20participation%20for%20adults%20with%20an%20intellectual%20disability.pdf

Chaplin, E., Paschos, D., O'Hara, J., McCarthy, J., Holt, G., Bouras, N., & Tsakanikos, E. (2010). Mental ill-health and care pathways in adults with intellectual disability across different residential types. *Research in Developmental Disabilities*, *31*(2), 458–463. https://doi.org/10.1016/j.ridd.2009.10.015

Christman, J. (2014). Relational autonomy and the social dynamics of paternalism, *Ethic Theory Moral Prac.* 17, 369-382. doi:10.1007/s10677-013-9449-9.

Cocks, E., Thoresen, S. H., O'Brien, P., McVilly, K., Thomson, A., Gadow, F., … Prain, M. (2016). Examples of individual supported living for adults with intellectual disability. *Journal of Intellectual Disabilities*, *20*(2), 100–108.

Conder, J., Milner, P., Mirfin-Veitch, B., & Schumayer, D. (2009). *The Great Life Project*. Dunedin, New Zealand: Donald Bealsey Institute.

Conder, J., Mirfin-Veitch, B. & Gates, S. (2015). Risk and resilience factors in the mental health and well-being of women with intellectual disability. *Journal of Applied Research in Intellectual Disabilities,* 28(6), 572-583. doi:10.1111/jar.12153.

Daly, M., & Delaney, L. (2013). The scarring effect of unemployment throughout adulthood on psychological distress at age 50: Estimates controlling for early adulthood distress and childhood psychological factors. *Social Science & Medicine*, *80*(Supplement C), 19–23. https://doi.org/10.1016/j.socscimed.2012.12.008

Duffy, S. (2017). The value of citizenship. *Research and Practice in Intellectual and Developmental Disabilities*, *4*(1), 26–34.

Ellingson, L. L. (2011). Analysis and representation across the continuum. In N. K. Denzin and Y. S. Lincoln (Eds) *The SAGE handbook of qualitative research (4th ed.).* Los Angeles: Sage.

Emerson, E. (2011). Health status and health risks of the "hidden majority" of adults with intellectual disability, *Intellectual and Developmental Disabilities,* 49(3), 155-165

Emerson, E., & Hatton, C. (2014). *Health inequalities and people with intellectual disabilities*. Cambridge, UK: Cambridge University Press.

Emerson, E., Hatton, C., Baines, S., & Robertson, J. (2016). The physical health of British adults with intellectual disability: cross sectional study. *International Journal of Equity in Health*, *15*(11). https://doi.org/10.1186/s12939-016-0296-x

Enabling Good Lives. (n.d.). *A Toolbox for Enabling Good Lives and Choice in Community Living.* Retrieved from http://www.enablinggoodlives.co.nz/about-egl/resources/providerresources/enabling-good-lives-toolbox/

Foley, K-R., Blackmore, A., Girdler, S., O'Donnell, M., Glauert, R., Llewellyn, G., & Leonard, H. (2012). To feel belonged: The voices of children and youth with disabilities on the meaning of wellbeing, *Child Indicators Research.* 5, 375-391*.* doi 10.1007/s12187-011-9134-2

Gravell, C. (2012). *Loneliness and cruelty: People with learning disabilities and their experiences of harassment, abuse and related crime in the community.* London: Lemos and Crane.

Helps, S. (2015). Psychopathology, Anxiety, Depression and Schizophrenia. in J. Matson & M Matson (Eds), *Comorbid conditions in individuals with intellectual disabilities.* Cham:Springer doi 10.1007/978-3-319-15437-4_4

Inclusion International. (2012). *Inclusive communities = stronger communities. Global report on Article 19: The right to live and be included in the community. Inclusion International.* Retrieved from: inclusion-international.org/wp-content/.../Global-Report-Living-Colour-dr2-2.pdf

Karban, K., Paley, C., & Willcock, K. (2013). Towards support: evaluating a move to independent living. *Housing, Care and Support*, *16*(2), 85–94. https://doi.org/10.1108/HCS-02-2013-0001

Kober, R. (2010). The effect of employment on the quality of life of people with intellectual disabilities: A review of the literature. In R. Kober (Ed.), *Enhancing the quality of life of people with intellectual disabilities: From theory to practice* (pp. 127–138). New York: Springer.

Kreuger, R. A. (1998). *Analyzing and reporting focus group results.* Thousand Oaks: Sag

Kuijken, N. M. J., Naaldenberg, J., Nijhuis-van der Sanden, M. W., & Schrojenstein-Lantman de Valk, H. M. J. (2016). Healthy living according to adults with intellectual disabilities: towards tailoring health promotion initiatives. *Journal of Intellectual Disability Research*, *60*(3), 228–241.

Lahman, M. K. E., Geist, M. R., Rodriguez, K. L., Graglia, P., & DeRoche, K. . (2011). Culturally responsive relational reflexive ethics in research: the three rs. *Qualitative Quantitative*, *45*, 1397ative Quantitative M. R., Rodriguez, K. L., Gragl

Leech, N. L. & Onwuegbuzie, A. J. (2009). A typology of mixed methods research designs, *Qualitative Quantitative,* 43, 265-275.

Lincoln, Y. S., Lynham, S. A., & Guba, E. G. (2011). Paradigmatic controversies, contradictions, and emerging confluences, revisited. In N. K. Denzin and Y. S. Lincoln (Eds) *The SAGE handbook of qualitative research (4th ed.).* Los Angeles: Sage.

Livermore, G. A., Bardos, M., & Katz, K. (2017). Suppplemental security income and social security disability insurance beneficiaries with intellectual disability. *Social Security Bulletin*, *77*(1), 17–40.

Malatest International. (2016). Feedback from people living in Ministry of Health funded residential services. Retrieved from http://thehub.superu.govt.nz/publication/feedback-people-living ministry-health-funded-residential-services-people-disabilities-0

Mental Health Foundation. (2013). Five ways to wellbeing: A best practice guide. Retrieved https://www.mentalhealth.org.nz/assets/Five-Ways-downloads/mentalhealth-5waysBP web-single-2015.pdf

Milner, P., & Mirfin-Veitch, B. (2012). *"I am here" The Article 19 Project: Finding a place for the life stories of disabled people*. Wellington, New Zealand: CCS Disability Action.

Milner, P., Mirfin Veitch, B., & Conder, J. (2013). *On the Margins of Good Health: An analysis of the health status, health knowledge and health literacy of people with learning disability who completed te Special Olympic Health HAS Health Promotion Screen*. Dunedin, NZ: Donald Beasley Institute.

Ministry of Health. (2011). Health Indicators for New Zealanders with Intellectual Disability. Retrieved January 26, 2016, from http://www.health.govt.nz/publication/health-indicators-new-zealanders-intellectual-disability.

Mirfin-Veitch, B. (2106). *Exploring Article 12 of the United Nations Convention on the Rights of Persons with Disabilities: An integrative literature review.* Dunedin: Donald Beasley Institute.

Mirfin-Veitch, B., Conder, J. Payne, D., & Channon, A (2017). *Know who I am: Women with*

learning disability and their understanding and experiences of women's health screening in New Zealand. Dunedin: Donald Beasley Institute.

National Health Committee. (2003). *To have an 'ordinary' life: community membership for adults with an intellectual disability.* Wellington, New Zealand: Author.

Northway, R. (2015). What does independence mean? *Journal of Intellectual Disabilities*, *19*(3), 203–204. https://doi.org/10.1177/1744629515593659

Office for Disability Issues (2016). *The New Zealand Disability Strategy in Action 2016-2026,* Wellington, New Zealand: Author.

Palis, H., Marchand, K., & Oviedo-Joekes, E. (2018). The relationship between sense of community belonging and self-rated mental health among Canadians with mental or substance use disorders, *Journal of Mental Health.* (early online), doi: 10.1080/09638237.2018.1437602

Patton, M. Q. (2002). *Qualitative research and evaluation methods. (3rd ed.).* Thousand Oaks: Sage

Rand Health. (n.d.). *More About the 20-Item Short Form Survey (SF-20).* Retrieved from http://www.rand.org/health/surveys_tools/mos/20-item-short-form/more.html

Ray, R. A. & Street, A. F. (2004). Ecomapping: an innovative research tool for nurses. *Journal of Advanced Nursing,* 50 (5), 545-552.

Santilli, S., Nota, L., Ginevra, M. C., & Soresi, S. (2014). Career adaptability, hope and life satisfaction in workers with itellectual disability. *Journal of Vocational Behavior*, *85*, 67–74.

Sheerin, F., Griffiths, C., de Vries, J., & Keenan, P. (2015). An evaluation of a community living initiative in Ireland. *Journal of Intellectual Disabilities*, *19*(3), 266–281. https://doi.org/10.1177/1744629515573679

Silverman, D. (2011). *Interpreting qualitative data. (4th ed.).* London: Sage

Stancliffe, R. J., Lakin, K. C., Larson, S., Engler, J., Taub, S., & Fortune, J. (2011). Choice of living arrangements. *Journal of Intellectual Disability Research*, *55*(8), 746–762. https://doi.org/10.1111/j.1365-2788.2010.01336.x

Statistics New Zealand. (2014). *Disability and the labour market: Findings from the 2013 Disability Survey.* Retrieved from Available from www.stats.govt.nz.

United Nations. (2006). United Nations Convention on the Rights of Persons with Disabilities. United Nations. Retrieved from http://www.un.org/disabilities/convention/ conventionfull.shtml

Weafer, J. (2010). *Independent and community living - the views of people with disabilities families and frontline staff: Focus group consultation report.* National Disability Authority.

Williams, V. (2013). *Learning disability policy and practice.* Basingstoke: Palgrave MacMillan

Williams, V. & Porter, S. (2017). The meaning of 'choice and control' for people with intellectual disabilities who are planning their social care and support. *Journal of Applied Research in Intellectual Disabilities,* 30. 97-108. doi. 10.1111/jar.12222

Wilson, N., Jacques, H., Johnson, A. & Brotherton, M. (2017). From social exclusion to supported inclusion: Adults with intellectual disability discuss their lived experiences of a structured social group. *Journal of Applied Research in Intellectual Disabilities.* 30, 847-858.

Winefield, A. H., Delfabbro, P. H., Winefield, H. R., Duong, D., & Malvaso, C. (2017). The psychological effects of unemployment and unsatisfactory employment on young adults: Findings from a 10-Year longitudinal study. *The Journal of Genetic Psychology*, *178*(4), 246–251. https://doi.org/10.1080/00221325.2017.1342594

Appendix 1: Topics for semi-structured interviews

About you:
Brief history/ background, including age, where were you born or grew up, when did you first leave the family home?

What does living independently mean for you?

Your interests:
What do you like to do? Hobbies, sports, TV programmes, movies, facebook etc.

Your friends and family:
Use the ecomap to explore relationships – who are your friends, family? How often do you see them? How well do you get along with them? How do you keep in touch?

Your work and education:
Where did you go to school? What was school like for you? Have you certificates or qualifications from school or other education after school?
Are you employed? Tell me about your job? How do you feel at the end of a day at work? What (other) jobs have you had? If no job, would you like a job? What makes it hard for you to get a job?

Your income and money management:
Do you get a benefit? Tell me about how you manage your money (include budgeting, independence, banking systems)?

Your housing:
What do you like about where you are currently living (looking for a wide range, including warmth, accessibility of home)? Is there anything you would you like to change about where you live? If you think about each room in your house, which do you like best? Tell me about any rooms that make it difficult for you to live independently.
What did you need to do to rent your house? Did you understand all the information that you were given when you rented your house? (this question will depend on their living arrangements)

Your health:
Do the SF20 assessment. This will identify if they have health concerns.
Tell me about your health concerns and the help that you get to manage these. Are you taking any medication? Tell me how you manage that.
How often do you go to your GP? How well do you get along with your GP and the other staff there?
How often do you go to a dentist or have someone check your mouth?
Tell me about the help you need to manage your health.
Have you had (name appropriate screening e.g. cervical, breast, testicular, bowel)?
Do you get regular flu vaccines and/or know if your immunisations are up to date?

Your wellbeing:
Tell me about the physical activity that you do (walking, sports etc.).
When did you last go on holiday? Where to?
Have you been to movies or community festivals recently?
Do you feel safe at home, work or in the community?
What do you do if you are feeling lonely?
Tell me about the meals that you usually eat? Do you get help with shopping and/or cooking? Are you able to choose what you eat?
Do you belong to any spiritual and/or cultural groups? (aim to get to a spiritual and cultural sense of self – further questions might be about how they feel within these groups)

Your participation as a citizen:
Are you enrolled to vote? Do you vote and, if not, why not?
Have you had contact with the police, lawyers and the courts? Were you able to get the help you needed? (if never had contact) Tell me how you would contact the police or get help from a lawyer?
Do you belong to any advocacy or other groups that represent your community? How would you join one of these groups if you wanted to belong?

Your mobility:
Are you able to get to the places that you want to go to?
Do you feel frightened when you are moving about town, are there places that you wouldn't go?
What transport do you use? Does the transport meet your needs? Is there something that would make it easier for you to get around?

Your plan:
Do you have a personal plan? If yes, were you able to have the people that you wanted at your planning meeting? What do you understand is the purpose of your plan? Tell me about your goals? How have your goals changed over time? Who helps you to meet your goals? If you are not getting the help you need to meet your goals, what would you do about it?

The support you get:
Who provides you with support?
How many hours paid support do you get each week?
Tell me about other people who are not paid who help you?
Does your support change very often? Tell me about the changes.
If you were able to get the support you would like, what would it look like?

Finally:
What is the best thing about living independently? What do you like most about living independently?

Appendix 2: SF20 Results

There are 20 questions to the SF20. The combined responses to each question are presented below using pie graphs. Raw numbers are displayed with each segment to identify the number of people who responded with that option. Most people answered all questions, where that did not happen the number of non-responders is included in the pie graph. To keep the graph simple, only chosen responses to each question are presented.

Question 1: In general you would say that your health is?
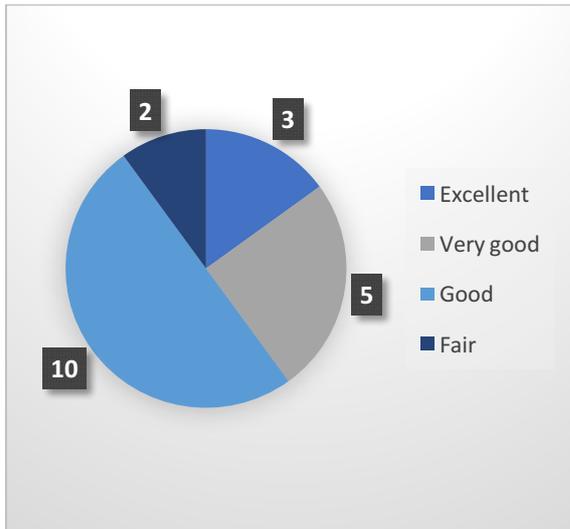
Question 2: For how long (if at all) has your health limited you in each of the following activities?

a. The kinds or amounts of vigorous activities you can do, like lifting heavy objects, running or participating in strenuous sports
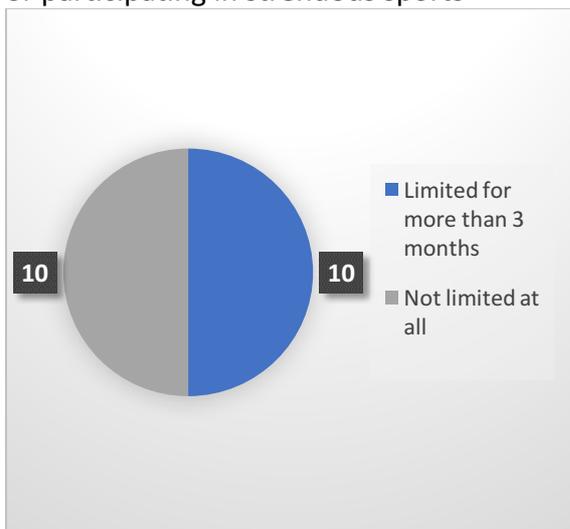
b. The kinds or amounts of moderate activities you can do, like moving a table, carrying groceries, or bowling
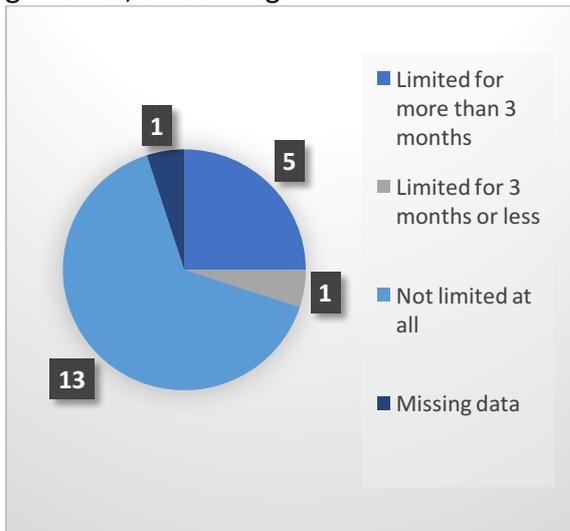
c. Walking uphill or climbing a few flights of stairs
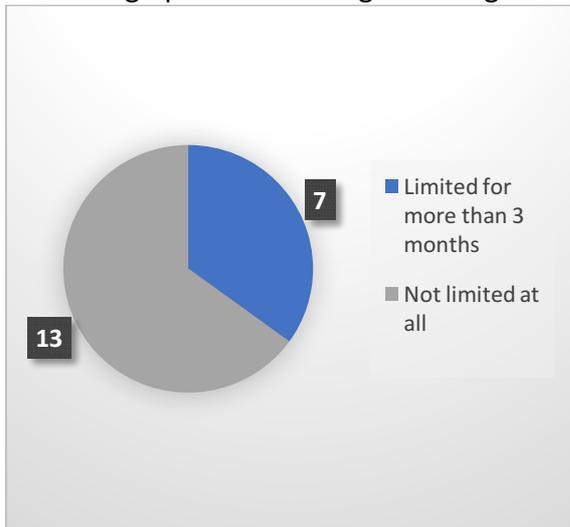
d. Bending, lifting, or stooping
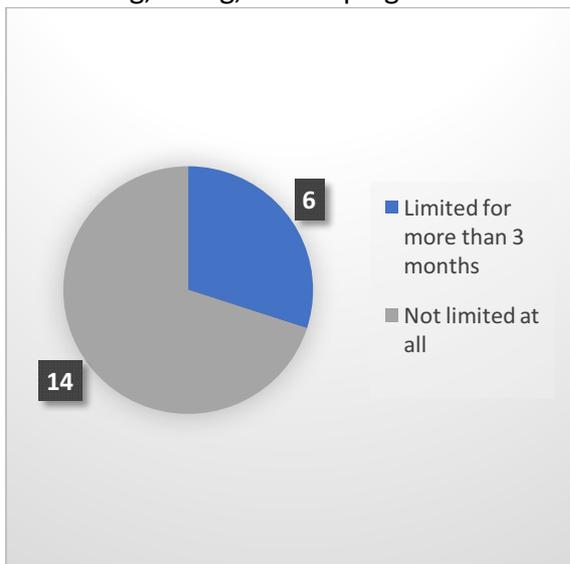
e. Walking one block
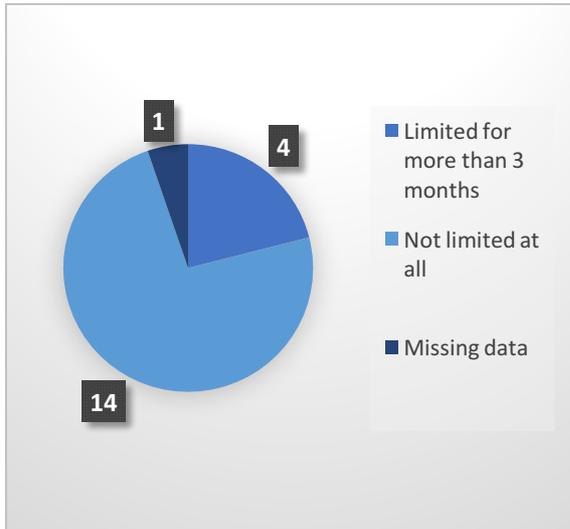
f. Eating, dressing, bathing, or using the toilet
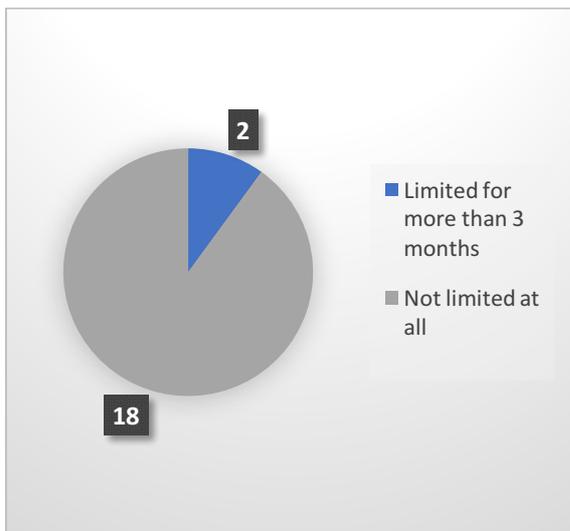
3. How much bodily pain have you had during the past 4 weeks:
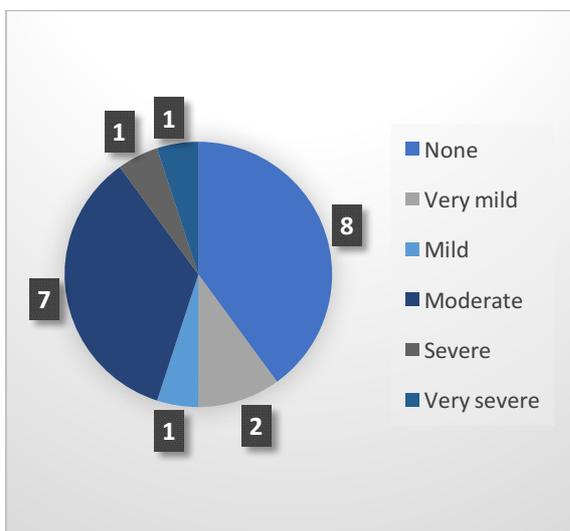
4. Does your health **keep** you from working at a job, doing work around the house, or going to school?

Legend:
- Yes, for more than 3 months — 4
- Yes, for 3 months or less — 1
- No — 15
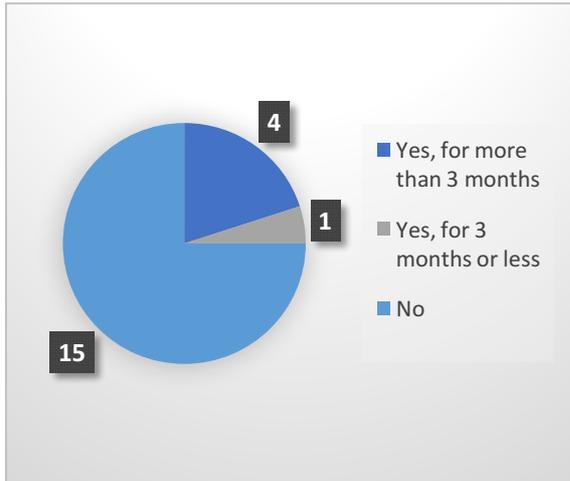
5. Have you been unable to do **certain kinds or amounts** of work, housework, or schoolwork because of your health?

Legend:
- Yes, for more than 3 months — 6
- Yes, for 3 months or less — 3
- No — 11
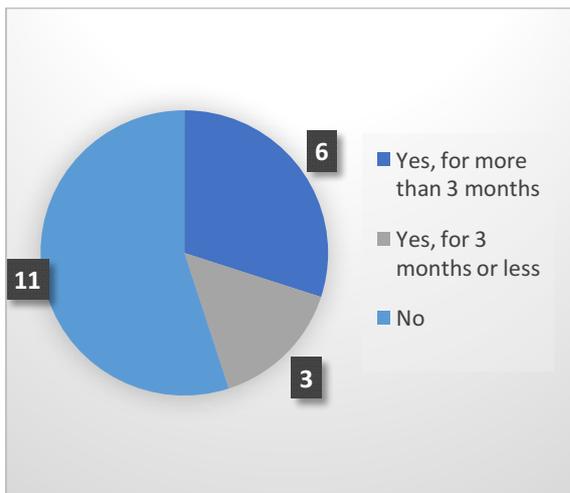
6. How much of the time, during the past month, has your **health limited your social activities** (like visiting with friends or close relatives)?

Legend:
- All of the time — 1
- Some of the time — 1
- A little of the time — 1
- None of the time — 17
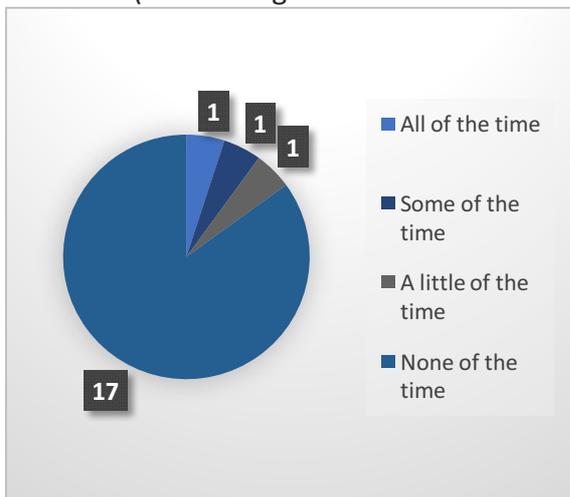
7. How much of the time, during the past month, have you been a **very nervous person**?
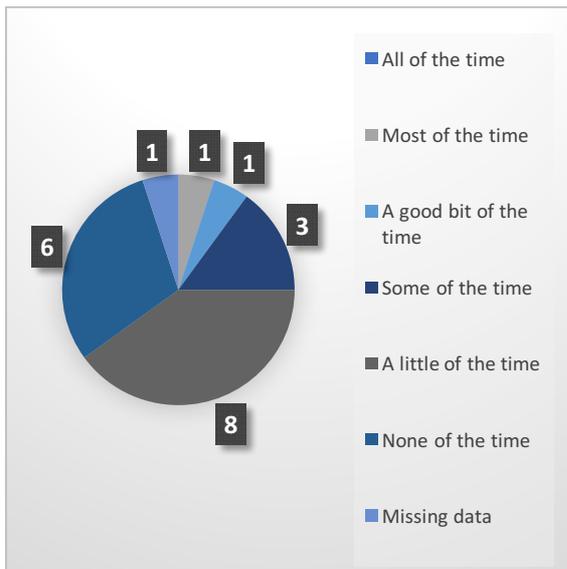

8. During the past month, how much of the time have you felt **calm and peaceful**?
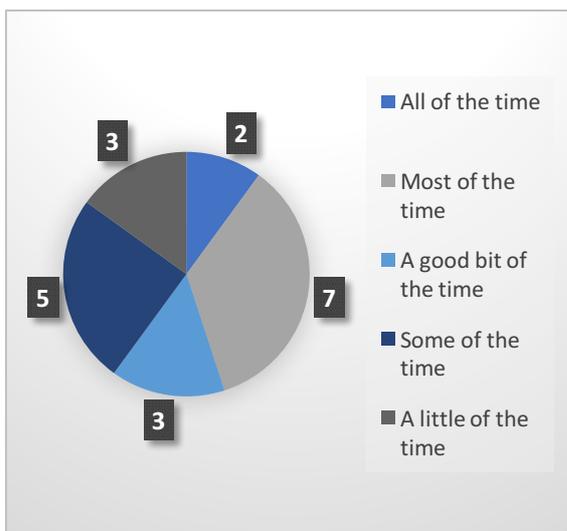
9. How much of the time, during the past month, have you felt **downhearted and blue**?
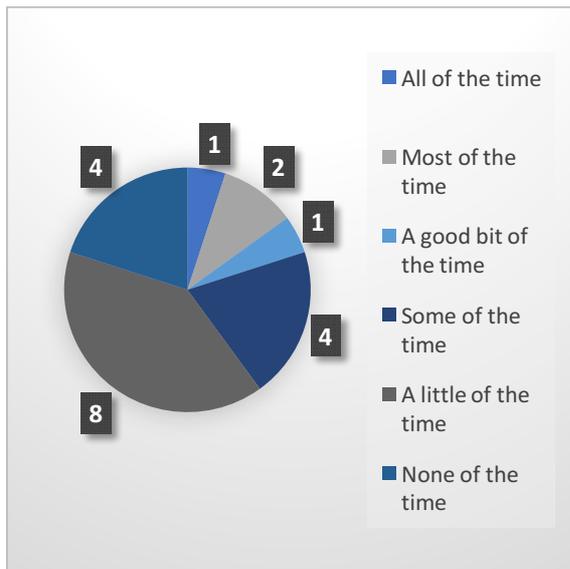
10. During the past month, how much of the time have you been a **happy person**?
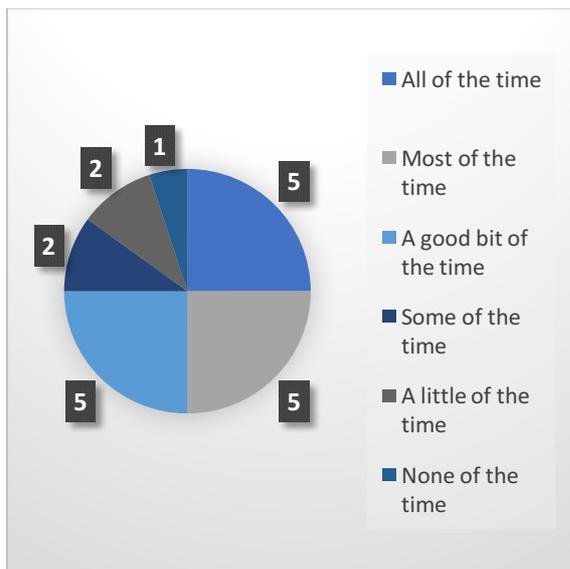
11. How often, during the past month, have you felt so **down in the dumps that nothing could cheer you up**?
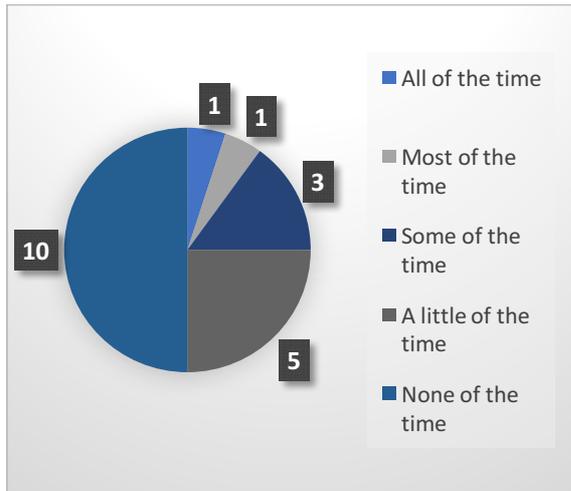

12. Please mark the circle that **best** describes whether **each** of the following statements is **true** or **false** for you.

a. I am somewhat ill
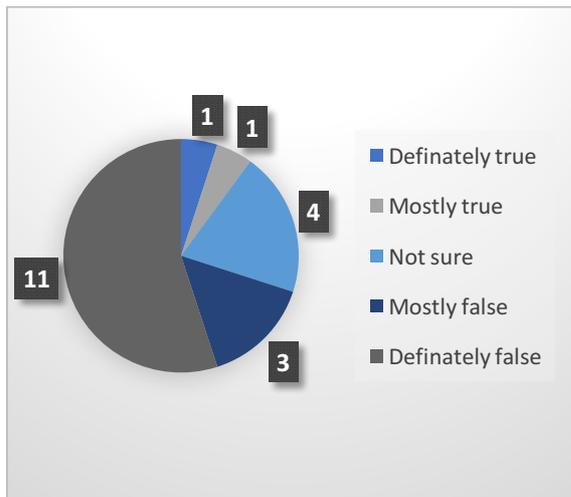
b. I am as healthy as anybody I know

Legend:
- Definately true
- Mostly true
- Not sure
- Mostly false
- Definately false

Values: 1, 3, 8, 3, 5

c. My health is excellent

Legend:
- Definately true
- Mostly true
- Not sure
- Mostly false
- Definately false

Values: 3, 5, 2, 2, 8
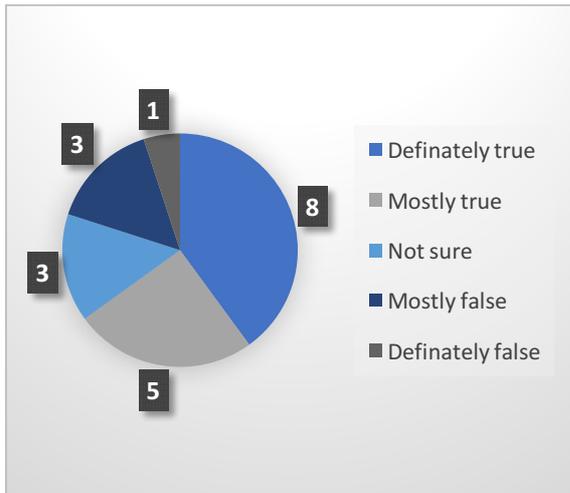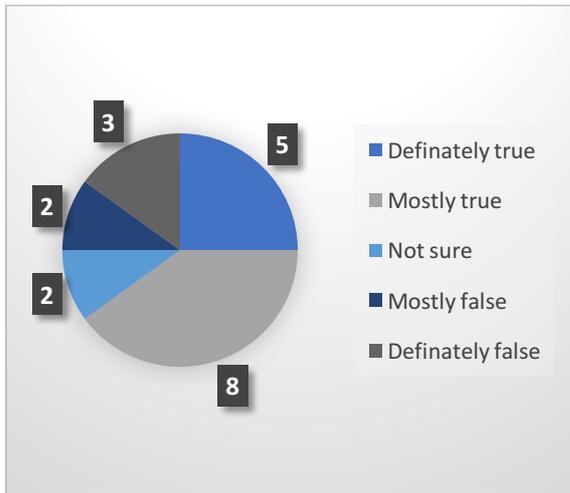
d. I have been feeling bad lately

Legend:
- Definately true
- Mostly true
- Not sure
- Mostly false
- Definately false

Values: 1, 2, 2, 11, 4