



# **Quality of life among Icelandic people with intellectual disabilities: Exploring positive characteristics**

Margrét Brynja Guðmundsdóttir

2015

BSc in Psychology

Author: Margrét Brynja Guðmundsdóttir  
ID number: 280992-3139

Department of Psychology  
School of Business

## Foreword

Submitted in partial fulfilment of the requirements of the BSc Psychology degree, Reykjavik University, this thesis is presented in the style of an article for submission to a peer-reviewed journal.

### Abstract

The aim of the current study was to examine whether there was a difference in the perception of Quality of life (QOL) among adults with an intellectual disability (ID) and adults without ID. The study was conducted in the beginning of 2015 and mixed methods research design was used. With quantitative research methods, QOL was assessed with the Personal Wellbeing Index. Participants in the survey were 39 and between the ages of 18 and 50 years. Mean QOL score among people with ID was 61.4% of the scale maximum, and the mean score among people without ID was 70.6%. Participants without ID perceived their QOL significantly higher, contradictory to previous studies. With the use of qualitative research methods, factors contributing to life quality that interviewees considered of most importance were analyzed. Participants were six and between the ages of 21 and 49 years. The main factors effecting QOL among interviewees were self-determination, social status, and emotional well-being, and although interviewees all faced some difficulties on account of their disabilities, they illustrated various coping resources. It is hoped that the results of this study will encourage further and larger research on the QOL of Icelandic people with ID.

*Keywords:* Quality of life, intellectual disability, life satisfaction

### Útdráttur

Hugtakið lífsgæði (e. Quality of life) er vel þekkt innan félags- og heilbrigðisvísinda, en markmið rannsóknarinnar var að kanna hvort munur væri á skynjun lífsgæða á milli einstaklinga með eða án vitsmunalegrar skerðingar. Rannsóknin var framkvæmd í byrjun árs 2015 og notast var við blandaðar rannsóknaraðferðir (e. mixed methods). Með meginðlega spurningalistanum Personal Wellbeing Index voru lífsgæði mæld, og þátttakendur voru 39 talsins á aldursbilinu 18 til 50 ára. Meðaltal heildarskors lífsgæða meðal vitsmunalega skertra var 61,4% og 70,6% meðal einstaklinga sem ekki voru vitsmunalega skertir. Þátttakendur sem ekki voru vitsmunalega skertir mátu lífsgæði sín marktækt hærri, ólíkt niðurstöðum fyrri rannsókna. Með eigindlegum viðtölum voru greindir jákvæðir þættir sem áhrif höfðu á lífsgæði vitsmunlega skertra einstaklinga. Viðmælendur voru sex talsins á aldursbilinu 21 til 49 ára. Meginþættir sem áhrif höfðu á lífsgæði viðmælenda voru sjálfsákvörðunarréttur (e. self-determination), félagsstaða og tilfinningaleg vellíðan (e. emotional well-being). Þrátt fyrir að viðmælendur upplifðu að einhverju leyti örðugleika vegna sinnar skerðingar sýndu þau fram á margvísleg bjargráð og seiglu. Vonast er eftir því að niðurstöður rannsóknarinnar hvetji til áframhaldandi og víðtækari rannsókna á lífsgæðum vitsmunalega skertra einstaklinga á Íslandi.

*Efnisorð:* Lífsgæði, vitsmunaleg skerðing, fatlaðir einstaklingar, lífsánægja

### Quality of life among Icelandic people with intellectual disabilities

There has been a rise in research focusing on positive characteristics of people in the recent decades, and in the field of disability studies, an augmentation has been on identifying the abilities that people with intellectual disabilities (ID) possess, with the aim to strengthen community inclusion and Quality of life (QOL) outcomes (Shogren, Wehmeyer, Buchanan, & Lopez, 2006). Disability studies have shifted from models that indicate pathology and rejected disability as a personal misfortune (Swain & French, 2000); although a disability affects people's ability to make self-determined choices and living a considerably normal life requires support (Schalock, 2004), a focus is on the recognition that people with ID have the capacity to make decisions about their lives (Shogren et al., 2006). In addition, international studies have shown that self-determination is correlated with increased QOL (Lachapelle et al., 2005; Nota, Ferrari, Soresi, & Wehmeyer, 2007; Wehmeyer & Schwartz, 1998).

QOL indicates a person's general well-being and when it's measured, both subjective and objective measures are considered valid indicators and should be used together (Brown, Hatton, & Emerson, 2013; Chowdhury & Benson, 2011; Cummins, 2005b; Cummins, 1997a; Schalock, 2004; Schwartz & Rabinovitz, 2003). Studies have shown that people with ID generally have lower objective QOL than the general population (Beyer, Brown, Akandi, & Rapley, 2010; Hensel, Rose, Kroese, & Banks-Smith, 2002; Verri et al., 1999). Despite this tendency, the majority of disabled people in Western countries reports being content with their QOL, are able to adapt to their objective circumstances (Albrecht & Devlieger, 1999; Verri et al., 1999), and that they can be optimistic about their future despite negative events experienced (Flynn, 1989; Janicki, Krauss, & Seltzer, 1988).

Measures of objective QOL have been effective in improving living standards, but they have also hoisted the implied belief that better objective QOL leads to improved subjective QOL (Verri et al., 1999). A proof of that being an unreasonable assumption is that

the domains of interpersonal relations and social inclusion have been most often referenced in QOL studies (Schalock, 2004), and increased variety of community activity and relationships with friends have been found to contribute to an increased well-being (Emerson & Hatton, 2008). Furthermore, a number of studies have shown that people with ID perceive their QOL equal or even higher than the general population (Asselt-Goverts et al., 2014; Boland et al., 2009; Cummins, 2005a; Emerson & Hatton, 2008; Lucas-Carrasco & Salvador-Carulla, 2012; Verri et al., 1999).

Research suggests that people in the Nordic countries have high life satisfaction (Bränholm & Degerman, 1992; Hughes & Gove, 1981) and Iceland normally ranks high on scales measuring happiness. In the World Value Survey which was conducted to assess the well-being of people in OECD countries between the years of 1981 to 2007, Iceland ranked third on life satisfaction, and control and freedom of choice had a strong association with life satisfaction (Fleche, Smith, & Sorsa, 2012). However, little information is known about the well-being of people with ID since they are usually excluded from public health studies, thus the results cannot be representative of the gross Icelandic population. According to the Convention on the Rights of Persons with Disabilities published by the United Nations and adopted in Iceland in 2007, people with disabilities should have "full and effective participation and inclusion in society" (United Nations, 2006). People with ID should therefore gain increased inclusion in public health studies to provide better information about their well-being status.

With the use of mixed methods research design, the aim of the study was to gain knowledge of how people with ID in Iceland perceive their QOL. By using quantitative research methods, the first hypothesis, based on previous studies, is that the overall QOL score is the same among participants with and without ID. The Personal Wellbeing Index (PWI) was used to measure QOL, particularly because it contains parallel versions for people

with and without ID (Cummins & Lau, 2005). It has been difficult to compare the life QOL of people with ID and people from the general population (Finlay & Lyons, 2001) and therefore, the feasibility to compare QOL scores is one of the main benefits of using the PWI. The PWI survey has established adequate reliability and validity for use among people with ID, and has been used in at least 48 countries (McGillivray, Lau, Cummins, & Davey, 2009).

Furthermore, satisfaction with life is commonly used alongside measuring QOL (Hensel et al., 2002) and the scores of people with and without ID have been found to be positively correlated (Cummins, 1995; Schwartz & Rabinovitz, 2003). The second hypothesis is therefore that the life satisfaction among people with and without ID is the same. With the use of qualitative research methods, factors contributing to life quality that interviewees considered of most importance were analyzed, and the research question is: "Which positive factors contribute the most to Quality of life?"

## **Method**

### **Research design**

Mixed methods research has been found to be of increasing value for both theoretical and methodological argumentations in the area of QOL research (Klassen, Creswell, Clark, Smith, & Meissner, 2012). The quantitative approach was postpositivist and involved a survey research. The independent variables were the seven domains measuring QOL and the dependent variable was the overall QOL score. The qualitative interviews were semi-structured and based on a phenomenological approach where the emphasis is on the quality and texture of the subjective experience of participants (Willig, 2013, p. 16).

### **Participants**

Participants in the survey were 39 and the sampling was both purposive whereas participants were either in a group of adult individuals with or without ID, and of convenience. Participants with ID were 13 men and 5 women between the ages of 19 and 47

years ( $M=27.3$ ;  $SD=9.4$ ), and participants without ID were 6 men and 15 women between the ages of 18 and 50 years ( $M=22.9$ ;  $SD=8.1$ ). All of the participants were studying at the same Icelandic college, except for seven participants with ID that were working at a supported employment. Criterion for participation was that all participants had to be older than 18 years, and participants with ID either had mild or moderate ID and the verbal ability to answer questions. All participants were asked on the same day of data collection if they were willing to participate, and were given some time to consider participation.

For the qualitative data, six participants were interviewed, four men and one women working at a supported employment, and also a superior managing a supported employment. Seven individuals with ID that were eligible to participate and working on the days the interviews took place were informed about the study and asked if they would like to participate. Two possible candidates rejected. All of the participants with ID were working in a 50% employment at the supported employment visited. Participants were the following:

**Marsibil Rós Friðriksdóttir**, a 39 years old female, a wife and the mother of two children. She lives independently with her family.

**Hreimur Högnason**, a 21 year old autistic male living with his family.

**Viktor Traustason**, a 23 year old autistic male living with his family.

**Unnsteinn Ólafsson**, a 30 year old male living on his own with support.

**Logi Þór Smárason**, a 33 year old male that lives in a community residence.

**Klara María Magnúsdóttir**, a 49 years old female, and a superior of the supported employment visited. She has been working with people with ID for 30 years.

### **Instruments and measures**

*Quality of life.* The Personal Wellbeing Index (PWI) developed by Cummins and Lau (2005) was translated to Icelandic and used to measure QOL. Two parallel versions were used, the 5th version created for adults (PWI-A), and the 3rd version created for adults with

ID (PWI-ID). The PWI-ID version is dissimilar from the normal version in that the wording is simpler, and it involves pre-testing to assure participants are able to use the scale and to test for acquiescent responding. All of the participants succeeded pre-testing. The surveys both have eight questions, a question about life satisfaction, and seven questions that consist of seven domains measuring QOL: health, personal relationships, standard of living, safety, life achievement, future security and community-connectedness, (Cummins & Lau, 2005) (see Appendices A and B). Two socio-demographic items were added to the survey; questions about the age and gender of participants. Participants were asked to rate each item on an 11-point Likert scale ranging from 0 (very dissatisfied) to 10 (very satisfied). A picture with five faces was also used to ease understanding for participants with ID (see appendix H).

The qualitative interviews were semi-structured and developed after examining the literature on the QOL concept, particularly by the eight domains of QOL that are generally accepted in the literature; personal development, self-determination, interpersonal relations, participation, rights, and physical, emotional and material well-being (Schalock et al., 2002; Verdugo, Navas, Gómez, & Schalock, 2012). The question framework for participants with ID was thorough and incisive to facilitate their comprehension on the subject. Frameworks for interviewees with ID and the specialist can be seen in appendices C and D.

## **Procedure**

In October 2014, the principal and the superior of a program for students with ID in an unnamed college in Iceland were contacted, and they permitted administration of the PWI. A superior of a supported employment located in the same commune was also contacted, and permission to administrate the PWI and to conduct qualitative interviews there was obtained. The quantitative data collection was conducted at these two places on the 22nd of January 2015. All of the participants without ID answered themselves at the same time in class, and it took them about 2-5 minutes to answer the survey. Participants with ID were administered the



survey one at a time in a face-to-face interview format where the scale was read aloud to them. The superiors at the college and the supported employment recruited participants. All of the eligible participants at the college agreed to answer the survey but four individuals working at the supported employment refused to participate. It took about 15-20 minutes to submit the survey to each participant. At both locations, the researcher had facilities in a private room with a table and two chairs where the researcher and participant sat against each other. The qualitative interviews took place on the 24th and 25th of February, 2015, with three interviews each day and at least an hour break between interviews. Interviews were recorded with a mobile device, and were between 31 and 66 minutes of length ( $M=51.5$  minutes).

### **Analysis**

Results from the PWI scales were put in SPSS where all statistical analyses and data screening were performed, and there was no missing data. Each interview was transcribed verbatim into a computer, compared and analyzed using Grounded theory approach, where the progress of category identification aims to identify themes in the data and develop a theory (Willig, 2013, p. 70). The data was repeatedly read and the process of coding was performed to discover themes that were to reflect the factors most important to the participants when thinking of a life of good quality. Notes and mind maps were also used to analyze the data. Three themes emerged.

### **Research Ethics**

Applications for ethical approval were sent to the Reykjavik University Research Ethics Committee and The National Bioethics Committee in Iceland (Vísindasiðanefnd), and full approval was obtained in December 2014 (no. of application: VSN-14-170). The research was also notified to the Data Protection Authority (Persónuvernd). Individuals with ID are a vulnerable group to inspect, but subjective well-being cannot be determined by objective

measurements or from proxy responding, and thus it is vital that it is measured from the individuals' own perception of their life and what they find important (Cummins, 1997b; Schalock et al., 2002). The names of the interviewees were changed and every substantives they mentioned in the interviews were altered to ensure anonymity and so they would be untraceable. Participants were given clear instructions about the purpose of the study and that it was voluntary and did not require personal experience. Furthermore, participants were offered to keep an information sheet about the study and to contact the researcher if any questions emerged (see appendix G). All of the participants with ID gave informed consent (see appendices E and F). Potential discomfort for participants was minimal and if a participant would have manifested feeling uncomfortable, his or her participation would have been terminated. No participant reported discomfort.

## Results

### Characteristics of the Personal Wellbeing Index domains

Noteworthy, QOL scores based on gender were not explored since the proportion of gender in the two groups was not equal; 72% of the 18 participants with ID were male, and 71% of the 21 participants without ID were female. Relationship between age and QOL was neither explored due to small sample size ( $N=39$ ). By using a formula presented in the PWI manual, the data was standardized by converting reported values to a Percentage of Scale Maximum (%SM). Mean scores of each QOL domain categorized by the two groups can be seen in Table 1.

Table 1

*Mean scores of the PWI domains*

QOL domains	People with ID		People without ID	
	Mean	SD	Mean	SD
Standard of living	78.3	17.9	77.6	10.9
Life achievement	69.4	24.4	80.5	10.7

Community involvement	73.3	13.7	83.3	10.1
Personal relationships	76.1	16.5	85.2	9.8
Personal safety	63.3	26.3	85.2	10.3
Health	61.7	17.9	76.7	14.2
Future security	78.3	22.3	69.5	14.6

The highest mean scores of domains among people with ID were for “standard of living” and “future security”, and the lowest mean score of domains was for “health”. The highest mean scores of domains among people without ID were for “personal relationships” and “personal safety”, and the lowest mean score of domains was for “future security”. The difference between mean scores of groups was only statistically significant ( $p < 0.05$ ) for the domains of "personal relationships" and "personal safety".

#### **Mean scores of “satisfaction with life as a whole” and Personal Wellbeing Index**

The overall QOL scores of participants was computed combining together the seven factors that measured QOL, and the data was analyzed using independent samples t-test. Z-scores were computed for raw scores and examined to evaluate if there were any outliers. 95% of the scores were less than 2 standard deviations away from the mean, thus there were no scores significantly influencing mean scores. Descriptive data with mean life satisfaction and QOL scores of the two cohort groups can be seen in Table 2.

Table 2

*Descriptive data of life satisfaction and PWI scores*

Demographic characteristics			Life satisfaction		Overall QOL score	
	N	%	Mean	SD	Mean	SD
Overall	39	100	79.2	16.4	66.4	8.8
People with ID	18	46	72.2	20.7	61.4	9.4
People without ID	21	54	85.2	8.1	70.6	5.5

With the distribution of 0 to 100, the overall life satisfaction of participants with ID was on average 72.2 and 85.2 among participants without ID. The difference between the groups was statistically significant [ $t(21.46) = 2.50$ ;  $p > 0.05$ ], whereas participants without ID reported being more satisfied with their lives. The lowest observed QOL score among participants with ID was 46.5 and the highest 82.8 ( $M=61.4$ ), and the lowest score among participants without ID was 56.5 and the highest 79.5 ( $M=70.6$ ). People without ID generally rated their life quality higher than people with ID [ $t(26.47) = -3.68$ ;  $p > 0.05$ ].

### **Internal reliability, validity and assumptions**

For both the sample of individuals with ID and the sample of individuals without ID, the alpha reliability was .58. Overall QOL scores showed moderate correlation with "life satisfaction" (.417;  $p < 0.01$ ), implying convergent validity.

Of the six assumptions required for an independent t-test, five of them withstood; QOL (dependent variable) was measured on a continuous scale, the independent variables were two independent groups (people with ID and people without ID), there was independence of observations, no significant outliers, and QOL was approximately normally distributed for each group because the Sig. values of the Shapiro-Wilk test were greater than 0.05 for both groups. However, Levene's test for equality of variance was statistically significant ( $F(1, 37) = 4.5$ ;  $p < 0.05$ ), thus the assumption of homogeneity of variance was violated, and equal variances therefore not assumed.

### **Qualitative interviews**

When data was analyzed, positive factors of QOL among interviewees were explored. Three themes emerged and are the following: independence, social status and well-being.

**Independence.** In general, interviewees assumed they had autonomy over themselves and what they preferred to do, Unnsteinn for example said he experienced more self-confidence performing things on his own. When going over her career in services for people

with ID, Klara stated that she had experienced positive changes in QOL among people with ID in the last 30 years. She felt that young people with ID experienced more independence today, and talked about the importance of recognizing their chronological age instead of the degree of maturity. Some interviewees did however express constrained independence in terms of their disabilities, Hreimur for instance narrated hopelessness and that he didn't see the point in setting goals or think about the future because of his limited self-determination; his social interactions were restrained by his parents and he had tried talking to them about it but given up.

Although interviewees wanted to feel independent, they recognized that they needed some assistance in daily life, and living entirely alone was not a desirable option for any of them. Marsibil and Hreimur had strong opinions about their autonomy and disliked when people interfered or domineered them. They both stated that it happened frequently to them, Hreimur for example said that the instructors at work sometimes talked to him like a child and that his choice of assignments was limited. As demonstrated and stated by Klara, work is a part of a person's sense of self-determination, and she said that work at the supported employment was structured to teach individuals to follow instructions and obey the rules of the workplace, and that employees participated according to their abilities. The majority of interviewees were satisfied working at a supported employment, particularly because of social interactions, and two of the interviewees reported having other part jobs and that they enjoyed meeting friends there. The two youngest participants did however say they'd like to work somewhere else, but felt their options were narrow. To conclude, the importance of feeling independent to interviewees was described as being respected by others, and it was also linked to their perception of their future; while some were content with how things in their life were, interviewees also expressed worries in terms of their future regarding choices and opportunities in life.

**Social status.** All of the interviewees found social interactions to be a core factor of QOL, but Viktor felt they were complicated although he would like to be more outgoing. Interviewees all assumed they had good relations with their friends and family. Unnsteinn said he tried to see the best in people and not to judge, and the majority of interviewees spoke of trust being the key of good friendships, and that they confided in their friends. Three of the interviewees did however report experiencing difficulties communicating with family members from time to time, and that they sometimes interfered excessively which offended them. In addition, interviewees also talked about loving animals and caring for them; Unnsteinn for example said that he had a strong bond with his dog and thought of him as his son. Viktor and Unnsteinn both narrated positive feelings of social inclusion and peer acceptance when they were at college. Furthermore, Klara talked about the importance of acknowledging that people with disabilities are diverse and should experience equality among the general population.

When asked how interviewees perceived the services they received they were rather content in general, although Hreimur sometimes thought he was receiving too much assistance. Klara stated that employees with ID consulted instructors when experiencing tribulations, and Unnsteinn declared a positive experience whereas he'd been taught to understand social communication better by instructors at the supported employment. Regarding education, three interviewees said they did not benefit much from it; Marsibil stated that she didn't learn what her line of interest concerning career was, and Viktor was unsatisfied with not being able to study what he wanted. On the whole, interviewees assumed that social interactions had positive effects on their well-being, and that social support from friends and family helped them dealing with difficulties.

**Well-being.** When asked what interviewees liked doing in their free time, playing video games, listening to music, watching TV and being on Facebook came first to

mind, and all of them reported enjoying social activities except Viktor. The emotional lives of interviewees were complex, particularly because of their disabilities. Viktor reported experiencing a great deal of stress in daily life and that there was a long time since he last experienced joy in his life. He said he felt like he condensed his emotions in a bottle which sometimes exploded, and after exploding he reported becoming emotionally numb. Two other interviewees also expressed feeling emotionally numb sometimes; Marsibil because of difficulties coping with the loss of loved ones, and Hreimur because of his medication which he felt blocked his emotions and attenuated his morality.

Interviewees spoke of various ways to cope with stress and negative thoughts; two of the interviewees said they used positivity as a coping resource instead of letting negative thoughts break them down. Viktor reported using boxing, music and video games to calm him down, and as he said: "I put all my hate and stress in video games. So I get an outlet playing". Also, Unnsteinn said he used coping resources by conquering his emotional difficulties in his dreams, that he always defeated the monsters which made him feel good. Furthermore, two interviewees showed signs of resilience regarding adversity and that they had to accept tribulations to be able to move on in life.

Participants generally expressed financial difficulties and three of the interviewees all presumed that the material well-being of Icelandic people with ID was bad. For example, three of the interviewees talked about difficulties surviving the month; that it was limited what they could do with their money and that they would like to be able to afford more things. However, two of the interviewees didn't find money important, Unnsteinn said for instance that he disliked money because they made him greedy and unrestrained. Marsibil assumed that there was a positive correlation between financial status and QOL, and said: "If you don't own anything and can't afford anything, then you're not happy".

When asked about their health status, participants in general thought that it was good, Viktor for example demonstrated a positive body image and said he tried to exercise regularly. Marsibil and Hreimur did however receive criticism from family members regarding their weight which they disliked, further stating their disfavoring of interference. The superior said that the diet of people with ID is often unrestrained, and in line with that, Marsibil found it difficult to eat food that was wholesome and that it was easier to eat unwholesome food. In general, it was prominent that interviewees talked about their physical health but did not mention their perception of their mental health, and although most of them expressed some emotional difficulties regarding factors contributing to life quality, they seemed to be unaware of the effects on their well-being.

**Positive factors contributing to Quality of life.** The factor that were of most importance to each interviewee can be seen in table 5. Throughout the interview, Marsibil talked about her relationship with the people around her, that she had met wonderful people and that her family was the most important thing contributing to her life satisfaction. Unnsteinn reported resilience when coping with negative emotions and numerous experiences where he talked about feelings, particularly that love had the most effect on his health, both negative and positive. The interview with Hreimur was tendentious toward his deficiency of autonomy and control, and he narrated that his QOL would improve if he would gain more control over his life. In line with Hreimur, Klara thought that the factor contributing most to well-being, independent of disability, was self-determination, the sentiment of having something to say about one's own life. For Viktor, experiencing social inclusion was among the best experiences in his life, whereas he reported that he had felt normal: "They looked at me like I wasn't just someone disabled". Finally, Logi talked about happiness being a core factor of his QOL, and when asked what had been a main contributor to his well-being, he said: "Just, being with happy people. I am happy. I have lived a good life."



Table 3

*Core QOL factors among interviewees*

Marsibil Rós	Unnsteinn	Hreimur	Klara María	Viktor	Logi Þór
Social interactions	Emotional well-being	Self-determination	Self-determination	Social inclusion	Emotional well-being

### Discussion

The goal of this study was to explore whether there was a difference in the perception of QOL among people with ID and without ID, and to examine what QOL factors were of most importance to people with ID. The first hypothesis that the QOL score was the same among participants with and without ID was rejected. Unlike previous studies establishing that people with ID had equal QOL compared to the general population (Asselt-Goverts, Embregts, & Hendriks, 2014b; Boland et al., 2009; Cummins, 2005a; Emerson & Hatton, 2008; McGillivray et al., 2009; Verri et al., 1999), the QOL score among people with ID was significantly lower than the score among people without ID. The mean QOL score among people without ID (70.6) falls within the normative range for mean scores in Western populations, which is 70-80 points (Lau, Cummins, & Mcpherson, 2005), while the mean QOL score among people with ID (61.4) does not. The second hypothesis that life satisfaction among people with and without ID was the same was also rejected, the mean life satisfaction score among people with ID was also significantly lower than the score among people without ID.

The results are most likely unreliable since Cronbach's Alpha was .58 for both surveys, therefore indicating internal inconsistency. The low value might be because of the diversity of the QOL construct being measured, but since the surveys have established good reliability and validity in various studies (McGillivray et al., 2009), it is unlikely. A more likely reason is because the sample was not representative, so the best way to assess the

reliability of the PWI among Icelandic people would be to present the survey to a larger and more representative sample. The lower QOL mean score among people with ID does however indicate that the subject needs to be explored further to see if there are possible reasons why participants with ID perceived their overall life quality lower.

The qualitative interviews proclaim the diversity of what factors contribute most to people's QOL. However, shared characteristics were observed in each of the presented themes, and the qualitative results were more in line with previous studies compared to the quantitative results, validating the comprehensive effects of using mixed methods research design. Results underpin the positive effects of self-determination on QOL like previous studies have demonstrated (Lachapelle et al., 2005; Nota et al., 2007; Wehmeyer & Schwartz, 1998), and as control and freedom have shown to be of importance among the general Icelandic population (Fletcher, 2009), this study indicates that they are also of importance among Icelandic people with ID.

In accordance with QOL studies, social relations and inclusion were generally of most importance among interviewees (Schalock, 2004), and although their social interactions were described as complex in many ways, they were nevertheless of great importance to them. The main part of each interview involved reports of factors affecting their well-being, and they all exhibited in various ways how they used coping resources to deal with adversity, in line with what previous studies have shown (Albrecht & Devlieger, 1999; Flynn, 1989; Janicki et al., 1988; Verri et al., 1999). When asked if they experienced exclusion to community involvement compared to the general population, four of the participants stated that they were unsatisfied with their opportunities to educate themselves or work at the general labour force, especially the youngest interviewees. By increasing various career opportunities among people with ID in Iceland, their social inclusion and well-being is likely to enhance.

Interestingly, there was an inconsistency in the results of the PWI survey and the qualitative interviews; while the domain of standard of living had the highest mean score of the seven questions measuring QOL among people with ID, four of the five interviewees exposed dissatisfaction regarding their material well-being and that they often couldn't afford things that they wanted or needed. A possible explanation for this difference is that the perception of participants differs from when they're giving it a number in a survey to when they're describing it by giving examples. In continuation, it would be interesting to further explore the material well-being of Icelandic people with ID, and why this difference between quantitative and qualitative methods might have emerged.

The lowest mean score of domains among people with ID was regarding their health. Furthermore, the superior stated that the monitoring of health of people with ID was often deficient, especially among those receiving less service. Studies examining health problems have shown that people with ID have up to 2.5 times more incidences of health problems (Valk, Metsemakers, Haveman, & Crebolder, 2000) and are at a higher risk of developing mental health problems compared to the general population (Holland & Koot, 1998). The findings of this study indicate a need for further research on the health status among Icelandic people with ID, and that by better educating people with ID about a healthy lifestyle, precautionary measures would be beneficial both to the individuals themselves and the health care system by decreasing the cost of preventable health problems.

The main limitations of the study were small sample size both for the survey and the interviews, and therefore, the results cannot be representative. It would have increased validity to have interviewed a wider group of individuals with ID, not only employees at a supported employment. The reliability was also unacceptable regarding the quantitative survey. In conclusion, the results of the study connote that a gap exists between the perception of QOL of people with and without ID, and that each domain of QOL needs to be examine

more explicitly to gain a better idea of the well-being of Icelandic people with ID. By conducting more and narrower studies asking people with ID themselves, information would be obtained on how services provided for them could further enhance their life satisfaction and increase positive traits. The findings from this study contribute to a base of knowledge regarding the QOL of Icelandic people, and the main benefit of the study is the awakening of conducting QOL research among people with ID; few studies in Iceland have directly examined QOL although many have explored the various factors contributing to QOL. The lives of people with ID are undeniably formed by their disabilities, but it is nevertheless important to alliterate an awakening in the society by acknowledging their potential and strengths that can be enhanced, instead of focusing on limitations.

## References

- Albrecht, G. L., & Devlieger, P. J. (1999). The disability paradox: High Quality of life against all odds. *Social Science & Medicine*, 48(8), 977–988.
- Asselt-Goverts, A. E., Embregts, P., & Hendriks, A. H. C. (2014). Social networks of people with mild intellectual disabilities: Characteristics, satisfaction, wishes and quality of life. *Journal of Intellectual Disability Research*, 1–12. <http://doi.org/111/jir.12143>
- Beyer, S., Brown, T., Akandi, R., & Rapley, M. (2010). A Comparison of Quality of life outcomes for people with intellectual disabilities in supported employment, day services and employment enterprises. *Journal of Applied Research in Intellectual Disabilities*, 23(3), 290–295. <http://doi.org/10.1111/j.1468-3148.2009.00534.x>
- Boland, M. C., Daly, L., & Staines, A. (2009). Self-rated health and Quality of life in adults attending regional disability services in Ireland. *Disability and Health Journal*, 2(2), 95–103.
- Bränholm, I.-B., & Degerman, E.-A. (1992). Life satisfaction and activity preferences in parents of Down's syndrome children. *Scandinavian Journal of Public Health*, 20(1), 37–44. <http://doi.org/10.1177/140349489202000108>
- Brown, I., Hatton, C., & Emerson, E. (2013). Quality of life indicators for individuals with intellectual disabilities: Extending current practice. *Intellectual and Developmental Disabilities*, 51(5), 316–32.
- Chowdhury, M., & Benson, B. A. (2011). Deinstitutionalization and Quality of life of individuals with intellectual disability: A review of the international literature. *Journal of Policy and Practice in Intellectual Disabilities*, 8(4), 256–265. <http://doi.org/10.1111/j.1741-1130.2011.00325.x>
- Cummins, R. A. (1995). On the trail of the gold standard for subjective well-being. *Social Indicators Research*, 35(2), 179–200. <http://doi.org/10.1007/BF01079026>

- Cummins, R. A. (1997a). *Comprehensive Quality of Life Scale: Intellectual/cognitive Disability (ComQol-15): Manual*. School of Psychology, Deaking University.
- Cummins, R. A. (1997b). Self-rated Quality of life scales for people with an intellectual disability: A review. *Journal of Applied Research in Intellectual Disabilities*, 10(3), 199–216. <http://doi.org/10.1111/j.1468-3148.1997.tb00017.x>
- Cummins, R. A. (2005a). Moving from the Quality of life concept to a theory. *Journal of Intellectual Disability Research*, 49(10), 699–706. <http://doi.org/10.1111/j.1365-2788.2005.00738.x>
- Cummins, R. A., & Lau, A. L. D. (2005b). *Personal Wellbeing Index - Intellectual Disability (PWI-ID): Manual*. Australian Centre on Quality of Life, Deakin University.
- Emerson, E., & Hatton, C. (2008). Self-reported well-being of women and men with intellectual disabilities in England. *American Journal on Mental Retardation*, 113(2), 143–155. [http://doi.org/10.1352/0895-8017\(2008\)113\[143:SWOWAM\]2.0.CO;2](http://doi.org/10.1352/0895-8017(2008)113[143:SWOWAM]2.0.CO;2)
- Finlay, W. M., & Lyons, E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment*, 13(3), 319–335. <http://doi.org/10.1037/1040-3590.13.3.319>
- Fleche, S., Smith, C., & Sorsa, P. (2012). *Exploring Determinants of Subjective Wellbeing in OECD Countries* (OECD Statistics Working Papers). Paris: Organisation for Economic Co-operation and Development. Retrieved from <http://www.oecd-ilibrary.org/jsessionid=atr665ro0jjpg.x-oecd-live-02content/workingpaper/5k9ffc6p1rvb-en>
- Fletcher, J. M. (2009). Childhood mistreatment and adolescent and young adult depression. *Social Science & Medicine*, 68(5), 799–806. <http://doi.org/10.1016/j.socscimed.2008.12.005>

- Flynn, M. C. (1989). *Independent Living for Adults with Mental Handicap: A Place of My Own*. London: Continuum International Publishing.
- Hensel, E., Rose, J., Kroese, B., & Banks-Smith, J. (2002). Subjective judgements of quality of life: A comparison study between people with intellectual disability and those without disability. *Journal of Intellectual Disability Research*, 46(2), 95–107.
- Holland, A. j., & Koot, H. m. (1998). Mental health and intellectual disability: An international perspective. *Journal of Intellectual Disability Research*, 42(6), 505.
- Hughes, M., & Gove, W. R. (1981). Living alone, social integration, and mental health. *American Journal of Sociology*, 87(1), 48–74.
- Janicki, M. P., Krauss, M. W., & Seltzer, M. M. (1988). *Community residences for persons with developmental disabilities: Here to stay*. P.H. Brookes Pub. Co.
- Klassen, A. C., Creswell, J., Clark, V. L. P., Smith, K. C., & Meissner, H. I. (2012). Best practices in mixed methods for Quality of life research. *Quality of Life Research*, 21(3), 377–380. <http://doi.org/10.1007/s11136-012-0122-x>
- Lachapelle, Y., Wehmeyer, M. L., Haelewyck, M.-C., Courbois, Y., Keith, K. D., Schalock, R., ... Walsh, P. N. (2005). The relationship between Quality of life and self-determination: An international study. *Journal of Intellectual Disability Research*, 49(10), 740–744. <http://doi.org/10.1111/j.1365-2788.2005.00743.x>
- Lau, A. L. D., Cummins, R. A., & Mcpherson, W. (2005). An investigation into the cross-cultural equivalence of the Personal Wellbeing Index. *Social Indicators Research*, 72(3), 403–430. <http://doi.org/10.1007/s11205-004-0561-z>
- Lucas-Carrasco, R., & Salvador-Carulla, L. (2012). Life satisfaction in persons with intellectual disabilities. *Research in Developmental Disabilities*, 33(4), 1103–1109.
- McGillivray, J. A., Lau, A. L. D., Cummins, R. A., & Davey, G. (2009). The utility of the Personal Wellbeing Index intellectual disability scale in an Australian sample. *Journal*

*of Applied Research in Intellectual Disabilities*, 22(3), 276–286.

<http://doi.org/10.1111/j.1468-3148.2008.00460.x>

Nota, L., Ferrari, L., Soresi, S., & Wehmeyer, M. (2007). Self-determination, social abilities and the Quality of life of people with intellectual disability. *Journal of Intellectual Disability Research*, 51(11), 850–865. <http://doi.org/10.1111/j.1365-2788.2006.00939.x>

Schalock, R. L. (2004). The concept of Quality of life: What we know and do not know. *Journal of Intellectual Disability Research*, 48(3), 203–216.

Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., ... Parmenter, T. (2002). Conceptualization, measurement, and application of Quality of Life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation*, 40(6), 457–470. [http://doi.org/10.1352/0047-6765\(2002\)040<0457:CMAAOQ>2.0.CO;2](http://doi.org/10.1352/0047-6765(2002)040<0457:CMAAOQ>2.0.CO;2)

Schwartz, C., & Rabinovitz, S. (2003). Life satisfaction of people with intellectual disability living in community residences: Perceptions of the residents, their parents and staff members. *Journal of Intellectual Disability Research*, 47(2), 75–84.

Shogren, K. A., Wehmeyer, M. L., Buchanan, C. L., & Lopez, S. J. (2006). The application of positive psychology and self-determination to research in intellectual disability: A content analysis of 30 years of literature. *Research & Practice for Persons with Severe Disabilities*, 31(4), 338–345.

Swain, J., & French, S. (2000). Towards an affirmation model of disability. *Disability & Society*, 15(4), 569–582.

United Nations. (2006). *Convention on the rights of persons with disabilities*. New York.

Valk, H. M. van S. L.-D., Metsemakers, J. F., Haveman, M. J., & Crebolder, H. F. (2000). Health problems in people with intellectual disability in general practice: A



comparative study. *Family Practice*, 17(5), 405–407.

<http://doi.org/10.1093/fampra/17.5.405>

Verdugo, M. A., Navas, P., Gómez, L. E., & Schalock, R. L. (2012). The concept of Quality of life and its role in enhancing human rights in the field of intellectual disability. *Journal of Intellectual Disability Research*, 56(11), 1036–1045.

<http://doi.org/10.1111/j.1365-2788.2012.01585.x>

Verri, A., Cummins, R. A., Petito, F., Vallero, E., Monteath, S., Gerosa, E., & Nappi, G. (1999). An Italian–Australian comparison of Quality of life among people with intellectual disability living in the community. *Journal of Intellectual Disability Research*, 43(6), 513–522. <http://doi.org/10.1046/j.1365-2788.1999.00241.x>

Wehmeyer, M., & Schwartz, M. (1998). The relationship between self-determination and Quality of life for adults with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities*, 33(1), 3–12.

Willig, C. (2013). *Introducing Qualitative Research In Psychology*. McGraw-Hill Education (UK).

## Appendices

## Appendix A - Survey for people with ID

**Persónubundin Velliðan Mælikvarðinn (PWI-ID) - Vitsmunaleg hömlun**

Aðferð: Hamingjukvarðinn (frá 0-10) sem sýndur var þátttakanda í forprófun er á ný sýndur.

Leiðbeiningar: „Núna ætla ég að spyrja þig nokkurra spurninga um það hversu glaður/glöð þú ert, með því að nota þennan kvarða frá 0 til 10. Eins og ég hef áður sagt, þá merkir núll að þú sért mjög leiður/ur (Bent er á vinstri hlið kvarðans). 10 merkir að þú sért mjög glaður/glöð (Bent er á hægri hlið kvarðans). Og miðjan á kvarðanum er 5, sem merkir að þú ert hvorki glaður/glöð né leiður/ur (Bent er á miðjuna). Með því að nota þennan kvarða frá 0 til 10.....“ (Haldið er áfram og spurt um hvert atriði hér fyrir neðan)

Hvaða ár ert þú fædd/ur?

Ár

Hvert er kyn þitt?

Karlkyn

Kvenkyn

Svörun þátttakanda

**11 stiga**

(0-10)

**Hluti I: Ánægja með Lífið í heild sinni (valfrjálst)**

„Þegar þú hugsar um líf þitt og þær kringumstæður sem þú býrð við, hversu ánægð/ur ertu með líf þitt í heild sinni?“ ☐

**Hluti II: Persónubundin Velliðan Mælikvarðinn - Vitsmunaleg Hömlun**

„Hversu ánægð/ur ertu gagnvart...?“

1. Hlutunum sem þú átt? Til dæmis peningum og hlutum sem þú hefur keypt? ☐
2. Hversu góða heilsu þú hefur? ☐
3. Hlutunum sem þú býrð til eða því sem þú lærir? ☐
4. Samböndum þínum við þá sem þú þekkir? ☐
5. Því hversu örugg/ur þér finnst þú vera? ☐
6. Að gera hluti utan heimili þíns? ☐
7. Því hvernig aðstæður verða seinna í lífi þínu, í framtíðinni? ☐

## 5. útgáfa

---

Ár

## Kvenkyn

Mjög											
Mjög óánægð/ur											
ánægð/ur											
	0	1	2	3	4	5	6	7	8	9	10

3. „Hversu ánægð/ur ertu með það sem þú ert að **afreka/frankvæma** í lífi þínu?“

Mjög										
Mjög óánægð/ur										
ánægð/ur										
0	1	2	3	4	5	6	7	8	9	10

4. „Hversu ánægð/ur ertu gagnvart **persónulegum samböndum** sem þú átt við aðra?“

Mjög										
Mjög óánægð/ur										
ánægð/ur										
0	1	2	3	4	5	6	7	8	9	10

5. „Hversu ánægð/ur ertu varðandi **öryggi** þitt?“

Mjög										
Mjög óánægð/ur										
ánægð/ur										
0	1	2	3	4	5	6	7	8	9	10

6. „Hversu ánægð/ur ertu varðandi **þátttöku þína í samfélaginu**?“

Mjög										
Mjög óánægð/ur										
ánægð/ur										
0	1	2	3	4	5	6	7	8	9	10

7. „Hversu ánægð/ur ertu gagnvart því hvernig **aðstæður** í lífi þínu verða í framtíðinni?“

Mjög										
Mjög óánægð/ur										
ánægð/ur										
0	1	2	3	4	5	6	7	8	9	10

**Spurningalistanum er nú lokið.**

**Kærar þakkir fyrir þátttökuna!**

## Appendix C - Framework for interviewees with ID

**Viðtalsrammi til viðmiðunar í viðtali**

– vitsmunalega skertir einstaklingar

**Undirbúningur:**

Skrifa undir upplýst samþykki. Lýsa hvernig viðtalið fer fram og ræða viðfangsefnið. Lýsa yfir áhuga á viðfangsefni og viðmælanda. Kveikja á upptökutæki.

*Upphaf viðtals*

Lífið almennt. Segðu mér frá sjálfri/sjálfum þér – bakgrunnupplýsingar (aldur, kyn, búseta, menntun, starf, áhugamál). Hvað hefurðu verið að gera í lífinu? (t.d. eitthvað sem stendur upp úr, eitthvað sem þú myndir vilja breyta)

Hömlun - hvernig upplifir þú fötlun/hömlun þína? En aðrir? Hvernig finnst þér að vera fatlaður/fötluað á Íslandi?

**Sjálfstæði**

- Persónulegur þroski (athafnasemi daglegs lífs)

Segðu mér frá venjulegum degi hjá þér. (góður, slæmur dagur)

Segðu mér frá hæfileikum sem þú býrð yfir.

Sem manneskja, hvernig finnst þér þú skipta máli?

Hverjir eru þínir helstu kostir/gallar?

- Sjálfstærðni (að velja sjálfur það sem maður gerir; markmið, ákvarðanir og val)

Segðu mér frá markmiðum þínum í lífinu. (Hefur þú náð að uppfylla mörg af þínum markmiðum?)

Hver er stærsta ákvörðun sem þú hefur tekið? Getur þú sagt mér aðeins frá því?

Hefur þú val til þess að gera og ákveða allt það sem þú vilt? (fylgja eftir)

Þegar þú hugsar um framtíðina, hvaða væntingar hefur þú? (fylgja eftir)

**Félagsstaða**

- Félagsleg samskipti (eins og vinátta)

Getur þú sagt mér frá samböndum sem þú átt við aðra? (fylgja eftir)

Hvað merkir vinátta fyrir þér?

Hvernig finnst þér fólk almennt koma fram við þig?

Hvernig líður þér vanalega innan um annað fólk?

- Þátttaka (í samfélagi og félagsleg innlimun/inclusion)

Segðu mér frá því sem þú gerir helst í frítíma þínum.

Hvað gerir þú helst með vinum þínum og/eða fjölskyldu?

Getur þú nefnt mér dæmi um eitthvað sem þig langar eða hefur langað að gera en ekki haft möguleika til?

Segðu mér frá vinnu þinni og hvað þú gerir vanalega í vinnunni.

- Réttindi (mannleg og lögleg)

Hver eru réttindi þín sem manneskja í samfélaginu? Er þeim uppfyllt?  
 Hefur einhvern tímann verið brotið á réttindum þínum? Hvernig þá?  
 Hvað gerir þú ef það er/væri brotið á þér?  
 Hvernig upplifir þú virðingu? Bera aðrir virðingu fyrir þér?  
 Hvað gerir þú ef einhver er leiðinlegur við þig og ósanngjarn?  
 Hvaða skoðun hefur þú á þeirri menntun sem þú hefur hlotið (takmarkaðir möguleikar?).

### **Vellíðan**

Getur þú gefið mér dæmi um það sem lætur þér líða vel?  
 Getur þú gefið mér dæmi um það sem lætur þér líða illa?  
 Þegar lífið er erfitt, hvað gerirðu þá (hvern finnst þér best að tala við)?  
 Færð þú hjálpann við að takast á við erfiðleika (t.d. eitthvað sem veldur þér vanlíðan eða streitu)?

#### - Líkamleg vellíðan (heilsa)

Hvernig finnst þér heilsa þín vera?  
 Hvað einkennir góða heilsu?  
 Hefur þú áhyggjur af heilsu þinni (ef, hvernig þá)?  
 Hvað hefur mest áhrif á heilsu þína? (matarræði – hreyfing)

#### - Tilfinningaleg vellíðan (öryggi)

Upplifir þú þig hamingjusama/n – hvernig lýsir sú tilfinning sér.  
 Hvað veitir þér öryggi? Hvað veldur því að þú upplifir öryggisleysi?  
 Upplifir þú oft stress eða áhyggjur (út af hverju)?  
 Segðu mér frá því sem þú hefur helst áhyggjur af.  
 Upplifir þú þig oft stressaða/n – hvernig lýsir sú tilfinning sér (fylgja eftir).

#### - Efnisleg vellíðan (fjárhagsleg staða)

Hvað er það verðmætasta sem þú átt, getur þú sagt mér frá því?  
 Skipta peningar þig miklu máli (hvernig þá)?  
 Spáir þú í merkjavörum eða dýrum hlutum? Að hvaða leyti?  
 Hvernig líður þér ef þú getur ekki fengið eitthvað sem þig langar í?

### **Almennt um lífsgæði**

Hvað merkir orðið lífsgæði fyrir þér?  
 Hvað telur þú vera góð eða slæm lífsgæði?  
 Hvernig telur þú þig hafa áhrif á lífsgæði þín?  
 Hvað er það sem hefur mest áhrif á lífsgæði þín, fyrir utan þig sjálfa/n?

Hvernig gæti samfélagið bætt lífsgæði þín?  
 Hvernig heldur þú að lífsgæði fatlaðra á Íslandi séu almennt?  
 Hvernig finnst þér samfélagið og sú þjónusta sem þér býðst koma til móts við þín lífsgæði/þínar þarfir eða langanir?

#### *Lok viðtals*

Er eitthvað sem þú vilt segja frá sem við höfum ekki rætt?  
 Hvernig líður þér eftir viðtalið?  
 Þakkað er fyrir og lýst yfir mikilvægi þátttöku einstaklingsins.

## Appendix D - Framework for specialist

**Viðtalsrammi til viðmiðunar í viðtali**  
- fagaðili**Undirbúningur:**

Skrifa undir upplýst samþykki

Lýsa hvernig viðtalið fer fram og ræða viðfangsefnið

Kveikja á upptökutæki

*Upphaf viðtals*

Getur þú sagt mér frá þínum menntaferli?

Getur þú sagt mér frá þínum ferli í málefnum fatlaðra?

Hvað fékk þig til þess að vinna við málefni fatlaðra?

**Sjálfstæði**

Telur þú fatlaða einstaklinga upplifa sjálfstæði?

Telur þú að fatlaðir einstaklingar hafi nóg að gera í sínu lífi?

Telur þú að fatlaðir hafi mikið val varðandi sitt líf?

Hefur þú tekið eftir því að fatlaðir setji sér markmið?

Koma starfsmenn til þín og leita ráðgjafar?

**Félagsstaða**

Telur þú að félagsleg samskipti séu stór hluti af lífi fatlaðra?

Hvernig upplifir þú að félagsstaða fatlaðra sé?

Hvernig telur þú samskipti meðal fatlaðra starfsmanna vera á vinnustaðnum?

- Þátttaka (í samfélagi og félagsleg innlimun/inclusion)

Telur þú að fatlaðir hafi jafn mikla möguleika og aðrir til þess að taka þátt í félagsstarfi og öðrum athöfnum í samfélaginu?

Hvaða skoðanir hafa fatlaðir starfsmenn almennt um vinnu sína á VISS?

- Réttindi (mannleg og lögleg)

Telur þú að fatlaðir séu upplýstir um sín réttindi í samfélaginu?

Verður þú vitni að því að brotið sé á réttindum fatlaðra?

Telur þú að almennt sé komið fram við fatlað fólk af virðingu?

Hvernig finnst þér fatlaðir einstaklingar takast á við mótlæti? (fá þeir stuðning?)

Hvað finnst þér um tækifæri fatlaðra til að sækja sér menntun?

**Vellíðan**

Hvað telur þú að skipti mestu máli þegar kemur að vellíðan fatlaðra?

Telur þú að fatlaðir ræði við einhvern um vandamál sín þegar þeim líður illa?

Hafa fatlaðir möguleika á að ræða við einhvern í vinnunni ef þeim líður illa?

Hvað með sálfræðilega hjálp?

- Líkamleg vellíðan (heilsa)

Hvernig finnst þér heilsa fatlaðra almennt vera?

Hvað telur þú að fötluðum finnist um sína heilsu?

- Tilfinningaleg vellíðan (öryggi)

Upplifa fatlaðir sig almennt hamingjusama að þínu mati? Að hvaða leyti?

Telur þú að fötluðum sé veitt nægt öryggi?

Tekur þú eftir því að fatlaðir starfsmenn upplifi oft streitu eða hafi áhyggjur? Hvernig er tekið á því?

- Efnisleg vellíðan (fjárhagsleg staða)

Hvernig telur þú fjárhagslega stöðu fatlaðra einstaklinga á Íslandi vera?

Hvaða máli telur þú að peningar skipti fatlaðra einstaklinga?

Upplifir þú að fatlaðir hafi ekki efni á einhverju sem þeim langar í?

**Almennt um lífsgæði**

Ef þú hugsar um heildar lífsgæði, hvernig heldur þú að lífsgæði fatlaðra einstaklinga á Íslandi séu?

Hvaða þættir heldur þú að hafi mest áhrif á lífsgæði fatlaðra?

Hvernig gæti samfélagið bætt lífsgæði fatlaðra?

*Lok viðtals*

Er eitthvað sem þú vilt nefna varðandi lífsgæði sem við höfum ekki rætt?

Þakkað er fyrir og lýst yfir mikilvægi þátttöku einstaklingsins.



## Appendix E - Informed consent, survey

**Upplýst samþykki vegna þátttöku í rannsókninni „Lífsgæði einstaklinga með vitsmunalega hömlun á Íslandi“**

Markmið þessarar rannsóknar er að kanna hvernig einstaklingar með vitsmunalega hömlun skynja og túlka lífsgæði sín, og borin verða saman lífsgæði þeirra við einstaklinga sem ekki eru með vitsmunalega hömlun.

Lífsgæði eru öll þau atriði sem stuðla að góðu lífi, og eru mæld með spurningalista sem er alls 10 spurningar. Auk þess verða tekin nokkur eigindleg viðtöl við fatlaða einstaklinga sem ætlað er að veita frekari innsýn á þeirra skoðun á sínum lífsgæðum og hvað þeim finnst skipta máli varðandi gott líf.

Að svara spurningalistanum tekur í kringum 10-20 mínútur. Þú, kæri þátttakandi, ert ekki skyldugur til þess að taka þátt og hefur rétt á að hætta hvenær sem er. Einnig þarft þú ekki að svara spurningu ef þú vilt það ekki. Rannsóknin er nafnlaus og verður gögnum eytt að rannsókn lokinni.

Ef þú vilt vita meira um rannsóknina getur þú haft samband við mig, rannsakandann, Margréti Brynju Guðmundsdóttir (margretbg12@ru.is, sími 661-5015), eða leiðbeinanda minn, Margréti Lilju Guðmundsdóttur (margretlilja@ru.is).

Með því að skrifa undir hér að neðan staðfestir þú þátttöku þína og að þú skiljir tilgang rannsóknarinnar.

---

 Nafn þátttakanda

---

 Dagsetning

---

 Undirskrift

---

 Rannsakandi

---

 Dagsetning

---

 Undirskrift

Ef þú hefur áhuga á að fá helstu niðurstöður rannsóknarinnar getur þú skrifað niður netfangið þitt og niðurstöður verða sendar í tölvupósti.

Netfang: \_\_\_\_\_

## Appendix F - Informed consent, interviews

**Upplýst samþykki vegna þátttöku í rannsókninni „Lífsgæði einstaklinga með vitsmunalega hömlun á Íslandi“**

Markmið þessarar rannsóknar er að kanna með viðtölum hvernig vitsmunalega skertir einstaklingar túlka lífsgæði sín, eða öll þau atriði sem stuðla að góðu lífi.

Viðtölunum er ætlað að veita frekari innsýn á skoðun viðmælenda á sínum lífsgæðum og hvað þeim finnst skipta máli varðandi gott líf. Viðtalið er í kringum 60 mínútur og spurt verður hálfopinna spurninga sem merkir að svörin geta verið ítarleg og byggð á reynslu, svör byggja alfarið á upplifun viðmælenda.

Viðtalið verður tekið upp en nöfn viðmælenda koma aldrei fram í rannsóknargögnum og svör því órekjanleg. Fullur trúnaður mun ríkja með allar þær upplýsingar sem viðmælandi mun koma til með að gefa rannsakanda.

Þú, kæri þátttakandi, ert ekki skyldugur til þess að taka þátt og hefur rétt á að hætta hvenær sem er. Einnig þarft þú ekki að svara spurningu ef þú vilt það ekki.

Ef þú vilt vita meira um rannsóknina getur þú haft samband við mig, rannsakandann, Margréti Brynju Guðmundsdóttir (margretbg12@ru.is, sími 661-5015), eða leiðbeinanda minn, Margréti Lilju Guðmundsdóttur (margretlilja@ru.is).

Með því að skrifa undir hér að neðan staðfestir þú þátttöku þína og að þú skiljir tilgang rannsóknarinnar.

_____	_____	_____
Nafn þátttakanda	Dagsetning	Undirskrift
_____	_____	_____
Rannsakandi	Dagsetning	Undirskrift

## Appendix G - Information sheet, survey

**Upplýsingar um rannsóknina** „Lífsgæði einstaklinga með vitsmunalega hömlun á Íslandi“**Til þátttakenda**

Kæri þátttakandi, þú ert beðin/n um að taka þátt í þessari rannsókn og skiptir þátttaka þín miklu máli. Áður en þú ákveður hvort þú viljir taka þátt er mikilvægt að þú skiljir hvers vegna og hvernig þessi rannsókn er gerð. Ef þú samþykkir að taka þátt verður þú vinsamlegast beðin/n um að skrifa undir upplýst samþykki, og ef það er eitthvað sem þú skilur ekki varðandi rannsóknina ert þú beðin/n um að segja frá því. Þú mátt taka þér nokkrar mínútur í að hugsa vel og ákveða um þátttöku. Tilgangur rannsóknarinnar er að kanna lífsgæði (*Quality of life*) einstaklinga með vitsmunalega hömlun og bera saman við lífsgæði einstaklinga sem ekki eru með vitsmunalega hömlun.

**Þátttaka**

Þátttaka í þessari rannsókn felur í sér svörun á spurningalista sem metur lífsgæði og það er alfarið þín ákvörðun hvort þú vilt taka þátt eða ekki. Þó þú samþykkir þátttöku er þér frjálst að hætta hvenær sem er og án þess að gefa upp ástæðu. Ef þú samþykkir að taka þátt mun verða lagður fyrir þig spurningalisti sem tekur í kringum 10-20 mínútur að svara. Spurningarnar eru byggðar á sjö þáttum sem tengjast lífsgæðum; 1) *lífskjörum* 2) *heilsu* 3) *afrekum í lífinu* 4) *persónulegum samböndum* 5) *öryggi* 6) *hlutverki í samfélagi* og 7) *öryggi í framtíðinni*. Þátttöku er lokið þegar búið er að svara spurningunum.

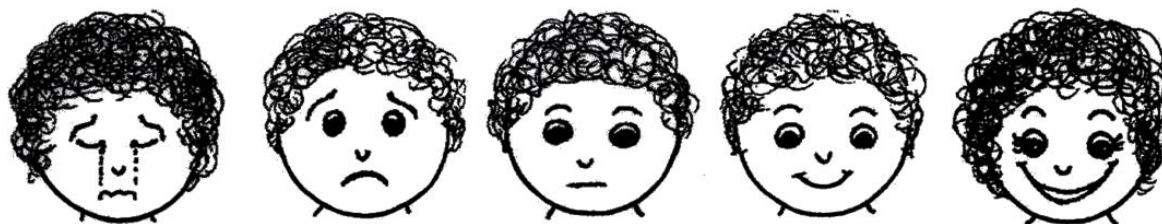
**Ávinningur og áhætta við þátttöku í rannsókninni**

Þátttöku fylgir enginn skaði og ætti þátttakandi ekki að finna fyrir óþægindum. Ef spurningar valda vanlíðan er þátttakandi vinsamlegast beðin/n um að segja frá því. Sé óskað eftir því að fá niðurstöður úr rannsókn að henni lokinni er hægt að skrá niður netfang og sendar verða helstu niðurstöður.

**Frekari upplýsingar**

Ef óskað er eftir frekari upplýsingum um eitthvað varðandi rannsóknina er hægt að hafa samband við rannsakanda, Margréti Brynju Guðmundsdóttur, annaðhvort með því að senda tölvupóst eða að hringja. Netfangið er [margretbg12@ru.is](mailto:margretbg12@ru.is) og símanúmerið er 661-5015. Ef að óskað er eftir því að hafa samband nafnlaust er hægt að hafa samband við deildarstjóra sálfræðisviðs Háskólans í Reykjavík ([jack@ru.is](mailto:jack@ru.is)).

## Appendix H - Five faces used with survey for people with ID



## Appendix I – Summary Report

Samantekt á niðurstöðum rannsóknarinnar „Lífsgæði meðal vitsmunalega skertra einstaklinga: Að einblína á það jákvæða“

Markmið rannsóknarinnar var að kanna hvernig einstaklingar með vitsmunalega skerðingu skynjuðu og túlkuðu lífsgæði sín, en með spurningalistanum Persónuleg Vellíðan Mælikvarðinn (Personal Wellbeing Index) voru borin saman lífsgæði þeirra við einstaklinga sem ekki voru með vitsmunalega skerðingu. Alls tóku 39 einstaklingar á aldursbilinu 18 til 50 ára þátt, en meðalaldur var 25 ára. Einnig voru tekin viðtöl við fimm einstakling með vitsmunalega hömlun og við fagaðila en þau voru á aldrinum 21 til 49 ára, og var meðalaldur 32,5 ára.

Niðurstöður spurningalistans voru á þá vegu að þátttakendur sem ekki voru vitsmunalega hömlun máttu lífsgæði sín marktækt hærri heldur en þátttakendur sem voru vitsmunalega hamlaðir, ólíkt niðurstöðum fyrri rannsókna. Einnig var lífsánægja þátttakenda sem ekki voru vitsmunalega skertir marktækt hærri heldur en hjá þátttakendum sem voru vitsmunalega skertir. Þó er vert að nefna að ekki er hægt að alhæfa niðurstöður þar sem þátttakendur voru fáir, en niðurstöður benda til þess að skynjun vitsmunalega skerta einstaklinga á sínum lífsgæðum sé frábrugðin skynjun þeirra sem ekki eru vitsmunalega skertir, og væri því athugavert að kanna nánar hvaða þættir valda þessum mismun.

Niðurstöður viðtalanna leiddu það í ljós að meginþættir sem áhrif höfðu á lífsgæði viðmælenda voru sjálfsákvörðunarréttur (e. self-determination), félagsstaða og tilfinningaleg vellíðan (e. emotional well-being). Það sem hafði hvað mest jákvæð áhrif á lífsgæði viðmælenda voru samskipti þeirra við fjölskyldu og vini, viðmælendur töldu það einnig mikilvægt að þau hefðu stjórn á sínu lífi, og einnig bjuggu þau yfir ýmsum bjargráðum til þess að koma í veg fyrir neikvæð áhrif á vellíðan og að hjálpa sér að takast á við erfiðleika.