

The Great Life Project

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A plain language report prepared for IHC/IDEA
Services by the Donald Beasley Institute in
collaboration with the IHC Self Advocacy Advisory
Committee

The Great Life Project Research Team

Donald Beasley Institute

Jenny Conder

Paul Milner

Brigit Mirfin-Veitch

Daniel Schumeyer

IHC Self Advocacy Advisory Committee

Alyssa Dimock

Waata Houia

Stuart Jenkins

Linda King

Donald Neal

Dianne Pelvin

Artist

Ron Baker (Dunedin)

The kea was chosen for the front cover by members of the SAAC because it represented to them a very intelligent bird that marks its territory and knows what it wants

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1

Introduction

Before the Great Life Project (GLP) started Wendy Rhodes at IDEA Services had talked with Donald Beasley Institute researchers, Brigit Mirfin-Veitch and Paul Milner, about how IDEA services could find out if people were living a good life. They talked about writing a questionnaire that would ask people questions about their life.

The questionnaire would be a tool to help other people understand about a person's quality of life. It was hoped that this would help IDEA services find ways to improve service user's quality of life. There were other questionnaires that had been used but they wanted one that people with intellectual disability had helped to write. That way they would know that the questions were about the things that IDEA service users thought were important to them leading a good life. This is the first time people with intellectual disability have written their own quality of life measure.

About the same time as the project started the IHC Board had set up the Self-Advocacy Advisory Committee (SAAC). The SAAC were asked to help the Donald Beasley Institute (DBI) researchers with the project. This was good timing as it made it possible for members of SAAC and DBI researchers to work together as a team during all stages of the project. The first thing SAAC

did was name the project: The Great Life Project (GLP). The SAAC members have written a report about their role in the project.

This report is about the project and has been written by the DBI researchers with the help of the SAAC. In the report there is an outline of the steps in the project, the results from the focus groups that were held and the trial of the questionnaire. There is also a brief discussion about the results along with recommendations that the DBI researchers and the SAAC would like IDEA services to consider.

2

What has been written about Quality of Life

Researchers have been trying to understand what helps people to live great lives for a long time. The name generally used to describe this work is Quality of Life (QOL) research.

Quality of Life research has been important to people who need support because the research has helped to change the way we think about what living a good life means for people with intellectual disability. Up until October 2006, some New Zealand men and women with intellectual disability still lived in institutions. One of the reasons they no longer do is because people with disabilities and their families said that living in an institution stopped people from having the chance to enjoy things that made the lives of other New Zealander's good.

In the 30 years that people have been writing about the quality of life of people with disabilities we have learnt that it is very difficult to measure how good people's lives are. No two lives are the same and so the things that make people happy are different for everyone.

We have also learnt that how much of something people have (objective wellbeing) makes little difference to how satisfied people say they are with their lives (subjective wellbeing). People like to feel happy and they find things about their lives that make them feel good whether they live in a prison or a palace.

When people are asked to say how satisfied they are on a scale that measures their Quality of Life, most people tend to rate themselves as 75% happy, no matter where or how they are living.

One of the other reasons it has been hard to know more about the quality of service user's lives is because many people with intellectual disability find it hard to say how happy they are by using a questionnaire. Research has found that about 70% of people with intellectual disability find it hard to answer questionnaires. Some people find it difficult to understand questions or make themselves understood.

Being interviewed by another person with an intellectual disability seems to help. When service users are asked questions by other people with disabilities, research has found they are more likely to answer questions and less likely to always say life is good.

Although there are problems measuring people's Quality of Life, most researchers agree that it is possible to list a set of things that are important to everyone. They call this list the set of core domains. Researchers tend to list between 6 – 8 domains that they say cover everything that is important to life quality. Each of the core domains is supposed to add to life quality in ways that are different to other domains.

In the Great Life project the research team chose the set of core domains that most researchers have used, but changed the names of the domains to make it easy for everyone to understand. The eight core domains used to build the Great Life Questionnaire were;

1. How I feel inside myself
2. Friendships and relationships
3. Having what I need
4. Growing and learning
5. Feeling well fit and healthy
6. Being able to do things for myself
7. Participating in the community
8. Rights

In each core domain, examples of particular things people say make them happy can be grouped. For example, within the domain of *Participating in the community*, some people might love going out with lots of people to a nightclub, whereas others may especially value going to a favourite café with a friend.

When people with intellectual disability have been asked what makes life good, they sometimes tell us things we didn't expect. For example, people who use disability support often mention how important their relationships with staff can be. They also tell us that it can be just as important to have private time away from staff. People with disabilities often stress the importance of paid employment, contributing in the community, and continuing to learn. They also often say how important it is to be able to show others people things they can do well.

When researchers have made tools to measure life quality, the things people with disabilities say are important can be missed out. It makes sense then that people with disabilities should say what counts as a good life. This project is the first time people who use a disability service have had the chance to say what should count. The aim was to make a questionnaire that allowed IDEA service users to let others know if they were living a great life.

3

The way the Great Life Project was organised

The Great Life Project needed to be well organised as there were a lot of people helping at different times. People helping with the project included the six SAAC members and the people who use IDEA services for residential or vocational support. Having a lot of people helped to make sure that there were plenty of ideas about quality of life. Also, about sixty people were needed to test the questionnaire. A plan helped to make sure that everybody knew what would happen.

This section outlines how the plan was carried out. Sometimes there were changes to the plan if the researchers or participants thought that another way would be better. The project took a participatory action research approach and so it was expected that there would be changes at times.

Before starting the project the National Ethics Committee approved the plan. They also agreed to the information and consent forms that participants were given and asked to sign. A copy of the information (see Appendix One) and consent form (see Appendix Two) can be found at the end of this report.

Step 1: the first focus group

Seven focus groups were held, three in Auckland (31 participants) and two in each of Dunedin (17 participants) and Christchurch (15 participants). The goal of these focus groups was to ask people about the things that were important to them and their quality of life.

Three questions were asked by SAAC members:

1. What makes life good?
2. What would make life better?
3. What stops life from being good?

After people had answered these questions the groups put their ideas into one of eight domains.

This step is written about in more detail in the results section.

Step 2 and Step 3: Preparing for question writing / drafting the questionnaire

The DBI researchers went through all the 544 ideas from the focus groups to find the main things that were important to service users quality of life. Similar things were put together in 'themes'. These themes were then used to write questions for the questionnaire. The SAAC members and the DBI researchers wrote the questions at a meeting in Wellington.

All eight domains of quality of life were included in the final questionnaire however there were more questions for the domains that people in the focus group had said were most important.

Step 4: Testing the questionnaire

Members of SAAC were taught how to administer the questionnaire before testing started. There were two hours for this teaching, which both SAAC members and the DBI researchers think should have been longer.

SAAC members asked each of the 64 participants if they wanted help with the questionnaire. In most cases the SAAC members then asked the questions while the DBI researchers watched and helped when needed. Some people completed the questionnaire by themselves.

The DBI researchers learnt a lot from watching the testing of the questionnaire. The results section will include more about what was learnt from watching people answer the questionnaire.

There was a lot of organising to get people to their individual appointments. People completed the questionnaire more quickly than planned. This meant that they were waiting around and in some cases it was annoying for them. In some places there was not much privacy for people to answer their questionnaire.

Step 5: Analysis of results from questionnaire

Each person's results were put into the computer using a special programme named SPSS. Using this programme allowed the DBI researchers to compare all of the answers. By doing this the research team could tell if their were

differences in overall QOL or the core domains that might help IDEA Services know how to improve some service user's lives. The questionnaire provided lots of information and the programme helped the research team to write the report. The results section illustrates how the information from the questionnaire can be applied.

Step 6: the second focus groups

Forty-one people took part in the second round of focus groups. There were three purposes to these groups:

1. For the participants to tell the research team what they thought about the questionnaire,
2. To tell the participants about the results of the questionnaire,
3. To ask the participants about the way the questionnaire should be changed and how it should be used in the future.

The answers from the participants of the focus groups are presented in the results section.

Step 7 and Step 8: Revision of the questionnaire and presentation of report

After the second focus groups the DBI researchers used the suggestions from the participants to make changes to the questionnaire. The DBI researchers and the SAAC members had also thought about changes that might make it a better questionnaire. We met in Wellington to discuss which changes should be made. We also discussed the recommendations that we should tell IDEA services.

The new version of the questionnaire and the recommendations are included in the reports that have been written. The recommendations are in the last section of this report. The new version of the questionnaire is at the end of this report (see Appendix Three).

4

What we heard at the first Focus Groups

IDEA service users who participated in the Great Life Project began to help by coming to a focus group held in their region. The aim of the focus group was for participants to help each other think about all of the things that made life good. The research team wrote their ideas down.

Members of the SAAC team asked participants three questions to start them thinking.

1. When you think about your life now, what makes life good?
2. When you think about your life now, what would make life better?
3. When you think about your life now, what stops life being good?

When all of the ideas were collected the research team had 544 different statements about what made life good or not so good. Most people found it easier to say what made life good. Over half of the ideas were about the good things in people's lives.

In the second half of the focus group, participants were asked which of the eight core domains they thought their ideas belonged. Participants often

couldn't decide between domains. They said that some ideas affected more than one part of their lives. For example, participants said having a paid job was important because it helped them feel part of the community **and** it was where they met their friends **and** it enabled them to earn more money.

When all of the ideas were added, it became clear that participants spoke more about things that made life good in some core domains than they did in others. The four domains with the most ideas were '*How I feel inside myself*,' (140 ideas), '*Friendships and relationships*,' (183 ideas), '*Growing and learning*,' (115 ideas), and '*Participating in the community*,' (168 ideas). Participants did not speak very often about ideas they felt belonged in the domains '*Having what I need*,' (56 ideas), '*Feeling well, fit and healthy*,' (33 ideas) and '*Rights*,' (55 ideas).

When the research team grouped participant's statements, similar themes kept coming up. The ideas that participants spoke about most often had something to do with aspects of their relationships. This included the relationships participants had with staff, friends and family, people in the community or the men and women they lived or worked with. Feeling well supported, being able to meet new people or go out with friends and having the chance to feel close to others were important. Participants also said it was good to feel part of the community and that it was especially good to help other people. Having a paid job was often mentioned as the best way to feel part of the community. Some people also said having to live or work with people that they didn't like stopped them having a good life and that when they were hurt or teased it was important that their service listen and act quickly.

Other researchers have already written about how important having good relationships are to people with disabilities. IDEA service users tended to agree.

By speaking directly to people with an intellectual disability, new ways to improve the quality of people's lives also became clear. Many participants said they found it difficult when people left and that it was hard to know the best way to act sometimes. They said having someone to talk to about their relationships would help. Although many participants told us how important their flatmates were, others spoke about feeling unsafe at home or in the workplace. And finally people spoke about how they loved going out, but that they would also like to have their friends and family visit them.

Not much has been written about the impact of these things on the quality of service user's lives. IDEA service users have given researchers new things to think about. They also made sure the Great Life Questionnaire asked questions that would have been missed if people who didn't use disability services had written it.

Sometimes noticing what isn't said tells us about life quality too. Things that participants did not say did not make the questionnaire. Repeating the Great Life Project later would help everyone know whether the things people said helped make a good life and the things they never thought to say were any different in the future.

5

How people answered the Great Life Questionnaire

In the Great Life Questionnaire, each question asked participants to rate how often good (or bad) things happened or how happy they were with parts of their life on a five-point scale. Five was the top score and one was the lowest. As the DBI researchers sat and watched SAAC members administer the questionnaire they noticed participants tended to answer in one of two ways.

Some participants almost always answered at the top of the scale, indicating that good things *'always'* happened or they were *'very happy.'* Service users who answered this way tended to answer that good things *'never,'* happened or they were *'very unhappy,'* when they felt life wasn't so good, but rarely gave answers in between.

Another group of participants answered questions across the scale. This group often explained their answers to the SAAC member, re-telling stories from their own lives.

Although statistical tests showed participants answered the questionnaire differently, neither the sex, age, type of service used or region service users

came from appeared to influence which of the two patterns of answering a participant would follow.

Other research has found that people with an intellectual disability are more likely to always answer questions about their lives positively. There are two common explanations for why people do this. First, people with an intellectual disability may feel they are being judged and want to answer in ways that would make it seem they were doing well. The second reason may be that the question and/or scale is difficult for them to understand.

When the research team looked to see if it was possible to learn things that could improve wellbeing, they found that it didn't matter how participants answered. All participants were able to tell the research team ways to improve the quality of their lives if careful attention was paid to how they scored questions and to the stories people told as they answered the questionnaire.

When all of the question scores were added together most participants overall scores clustered about an average of 4.2 (on the five-point scale). This score is slightly higher than we expected. Previous research led us to expect an average score closer to 3.75 because this represents 75% of the scales top score. The higher average found in the Great Life Project occurred because of the number of people who answered that their life was good in all domains.

One of the aims of the Great Life Project was to see if it was possible to identify differences in the life quality of IDEA service users. We used statistical

models to test whether differences in sex, age, type of service used or region participants came from explained variation in overall scores. None of the ways participants were known to differ appeared to influence their overall score.

Participants, on average, rated their quality of life highest in the domains '*Feeling well, fit and healthy*,' ($M=4.51$; $SD=0.62$) and '*Having what I need*,' ($M=4.27$; $SD=0.72$) and lowest in the domains '*Participating in the community*,' ($M=4.08$; $SD=0.68$) and '*Rights*,' ($M=4.09$; $SD=0.68$).

Although the finding that participants should rate their quality of life highest in the domain '*Feeling well, fit and healthy*,' seems unusual, it has been reported elsewhere. Researchers have recently suggested that one of the ways people are able to keep feeling good is by increasing the value of things people have in their lives and decreasing the value of things that they do not have access to.

The Great Life project adds to existing research about how people maintain a sense of positive overall wellbeing. The research team found that participants tended to rate their quality of life lowest in the domains they spoke most often about in the first focus groups and highest in the domains they spoke about the least.

6

What we heard at the second Focus Groups

At the second focus groups participants were asked a number of questions. In this section their answers have been put together to tell you the main points.

Why did people take part in the project and what did they get out of taking part?

There were three main themes in the answers to these questions. The first theme was that people wanted to be helpful. It seemed that this meant both being a helpful person when someone asks you to do something and helping with the project itself. In terms of helping with the project, people talked about wanting to make sure that the questionnaire was good. A good questionnaire was seen as a way to tell IDEA services about the important issues for their quality of life. Whether or not people see this goal achieved will depend on how IDEA services use the questionnaire in the future.

Secondly, people saw that taking part in the project would be a good way to learn about research. They also thought that they might learn skills that would help them in other areas of their life. One good example of this was when one person commented on how much better she understood what informed

consent meant. People were also surprised about what they learnt about other people's lives and the things that were important to them.

Finally, the participants saw that the research was a way to meet new people and do something different. Although many people knew each other beforehand, at all groups there were people who didn't know each other. Coming to the meetings meant that they were getting away from their usual routines.

What did people think about the questionnaire?

Some people thought that the questionnaire was too simple but others found the questions hard to answer. If questions were not asked carefully enough they were hard to answer. For example people didn't want to say they were bullied, bossed or teased if it was just one person that teased them occasionally.

The participants thought that the number of questions was about right. They felt that the topics covered most of the things that had been talked about in the first focus group. The one topic that people thought should have more questions was meaningful work.

Who would people want to do their questionnaire?

The SAAC members had administered the questionnaire for the project. At the second focus group, participants were asked if there were other people that they would want to have ask them the questions. 'Insiders,' that is people who knew about the service, were seen as a good choice. Some people said they would like to do their questionnaire with a family member. Others disagreed. Friends either within IDEA services or outside of the service were also chosen.

Most important was that the questionnaire was done with someone who cared about the person's answers. Most people said they did not want their direct care staff to do the questionnaire with them. Participants felt that it would be too difficult to give honest answers and it was important to them to keep a good relationship with their staff.

Other things discussed at the second focus group

Two scales had been used with the questionnaire. Participants were asked whether these scales were the best. They decided that the wording on the frequency scale should be changed so that the word 'seldom' became 'not often' (Figure 1).

	☐	☐	☐	☐	☐
	Always	Often	About half the time	Not often	Never

Figure 1 The Great Life Questionnaire frequency scale

A happiness scale was the other scale used. It had faces (Figure 2) to indicate happiness. Most people liked this scale but a few did not like it at all. Those who did not like it thought that it was used too much within their service. They reported that although people had said that they were unhappy there had been no change, so it was seen as a scale that did not make a difference.

Also discussed at the focus group was whether or not people wanted to put






					
	Very happy	Happy	Neither happy, nor sad	Sad	Very sad

Figure 2 The Great Life Questionnaire happiness scale

their name on the questionnaire. Most people felt that by putting their name on it they 'owned' their questionnaire. It would give them some control over how it was used. There was not a lot of time for this discussion. People mostly decided that the important thing was that they should know who will see their questionnaire and how it will be used before deciding about whether to put their name on it. Some participants wanted to be able to share it with their family or friends.

7

Discussion

There have been a number of good ideas that have been learnt by doing this project. Service users have told us what is important to their quality of life. Having strong relationships and not having to do the same thing all the time are important. People like having a real job. Being part of the community and having groups that they belong to also makes people feel good about their life. While some other writers have mentioned these points, this project has been the first to ask the people with intellectual disability themselves.

The project team has also learnt that one of the best ways to find out about a person's quality of life is to talk to them. Talking about what is good about your life helps you think about what you would like to change. IDEA services could use the questionnaire to help people to talk about their lives and tell the service how they would like to improve their quality of life. The stories that people told when doing the questionnaire were often more helpful than their answers to the questions.

The participants were important to completing a successful project. As well as telling the project team what made their life good, they have given their time to the project. Because the DBI researchers and the SAAC members met the participants three times they could check that they understood what had been said at each meeting.

As well as the good ideas that have been learnt there are also some important points to think about. One is why the questionnaire might be used. The Great Life Questionnaire will be most helpful when used with individual service users to discuss their quality of life. Because people usually tell us that they are happy when we ask them, we cannot expect the Great Life Questionnaire to measure the quality of life of a group of people. This is because their scores would be averaged and the higher number of very happy people would mean that the voices of people who were not so happy would be lost. If the questionnaire were used to find out about the quality of life of a lot of people it would need some different types of questions added to it. Research has shown questions that ask about things that can be measured works best. For example, how much money do you earn?

There were a lot of participants that said their life was very good. While this sounds fine it is a worry to the project team as it may mean that these people did not understand the questions. It could be that the questions were not clear. In the second version of the questionnaire (see Appendix Three) some questions have been changed to make them more easily understood.

The person who asks the questions may also be able to help people understand the question better. It will be necessary to have more people to administer the questionnaire if it were going to be used within IDEA services. Training people so that they can ask the questions in a helpful way may mean that service users are less likely to always answer all the questions the same. This would mean that the project team could be more certain that the questionnaire was doing what it should do.

Participants in the second focus group and the SAAC members did not think that direct care staff should administer the questionnaire. There were a number of reasons for this. However if the person is to make changes to their life to make it better, they may need help from their direct care staff. The project team hasn't had the time to find a way to make sure that information available to staff after a service user fills out the questionnaire is used to make a positive change in people's lives.

Everybody involved in this project has learnt something from taking part. Using a similar approach that involves people who may be able to help IDEA services to make use of the questionnaire would be a good way to move forward. In other words service users, support workers, family and friends working together might find the best way to improve people's quality of life.

By asking service users for their ideas, the GLP has added to what was already known about quality of life for people with intellectual disability. The project has helped us to learn about their issues. It has also suggested some new ways that the lives of people with intellectual disability could be improved. The last section of this report tells IDEA services what the project team think should happen now.

Recommendations

From the participants in the project and the thoughts of the project team members there are five recommendations. Recommendations are the things that IDEA services should do or need to think about if they want to improve service users quality of life.

1. Trial the latest questionnaire

The latest questionnaire hasn't been used yet. It needs to be tested to see if the new questions are better.

2. Training of administrators

The administrators need to be trained so that they can help people answer each question. Other writers have suggested how to train advocates for this role.

3. Future use of the questionnaire

There were three points to consider when thinking about using the questionnaire. The first is ownership. Participants wanted to be able to choose who saw their questionnaire and how it was used. A second point is whether using the questionnaire should take place alongside the personal planning process. The third point is the project team think that

IDEA services should involve people from within the service as they plan how to use the questionnaire.

4. Options for administration of questionnaire

People liked having the SAAC members ask them the questions in the questionnaire. Some participants thought that it would be okay if other people asked the questions, for example a family member or friend. It is important that people can choose the person that they want to do their questionnaire.

5. Share findings and progress with participants

The participants have given a lot to this project. They must be told about the project. They should also be told what IDEA services do with the project in the future. This information can be put in newsletters that go to service users.

9

Recommended reading

This report is a plain language summary of a much larger report written by the Great Life Project research team. Copies of the full report are held at IDEA Services national office and at the Donald Beasley Institute library.

Members of the SAAC team wrote their own report. In their report SAAC members describe how they felt about the research, including what they thought were important findings and what they hoped would happen after the project finished. The SAAC report has been included as a separate chapter in the full report.

To prepare for the Great Life Project the research team needed to read what other researchers had found about the Quality of Life of people with intellectual disability. They were also interested to know how successful other researchers had been at measuring the life quality of service users and how the information could help services to improve the wellbeing of the people they support. This information guided the design of the project and helped us to understand what we had found.

The research that was important to the project is named in the full report. Nearly 100 different books or journal articles are named in the full report. We haven't included them all in this report, but for people who are interested in reading more we have listed some of the most useful books and journal articles.

For people interested in learning more about what researchers mean by Quality of Life and what influences how good we feel.

Cummins, R. (1995). On the Trail of the Gold Standard for Subjective Well-being. *Social Indicators Research*, 35(2), 179-200.

Cummins, R. A. (2005). Moving from quality of life concept to a theory. *Journal of Intellectual Disability Research*, 49(10), 669-706.

Schalock, R. (2005). Guest editorial: Introduction and overview. *Journal of Intellectual Disability Research*, 49(10), 695-698.

Shalock, R., Brown, I., Brown, R., Cummins, R., Felce, D., Matikka, L., et al. (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.

Verdugo, M., Schallock, R., Keith, K., & Stancliffe, R. (2005). Quality of life and its measurement: important principles and guidelines. *Journal of Intellectual Disability Research*, 49(10), 707-717.

For people interested in learning more about some of the problems researchers have found in trying to measure the Quality of Life of people with intellectual disability.

Ager, A. (2002). 'Quality of Life' Assessment in Critical Context. *Journal of Applied Research in Intellectual Disabilities*, 15, 369-376.

Hatton, C. (1998). Whose Quality of Life Is it Anyway? Some Problems With the Emerging Quality of Life Consensus. *Mental Retardation*, 36(2), 104-115.

Matikka, L., & Vesalla, H. (1997). Acquiescence in quality-of-life interviews with adults who have mental retardation. *Mental Retardation*, 35, 78-82.

Perry, J., & Felce, D. (2002). Subjective and Objective Quality of Life Assessment: Responsiveness, Response Bias, and Proxy:Resident Concordance. *Mental Retardation*, 40(6), 455-456.

Wolfensberger, W. (1994). Let's Hang Up "Quality of Life" As a Hopeless Term. In D. Goode (Ed.), *Quality of Life for Persons with Disabilities: International Perspectives and Issues* (pp. 285-321). Cambridge: Brookline Books.

For people interested in learning more about research that has also asked people with intellectual disability what makes life good.

Mactavish, J., Lutfiyya, Z., Iwasaki, Y., MacKay, K., Mahon, K., & Rodrigue, M. (2005). Thanks for asking me...Individuals with intellectual disability on life quality and leisure connection, *The Leisure Research Symposium*. San Antonio.

Marquis, R., & Jackson, R. (2000). Quality of Life and Quality of Service Relationships: experiences of people with disabilities. *Disability & Society*, 15(3), 411-425.

For people interested in learning more about research that has also employed people with intellectual disability to help measure the Quality of Life of disability service users.

Bonham, G., Basehart, S., Schalock, R., Marchand, C., Kirchner, N., & Rumenap, J. (2004). Consumer-Based Quality of Life Assessment: The Maryland Ask Me! Project. *Mental Retardation*, 42(5), 338-355.

For people interested in learning more about how services are trying to use what we know about Quality of Life to improve the way they support people with intellectual disability.

De Waele, I., van Loon, J., Van Hove, G., & Schalock, R. (2005). Quality of Life Versus Quality of Care: Implications for People and Programs. *Journal of Policy and Practice in Intellectual Disabilities*, 2(3/4), 229-239.

Reineck, C. (2002). Create a learning organization. *Nursing Management*, 33(10), 42-43.

Schalock, R., Verdugo, M., Bonham, G., Fantova, F., & Van Loon, J. (2008). Enhancing personal outcomes: Organizational strategies, guidelines and examples. *Journal of Policy and Practice in Intellectual Disabilities*, 5(4), 276-285.

For people interested in learning more about Participatory Action Research.

Kemmis, S., & McTaggart, R. (2003). Participatory Action Research. In N. Denzin & Y. Lincoln (Eds.), *Strategies of Qualitative Inquiry* (second ed.). Thousand Oaks: Sage Publications.

White, G., Suchowierska, M., & Campbell, M. (2004). Developing and Systematically Implementing Participatory Action Research. *Arch Phys Med Rehabil*, 85, S3-S12.

The Donald Beasley Institute Library has copies of all of this research. Krissy Wright, the Donald Beasley Institute Information Officer can help you if you would like any copies.

Mail address: 44 Dundas Street, PO Box 6169, Dunedin 9059.

Web address: www.donaldbeasley.org.nz

E-mail address: kwright@donaldbeasley.org.nz

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Appendix One

Study Information

Study Information

The Great Life Project

You are invited to take part in a project to develop a questionnaire for people with intellectual disability. The IHC Self-advocacy Advisory Committee and researchers from the Donald Beasley Institute are carrying out the project. The Donald Beasley Institute is based in Dunedin and does research in the area of disability.

The following information will help you to decide if you want to take part in this project.

What is this project about?

IDEA Services want to be sure that they are meeting the needs of people with intellectual disability. One way to know whether they are meeting their needs is to ask people about their life. This project is about choosing the questions to ask. To help people who use IDEA Service have more say in their life, we would like it if the questions could be asked by other people who also use IDEA Services.

Through this project we will:

- ❖ Develop a set of questions that are meaningful for adults with intellectual disability.
- ❖ Teach self-advocates from the IHC advisory group how to ask the questions.

Who can be included in the project?

Adults with an intellectual disability who use IDEA Services can take part in the project.

- ❖ You must be older than 18 years.
- ❖ You must be able to take part in a group discussion.
- ❖ You will need to be able to come to the group discussion.

What will taking part in the project involve?

If you take part in the project we would like you to come to two discussion groups.

- ❖ At the first discussion group we will ask you to tell us what makes life good for you.
- ❖ At the second discussion group we will ask you about the questions that we wrote after the first discussion group meetings. We will also ask you to tell us how it felt when a member of the self-advocacy advisory group asked you the questions.

Between the two discussion group meetings, we will ask you to come to a place where a self-advocate will ask you the questions.

How much time will be involved in taking part?

Each discussion group will take about two hours. It will take one hour for the person to ask you the questions on the quality of life questionnaire.

IDEA Services will help you to get to the meetings. At the start of the first discussion group we will tell you more about the project. You can ask us any questions that you have. If you decide not to stay for the rest of the meeting there will be a support person available.

Will the information I give you be kept private?

We will be careful to keep your information private. We will ask people in the discussion group not to talk about what other people said at the meeting. We will also ask the self-advocates to keep the answers to the questions private.

The information collected during the project will be kept at the Donald Beasley Institute. It will be locked away.

What happens if I don't want to be involved in the project?

It is your choice whether or not you take part in the project. You don't need to do anything if you don't want to take part.

IDEA Services will continue to support you whether or not you decide to take part in the project.

What happens if I would like to know more about the project?

If you would like to take part in the project please fill out the **colored** Participant Interest Form and post it to Jenny Conder at the Donald Beasley Institute using the Freepost envelope provided.

This study has been approved by the National Ethics Committee.

If you would like to know more about your rights as a participant in this study you may want to contact the Health and Disability Consumer Advocate: 0800 555 050

If you have any questions call Jenny Conder or Paul Milner at the Donald Beasley Institute.

Jenny Conder or Paul Milner

Donald Beasley Institute

PO Box 6189

DUNEDIN

Telephone 0800 878839

Fax 03 4792162

Email: jconder@donaldbeasley.org.nz or
pmilner@donaldbeasley.org.nz

Appendix Two

Participant Consent Form

The Great Life Project

Participant Consent Form

Read this form carefully. If you agree with the statements (what it says) sign the form at the end. The researchers will collect the form at the group meeting.

I understand the information I have been given about this project.

My questions have been answered.

I am happy to take part in the project.

I know that I will go to 2 group meetings.

I know that I will be asked questions by a self-advocate.

I know that I can stop taking part at any time.

I know that my support will not be affected.

I know that what I talk about will be kept private.

I know that I can contact Jenny Conder or Paul Milner at the Donald Beasley Institute if I have any questions about the study and that I can ask questions at any time. The toll free number is 0800878839

Please complete the following section.

I _____(full name)

want to take part in this project to develop a questionnaire for people with intellectual disability.

Date: _____

Signature: _____

This section will be completed by the researcher prior to the first focus group.

Full Name of Researcher: _____

Contact Phone Number: (03) 4798080 or 0800 878839

Project Explained By: _____

Project Role: _____

Signature: _____

Date: _____

Appendix Three

Great Life Questionnaire

(version 2)