

Participating in the Great Life Project (GLP)



GLP Team

IHC Team

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The Donald Beasley Institute



The Self Advocacy Advisory Committee



The support role



Objectives

- To have available a tool that focused on the individual's quality of life.
- To develop a quality of life tool in collaboration with people with intellectual disability.

Methodology / method

Participatory action research

- Common features of participatory research include:
 - Meaningful consumer involvement
 - Power sharing between researchers and participants
 - Mutual respect for each team members expertise
 - Bi-directional education of researchers and participants
 - Conversion of results into policy and action
(White, Suchowierska & Campbell, 2004)

Methodology / method cont.

Action component:

- Implies that change will result
- Represented as a 'problem solving' spiral
- Includes reflection throughout
- Likely to see "spin offs" as a result of reflection
- Can mean that it is never as tidy as it may appear on the original plan



Action cycle



Beginnings of working together

- The DBI researchers met the SAAC (co-researchers) prior to starting the project.
- At this first meeting decisions were made about:
 - The roles of the DBI researchers and the self-advocacy group members.
 - The name of the GLP.
 - The processes for recruitment and support of IDEA service users to enable them to participate.



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Questions about the Newsletter?

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The Great Life Project: The Great Update!

The Great Life Project: A research partnership between the Self Advocacy Advisory Committee and the Donald Beasley Institute.

Issue Three

28th August 2008

on your great work as co-researchers in the first Focus Group meetings!

News in brief

- The first Focus Group Meetings have run in Dunedin, Christchurch and Auckland.
- Paul and Danny will now start looking at the answers from the meetings.
- The whole team will meet in Wellington to talk about the next stage of the project.



Dianne and Linda working with Paul and Jenny in Dunedin.

Step 1: First focus group

- Focus groups were held in three centers.
- They were led by two self-advocates and two DBI researchers.
- There were two parts to the focus group:
 - In part one people were asked for their ideas about their quality of life.
 - In part two we put the ideas into the eight domains of quality of life.

To create questions for the questionnaire, we asked the participants the following:

1. When you think about your life now, what makes it 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?

Step 3 – Drafting the questionnaire



The Beastlie Awards!



Step 4 – Testing the questionnaire



Testing the testers

- For Paul and Jenny there was a desire to intervene and explore responses – multiple roles causing conflict
- For Stuart and other SAAC members some participant's answers worried them and it was important to have time to debrief at the end of the day
- For Julia and Judy there was the need to remove themselves, so as not to influence people's answers but they also needed to be available and provide support to both SAAC members and participants

Step 6 – The Second Focus Group



Step 6 – The Second Focus Group

Ask the participants thoughts about:

- Taking part in the project
- Having a self advocate administer the questionnaire
- How to improve the questionnaire

Step 7 – Revision of the Questionnaire

- Reflecting on the research results, both from the analysis of the questionnaire and the observations recorded during administration, the DBI researchers submitted revised questions and a new layout for the SAAC team to consider.

Changes to Great Life Questions

Q	Suggested changes	The old questions
5	I feel that there are people in my life who love me.	There are people in my life that enjoy being with me
23	Can you get to see the doctor when you want?	Do you have the things you need to stay well?

Step 8 – Presentation of the Project



In Summary...

- We have all enjoyed taking part in the GLP
- There have been challenges which have contributed to our learning
- A strong support system is crucial to the success of each step



In Summary...

Stay true to the principles of participatory methods including:

- Power sharing between researchers and participants
- Mutual respect for each team member's expertise
- Bi-directional education of researchers and participants

