



Using Focus Groups to Identify the Facets for a Comprehensive Assessment of Quality of Life (The DIS-QOL Project)

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AIM

- To report information about what people with intellectual disabilities (ID), caregivers and professionals believe are important to quality of life (QoL) for people with ID. This is part of DIS-QOL project financed by the EC.



DIS-QOL Project

(2005-2008)



Edinburgh, Scotland, UK



WHO, Geneva



Barcelona, Spain



Paris, France



Prague, Czech Republic



Tromsø, Norway



Izmir, Turkey



Vilnius, Lithuania



Sicily, Italy



Hamburg, Germany



Tilburg, Netherlands



Budapest, Hungary

China; Brazil; India*; Uruguay**

New Zealand; Australia**



Work Packages (WP):

WP1. Review of Literature

WP2. Taxonomy of Care

WP3. Focus Groups

WP4. Development of Pilot Modules

WP5. Pilot Data Collection

WP6. Pilot Data Analysis

WP7. Development of Field Trial
Modules

WP8. Field Trial of Measures

WP9. Dissemination/ Implementation

F.G. Methods

Participants

Fundació Catalana Síndrome de Down

Number of participants was 6 to 7

All FG lasted about two hours.

All FG were audio-taped.

All participants signed the consent form.

Ethical approval CEEAH – UAB.

F. G. Purpose

- To identify dimensions and items of QOL:
 - People with ID
 - Caregivers
 - Professionals
- Evaluate the WHOQOL-BREF
- Suggest additional items

F.G. Structure

Part 1 *(50 minutes)*

1. Introduction
Collection of Consent Forms.
2. QOL. Free Discussion

Part 2 *(60 minutes)*

4. Review of *WHOQOL* Facets
5. Review of New Facets
6. Suggestions for Items
7. Suggestions Wording Scales
8. Summary of Discussion
9. Collection of sociodemographics

A FG is a type of “group interview”, to gather people's ideas about an issue. The aim of the FG is to help us to identify issues that are relevant to the QoL for people with disabilities. In FG there are not right or wrong answers: we are interested in all points of view

Sociodemographic information

ALL Groups

- ✓ Gender
- ✓ Age, DOB
- ✓ Marital status
- ✓ N^o of children
- ✓ Home location
- ✓ Education
- ✓ Occupation/
daytime activity

Adults with ID

- ✓ Current living
circumstances/
Support required
- ✓ Health status
- ✓ Disability status
- ✓ Preferred terminology
- ✓ Use of medicines/
medical treatments

Professionals

- ✓ Profession
- ✓ Experience with ID
- ✓ Work setting
- ✓ View of QOL & Use
- ✓ Issues raised by
patients

WHOQOL-BREF

Physical	Pain and Discomfort; Energy and Fatigue; Sleep and Rest; Mobility; ADL; Dependence on Medication; Working capacity.
Psychological	Positive Feelings; Thinking, Learning, Memory; Concentration; Self-esteem; Bodily Image and Appearance; Negative Feelings; Spirituality, Religion, Personal Beliefs.
Social Relationships	Personal Relationships; Social Support; Sexual Activity.
Environment	Physical Safety; Home Environment; Financial Resources; Health & Social Care; Opportunities for new information; Participation & Opportunities Leisure; Environment; Transport

WHOQOL-DIS: Additional Dimensions & Facets

Dimensions	<i>Facets</i>
Devaluation Discrimination Social Equity Empowerment Freedom Personal Adjustment Communication Social Acceptance Social Inclusion Future Perspective	Ridicule Stigmatization Discrimination, Victimization Enabling, Advocacy Empowerment, Control Autonomy, Choice Personal adaptations, Self acceptance Communication ability, comm. support Social Acceptance, Respect Social network and interaction, Social integration and contribution Future prospects, Personal potential



RESULTS

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Cape Town, SA 2008

Focus Groups – Sociodemographics

Sociodemographics	Adults ID n= 6	Careers n=6	Professionals n= 7
Age (mean)	28	65.6	40.1
Gender – female %	83.3	60	57.1
Marital status - single %	100	83.3*	57
Education			
Primary school & Secondary	33.3	80	
Special school	66.6		
University degree		17	100
Living Circumstances & Support			
Own home-no support required	33.3		
Own home supported by family	33.3		
Own home supported by carers	16.6		
Community care house (support staff)	16.6		
Occupation - Paid employment %	100	33	100

*married

Focus Groups

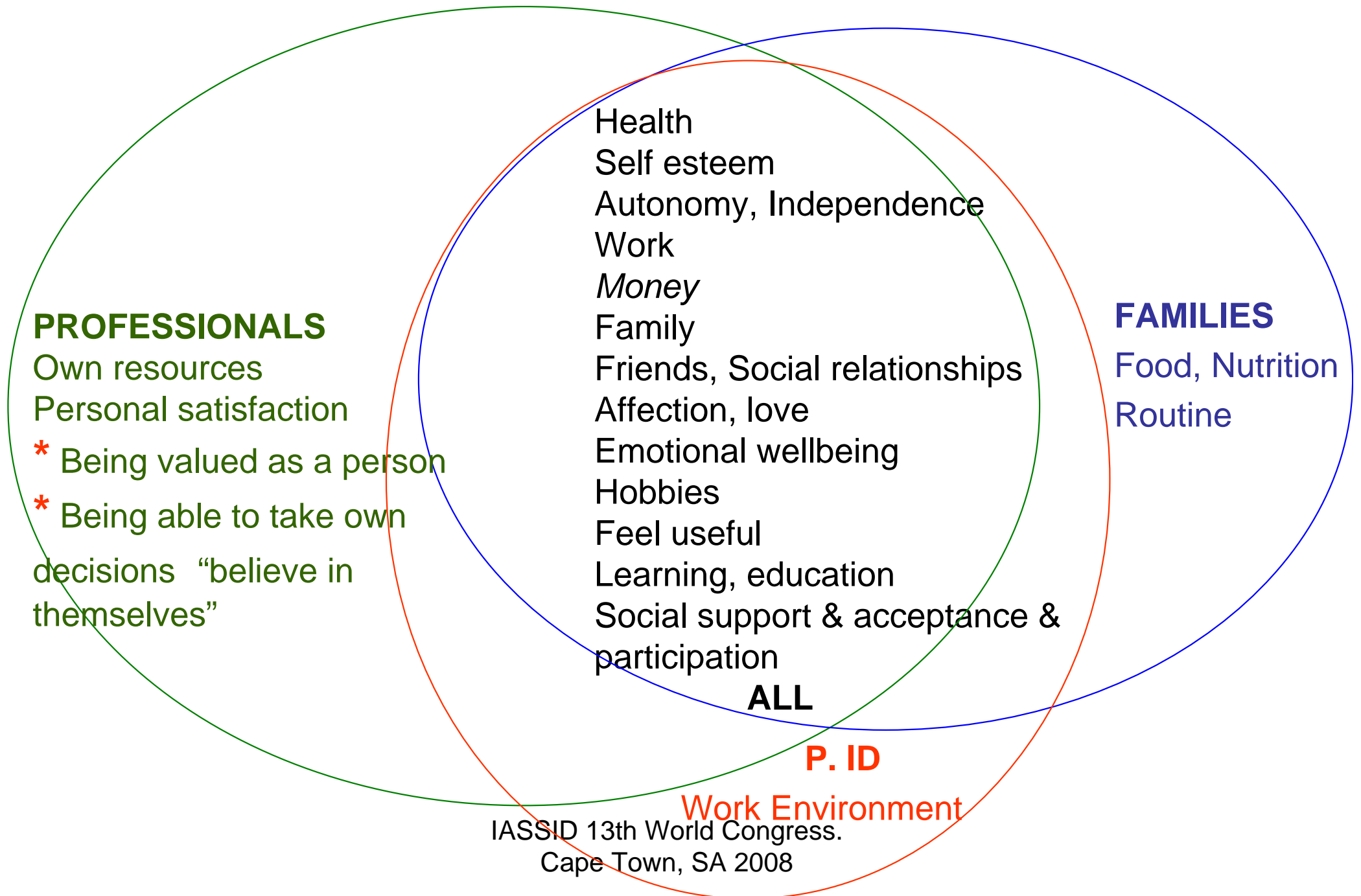
Participants *ID*: Health & Disability Status

Professionals: Work setting & Use

	%
Health - <i>healthy</i>	66.6
Type of disability	
- Mild	16.6
- Moderate	50.0
- Severe -Profound	0.0
Affect ADL: Yes	33.3
Medication use: Yes	33.3

	%
Work setting (%)	
Primary care	28
Domiciliary support service	44
Hospital	-
Other	28
Use QoL Assessments %	-

What do you think are the most important aspects of Quality of Life?



What issues in relation to Quality of Life do your clients discuss with you most frequently?

- financial situation
- independence
- autonomy
- personal and social relations
- freedom
- being able to made decision
- emotional wellbeing
- ability to reach goals

Some comments ...

ID Participants	Caregivers	Professionals
<p data-bbox="342 296 595 336">Self-Esteem</p> <p data-bbox="107 363 725 576">I am very happy and proud of myself, also I am proud of my roommates ... we share all activities in the house</p> <p data-bbox="230 603 696 643">Work & Independence</p> <p data-bbox="107 670 815 938">I have been working for 7 years, I work 8.5 hours/day, and I realize that I am independent now. But, if I had to look for another job now it will be very difficult</p> <p data-bbox="342 965 584 1005">Acceptance</p> <p data-bbox="107 1032 815 1193">I have found people that help me, I feel valued for what I am regardless of my disability</p>	<p data-bbox="1048 213 1285 260">Caregivers</p> <p data-bbox="1021 296 1317 336">Social support</p> <p data-bbox="869 363 1469 464">Not everybody have enough support from the government</p> <p data-bbox="1048 491 1294 531">Health Care</p> <p data-bbox="869 558 1469 770">Primary Care Physicians should know more about specific health conditions that people with Down Sd have ...</p> <p data-bbox="1081 798 1256 837">Nutrition</p> <p data-bbox="869 865 1469 1026">Because of the specific physical problems they have, it is important what they eat</p> <p data-bbox="1149 1053 1189 1077">...</p>	<p data-bbox="1675 213 1962 260">Professionals</p> <p data-bbox="1653 296 2007 397">Social Support & Awareness</p> <p data-bbox="1541 424 2119 692">People have to realize that persons with ID need to be integrated in society, and that there still many aspects that need to be changed</p> <p data-bbox="1597 719 2045 820">Self-Esteem, positive feelings</p> <p data-bbox="1541 847 2119 1002">When they see that they can do things as other people do, they feel really good</p>

Summary



- Overall, participants in all FG mentioned all WHOQOL-BREF areas and nearly all facets; as well as the new facets proposed for the specific module (Social Inclusion, Empowerment, ...)
 - Facets not mentioned spontaneously: sexual activity, SRPB
- Some specific topics: Routine, prevention, nutrition, food
- We found some different emphasis in some facets between the three groups
- QoL need to be emphasized in persons with Intellectual Disabilities!

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Conclusion

Information collected has allowed the construction of a Supplementary Module to the WHOQOL-BREF that currently is being used in a large cross-cultural field trial.

Further information will be presented.

Our special gratitude to ALL people who participated in the study

Thank you very much

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