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# Using focus groups to develop cross-cultural measures for people with disabilities

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# AIM

## *Develop 3 Cross Cultural Measures*

- 1) Accommodation and Care Fit Index *ACFI*
- 2) Disabilities WHOQOL *WHOQOL-DIS*
- 3) Attitudes to Disabilities Scale *ADS*

### *3 parallel versions*

Direct use with disabled persons *ADS-D*

Indirect use with proxy carers/family *ADS-P*

Direct use with the general population *ADS-G*



# 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\**
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## 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

# Focus Groups (F.G.)

- To identify dimensions and items of QOC, QOL and attitudes from the perspective of:
  - People with PD and ID
  - Caregivers
  - Professionals
- Evaluate the WHOQOL-BREF
- Suggest additional items to be included in the disability module.

## *Information to participants*

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, QC and attitudes towards people with disabilities. In FG there are not *right* or *wrong* answers: we are interested in all points of view.

# F.G. Structure

## Part 1 (50 minutes)

1: Introduction Collection of Consent Forms.	5'
2: Quality of Care (QOC) Free Discussion.	15'
3: Quality of Life (QOL). Free Discussion.	15'
4: Attitudes to Disabilities. Free Discussion.	15'
<i>Break and refreshments</i>	<i>10'</i>

## Part 2 (60 minutes)

5: Topic Guide-Review of <i>WHOQOL</i> Facets.	15'
6. Review of New Facets	10'
7: Suggestions for Items	15'
8: Suggestions for Wording / Response Scales	10'
9: Summary of Discussion	5'
10: Collection of socio- demographic Information	5'

## F.G. Socio-demographic Information

### ALL Groups

- ✓ Gender
- ✓ Age
- ✓ Date of Birth
- ✓ Marital status
- ✓ N° of children/  
grandchildren
- ✓ Home location
- ✓ Education
- ✓ Occupation/  
daytime activity

### Adults with disabilities

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

### Professionals

- ✓ Profession
- ✓ Experience with ID & PD
- ✓ Work setting
- ✓ View of QOC & Use
- ✓ QOC issues raised by patients
- ✓ View of QOL & Use
- ✓ QOL issues raised by patients
- ✓ View of Attitudes to Disabilities
- ✓ Use of Attitudes to  
Disabilities Scales
- ✓ Issues raised by patients

# Focus Groups Conducted

	Centre	Intellectual Disabilities	Mixed Physical Disabilities	Specific Physical Disabilities				Professionals	Relatives & Carers	Totals
				Parkinson's Disease	Hearing Impairments	Visual Impairments	Multiple Sclerosis			
1	Edinburgh	2		1	1			1	2	7
2	WHO									
3	Barcelona	1		1			1	3	3	9
4	Paris	1	1			1		1	1	5
5	Prague		1	1				1	1	4
6	Tromso			2					2	4
8	Izmir	1	1		1			1	1	5
9	Vilnius	1	1	1				1	1	5
10	Sicily	1	1	1				1	1	5
12	Hamburg	1	1			1		1	1	5
13	Tilburg	1	1	1				2	2	7
14	Guangzhou	1	1	1	1	1		1	1	7
15	Porto Alegre	1	1			1		1	1	5
16	Bangalore									
17	Montevideo	1	1	1				1	1	5
18	Auckland	1	1	1				1	1	5
19	Melbourne									
20	Budapest									
		13	11	11	3	4	1	16	19	78

# Results of F.G.

## Gender of Participants

	Male	Female	Total
Disability G.	92	92	184
Professionals	26	60	86
Relatives	29	61	90
Total	147	213	360

## Disability Type

	n	%
Intellectual Disabilities	56	30
Mixed Physical Dis.	45	25
Parkinson's Disease	49	27
Hearing Impairment	12	7
Visual Impairment	17	9
Multiple Sclerosis	5	3
Total	184	100

# Quality of Care

## General aspects

Patient / Client-based; Care (continuity, regularity, personnel, sensitivity; empathy); Rehabilitation; Knowledge and skills of professionals; Information; Bureaucracy; Finances; Access

## Disability-specific aspects (PD)

Patient-based, attention for partner

Multidisciplinary approach

Medical aids (equity, timing, S.E.)

To have a focal point / confidant

Home : adapted to disabilities

Practical advices

Transport

## Disability-specific aspects (ID)

Enough personnel

Continuity of Care

Autonomy

Environment

Daily care activities

Participation in the community

# Quality of Life

## General aspects

Family, Friends; Home; Environment; Leisure & Vacation;  
Finances, Mobility, Transport, Future prospects, Autonomy; Positive  
Feelings; Self-Esteem; Home Environment; Access to Health &  
Social services; Social acceptance

## Disability-specific aspects (PD)

Relationship with partner  
Negative feelings / hallucinations  
Fluctuations in functioning  
Side effects of medication  
Cognitive deterioration  
Apathy  
Barriers

## Disability-specific aspects (ID)

Eating  
Autonomy, Safety  
Leisure time  
Courses  
Religion  
Relationships with others  
Being able to live with persons  
who you like

# Attitudes to Disabilities

## General aspects

Persons are different → different attitudes: Positive attitudes: empathy, being helpful & Negative attitudes. Professionals / Family can also have negative attitudes. Underestimation. Discrimination.

## Disability-specific aspects (PD)

Impatience of others

Disability fluctuates and/or is not always visible → misunderstandings by others.

Stigmatisation

Discrimination

## Disability-specific aspects (ID)

Teasing

Calling names

Keeping distance

Ridicule

Discrimination

Protection

## F.G.: themes generated

Quality of care themes	618
Quality of life themes	709
Attitudes to disability themes	447

Development Process

Themes > Card Sort Task > Thematic Card

Clusters > Draft Facets > Draft items > Cross

Checked Original Themes

## Top Five Themes - Thematic Card Clusters

Quality of Care	Quality of Life	Attitudes
Ability of health Professionals	Social Acceptance and Inclusion	Lack of understanding of disability
Access to (non)medical services	Participation in/ opportunities for recreation	Compassion / helpful
Environmental support	Personal relationships	Exclusion / avoidance
Continuity of Care	Health&Social Care	Discrimination
Communication & Relationships	Home environment	Underestimation of ability

# Overview of Pilot Modules

Measure		General items	Specific facets	Total items	Items per measure
Quality of Care		0	14	44	44
Quality of Life	Base measure BREF	2	24	26	
	Supplementary module	1	19	20	46
Attitudes		0	18	38	38

## CONCLUSIONS

FG allows to discuss topics, which are important for the participants → generation of items /response scales

QoL - WHOQOL-BREF facets were confirmed & Additional disability-specific themes were identified

FG are useful for developing cross cultural measures in the field of disabilities.

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Thanks - To all participants: patients, families, professionals

## Collaborating Centers – Barcelona

*Day Hospital. Multiple Sclerosis Foundation*

*Parkinson Unit, Neurology. Sant Pau Hospital*

*Catalan Down Syndrome Foundation*

Thank you very much for your attention

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