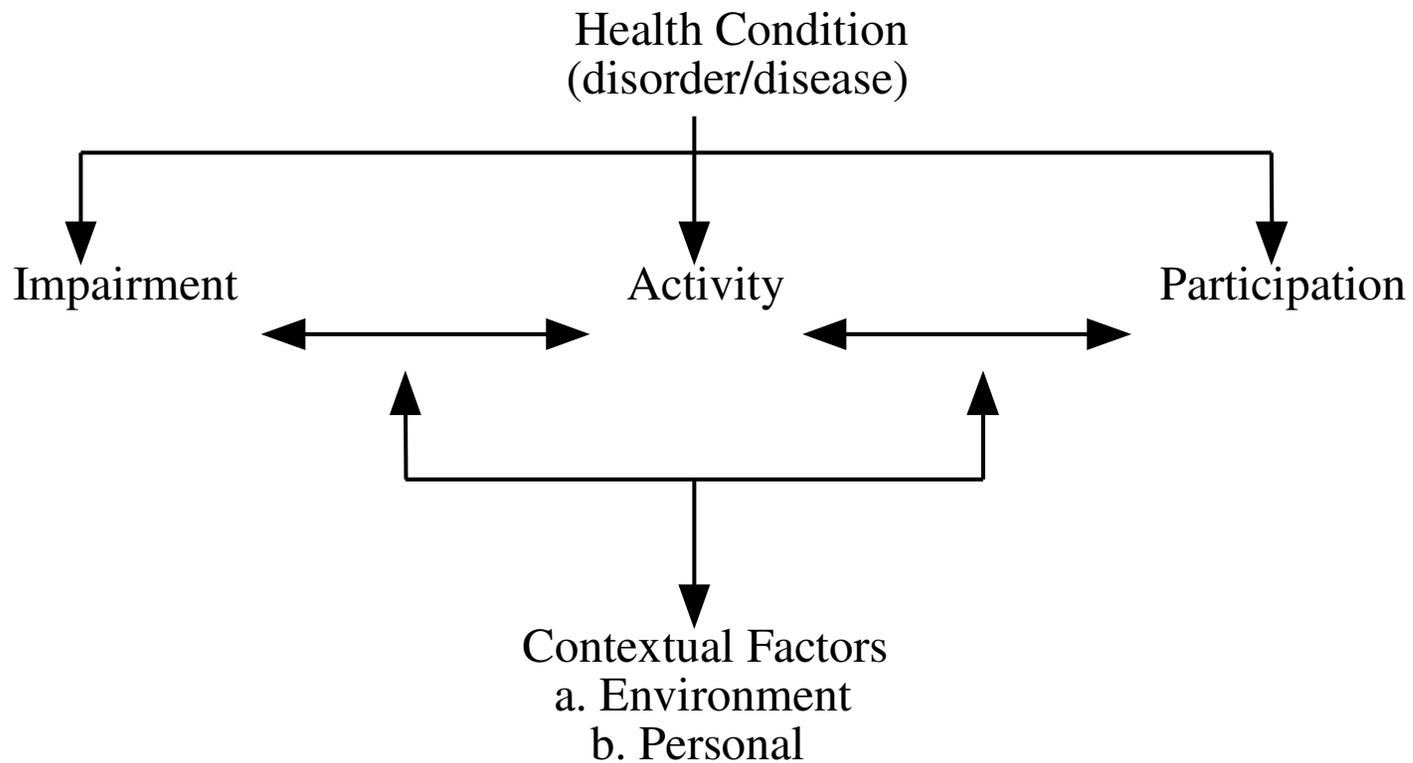# Ageing & Developmental Disability - Breakout

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Figure The model of the ICIDH-2

**International Classification of Impairment, Disability and Handicap:
World Health Organisation**

Define Ageing

- What is ageing?

- When are we aged?

- What are the features of ageing?

- Are there differences in the ageing process between those with and those without ID/DD?

AGEING - THE PROCESS AND THE CHALLENGE.

Two types of People -Two Issues:

➢Those who are aged now
➢Those who are younger

Ageing and disability represent a final life frontier. Decisions will at times need to be made without other scientific evidence.

Scientific information should be used in design, development and application of programmes. Quantitative and Qualitative Observational and Experimental

Physical health interventions have outstripped social and
psychological developments so it is critical that there are recognised ethical and professional responsibilities of governments, services and organisations to ensure these integrated (holistic) components support one another.

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Memorandum on a European Quality Principles Framework EQPF

Improving the quality of services to improve the quality of lives of people with disabilities and their families

Conclusion

- EASPD wants to promote a **EUROPEAN QUALITY PRINCIPLES FRAMEWORK (EQPF)** as the basis for service delivery in Europe. The EQPF should be supported by local quality standards which reflect these principles and practices.

  The European Quality Principles Framework should also be based on the direct link between quality of lives and quality of services.

  Only high quality services can contribute to high quality of lives. For that reason, the three different quality indicators - subjective, objective *and* organizational - must be

  implemented and applied.

EASPD Continued.

Furthermore, the EQPF needs to be active and developmental instead of rigid and permanent. We want to stress that this Memorandum does not endorse or recommend any specific quality accreditation system.

The focus is on quality principles serving as a guideline in service provision all over Europe and not on quality standards.

Finally, developing a European Quality Principles Framework requires a fundamental understanding of the concept of Quality of Life and taking into consideration key values such as dignity, equal opportunities, independent living, full participation in and contribution to society.

High quality services should be built on these values.

EASPD Continued

- **EASPD believes that a robust European Quality Principles Framework must be based on a**

- **combination of all these indicators. All indicators must reflect evidence based best practice.**

- **Setting of targets and the measurement of change**

- A valid model of service quality must not be based on static or minimum standards.

- Quality is a journey, not a fixed abode. Therefore, such a model must be dynamic and developmental.

- A valid model of service quality must enable organizations to pinpoint what needs to be improved.

- Furthermore, it must provide organizations with guidance on how to achieve improvement.

- The model must be able to demonstrate whether such improvement has been achieved or not.

What does the quality of life approach mean?

a) For the individual.

b) For the family.

c) For the community

d) For services.

e) For policy.

PLEASE NOTE DOWN YOUR VIEWS

If we use a quality of life approach:

- ❖ How do we define quality?
- ❖ What are we prepared to do socially and psychologically
- ❖ How will we sensitize our services
- ❖ What are we prepared to do economically?
- ❖ How can we help to shape policy

These are some of the questions we shall discuss.

FIGURE
QUALITY OF LIFE - THEMES AND CONCEPTS

QUALITY OF LIFE

Sensitizing concept relevant to individual perceived needs
Definitions Various
SPECIFIC QUALITY OF LIFE CONCEPTS
Intervention
Research
Measurement
Professional Practice / Education and Policy Ethical Issues
Programme Evaluation and Quality Assurance

QUALITY OF LIFE

Sensitizing concept relevant to individual perceived needs
Policy making, health-education, social promotion, advocacy etc.

e.g. Taylor 1994

Sensitizing concept relevant to individual perceived needs

- How would you go about discovering an individual's perceived need?

- What are the advantages of each method?

Quality of Life

Some key descriptors of quality of life

- Relates to the objective and subjective experiences of well-being
- Satisfaction of the individual
- Individual well-being
- Opportunity and choices
- A multidimensional concept involving well-being across life domains

Quality of Life Cont.

- **Experienced when a person's basic needs are met**

- **Opportunity to pursue and achieve goals in major life settings**

- **Discrepancy between a person's desires and unmet needs**

- **The degree to which an individual enjoys important possibilities in their life**

See, for example, Brown et al. (1989), Renwick, Brown, & Nagler (1996), Goode (1994), Felce & Perry (1997), Cummins (1997)

Opportunity to pursue and achieve goals in major life settings

For ageing person what are some of the likely opportunity to pursue and achieve goals?

Give some major examples and explore how meet these goals

Quality of Life

Some key descriptors of quality of life

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SPECIFIC QUALITY OF LIFE CONCEPTS

Domains of well being

Holism

Lifespan

Choices

Personal Control

Perception

Self Image

Empowerment

Inter & Intra Personal Variability

Values

e.g. Felce & Perry, Raphael, 1996, Nuefeldt & McGinley 1997, Warren 1997.

Domains must take into account

Social Indicators

Objective and Perceptual Factors

Relating to

Levels of Housing, Employment

Access, Barriers, Rights (Including right to living and dying)

Etc.

Schalock RL, 2006
The Interrogatories of Quality of Life Measurement

Interrogatory   Key Factors

What to measure: Quality of life domains

Quality of life indicators

Quality outcomes   (i.e.valued personal

experiences

circumstances that:
(a) follow as a result or consequence of

some activity,

intervention, or service; and

(b) are measured on the basis of quality

Schalock RL, 2006
The Interrogatories of Quality of Life Measurement (Cont'd)

How to measure: Subjective appraisal (e.g. satisfaction; importance)
Objective assessment (e.g. objective indicators of personal experience and circumstances; traditional social indicators)

Who should be involved: Individual with ID
Persons who know the individual well

Where to assess: Natural environment

When to assess: Depends on questions asked

Research method: Multivariate designs that focus on individual and environment predictors of quality outcomes preferred.
Methods that take into account the effects of individual choice.

*Correlation between subjective and objective indicators is generally low (Cummins, 1996; Perry & Felce, 2005)

Measurement QOL (Instruments)

The Resident Satisfaction Inventory (Burnett, 1989)

Rehabilitation Questionnaire. A Personal Guide to the Individual's Quality of Life (Brown & Bayer 1992)

The Comprehensive Quality of Life Scale (Cummins, 1993)

Quality of Life Questionnaire (Schalock & Keith, 1993)

The Quality of Life Instrument (Brown, Raphael & Renwick, 1997)

Table Family Quality of Life Domains

Family-Centred Well-being
Park et al (2003); Poston et al. (2003); Summers et al. (205)
     Family interaction   Parenting   Emotional
well-being   Physical/material   Disability related supports
Brown, I., et al (2006) www.surreyplace.on.ca
         Health of the family
         Financial well-being
         Family relationships
         Support from other people
         Support from disability related services
         Influence of values
         Careers and preparing for careers
         Leisure and recreation
         Community interaction

INTERVENTION/SUPPORT

Intervention in relation to concept of Quality of Life

Eg. Renwick, Brown I. & Nagler, 1996; Halpern, 1994

Brown, Bayer & MacFarlane, 1989

Service array. Values and Approaches
Individualization of Services
Time, Duration and Intensity
Control of Service
Who, When and how of Intervention

eg. Parmenter, 1988, 1997; Brown, R. 1996

Exclusion & Inclusion

CAN BE:-

PHYSICAL

SOCIAL

PSYCHOLOGICAL

EDUCATIONAL

Exclusion & Inclusion can be:-

1. Short or long term
2. Individual or Group
   (e.g. Gender or Intercultural)
3. Inter Generational
4. Institutional
5. Within the Community
6. Within the Home

It has rules and values which are exclusive & hierarchical

See Brown & Brown (2003)

INCLUSION REQUIRES:

- Conscious awareness and insight

- Personal choices and individual control

- Inter-relatedness   (i.e. Personal expression across life domains rather than program or policy domains)

- Lifespan in orientation

- Empowering, accessible and non-discriminating societies

- Non hierarchical

C2000 Roy brown

PROFESSIONAL / EDUCATION

Professional Practice

Values of Personnel

Training of Practitioners

Structure and Values of Service Delivery

Environment of Intervention/Support

Consumer choices re Intervention/Support

Activities of Intervention/Support

Ethical Issues

e.g. Renwick, Brown & Nagler, 1996
Brown, Bayer & Brown, 1992, Schalock, 1997.
Brown 1997, Goode 1994, Bach & Rioux, 1996

The professional behavior of all personnel is guided by a well thought out value system. What are your value systems
a) professionally and
b) personally?

Do these 2 systems differ in you?

Scenarios and questions

The following are a series of "Real Life" situations.

The issues are:

What would you do or recommend?
What would you need to take into account?
How might quality of life guidelines influence your decision making?

Professional and Personal

Views and Values

What are your views and values in relation to the following scenarios as a :

a) Private individual in relation to your family members?

b) Professional person in relation to those you support or care for?

Overall Concerns 1

Lack of adequate services

Particularly :
   Respite and in this context emergency respite

   Long waiting lists for services

   Concerns about personnel expertise and experience in providing services.

   Mental health services

   Facilities for ageing persons with disabilities

   Confusion about which services and how to access so many

Overall Concerns 2

Lack of support from relatives

Lack of help from friends and neighbours

Lack of support from religious communities
 to which individual families are affiliated

Challenges for siblings

Other Issues 1

Although the previous slides accented common occurrences there are many other issues often of lower frequency.

Family breakdown

This includes various aspects of service such as knowledge about services and getting information

Financial burdens associated with high cost of intervention or /and equipment

Life expectancy of relatives

Other Issues 2

A need to talk to a professional about family issues and concerns as well as disability

Experience suggests that most individuals (families) want to function effectively. They do not wish to be dependant "on the system"

They want to solve their own problems but need support for the family for key items and for stressful periods.

They wish to avert major stress and therefore services need be forward looking with forward planning.

Families as advisory

- In what ways would you involve parents and siblings?

A QUALITY OF LIFE PERSPECTIVE

SOME RECOMMENDATIONS RE AGEING AND DISABILITY (Examples only)
:
Personnel

How is this to be done?

Broadening the mandate, policy and coordination of Services

Changing professional education and experience at the front line delivery level

Recognition that "one size does not fit all"

Providing support for emerging and emergency family needs (personnel and funds)

Tap into social capital but ensure it has access to professional consultation

Recognise the wide range of variability amongst clients.

Similar conditions do not mean the same psychological or social behaviours are shown or that needs or requirements are identical.

Diseases and restrictions of ageing are interactive with a person's personal characteristics and environmental experience, causing an infinite range of responses.

Take into account that many support and care services are family based, others are jointly family and community agency based, and many are government funded.

Various professional considerations arise in these approaches....

- **Obtain subjective (perceptual) information as well as objective.**

- **Ensure collect qualitative as well as quantitative information.**

- **Listen to and observe the individual with disabilities who is ageing**

Note the individual's interest and choices and put these into action as far as possible

Gain supplementary information from the person they are closest to

Preserve the familiar wherever possible

Recognise that reminiscence can be a potent force in maintaining or promoting familiarity

Personnel

- Knowledge, experience, skills- What should these be?

- **Ensure personnel understand a quality of life approach and are sensitised to its various aspects**

- **Provide orientation that looks at an individual's professional values prior to hiring**

- **Provide orientation on professional and personal value differences so that personnel are fully aware of their approach. Integrated value systems are likely to produce more effective services.**

Diverse array of support and services are required.

Make certain these, and the value systems of the organisations, are clearly posted and <u>they do</u> represent the current status of the organisation.

Managers and personnel should be accountable for these values and approaches

◆ **Ensure frontline personnel are professionally educated with additional in-service and local opportunities for experience.**

(One of the concerns is that frontline personnel often do not know the geographical or social area in which they are working)

◆ **Ensure issues of human rights are understood from the client perspective.**

◆ **Ensure that adequate respite is available for nuclear family**

◆ **Provide supports within the home environment that enhance the nuclear family from the client's and family's perspectives.**

◆ **Ensure that frontline personnel have a common professional value system**

◆ **Ensure there is an adequate number of frontline staff that has shared likely life experiences of the clients/ consumers.**

◆ **Ensure there are adequate consultant opportunities to check on "unclear factors" relating to health, behaviour, and environment.**

- **Recognise that professional knowledge is not a substitute for personal experience of an individual but complementary**

- **Ensure personnel have opportunities for dealing with stress.**

- **Require managers and directors of services, including government services to visit (i.e. shadow) frontline personnel in action so they know what current life styles are like for frontline personnel.**

- Make certain that issues of agency insurance do not limit psychological, social and health maintenance or development

- Ensure that duty of care considers physical, social and psychological factors.

- Re-evaluate issues of risk

- Re-evaluate issues of control

Transition

- What are the major transitions in adult life?

- How should we prepare for and support people through these transitions?