

**Education and Quality of Life:
A Family Affair**

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&

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**QUALITY OF LIFE FOR OUR CHILDREN-
EDUCATION,
In HOME, at SCHOOL and within
COMMUNITY**

Roy I. Brown, PhD

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GUIDING PRINCIPLE:

All people with Down syndrome and their families are entitled to a life of quality.

Quality of life Life

Meaning for:-

The People with Down syndrome

The Family members

The School System

The School Principals

The Teachers and Support Personnel

Being

- Physical health
- Emotional health
- Spiritual health

Belonging

- Where you live
- People in your life
- Things around you

Becoming

- Practical activities
- Leisure activities
- Growth activities

QOL approach sequence:

Quality of life Concepts & Principles

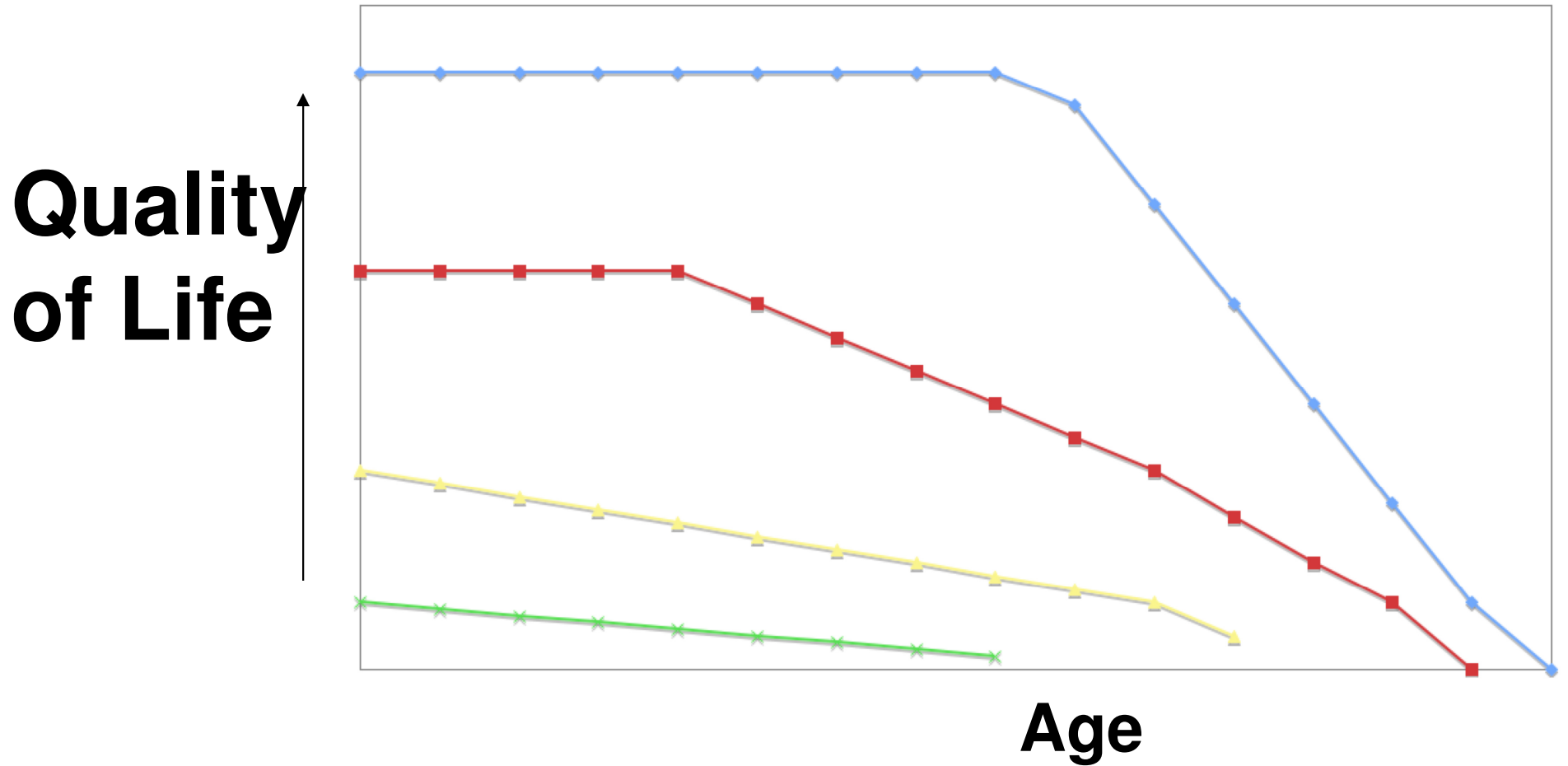
Quality of Life Measurement

Quality of life Application

Quality of Life Evaluation

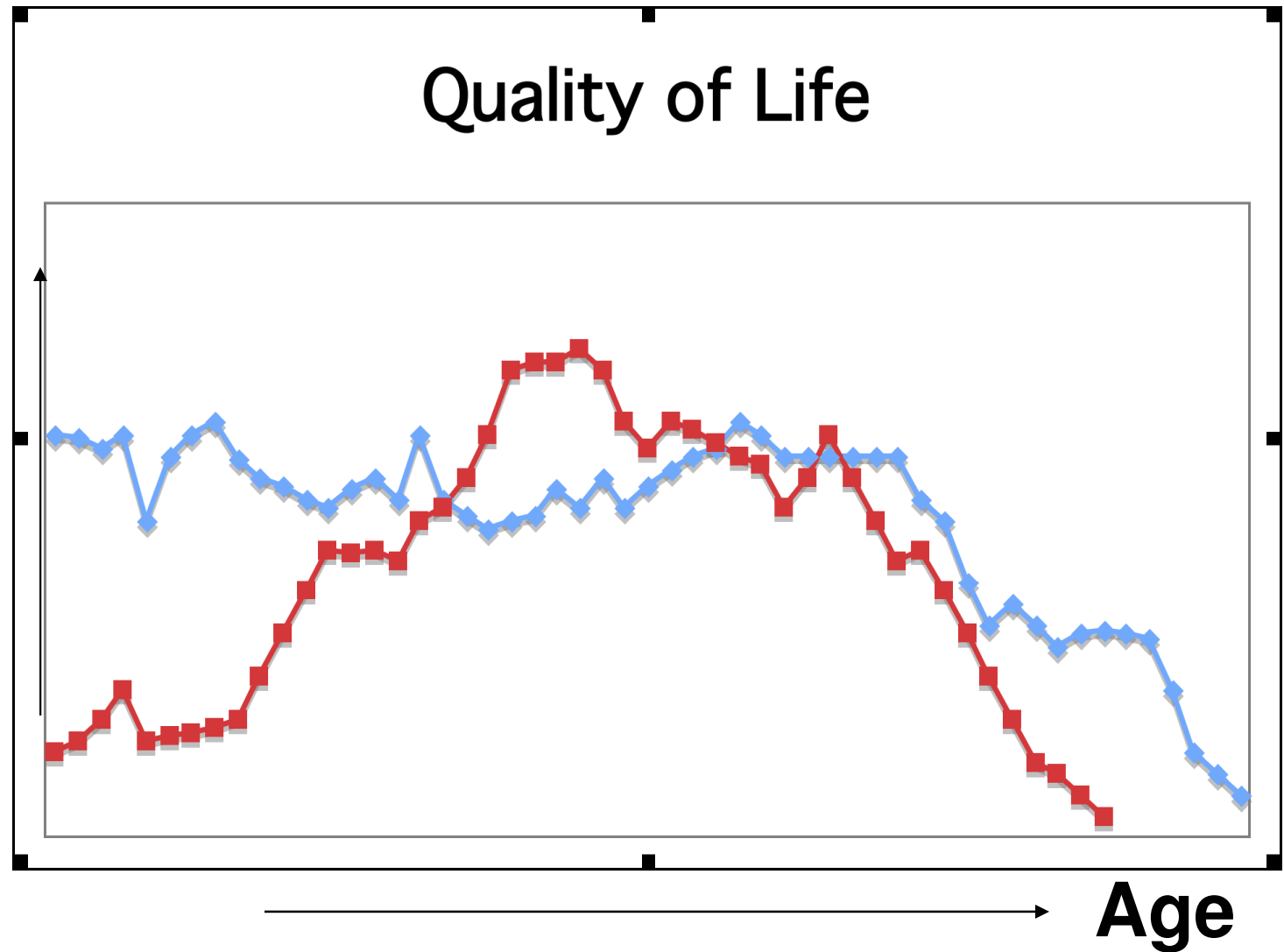
Quality of Life Standards

QUALITY OF LIFE



QUALITY OF LIFE - PROGRESS & VARIABILITY

**Quality
of Life**



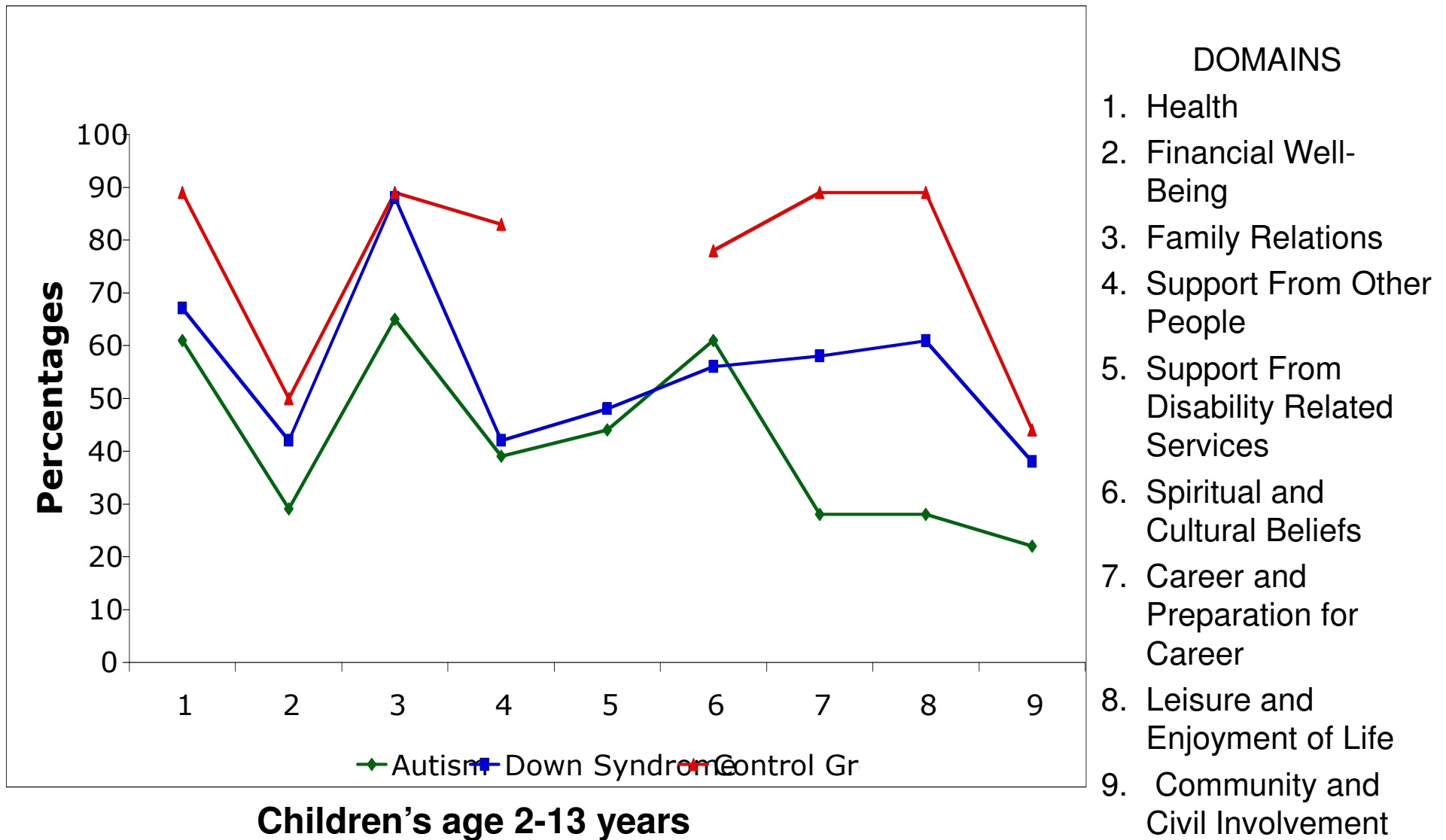
Question- Where does
Education take place?

Answer- Everywhere!

But let us start with Family

CANADA

(Line) Percentage of respondents satisfied or very satisfied with Family Quality of Life or each domain (Autism, Down Syndrome and Non-disability Group) (Adapted with permission from editor JPPID (see references))



**A quality of life Model and platform
Google- Roy Brown & Rhonda Faragher Nova
Science**

**Quality of Life and Intellectual Disability:
Knowledge Application to other Social and
Educational Challenges**

Editors: Roy I. Brown (University of Calgary,
Calgary, AB, Canada) and Rhonda M. Faragher
(Australian Catholic University, Dickson,
Australia), New York Nova Publishers

We will look at some principles and concepts for everyone and
everywhere

Quality of Life

General principles (1)

Dignity of disability Ensuring that people with disabilities are valued persons in their own right in all the environments in which the individuals live.

Ethically based policy and practice Policy and practice based on values relating to society but enriched by research knowledge and in the person's best interest as expressed by the individual or their chosen representative.

(See Brown, Roy, I., Cobigo, V & Taylor, W.D. (2015). Quality of life social inclusion across the lifespan: challenges and recommendations. Special Issue. 'Community care: past, present and future'. International Journal of Developmental Disabilities.)

Personal and professional values It is critical that professionals consider and take into account their personal and professional values in delivering services particularly when providing services in multiracial and diverse communities.

Duty of care, risk, and safety Risk is part of learning, but sensible support with boundaries provided as necessary for any particular individual.

Normalization Providing normal life experiences in normal or common environments.

Exclusion/Inclusion All aspects of life have opportunities for including or excluding an individual: optimize inclusion.

Specific aspects of development and learning (2)

The individual

Resilience The ability of an individual, due to an interaction of genetics and environment, to deal effectively with challenging situations.

Perception Perception is a major driver of behaviour and either assists or limits development.

Self-image Can be positive or negative with effects on cognitive, social, and emotional development.

Empowerment Providing environments and opportunities for the individual to assert their rights and choices in decision-making, thus empowering themselves.

Personal control Enhances self-image, therefore confidence and knowledge including experience.

Intra- and inter-personal variability Intra-variability acknowledges the day-by-day variability shown by any one person with implications for assessment, support, and intervention. Inter-variability refers to the variability between people with the same diagnosis.

The environment (3)

Life domains Areas of life in which individuals function : e.g. health, home, leisure, community, school, employment, etc.

Holism Links and support across domains relating to individual interests, skills, and challenges.

Imagining the future Seeing the positive possibilities for and by the individual for the future, e.g. early development, schooling, employment, and adult life.

Lifespan Planning for and supporting development and environmental opportunities as individuals age.

Opportunities and choices Choices are critical to development and need to be readily available.

A QUALITY OF LIFE APPROACH...

... Starts with perception-

person's own view

The families perceptions and then

Integrated with schools perceptions

For a consolidated approach.

ASPECTS OF EXCLUSION

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

ASPECTS OF INCLUSION

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)

- *LIFE SPAN IN ORIENTATION*

- *EMPOWERING, ACCESSIBLE AND NON-DISCRIMINATING SOCIETIES*

- *NON HIERARCHICAL*

When is Inclusion Exclusion?

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Exclusion can be in the:_
Inclusive School

The special education classroom

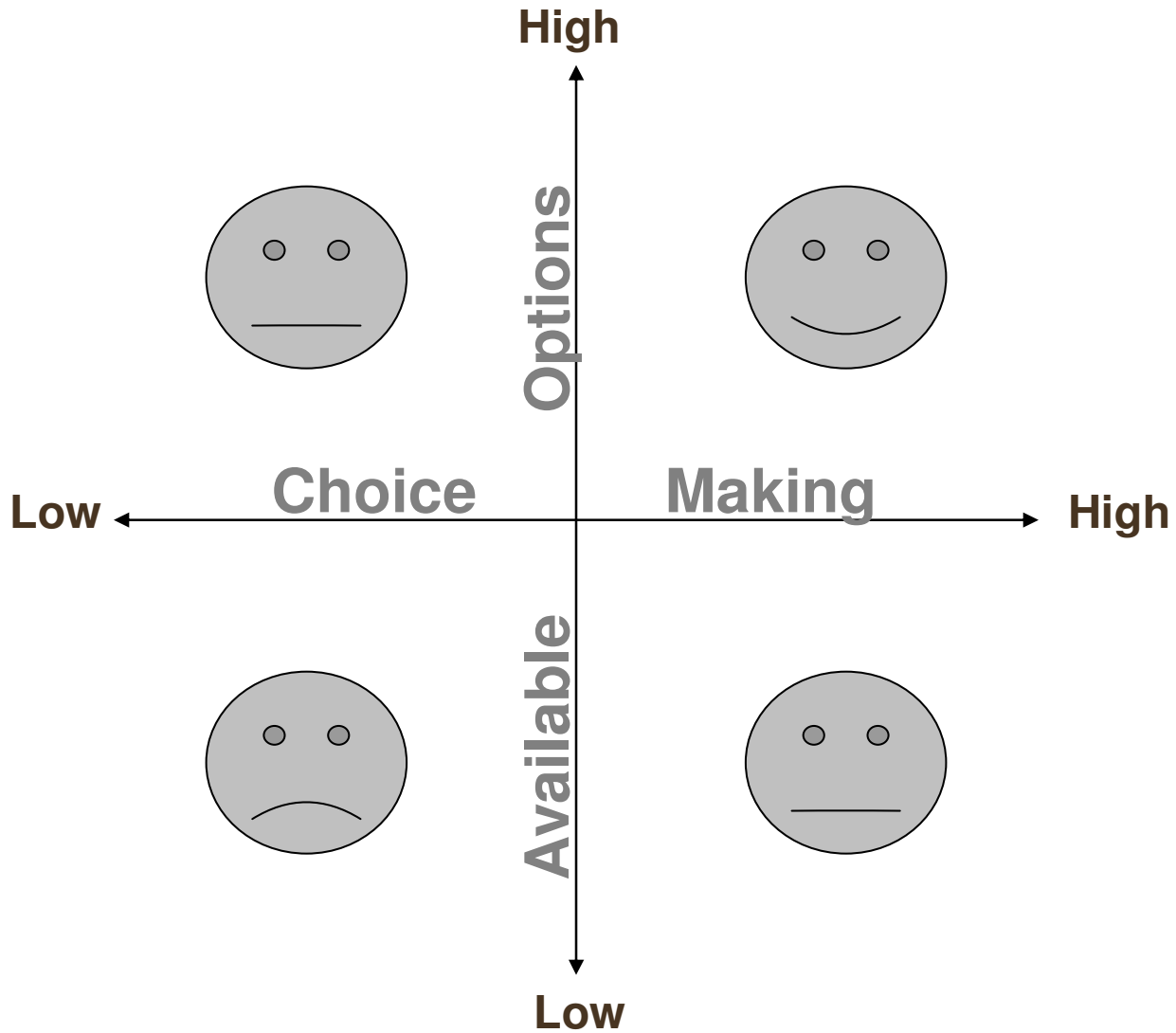
Home

In the Community

Education, social and health policies and practices.

It is probably never absent but we need to seek the best advantages to minimize exclusion in all these settings. They are all educational or non-educational depending on the experience the child or adult has.

Assessing Choice



HOW DO WE PROCEED WITH INTERVENTION?

Five steps:

- 1.Start from the place the person sees as most important.**
- 2.Provide opportunities to move forward.**
- 3.Follow the person's choices on how to proceed.**
- 4.Shape interventions to improve self-image.**
- 5.Encourage and support empowerment.**

**GOAL: To increase motivation and
success**

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