

Quality of Life for People with Autism in a Lifelong Perspective.

Point of view of a parent professional.

Hilde De Clercq

1. Evolution of a Mother-Child relationship

From 'What' towards 'Who'

2. Evolution in my way of thinking about

'handicap' and 'services'

From 'What' towards 'Who'

3. About Change and Acceptance

The problem is not in the person with Autism
but is within society

4. What does 'quality' of life' mean ?

1. Evolution of a Mother-Child relationship in Autism

FROM 'WHAT'? towards 'WHO' ?

Individual, changes over time

Who is the special one ?

Mothers labelled, categorized as :
'mama of...'

Diagnosis, Label, Feelings

All mixed and fluctuating

- Denial
- Fear
- Anger
- Protest
- Hope
- Satisfaction
- Disappointment
- Doubt
- Despair
- Depression
- Happiness
- ...

Magic words

- Acceptance...
- Letting go...

Adolescence and adulthood

Different starting point, different point of view :

Less emphasis on “WHAT”? but more on
“WHO”?

Not a mixture of all kinds of labels

A human being, not a sum of symptoms

2. Evolution in my way of thinking about 'handicap' and 'services'

From 'What' towards 'Who'

LABELS CAN BE LIFESAVERS !!!

(Mary Akerley)

- Importance of a diagnostic label
- Right label , right education
- Autism is different and specific

WHY IS THERE ONLY AN ANSWER TO :

- The “What” question : defect, limited chances for development...

LABELS CAN BE LIFESAVERS !!!???

- The 'Who'- Question :
- The child with his autism is a unique and irreplaceable human being

Different views on People with a Disability

Moral Model :

‘If it’s God’s will he will be cured...’

‘I will have a better life after this life...’

.....No control, fate...

(Bio) Medical Model

- There is a pathology**
- Medical causes, all kind of medical examinations**
- Deviating from the “norm”, deviating from “normality”**
- Seen as a deficiency, a fault...**

Consequences :

- **Professional Care**
- **Institutions**
- **Duty of Society : organizing 'Good Care'**
 - **Good food**
 - **Nice buildings**
 - **Big institution**
 - **In the country**
 - ...
 - **This is ok for some individuals with ASD !**

Functional, Developmental Model

**-The individual has a problem,
a 'disorder'**

-BUT :

**there are possibilities and opportunities
for development of the individual**

- **Consequences :**

**Care : Rehabilitation, training, services,
home training...**

Trainings in learning how to live

From big institutions to smaller units

In town, in society, in smaller groups

Emphasis on training, teaching

The 'Model of Citizenship' The Model of Human Rights

- **EVERY CITIZEN HAS THE RIGHT TO A LIFE IN SOCIETY**
 - vs. the deficiency-model : I am ok and he is not
 - the functional model : how far is he away from the “average”

- The problem is **WITHIN SOCIETY**, not in the person.
- Society has a problem, because there is no place for everyone
- It's about **ACCEPTANCE** within the society

3. About Change and Acceptance

The problem is not in the person but within society

Good elements in each model...

Put yourself in question :

- Which model suits you best (depending on your own philosophy, priorities...)?
- Are you prepared to ACT according to your ideas, priorities, values?
- Resistance to Change ?

IT IS ALL ABOUT CHANGE and acceptance ! (Van Hove)

- From the “We, the normals”-idea---
towards acceptance of differences between
people individually and between cultures

- From ‘the professional is the expert’- idea --- towards acceptance that the natural network has the best knowledge and wisdom

– ‘Mothers are the best allies’ (John O’ Brien)

- From starting with the 'deficiency' ---
towards starting from the possibilities/
competence in combination with the right
support
- From What ---towards Who
- From the individual ---
towards the individual in a natural context

- From the 'treatment' idea ---towards the 'support' idea
- From the 'independent' idea---towards the idea of interdependency

About Belonging

- From 'normalization' , the adaptation towards the 'average' ---towards acceptance of 'diversity' and 'neurodiversity'
- Inclusion is about :
 - 'Belonging'
 - 'Alliance, connection, solidarity...'

‘People can only be who they are because of the others whom they live together with’ (Van Hove)

Inclusion is About change...

- **Change is frightening...**
- **For Professionals :**
 - Afraid of new responsibilities**
 - Afraid of what they don't understand**
 - Afraid of losing their jobs**

Inclusion is About change...

- **Change is frightening :**
- **For Parents :**
 - **It's hard and difficult work**
 - **What about protection ?**
 - **Society is not ready for it !**

About change and quality of life

In the beginning... priorities

- The Label
- The IQ
- Eye-hand coordination
- Emerging skills
- Left handed . Right handed
- Fine motor skills
- Play skills
- Writing and reading
- Perspective Taking Skills
- ...IEP

Nowadays

- **WHO IS HE?**
- **HOW DOES HE FEEL?**
- **WHAT DOES HE NEED TO BE HAPPY?**

'PLAN FOR LIFE'-----'QUALITY OF LIFE'

4. What does 'quality' of life mean ? Important concepts :

- Human Rights**
- Citizenship**
- Support versus Care**
- Network,**
- Individualized Educational Programme**
- Belonging**
- Individualized 'Plan for Life'**

Change...Quality of Life

- **What is a good life?**
 - For this person (with a label)
 - According to HIM
 - According to his network
 - According to the people who love him
 - **NOT (ONLY) ACCORDING TO THE PROFESSIONALS**

Quality of life : About Happiness

- **Important Dimensions that are obvious to us**
 - **Physical wellbeing**
 - **Emotional wellbeing**
 - **Development, activities, competence**
 - **Material wellbeing**
 - **Social wellbeing**

Quality of life

- **Most of these areas are at risk for people with a label**
- **Especially : relations, making choices, dignity respect, status ...**

Dreams...wishes

Quality of life

- **No negative characteristics, problems, deficiencies**
- **What gives HIM energy ?**
- **What does HE (dis)like ?**
- **What does HE want ?**
- **How does HE see his future ?**
- **What does HE think about work ? Living ?**

"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has." -
Margaret Mead

- Good Services and good professionals will always be very important
- They have to find the strength of the person with autism and try to create chances for development in society

- Services and society have to change gradually
- A lot of work has to be done to change existing cultural patterns, especially for people with Autism, belonging to a different culture

Difficult Balance

- Not giving too little, not giving too much
- A Balance between the right to have a life of its own and the right to get adequate and maximal support in order to live this life !

Rights for Persons with Autism

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- THE RIGHT TO BE DIFFERENT
- THE RIGHT TO THINK DIFFERENTLY
- THE RIGHT OF NEURODIVERSITY
- THE RIGHT OF BEING A “WHO” INSTEAD OF A “WHAT “
- THE RIGHT NOT HAVING TO BE AS CLOSE AS POSSIBLE TO ‘THE AVERAGE’