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Down Syndrome: 'dis'abilities versus 'other' abilities

**a paradigm shift and its implications for
research, education and social participation**

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Introduction

The idea for this presentation was born during the 10th World Down Syndrome Congress in Dublin 2009. In the majority of the presentations, papers and posters of this Congress, the concept of *disabilities* played a major role.

As in previous congresses, the research questions, theories, specially developed educational and social programs etc, that were presented in Dublin, are all based on the assumption that persons with Down Syndrome are disabled. That is, they lack certain abilities and characteristics that so called normal people are supposed to have. Thus, the focus is on discovering what is *lacking* in persons with Down Syndrome and how to remedy those 'handicaps' as good as possible.

In general, this approach exhibits what anthropologists would call an *ethnocentric bias*. (Ethnocentric bias refers to the tendency to interpret and judge other humans solely by the values and standards of one's own ethnic, social or other group.)

In this presentation we want to leave this dominant paradigm that compels you to look for *disabilities* and ways to remedy them. Instead, we propose to shift to a alternative paradigm in which we start with the basic assumption that persons with Down Syndrome have *other* abilities than most 'normal' people.

Thus, we look at what they *have* instead of what they do *not have*.

Needless to say that changing the basic assumption also leads to quite different research questions, theories, programs and practices.

To elaborate this point, we will start with two examples. We look at them first from the point of view of the dominant paradigm, looking for what is not there. Then we proceed to look at the same example from the alternative point of view focusing on what is, on what special abilities we can detect.

The remainder of this presentation is devoted to specific other abilities that we find in persons with Down Syndrome.

We conclude with the implications for three issues: Education, Employment and Social Participation.

Paradigm shift

Dominant paradigm

Basis assumption:
Persons with Down Syndrome
lack certain abilities and characteristics
that 'normal' people have

Focus on disabilities and ways
to remedy them

Alternative paradigm

Basis assumption:
persons with Down Syndrome
has special abilities that 'normal'
people do not have

Focus on detection of special abilities
and ways to develop them

Paradigm shift: example 1

Low tongue position



In both photo's we see children with an open mouth and a so-called low tongue position.

The low tongue position is a natural characteristic of people with Down Syndrome which in the dominant paradigm is seen as a disability. It makes you look dumb. Thus we have to train them to close their mouth so that they are looking more like a 'normal' person. But if you look at it in an alternative way, you may notice a low tongue position as a sign for another state of awareness, where mental thinking activity is low and other senses are more dominant.

This ability is a special one. There are even management courses in the Netherlands that train this ability in order to make managers and other mentally occupied people more aware of their feelings. This is seen as an enrichment for business.

Let us do a little experiment with this low tongue position. Relax your tongue and try to lay your tongue at the bottom of your mouth. (Keep breathing through your nose!)

Can you see or feel the difference?

More mental perception



(more) feeling awareness



If you train yourself more and more, you will feel the difference.

If persons with Down Syndrome are trained to keep their mouth closed, one of their characteristic abilities is blocked. That is, the development of their special senses of feeling and awareness is blocked.

So looking at the low tongue position from the alternative paradigm some **suggestions for research** come up.

- 1) Which specific abilities are stimulated by the low tongue position?
- 2) What is the function of low tongue position on different types of awareness?
- 3) What are the consequences of 'remodeling' the tongue for this kind of awareness?

Paradigm shift: example 2

The effect of mental questions.

The next two photo's show an 8 years old boy I have been working with, as an example of the effect mental questions often have on persons with Down Syndrome.



In these photo's he is blocked and frustrated, because he is asked what he has made with his clay modeling. He was happily kneading and cutting the clay in different sizes and he is now frustrated because he was interrupted by the mental questions and has no words for what he was doing.

The next two photo's show what happens when he is left working by himself. I noticed that he was really experiencing the movement of the wood following the logical order of his own feeling. When I called his actions "wobble the wobble" he started smiling and repeating "wobble the wobble". While he is normally labeled as a child with attention problems, he was now enjoying working for about 15 minutes, feeling and discovering by doing. He also felt that his special 'other' abilities were recognized and acknowledged.

Wobble the wobble



He is learning by feeling and discovering what he can do



In the dominant paradigm these 15 minutes of repeating the same kind of playing would be interpreted as a sign of low intelligence. He has to be stimulated by giving him specific (mental) orders.

Using the alternative paradigm we see his special ability: learning by doing, learning by feeling the physical law of gravity. He is learning a lot and enjoying it when you let him play in his own way and stimulate him by acknowledging what he is doing and by giving him different materials and different places to experience.

So, based on this example, there are at least **two implications for research and education**:

- 1) What is the effect on the potential intelligence when being forced to learn in a mental way?
- 2) What kind of education stimulates the development of non-mental intelligence?

Some special 'other' abilities

After these two examples of a paradigm shift I now continue with discussing some of the special 'other' abilities of persons with Down Syndrome. The examples are based on what many Dutch parents have told us in person, on my own 15 years long experience with Down Syndrome in the Netherlands and in Romania and on the comments of 110 parents documented in two books.

1. Touching your heart with their cheerfulness and unconditional love



2. *Brightening depressive moods*

“If you feel down just spent an hour with J. and you are cheerful again.” This comment from one of the parents clearly shows that they have a special ability to brighten depressive moods.



3. *Social harmonizer*

Many of them are real social harmonizers and bridge builders, connecting people.



4. *Pure and authentic*

Their original being is pure and authentic. For ‘normal’ people there is an increasing range of special courses to learn and train these qualities.



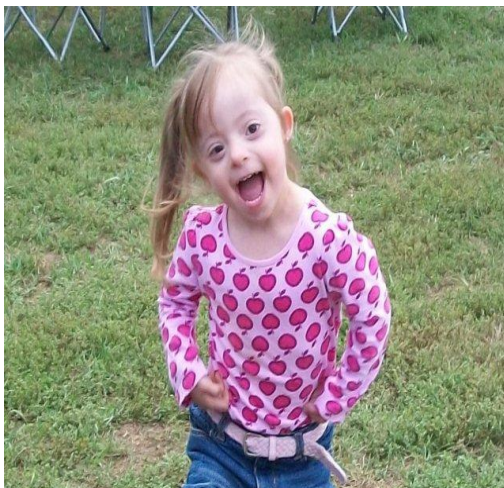
5. *Spontaneous, unconventional*

This photo is from internet. The lady on the right is our future queen. It is not customary to greet her like this. Pure authentic people like persons with Down Syndrome have the talent to make others happy with their spontaneous behavior. I am sure you recognize this.



6. *Confronting, self-willed, straightforward*

They are likely to ignore people with artificial behavior or turn their back on them. They help other people on their own initiative when they notice a need, although not always at the most convenient moment. When you try to hurry them up, they won't do it. They can also easily become upset and run away when talked to with difficult words.



In the dominant paradigm this kind of behavior is said to be impolite, they have to learn to adapt and be polite. In the alternative paradigm looking at this behavior as an 'ability', you may say: people with Down Syndrome are a mirror for us and stimulate us to be authentic and pure. They are straightforward. These qualities many of us have lost in the modern world.

7. *Sensitive, feeling atmosphere*



They are sensitive persons who feel it when you are not telling the truth, when you are stressed, when your attention is not in the here and now etc. When you are not clear about yourself and not honest in the communication, they can react with stress reactions: hyperactivity, shouting, crying, grumbling, recalcitrance. If you recognize their sensitivity as a specific ability, you may thank them again for acting as your mirror. Many parents have mentioned this aspect.

8. *Gifted in non-verbal comprehension*

They comprehend non-verbal communication very well and far better than most of us. They need only a few words for understanding a whole situation. That is why our use of too many words can drive them crazy. Because the largest part of human communication is non-verbal and our non-verbal part is not always congruent with our verbal part, they often cannot understand us.



In the dominant paradigm it is said that they cannot understand verbal communication very well. Using the alternative paradigm you can say they cannot understand our incongruent communication. You can test this alternative paradigm yourself: if you limit your speech to the essence and take care that your non-verbal communication is congruent and clear, you may find that you are being understood.

9. *Learning by awareness and experiencing*

Their special other ability is learning by awareness and experiencing, using logics of feeling instead of logics of mental thinking. That is why pure mental tasks are very tiring for most persons with Down Syndrome, because their talent is to be aware with their non-mental senses. They need a long recuperation period to find again their natural way of being.



In the dominant paradigm this long recuperation period is interpreted as laziness. “They are lazy and need more stimulation”. In the alternative paradigm the same situation is interpreted as a sign that pure mental tasks need to be limited to a level where such a long recuperation period is not needed. If this is not possible, sufficient time to recuperate must be allowed.

10. *Taking time to ‘experience’ nuances*

Their tempo of doing things has a specific quality too that we don’t have in the same intensity. They can very well experience the here and now and they can ‘taste’ little things in many nuances. After tasting in the here and now, they are ‘re-tasting’ and re-feeling in their memory and are thus developing deep feeling qualities. Just as a blind person becomes more sensitive in hearing, a person with Down Syndrome develops more intelligence in sensitive feeling qualities.



11. Sixth sense

This picture shows a 35 years old woman who was stimulated to develop her own specific abilities and has now become a real energy healer.



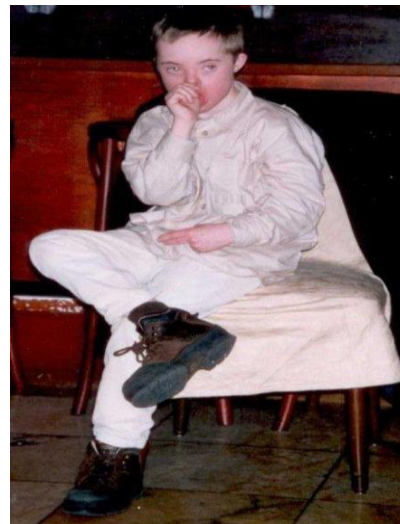
This is the summary of our selection of their 'other' abilities.

1. Cheerful, unconditional love
2. Brightening depressive moods
3. Social harmonizer
4. Pure and authentic
5. Spontaneous, unconventional
6. Confronting, self-willed, straightforward
7. Sensitive, feeling atmosphere
8. Gifted in non-verbal comprehension
9. Learning by awareness and experiencing
10. Taking time to experience nuances
11. Sixth sense

The next pictures show examples of what happens when the special other abilities of persons with Down Syndrome are not recognized as valuable contributions to society. When they are forced to adapt to 'normal' society they become chagrined and obstinate.



Desperation and frustration obstruct their development.



And.... After a long time with frustrations and disappointments, a long time of not being recognized and valued, they withdraw more and more into themselves and lose their 'other' abilities.



So, we very much like to advise this Congress:

Let us research the specific abilities of persons with Down Syndrome instead of their 'disabilities'. And let us start to focus on programs and activities that give them the chance to develop their own specific abilities. In short: let us become aware of the special gifts of persons with Down Syndrome and realize that they can make important and valuable contributions to society.

Implications, necessary pre-conditions.

We mention the following implications of the paradigm shift in the field of education, employment and social participation:

1) *Being recognized as specific ability.*

Persons with Down Syndrome need to be recognized as persons with specific abilities. When the value of these abilities is not acknowledged, we cannot coach their development.

2) *Being equally valued as 'normal' abilities.*

Their 'other' abilities are to be equally valued as 'normal' abilities.

If we train some of their specific abilities in stress-management and personality training courses (staying in the here and now, non-verbal comprehension, 'tasting' nuances, learning to be authentic, learning to be more sensitive, learning feeling awareness by low tongue position), if we train this kind of specific abilities, we have to grant that their 'other' abilities are equally valuable as our mental 'normal' abilities. Thus they may become our teachers in developing our feeling and other non-verbal capacities.

3) *Education focused on specific abilities.*

The alternative paradigm implicates that education should be focused on the development of their specific abilities.

It also implicates *a learning by doing method* with a minimum of mental tasks.

4) *Educators, employers and others involved must be(come) aware of the alternative paradigm.*

And.... This means that educators, employers and others involved in the social participation of people with Down Syndrome must also become aware of the basic assumptions on which their *own* actions are based.

We hope that this presentation will be of assistance in this task and.. that the future will let

'other' abilities radiate:



Thanks to:

All the parents who shared their information and photo's.

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