

# Down Syndrome: Authenticity versus Adaptation

A Social and Individual Dilemma



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## Introduction

Many of the lectures, research questions, theories and specially developed educational and social action programs, presented at successive World Down Syndrome Congresses over the years, are based on the central 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, within this dominant paradigm, research is focused on discovering what is lacking in persons with Down Syndrome and how to remedy these 'disabilities' as good as possible.

In 2012, Flud van Giffen (anthropologist) and I (mental health psychologist) proposed an alternative way of looking at and thinking about Down Syndrome, (an alternative paradigm) based on the central assumption that persons with Down Syndrome have *other* abilities than most 'normal' people.

Thus, instead of being compelled to look for disabilities and ways to remedy them, we looked at what they *have* instead of what they do *not have*.

We then initiated an exploratory research project on these specific abilities of persons with Down Syndrome. The findings of this research were laid down in the document *Down Syndrome, 'dis'abilities versus 'other' abilities. A paradigm shift and its implications for research, education and social participation*. First presented during the 11th World Down Syndrome Congress in South Africa, August 2012.

## 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

Adaptation

### Alternative paradigm

Basic 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

Authenticity

In that paper we discussed 11 abilities, all so-called 'being-oriented' characteristics.

Our presentation today builds on and expands this theoretical framework and research, and discusses the results of a follow-up exploratory enquiry. We asked our 60 respondents to study the basic 2012 document and answer a set of questions about their experiences with the 'other' abilities of their own child/pupil.

The following list shows the percentages of respondents identifying/recognizing the 'other' talents.



The time is too short to attend all these talents. I choose only the numbers 7,8,9 and 10 to explain.

## 95 % Sensitive, feeling atmosphere



7.

They are sensitive persons, who are really feeling atmospheres. This ability belongs to the authenticity of people with Down Syndrome according to 95% of the respondents.

Reading the initial 2012 paper, helped them also to recognize this ability.

How to recognize? Young children can start to cry when others are crying or are sad. Or:



" If he is in a place that does not feel right, he wants his jacket back on and wants to go away.  
If it is impossible, he wants his coat as protection."

*(We promised our respondents anonymity, so the quotes do not directly relate to the persons in the pictures)*

How it appears in adolescents and elderly: smiling and relaxing in good atmosphere. Withdrawing or oppositional behavior in restless atmosphere.

"He can get very upset in disputes, when hurried and with too little attention. He can also freeze. He forces me to look at my own behavior."



It goes well with them if you are just as sensitive and if you mention that you notice the changes in atmosphere. Previous opposite, withdrawing or compulsive behavior then disappears. Most respondents agree that it takes them a lot of time to acquire this sensitivity. It is also a serious dilemma for the person with Down Syndrome.

## Dilemma

- How can persons with Down Syndrome learn to interpret their own sensitive reactions when there are not enough people who recognize and acknowledge these in time?

**And are there enough people who are able to reassure them by specifically naming the changes in atmosphere?**

Advice: Do recognize their sensitivity as a specific ability and know how to reassure them if necessary.



8.

This ability is part of their authenticity for 85% of the respondents.

Persons with Down Syndrome comprehend non-verbal communication very well and far better than most of us.

50% of the respondents explain this ability as telepathy or sixth sense: no words or only a few are enough for them to understand a whole situation.



"Absolutely uncanny.... My daughter is our family healer and being such a pure soul we all look to her for giving us positive energy. She can predict every situation and we have seen it happen."



Some other quotes:

"If I have my worries, but try to make it light, my daughter is saying: Do not worry, mam, let it go, I'll be fine."



"He understands my intentions, I think. I test him by asking something in Spanish (he does not know that language) and he is doing what I am asking him."



"Our son is not talkative, but I notice that he understands difficult talks in his surrounding by his remarks."



35% of the respondents do not call this ability telepathy. However, they confirm that persons with Down Syndrome comprehend language better through a combination of gestures, pictures and exemplary behavior .

35% Comprehends through a combination of gestures, pictures and exemplary behavior



"Be sure to focus all your attention on the present moment, otherwise you will not get any attention and concentration for a new topic."



"If I use many words, he is going to do other things."

This brings us to dilemmas and implications for education.

## Dilemma

- If they are more telepathic than we recognize, then they pick up many of our mental images during our own distractions. That can be confusing to them and can be an important cause for their learning problems.
- Living among people with a busy mind, can create difficulties in their learning processes.

Advice: Do not assume beforehand that they are not intelligent enough, perhaps we are not focused enough for teaching them in a clear and unambiguous non-verbal way.



## 70% Learning by observing, doing and experiencing



9.

70% of the respondents recognize their special ability to learn by observing, doing and experiencing, using logics of feeling instead of logics of mental thinking.

Quotes.

"Anything that interests them they are up and active" ...  
"When I give my mental interpretations too fast, their interest goes quickly away"





"I learned not to be a guide when we are visiting a place. It irritates him. It interrupts his own observations."



" She is dancing and playing guitar hours and hours. She is happy all the time. She is not interested in results. I notice that she makes progression with very little steps.

For me she is a mirror. I like painting, but I often have only the results in mind. That blocks me!"

## Dilemma

- At school it is usually not allowed to spend hours and hours with only one interest.
- Many respondents notice that their children are more happy, active and concentrated at home than at school.
- Is the learning content of schools adapted to persons with Down Syndrome or do they have to adapt?

## 80% Taking time to experience nuances



10.

Recognized as authenticity: 80%.

Their tempo of doing things has a specific quality that we do not have in the same intensity. They can very well be in the here and now and can experience little things in many nuances. Afterwards they often repeat and re-experience these moments and are thus developing deeper feeling qualities.

"She often says:  
I am working with re-enjoying: I enjoy again and again"



"They act in their own time"





"For us it looks like doing mindfulness,  
for them it comes naturally"



## Dilemma

- In our society one must be on time. It is usually not accepted when you take your own time for what you are doing.
- And when you focus only on 'experiencing', you may be judged as maladjusted and even antisocial if the 'other' time-orientation is not properly understood.

This means that persons with Down and their parents and caretakers live in a society with a lot of time pressure, which creates a lot of frustrations and stress.

Another example mentioned by one of our respondents is the situation of a person with Down Syndrome who during meals focuses on eating only in the here and now. And withdraw himself after eating for re-tasting his meal. This may look maladjusted and even antisocial if the time-orientation of a person with Down Syndrome is not properly understood.



Advice: Try to understand and honor this ability. Let them take their own time. It will be healthy for all of us.

## Conclusion

- 'Being-oriented' abilities can only develop if they are recognized, acknowledged and also stimulated in schools and other social contexts.
- Persons with Down Syndrome provide good examples for 'normal' people.

We hope that our study will contribute to the development of these value-adding abilities needed to the mental health of our society.

Or as many of our respondents say:  
"I learn a lot from him/her."

*Thank you parents and caretakers for sharing your information and pictures with us.*

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