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Working with mothers and fathers of children with disabilities: metaphors used by parents in a continuing dialogue

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SUMMARY: Within this article we will introduce some metaphors as they were developed and used by mothers and fathers we worked with: the traveller, the warrior, the builder of bridges, the discoverer, the trainer/teacher, the in-between-er, the manager... We will position these metaphors as tools parents are using in their confrontation with normalising discourses of disability and education. In this sense mothers and fathers of disabled children can be seen as 'parents on the margins' from whom we can learn a lot about parenting in general. In that sense the metaphors we will present can be situated as a meta level parents present in their continuing process of reflection on their living together with their children with disabilities.

RÉSUMÉ: Nous présenterons, dans le cadre de cet article, quelques-unes des métaphores développées et utilisées par les pères et mères avec lesquels nous avons travaillé: le voyageur, le guerrier, le bâtisseur de ponts, l'explorateur, l'entraîneur/le professeur, l'intermédiaire, le manager... Nous considérerons ces métaphores comme des outils que les parents utilisent dans leur confrontation avec les discours normalisateurs sur le handicap et l'éducation. En ce sens, les pères et mères d'enfants handicapés peuvent être vus comme des 'parents à la marge' auprès desquels nous avons beaucoup à apprendre en termes d'éducation des enfants en général. Les métaphores que nous présenterons peuvent, en ce sens, être situées comme un méta-niveau que les parents présentent dans leur processus permanent de réflexion sur la vie commune avec leurs enfants handicapés.

ZUSAMMENFASSUNG: In diesem Artikel werden wir einige Metaphern vorstellen, die von Müttern und Vätern entwickelt und verwendet wurden, mit denen wir gearbeitet haben: Der Reisende, der Krieger, der Brückenbauer, der Entdecker, der Trainer/Lehrer, der Zwischenhändler, der Manager... Wir werden diese Metaphern als Instrumente positionieren, die Eltern in ihrer Konfrontation mit der Normalisierung der Diskussion von Behinderung und Erziehung verwenden. In diesem Sinne können Mütter und Väter behinderter Kinder als 'Eltern am Rande' gesehen werden, von denen wir viel über Kindererziehung im Allgemeinen lernen können. In diesem Sinne können die von uns vorgestellten Metaphern als Meta-Ebene situiert werden, die Eltern in ihrem kontinuierlichen Prozess der Reflexion über ihr Zusammenleben mit ihren behinderten Kindern präsentieren.

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RESUMEN: En este artículo introduciremos algunas de las metáforas desarrolladas y utilizadas por los padres y madres con los que hemos trabajado: el viajero, el guerrero, el arquitecto, el descubridor, el formador/profesor, el mediador, el gestor, etc. Consideraremos dichas metáforas como herramientas utilizadas por los padres y madres para afrontar discursos normalizados sobre discapacidad y educación. En este sentido, los padres y madres de niños discapacitados pueden verse como ‘padres al margen’ de los que podemos aprender mucho sobre el cuidado de los hijos en general. En este sentido, las metáforas que presentaremos pueden tomarse como un metanivel que los padres presentan en el proceso continuado de observación de su vida junto a niños con discapacidad.

Keywords: children with disabilities; parenting; families; parent empowerment; metaphors

Background

Fathers/mothers of children with disabilities have always taken a unique – and sometimes controversial – position in the history of care.

Fathers were often absent for a large part in this history or were portrayed as onlookers who were unable to talk about their feelings and decided to immerse themselves in their work outside the home. Mothers have taken up all kinds of positions: some were overprotective and were accused of building a symbiotic relationship with their children. As a consequence of this symbiotic relationship the mothers continued to treat their children as small children, even when they were adolescents and young adults. These mothers were also accused that too often they were speaking for their children instead of letting them speak for themselves.

Other mothers however were described as ‘fridge mothers’ who were unable to bond emotionally with their child. For a while this last instance was even regarded in some psycho-analytical circles as a possible cause for the label ‘autism’ that was attached to some children (Van Hove, De Belie, and De Waele 2002).

Furthermore, clinicians called the entire family of a child with a disability a ‘family with a disability’. Due to the frame of mind of these clinicians, entire generations of young care assistants received their training with images such as ‘the neurotic parent’, ‘the suffering parent’, ‘the dysfunctional parent’, ‘the powerless parent’, etc. (Ferguson 2001, 379–84).

It is clear that the concept outlined above discredits those fathers and mothers who in the course of history have stood on the barricades, in their own environment or in wider society, and tried to improve the quality of life of their children and/or secure a place in society for them.

The tide is clearly turning. People involved in training and research are increasingly faced with the fact that the old ‘clinical view’ fails to understand some fathers/mothers. Goode (1995), for example, maintains that professionals must be aware that the parental and familial understanding of children encompasses considerable complexity and depth. Families come to attach meanings to the actions of their child through participation in shared routines. These constituted a broad base of knowledge from which to access the actions of the child. Professional assessments inevitably defer to the knowledge of families. On the other hand, many new forms of support now take their departure from a close cooperation in equal parts with fathers/mothers and the natural network (De Belie and Van Hove 2005; Fisher and Goodley 2007;

Landsman 2003; Read 2000; Ryan 2005; Ryan and Runswick-Cole 2008). Pippa Murray describes this 'partnership' as follows:

...I am referring to relationships within which my son was positively valued in addition to being central and of foremost importance; where, in the light of his medical condition, his learning and communication difficulties, my parental knowledge was seen as crucial to forming and maintaining a relationship with him; where different roles with regard to my son were recognised and the boundaries between those roles respected by all parties; and finally, and most importantly, they were relationships with which my son was happy... (2000, 683)

Fathers/mothers themselves also realise more and more that their perspective is important and that it has a great deal of influence on the path their child will take (see e.g., Habib 2007 and Ferguson 2003).

The above lines, namely, the need for changed images so fathers and mothers are better understood and 'to work together in equality', will be at the heart of this article.

Research context

We live in a time where grand theories and master narratives are under attack by personalised and localised narratives (Goodley et al. 2004). The 'little narratives' we will present in this paper have to be considered as part of a wider movement of qualitative researchers believing in the idea that individual stories reveal common meanings (Andrews et al. 2000). Within this paper we will also try to illustrate the oscillation of parents between being complicit with and countering aspects of master narratives. Those master narratives impose how parents of young children are expected to think, act and live (Bamberg 2004). Writing this article was made possible by collecting empirical data from researchers who have an extremely close relationship with fathers/mothers of children with disabilities.

The research material for this article was sourced from three main research projects:

- For the last 10 years the first three authors have been closely involved, in the form of action research, with a family project in Flanders (Ouders voor Inclusie [Parents for Inclusion]) which advocates that families decide for their child with special needs – and this often against professional advice – to be educated in mainstream educational facilities (Van Hove et al. 2008).
- Bosteels and Desnerck have held in-depth conversations for a lengthy research project with the fathers/mothers of first generation children that were given a cochlear implant in Flanders. The fact that young fathers/mothers of young children have to make a decision so early in life about this extremely invasive procedure is not without consequences.
- Van Loon has been involved since 1994, both in practice and via research, with the deinstitutionalisation of more than 400 children and adults with mental disabilities in the region near the Dutch-Belgian border. These children and adults no longer live together on a closed campus in large groups. They live in society, either by themselves, in small groups or in foster families. It is clear that this process has had a huge impact on the families involved.

These three starting points for research show that the authors of this article work predominantly with ‘fathers/mothers in the frontline’. The situations researched can in our opinion be described as ‘extreme cases’ (Yin 1994). The situations of these families and the choices they make therefore are used as ‘field tests’ by practice workers and researchers to look at certain attitudes and reactions in a different light and to start a dialogue with the fathers/mothers to see how they can work together.

Metaphors

As non-linguists we still dared to collect images and metaphors as research material given to us by fathers/mothers. We learned basic theoretical insights from the work of Brown (1976) and Lakoff and Johnson (1980). Brown identified three kinds of metaphors: ‘analogic’, ‘iconic’ and ‘root’ metaphors. In our ongoing dialogue with parents we were confronted with ‘root metaphors’ as a representation of previously unrecognised assumptions and ideologies of the metaphor’s creator. Lakoff and Johnson’s ‘deep’ metaphors (in opposition to ‘surface’ metaphors) were similar to Brown’s root metaphors in reflecting the ideological positions and subjective stances of the parents.

From the field of educational sciences we found the work of Danforth (2008) very helpful. Danforth rightly states that ‘the analysis of metaphors within cognition and language has to be seen as one way to illuminate and interrogate the social meanings of disabilities that are produced within cultural activity...’ (2008, 386). Because of his study on metaphors which are used in the US to acquire a better understanding of behavioural and emotional problems of children, he already had extensive experience in this matter. In a previously published article about using the ‘machine metaphor’ to study autism (Danforth and Naraian 2007) he describes the use of metaphors for the (educational) sciences as follows:

...Traditionally, metaphor has been viewed a literary trope standing in opposition to literal forms of writing in the natural and social sciences. In recent decades, however, a multi-disciplinary field of cognitive linguistic research has developed. This research finds metaphor at the heart of both everyday and scientific thinking. Metaphor is understood to be vital to the development of useful theories within the sciences... (273)

Methodology

This research project was realised using a variety of ethnographic techniques (direct, first-hand observation of daily behaviour, conversation with different levels of formality, in-depth interviewing and problem-oriented meetings) (Hammersley and Atkinson 1995).

We were spending a considerable amount of time with the parents. We wanted to gain as good a knowledge of their lives as possible so we attempted to get an understanding from their perspective (Sigurjonsdottir and Traustadottir 2000). Within these different meetings the metaphors for this article were gathered by a ‘key incidents’ method (Emerson 2004, 457). Key incidents are events or observations that help to open up significant, often complex lines of conceptual development (Emerson 2004, 456). It is a research strategy that is coupled to the ethnography from the actual experience of many ethnographers that their analyses

were strongly shaped by particularly telling or revealing incidents or events that they observed and recorded (Emerson 2004, 459). A key incident (Emerson 2004, 469) attracts a particular field researcher's immediate interest, even if what occurred was mundane and ordinary to participants. This 'interest' is not a full-blown, clearly articulated theoretical claim, but a more intuitive, theoretically sensitive conviction that something intriguing has just taken place. These key incidents are helpful for a naturalistic analysis that is necessarily open-ended and emergent, tied to and deriving from specific pieces of what has been seen, heard and recorded (Emerson 2004, 458).

It helps the 'naturalistic retroduction' moving back and forth between observations (here: images and metaphors) and theory (here: about parenting and children with disabilities and about power mechanisms between early childhood educators and parents). So, original theoretical statements are modified to fit observations, and observations are collected that are relevant to the emerging theory.

Research findings

Below we will introduce to the reader the metaphors used by fathers/mothers. We will embed this metaphorical description in the key incidents where we were able to discover these metaphors.

The traveller

'...My child is my voyage around the world, so I am a world traveller...' is one of the extraordinary positions presented to us by a mother. It turned out that she and her partner had their first child at a very young age. The pregnancy was not planned, on the contrary, both parents – who were in their final year of secondary education when the pregnancy occurred – had just made plans to take a gap year to explore the world after they finished their secondary education. With the arrival of their child these plans became rather less practicable. Moreover, when it turned out that the baby was born with various disabilities these wonderful plans became totally unrealistic. And still... talking to the mother later on we learned that these young people didn't throw in the towel. Living in Belgium they found that they received too little information about supporting and stimulating their child, so they began to look for it across the border. Eventually they found a treatment centre in the USA which they travelled to with their child. They were admitted to an intensive and short support programme. Our young world travellers were not to be stopped and they obtained permission to move into a mobile home next to the university campus, where the treatment centre was based, for the duration of the treatment programme. This experience laid, as it were, the foundation for later family excursions into Europe, usually for the purpose of some kind of treatment/support for their child.

Tintin in the land of care providers

Fathers/mothers indicate that the moment their child was diagnosed, they landed in a completely 'different' world, a new territory. They had – just as other fathers/mothers – so many dreams and expectations for their child and suddenly all that

changed. They came into contact with professional care where they seemed to have all the ‘answers’ to the questions concerning the life of their child: medical care, school, nutrition, leisure time, therapy, communication, etc. The parent however always remains the gatekeeper. They are given information and it’s their decision: does this actually help my child? Is it in his/her interest? One mother says about this:

When the time came for my daughter to go school, we followed the path that we thought we should follow. It was very difficult to subject her to an intelligence test. A multi-disciplinary team referred her to a type 2 school. They gave us an overriding motive: our daughter had multiple medical problems. Therefore the school should have a well-equipped medical department. [...] We then went back to the MDT with a request to have our daughter reassigned. The gap between what she was doing at home and what the school was doing became too big. For the two years extended pre-primary classes we wanted her in a type 4 school, where they could give her maximum support regarding communication. The school that agreed to try it, warned us from the start: it will probably not be for longer than two years. Your daughter doesn’t really fit in our target group, she shows no interest, the gap between her and the other children is too big... We saw her make huge progress and she really tried her best in those two years to catch up, but it wasn’t enough for the school. Our daughter didn’t make the grade for standard primary schooling in special education.

The diagnosis of their child is often the first time that fathers/mothers are confronted with a position as ‘user/client’ within the care for people with disabilities. For many of them this goes together with a significant feeling of dependence as regards professional care. From conversations with fathers/mothers it seems they are given a great deal of information from a professional angle. They are told about the extent of their child’s problems, given recommendations about what is best for their child and which therapy they should go for, etc. In this it is obvious that most of the professional advice is predominantly problem-oriented. This is often confusing for some fathers/mothers because they have to find a place for their child as well as themselves on this course that has been mapped out for them. One mother described her confusion literally after being given a diagnosis: ‘...When I was driving home I looked in my rear-view mirror and wondered if my son, sitting there in his car seat, was still the same after the new diagnosis...’

However, this is not the first time that fathers/mothers are confronted with the fact that their child is different. For all children there is a history of many concerns, questions and making choices prior to the diagnosis. Fathers/mothers build up a defence mechanism of sorts in order to deal with the (negative) news about their child. They draw strength from the progress and (slow) evolution they see in their child, in spite of all the question marks and problems. They live with and care for their child by trial and error, day after day.

The manager

During some discussion evenings between fathers/mothers and professionals, attended by one of the authors of this article, we had the privilege of meeting a very special father. He introduced himself straightaway as follows: ‘...I am X, father and manager of Johan, my son who has a serious mental and psychological disability...’ During the discussion evenings X told his story with a great deal of emotion and energy. It all started for him in the first (special) day care centre where he took his

son. He soon realised that he had arrived in ‘a new world’ (his words), a world with very specific terminology and conventions. Multi-disciplinary team, treatment planning discussion, ‘snoezelen’¹ are examples of this new terminology. He also soon realised that sometimes changes were made in the daily routine after this had been discussed in a meeting... without inviting the fathers/mothers. They were informed afterwards via ‘the communication notebook’ (another new word again). If they didn’t quite understand it they could ask the ‘counselling assistant’ to explain; if they didn’t agree with the changes they had to convey their objections to the ‘remedial educationalist’, who would then raise it at the next meeting, usually a few weeks later... When after a time it turned out that quite a few changes were being made and that he did not really approve of these changes, but they proved to be irreversible (as decided in a meeting after considering the queries and objections), this father decided that enough was enough. He started a kind of protest action and parked himself – without having made an appointment – near the office of the principal (who initially was too busy to see him) until he was granted a short interview. In this interview the father made the following demands: ‘...No meetings will take place here about my son without me attending in person. I also want to know prior to the meeting which points on the agenda relate to my son so that I can be prepared... or else I will remove my son from this school right now...’ At that moment quite a few reasons were dug up why it would not be such a good idea for the father to attend (difficult terms were used at the meetings, it would be emotionally very demanding for the father, the staff was not used to having fathers/mothers at their work meetings, the other fathers/mothers might start to ask questions too, etc.). The father stuck to his guns and since then he lives with a ‘double agenda’: his own agenda (he works in a creative sector where arranging appointments and meetings is already extremely flexible) and the agenda of his son. The second agenda always has priority and quite often he has to rearrange his work meetings in order to accommodate the second agenda.

The trainer/teacher

One of the mothers we have a close working relationship with as regards inclusive education was at the start of her professional career an extremely talented and promising research assistant at a university. In addition to the research she conducted in preparation of a doctorate, she was frequently asked by her promoter (who guides PhD students through their work) to work together with small groups of students in research seminars. This life came to a halt when she became a mother and especially because she became the mother of a son with Down’s syndrome. After an initially confusing time she and her husband started to look for solutions that fit in with the very clear education project that they had in mind. In this project language, solidarity, cooperation, a questioning and searching frame of mind, etc. played an important part. In their quest this family joined the Stichting Down Syndroom [Down’s Syndrome Foundation] and Ouders voor Inclusie [Parents for Inclusion]. And so a second career began for this mother. She first gave lectures about what their family life was like with a son with a disability. Then, in a next phase, she participated in research based on the way in which families in Flanders make choices with/for their children with disabilities. In her activities at the Stichting Down Syndroom she even went one step further: she got the opportunity to give talks to GPs in training about Down’s syndrome as experienced from the parents’ perspective. We should now go back a little in the

history: it was with some doctors that the mother heavily collided with soon after her son was born. For instance, she was advised not to breastfeed (children with Down's syndrome were supposed to be too weak for this) and she was incensed about some of the advice she was given in some therapeutic centres. But now she could present an information package about Down's syndrome to young doctors in training and talk freely about the sensitive issues that arise in the communication with fathers/mothers. 'I feel like a proper teacher', she often says, 'with this distinction that I am not speaking from my knowledge as a Master of Science but about my personal life story and emotions...'

It is clear that working with a large group of people around a child – professionals or otherwise – made experts in certain fields of the fathers/mothers going through the education process. A 'father-trainer' says:

...It is a sort of timeline, at different stages in the education process of our daughter different people have been involved. Initially they did not need anybody else in the classroom, a family support worker was involved and if there were special activities (school trip) my wife or I sometimes went along to help. Later on we were working according to the principle that we would pass on everything that could be passed on. And then we had student teachers joining us and volunteers and other fathers/mothers also gave their support for certain activities...

The bridge builder

In Belgium we have – just as in some other western countries – the system of a personal budget (in addition to the still prevalent collective provisions for persons with disabilities who need support). This system of financing means that the support for people with special needs is no longer arranged via collective care and support systems. The fathers/mothers of a child with a disability have a budget at their disposal and can use this to hire people or to pay for services for their child.

All this means that families can find the services that are needed to best suit their family, but on the other hand this brings with it a great deal of responsibility for these fathers/mothers. These people suddenly find themselves to be employers, something which is not always easy to combine with their role as father and mother.

With the many fathers/mothers that find themselves in this position due to this system, we see that the way they go about it varies enormously. Time after time we have been enchanted by one of the mothers who describes herself in her new role as a 'bridge builder'. We will illustrate this description of her position with two examples.

This mother/family manages to organise a 'Christmas party' every year to which everyone who means something to the family is invited. Due to the warm atmosphere in this family all year long, many people always turn up at this party. This includes people (e.g., teachers) who are no longer directly involved in the support of the child.

In this way the mother succeeds to involve the 'top supporters' who will use their expertise to support the situation at school. This elicited the reaction of one of the teachers that 'it is really comfortable to work in a class if there is this kind of support, particularly because they can help other children too'.

While we were working with this mother it became clearer all the time what she meant with her bridge-building metaphor. She ensures all parties feel comfortable and

lets people know that they are appreciated and welcome, in a way that is natural and without being pushy, but it does happen and it makes an impression.

The tight-rope walker

Fathers/mothers are experts in the 'art of balancing': in the learning process you always have to look for a state of equilibrium. Two parents who often look to find a balance, describe it as follows:

You never know beforehand. You don't know either whether her disability is the reason for what she cannot achieve. You are not sure what will be possible and what will not be possible. It is a matter of finding a balance and to push out the frontiers all the time. We encourage the nursery to try out things with our daughter. We have clear expectations about this, but we don't want to push it. We sometimes have to stop and think about what should come first, we must not expect things to happen all at once...

We see fathers/mothers also constantly balancing between 'normal' and 'special'. How do I regard my child? What does my child need? Which terms do I use when I talk about my child? What part does my child play in our family and wider society? Many fathers/mothers imply that they keep this as normal as possible, usually with their other children as reference. However, their child will often need extra attention, care and support. The father of Jan describes this as follows:

Jan is a boy who will always need extra care from us. All his life we have to consider carefully what is possible for him and how we can help him. He is definitely ill more often than our other children. But we still try to treat him the same as our other children whenever possible. We don't want him to become a spoiled brat. He is the oldest child of the family. The other children grew up with him. We always try to include him as much as possible and sometimes we will adjust the activities somewhat to make it easier for him.

The strategist/diplomat

Fathers/mothers often turn out to be seasoned diplomats. Communication is a recurring theme here. And in this communication the 'circumspection' in the 'open communication' is evident. Fathers/mothers often opt for an extremely strategic approach because of their 'vulnerable position'. One of the mothers we are working with, states:

I think that's why sometimes I think and act very strategically (with those from whom I definitely need support) because call it what you want, we are often only 'tolerated' in the school. Sometimes you will go and have a one-to-one chat with the principal, or you will raise something with the care coordinator or the assistants... You always have to weigh up the pros and cons, because after all our child is in a more difficult position. Other fathers/mothers tend to voice their opinion freely, but we, we have to think it over first.

Some fathers/mothers in this position are therefore always looking for strategic allies. Almost automatically they come into contact with all kinds of professionals, therapists, experts, etc. They are looking for an attentive ear, people that make them feel at ease, people that will not judge them but help them with questions

they have about their child. We see that fathers/mothers also try to find an ally who will help them to defend and support their child. Some fathers/mothers don't want to be on their own and don't have the required know-how about a child with a disability.

The warrior

Life with a child with a disability doesn't always run smoothly. In our opinion too little attention is paid to the situation of families with children with 'non/invisible disabilities'. The beautiful child with autism, the pretty child who is hearing impaired, the adorable toddler with a development delay... they often don't meet the expectations of the environment. And just because 'it doesn't show', other people often judge wrongly and think that the child is 'obstinate' or 'not brought up properly' or...

This is the case with Mathias, a good-looking boy who already from the first steps he was expected to make in his development could not (quite) deliver or who gets extremely anxious if he is expected to do something which he finds impossible to do. Initially he often caused his parents to feel 'disillusioned' too, but once they realised there was indeed a 'problem' they – especially the mother – stood on the barricades for him.

The mother went even further and indicated that she was willing to go on the warpath for her child. And a confrontation with this mother on the warpath is definitely not easy. She is extremely gifted in what we can call 'associative thinking' and can make connections in less than no time. Furthermore, she has studied law so when pushed to the limit she will put on a different hat and threaten with lawsuits and complaints. Our mother on the warpath fights above all for her son to have the same rights – regarding the right to diversity and support – as children with obvious, visible disabilities.

Fathers/mothers are obliged to have a list of all the arguments for the choices they make and to explain them to the outside world on various occasions. Their choices are often questioned and fathers/mothers feel that they have to convince people of their choice over and over again. The mother of Mathias writes in an e-mail:

What rights do I actually have here? Mathias has been diagnosed and that has consequences, but it seems that I am regarded as a mother who is being difficult and they just ignore me. I suppose their argument is that he attends a normal school and is in the fifth year, so he should be fine! This is very frustrating for me, because his autism won't disappear with age. When will we finally get the enforceable rights for our child? Or must we continue to be dependent on the goodwill of the school?

Fathers/mothers fight and will go on fighting for what they consider to be important for their son or daughter, based on the belief in the possibilities of their child. They 'get used' to dealing with opposition. They try to change and adjust situations to get what they think their child needs. If this is not successful they'll look for other ways. Fathers/mothers often experience that they and their child are isolated. One of the fathers we work with says:

If I get the feeling that they would like to put her somewhere else they've got the wrong man. It will make me react in a contrary way. I don't want to push things. If they ask me in a rational and pleasant way I will comply, but not like that, I've made my decision and

I won't change my mind. That is how I am. And to simply say that is the rule here...
Well, rules are there to be changed.

The explorer

At the University we often ask fathers/mothers to take part in lectures and presentations for students. One of the mothers we asked a few years ago for the first time to talk about her son and family did so, but she was very nervous about it. She found it quite daunting to be faced with the students and university. 'I myself am just a nurse', she kept repeating. However, she had collected a great deal of material, photographs, stories and anecdotes about her child. She indicated that secretly she dreamt of making them into a book. When we met later on, this mother seemed to have acquired a taste for studying and followed a Bachelor course in Family Sciences. She often mentions that in all this she discovered 'many talents in herself'. Earlier inhibitions disappeared to be replaced by reflections about the path taken by her own children, but she also had further thoughts about education and questions about education. In our most recent meetings our 'explorer' stated that she wanted to study for a university degree after her Bachelor course, because her new insights raised as many new questions and she definitely wanted to further explore these. She also says that she feels so much stronger now. That she used to be quite timid and hardly dared speak her mind, but that through the years, due to the situation with her son, she became much more self-assured. That she felt totally at ease in a meeting with the principal. Earlier on she wouldn't even have gone there. So, in addition to discovering qualities in her son she also discovered a number of talents in herself that up till then had been uncultivated.

Isarin (2004) states that the relationship between a mother and her child with a disability is not always reciprocal. Usually the relationship will still be regarded as being meaningful by the mother. The child wants to be taken *as it is*. The child touches the mother by *how* it is and *what* it is. The child changes her, her relationships and her view of and approach to life.

Interpretation

First and foremost we want to stress that we do not want to judge the value of any of the metaphors whatsoever. It is not about the right or wrong choices made by fathers/mothers here, but about attitudes and choices that are needed to make it possible for the fathers/mothers 'to live through another day'. It is not for nothing that Goodley calls them the 'philosophers of the day' (Fisher and Goodley 2007; Goodley 2007).

We are of the opinion that the metaphors we were able to collect were introduced in our communication by the fathers/mothers consciously and purposefully to make their own positions clear. In this way they try to build a barrier against the preconceived ideas of 'the parents' that were installed over the years. In this we follow Steen (2007) who is of the opinion that there is indeed a relation between the language used and cognitive processes.

Some positions (Maccartney 2008) (e.g., the manager, the warrior) are explicitly taken up by the fathers/mothers to protest against the defectological/deficit discourses used by some professionals (and their systems) for their children. Goodley (2007) introduces the work of Deleuze and Guattari to show that many practices of social care

are based on binary thinking, where children with disabilities are put in contrast with classifications such as 'healthy', 'normal' and 'fully participating' (see also Winance 2007; Maccartney 2008). These practices threaten to territorialise the mind, self and body. It is from these defectological discourses stated in the position 'Tintin in the land of care providers' that the parents are given advice about education, schooling, therapy, etc. that threatens to put them on the sideline. This advice is given by experts who underline their expert status by their specific techniques of classification, assessment and labelling and thus ignore the expertise of the fathers/mothers. It is also these processes that make the children end up in 'a special circuit', a circuit where because of their special needs they are seen as requiring a different 'treatment' than their 'normal' peers. With all this going on we see some fathers/mothers revolt and take on the fight.

A number of other positions (the bridge builder, the diplomat, the tight-rope walker) teach us about fathers/mothers who do not revolt as such but use 'clever strategies' to retain more control over the education of their child. These positions could be compared with a kind of 'working through' as introduced by Braidotti (2004, 29). This author describes the process in which people take up a position where on the one hand they do what is expected of them. On the other hand people make their own assessment of the position and look for new codes and opportunities. The fathers/mothers from our study use this very deliberately to improve the participation of their child, e.g., by finding 'important allies', by networking with people who 'can help' to realise the plan for their child, by avoiding conflicts with persons and agencies that you want to be on your side when you are trying to effect more participation for children with disabilities. Fathers/mothers are transformed in their position as a parent. This cannot just be described in terms of 'learning to live with' their child with a disability. The previous history and their experiences 'define' them in a certain way as a parent. 'Conditions for such a transformation are for the fathers/mothers: the ability to accept their child as it is, with the intention to make the best of it, the conviction that this father/motherhood is meaningful, building up confidence and the ability to live with uncertainty' (Isarin 2004, 154).

There are also positions (the traveller, the explorer) which show that people, in their role as 'father/mother' as well as in their personal development, sometimes draw on a special source of energy and consequently are far away from the linear thought that 'insecurity paralyses' (Fisher and Goodley 2007; Goodley 2007). These fathers/mothers will start searching, go on a journey (literally and figuratively speaking) and take unexpected steps for their child and themselves. They bring us to the concept of 'nomadism' as outlined by Braidotti (2004, 40): these fathers/mothers do not renounce their 'old self', but exploit the situation with their child with special needs to reinvent themselves (and their family). They show us that they possess exceptional intelligence and creativity. They show us that they excel themselves and at the same time get modestly flustered when they look at their own 'achievements', their own way of grasping opportunities, their own way of developing and exceeding their own expectations.

Fully in line with the latest versions of the labelling theory (Link et al. 1989) there are also fathers/mothers who choose a position as trainer/teacher. They don't place themselves – as in earlier versions of the labelling theory – in a kind of passive victim position, feeling they cannot compete with the people who attach a label to their children (with all the negative consequences of this label as a result). On the contrary,

they want to exploit the special situation of their child to supply information in order to prepare (future) professionals for a relationship with their children.

Finally we would like to make it clear that the fathers/mothers from our study do not let themselves be pinned down in one single position. They tend to tell us first about the position they find strategically important; however, most of them are flexible enough to fulfil various parts. In this way fathers/mothers show us how ‘revolutionary’ their actions can be, revolutionary in the meaning (Allan 2008, 67–9) of the description by Deleuze and Guattari: the action by which something or someone continues to become other [...] involving the invention of new forms of subjectivity and new connections [...] while continuing to be what they are.

Discussion

We are convinced that the results of our paper are equally valuable for professionals and for researchers. Though a lot has changed in the disability field, there seems to be a great dominance of the basic ideas that having a child with a disability leads to grief, coping and survival. It is as if the grief model of Kubler-Ross, for example, still dominates the way professionals think of and serve families. In this way they neglect nearly two decades of research about positive perceptions of families with children with disabilities, and they reinforce the medical model way of thinking, which holds that having a disability is a tragedy (Yuan 2003, 207).

Researchers are confronted with a ‘parallel dominance’: it is the ABC-X model that narrows the reality of a child with a disability in a family as a ‘stressor’ (Ferguson 2001). While using standardised instruments (mainly questionnaires) based on this model, researchers are building up an image of families that gives too little space to the existent in group variation.

With our paper we want to contribute on the one hand to the practice field while giving ‘real examples’ of the creative way parents are using images that do not fit into the tragedy model. On the other hand we want to show the research field that the analysis of narratives can provide evidence for the necessary variations to the one-model-fits-all research approach.

Note

1. *Snoezelen* or *controlled multisensory stimulation* is used for people with disabilities, and involves exposing them to a soothing and stimulating environment, the ‘snoezel room’. These rooms are specially designed to deliver stimuli to various senses, using lighting effects, colour, sounds, music, scents, etc.

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