

## UNCONDITIONAL FAMILY FOCUS &amp; THE COMPETENCE OF THE FAMILY

The first time I came to Copenhagen was in sixty-five (65) to buy cutlery, because I liked very much the Danish design and could not find what I wanted in my own country at a reasonable price. Forty years later, I want to thank very warmly the organizing committee who invited me. I don't need anymore to buy cutlery, but it gives me the opportunity to see once again the little mermaid that I love even more than the Danish design cutlery.

In 1995, I wrote a book untitled in French: "La compétence des familles". It is translated in German, Dutch, Spanish and Portuguese but not yet in English. The title should be: "The Family competence". I will first present the major ideas of this book, and doing so, I shall present my own way of working with families.

My first inspiration came from the book of a French historian, Jean Delumeau<sup>1</sup>: "Le péché et la peur", what could be translated as: "Sin and fear", of which the principal thesis is that, in Judeo-Christian Civilization, the base of the educational system is the fault to correct, by means of culpability: one highlights the mistakes instead of enhance the qualities. That's what I was going through as a child: at that time, there was no dishwasher machine, I was the dishwasher! When the washing-out of the dishes was well done, my parents did'nt notice and did'nt congratulate me, but there were much reproachs when only one plate was not all clean.

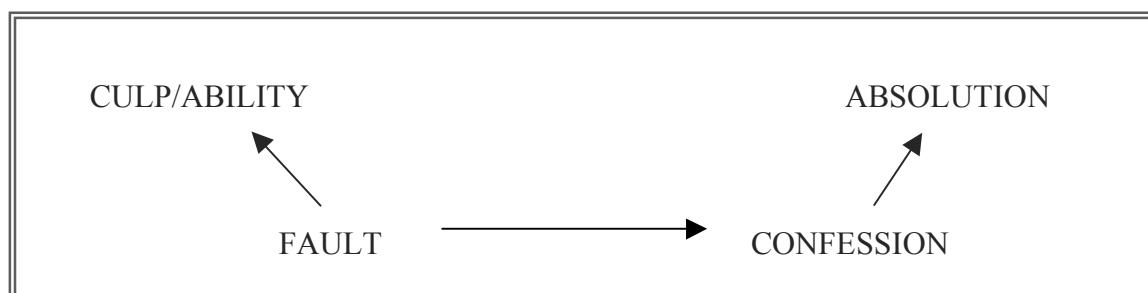
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1. Delumeau, Jean: "Le péché et la peur" – la culpabilisation en Occident", Paris, Faubert, 1983.

In my country, many parents still fear to praise their children. Since the original sin in the Bible was one of pride, they don't want their child to become proud and therefore don't praise them. The children then may encounter many difficulties in building a good self-esteem. On the other hand, many young parents, and often parents of disabled children, value too much anything their kids do. They are then at risk of developing a narcissistic personality and may run into many problems in her future life. Children need to be praised and acknowledged, and the happy medium is to praise them enough but not too much.

(I think it was also the dominant culture in Denmark, even if things have surely evolved since. There are two Danish movies that I like very much: “Ordet” from Carl Dreyer, that takes place in the 1930’s, and “Le festin de Babette”, (Babettes Gaestebud) from Gabriel Axel, based on a “nouvelle” by Karen Blixen, that takes place in the late nineteenth Century. In these two movies we see a very rigid protestant community, that doesn’t tolerate pleasure and even less pride. The fault and the sin are everywhere and modesty is a fundamental virtue. But in “Ordet” a little girl believes in her uncle Johannes’ word (Ordet) and that is what makes the resurrection of her mother. Her competence is her faith in her uncle’s word and the word makes the miracle. I will demonstrate that the word, the information, is essential for competence to emerge.)

This all brought me to think about the following diagram that shows the Judeo-Christian cultural context in which we stand:



The fault can be partly forgiven, one can even receive absolution if there is a confession. But one always remains with culpability and culpa-ability is literally the capacity to make other faults.

Inspired by the work of Brazelton<sup>2</sup>, I started to look closer at the notion of competence. Brazelton said recently in a preface in the “Pediatrics” review: “When I first began to work...at the time, we did not recognize an infant’s ability to make and respond to choices of stimuli from their environment...The infant was seen as passive...Yet, as a clinician, it was apparent to me as I examined newborns that they were far more competent than was thought and that the newborn influenced his parents’ responses to him or her in a significant way”.

I could say the same talking about disabled children. As a family therapist, inspired by the General System’s theory, I was mostly hearing about dysfunctional families, resistant and non-collaborative with the treatment. Applying this notion of competence to the family, my practice was radically modified. Instead of clients, I was now meeting with collaborators; instead of dysfunctional families, I was meeting with families who wanted the best for their child, I was working with parents who had unexpected resources.

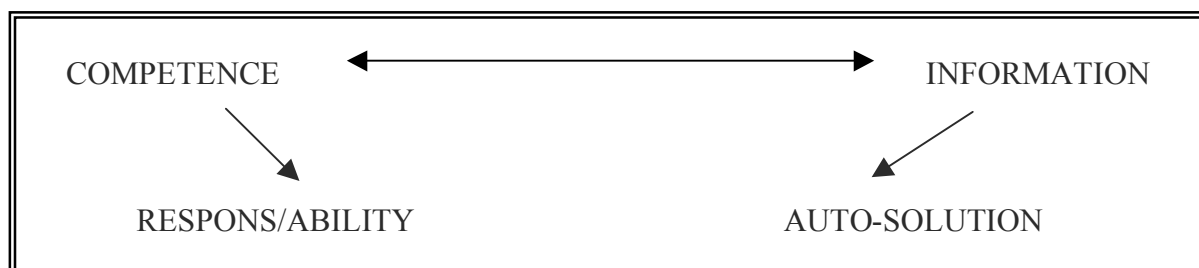
It brought me to my first postulate, I call the postulate of competence: **“a family can only create a problem that it is able to solve”** If a family has built a problem, they are able to solve it because they know how it is built. Thus, for competence to emerge we need to obtain information on what people know, on what they can do, instead of focussing on their lacks and failures, on what they cannot do. We are thus looking at information coming from the family and returning to the family, since members of the family hear what they are able to do. It’s my second

postulate: **“pertinent information is the one that comes from the family and goes back to the family”**

With this information, they find themselves competent; this same information becomes a resource that increases their competence in a real back and forth process. Progressively, new solutions will emerge from the interaction between family carers and the members of the family. This is what I call “auto-solution” because it is about an innovative solution that is appropriate to this family. The increase of competence allows the increase of responsibility, which I am translating in response-ability. Here we find again what Brazelton said: “infant’s ability to respond...” which applies not only to the child but to the family as well.

Having a disabled child is not a problem that the family, itself, has created, it is a problem that falls onto the family. In such a situation, we have to give the family information on how to deal with a disabled child. There are thus two kinds of information: the one coming from the family and returning to it and the other one coming from the family care worker.

So I have replaced the previous diagram with one centered on competence:



When we are talking about competence, we mean the capacity to find new resources when we are confronted with a new problem that presents characteristics similar to problems previously encountered. The notion of resources is found in the center of competence since resources are the ones at work for solving the problem. Without resources, there is no competence. We, as professionals, are the resources.

This was a kind of introduction to what I 'm about to present. We will now see how the notion of competence and resources can help us to work with disabled children and their families. I will not speak only about family respite but first about the problems a family with a disabled child is confronted with. I will present later the model of family respite that my team and I have developed in Quebec. Let's look first at the parents, then at the disabled child and finally at the professional care worker.

**First of all, the parents.** The mother of a trisomic child once told in a congress the following story (unfortunately I don't have the reference):

“You are in an airplane, you are going to live in Italy, in a marvellous place in Toscana. When the plane is about to land, you hear a voice saying ‘we just arrive in Schiphol, airport of Amsterdam’. Then you say ‘there must be an error, I'm going to Italy, Toscana. I learned a bit of Italian, but I don't speak a word of Dutch’.

Then the hostess says ‘ it's sad, but you are landing in Amsterdam and this is where you are going to live’.

- ‘But I don't want that.

- ‘But that's your reality. You will now live forever in Amsterdam’.

- ‘Amsterdam is a very nice place that I love very much (like Copenhagen!), but it’s not there that I want to live’,
- ‘But you have no choice’.”

This is a nice metaphor of what parents have to live with a disabled child, at the birth or later: disillusion, anger, resignation.

The parents with disabled children that we meet may present themselves in various modes, more often in opposite positions:

- collaborative or aggressive and demanding;
- hyperactive or depressed, exceeded and exhausted;
- overprotective or rejecting.

They are hurt and their reaction is more often what I call a legitimate defence. But what characterize them all is **culpability**:

- culpability of having giving birth to a child that is not like the others;
- culpability of having been disappointed and to have tried to reject him;
- culpability of not having been able to do more and
- culpability of having to delegate a part of the cares to professionals.

It is this same culpability who underlies their aggressive attitude: aggressive because guilty, depressed because guilty, overprotective because guilty, and so on...

As care workers we cannot eliminate this culpability but we can work to replace it as much as we can by responsibility. I translate responsibility into **response-ability**. How can we work in order to implement their ability to respond first at their own needs, wishes and dreams, secondly to the needs, wishes and dreams of their children?

A girl of fourteen years old did not go to school for four months and had stolen money from her mother. A social worker was sent to evaluate what the problem was. When she came in and wanted to sit at the table, the mother said: “don’t take that chair because my son risks to bite you”. There was a boy of six or seven years old beside her who looked “bizarre”. Then the mother explained: “my son is an autistic child and he dislikes foreign persons. He had a car accident six months ago and spent three days in coma and three weeks in the hospital. Since then, he is at home, and I am exhausted and I have no time to look after my daughter. Luckily, she helps me very much, otherwise, I would have fallen into depression.” This mother was no more able to respond to her daughter’s needs but neither at her own needs. The first thing to do was to help the mother respond at her own needs and later on to the needs of her son and of her daughter. I will come again later at the situation of the girl.

To implement response-ability, we have to be convinced that they have the competence to achieve new goals. We have to search actively this competence. And, as I said before, competence is based on resources. Parents have many resources, but, often, they don’t know they do. Consequently, it is our job to reveal to them these resources that they don’t know they have.

In order to do that, we have to change the **representation** we have of them. We often forget that we don’t work with the real parents but with the representation we have of them. If our representation is a negative one, we increase our chance of having a negative relation with them. If we look at the competences of a person, at her qualities, at her abilities, we have a great chance to find them. If the social worker had seen this mother as incompetent and neglectful, nothing then could have been done. By having a perception of her as probably competent but now

exhausted, a good relation could be built with her first, and with her daughter later on. I will come back later on what happened with the daughter. We are responsible of the representation we have. It is the ethical dimension of our work.

We don't need to understand the parents but we do need to help them discover their own resources, the ones they know they have and the ones they don't know they have. Anyway, we will never be able to understand what their living is, and more often, by saying: "I understand", we hurt them more than we support them. What can the social worker understand of the life of a single mother living with an autistic child and a difficult teenager? What can she understand of her distress?

We don't have to define the goals the parents need to reach, but we do have to help them to see what they do best. We certainly don't have to judge them on what they do, but we do have to reassure them on their competence. Even me, as a father don't have all the competences but I have competence. Parents have, too many times, been judged by professionals, saying that they were too much like this, or not enough like that...

The usual attitude of the professionals is easy to understand because we, as professionals, are surrounded by the Judeo-Christian culture centered on fault. In our trainings, we have learned to look what goes wrong instead of looking at what goes well, we have learned to look at the symptoms and not at the resources. Usually, we see immediately that a mother is overprotective toward her children and we don't notice that she is above all a loving mother. We also see the authoritarianism of a father and we don't see that he wants mostly for his children is to be well and successful.

In summary, we have to approach the parents with great respect and a firm believe in their competences. We have to look actively at their resources. We don't need:

- to understand them,
- to define the goals they have to reach,
- and certainly not to judge them.

**Now, let's look at the children.** Handicapped children do not have only handicaps, they also have competences. But often adults surrounding them, by generosity, by pity, by compassion or because they are discouraged and don't believe anymore in the resources at their disposal, these adults don't give handicapped children the opportunity to reveal their competences. That's were a short break can appear particularly useful.

Indeed, all the children of the world don't act the same way when they are not with their parents, and, even often, they act quite better. It is the same with handicapped children. Let's take an example: a 14 years old boy with Asperger autism had never ridden a bike. He comes to our place for a weekend respite. He sees the other children riding a bike. He seams interested. The educator proposes him to try. He says no. A little while later, he comes back to the educator and tells him that he would like to try. The day after when his parents come to get him, to their great astonishment, he his all proud to show them that he can ride a bike. They had tried before to show him how to ride a bike but he had always refused saying he was too afraid to try, and his parents, of course, didn't want to force him. In a different environment, with the educator's proposition and seeing the other children, it allowed him to overcome his fears.

I would like to speak now about a subject that we rarely speak of and that I affectionate very much: **brothers and sisters of handicapped children**. When we speak of the burden of family caregivers, we mostly think of parents and sometimes grand parents. Most of the time we forget the siblings. However, they have a heavy burden to carry too. But they don't complain and even sometimes don't realize the sacrifices to which they must agree. Since a long time they have heard their parents telling them: "I don't have time for you, I need to take care of your brother, of your sister", or "manage yourself, you are lucky not to be handicapped", or "can you take care of your brother, your sister, I have to prepare diner".

Let's come back to the story of the fourteen years old girl with an autistic brother. Why did she leave the school for four months and stole money to her mother? One day, four months before, her mother asked her to go buy a pint of orange juice. When she came back with the juice, she met a group of teenagers of her class in a park. They asked her to have juice because they were thirsty. She gave them the juice, began to discuss and finally came back at home at eleven in the evening, without the juice. Her mother asked her why she came back so late, started an argument with her daughter; the girl decided to run away for the night. Since then, she didn't go back to school and stole money from her mother to buy drinks for her friends in the park. She later explained that, since the car accident of her brother, she had no more time to herself because she had to make up for her depressed mother who was no more able to do her job. She thus decided not to go to school anymore and to take a little recreation with her friends of the park. If the social worker had not taken into account the particular situation of this sister of a handicapped child, this girl could have been labelled as truant or even delinquent. That's the end of the story.

Most often weekends and holidays are planned around the handicapped child. Again, the other children have to cope with that reality. And sometimes even, when a family has a mentally or intellectually disabled child, other members of the family avoid inviting them. They say: “ We would invite you, but with him, or her, it is too difficult”. The siblings cannot thus see their uncles and aunts. For the non-handicapped children of the family, a weekend with the parents entirely available for them is very precious.

Sometimes they overreact but they don't dare to say or even to think that the disabled child is the cause of their own problem. The brother of a young girl dealing with mucoviscidosis or cystic fibrosis began to show signs of obsessive-compulsive troubles three years after the birth of his young sister. At 14 years old, he was gravely affected and invaded by obsessive-compulsive rituals. The psychiatrists that had treated him knew that his sister was sick but never established the link with her pathology. When they exposed me the case, I immediately convened a family meeting. And then, in a very moving way, the young girl immediately established the link between her own disease and that of her brother.

Fortunately, most of these brothers and sisters do not develop pathology. On the contrary, they are shown often brilliant, as if they wanted to compensate for their parents the deficits of the handicapped child. They are also often shown very autonomous because they quickly realized that their parents did not have the time to take care of them and, being so, that they had to manage by themselves. Becoming adults, they often choose a helping related profession. Maybe there are some in this room today... A little part of them may become depressive as adults because they had not really the opportunity to live their childhood because they were parentified.

But that can easily be cured by narrative psychotherapy, acknowledging them all what they did as a child.

So what can we do for them? It is not really about taking care of them but to bring the parents to be aware of the fact that the non-handicapped children also need their parents, that they need to be praised, that they need their recognition. One day, when I was talking about the same subject during in a two day conference, a mother came to see me during the break of the second day. She had been astonished by what I had said and had talked about it the previous night with the brother of her trisomic child. She had asked him: “ Do you think that your brother takes too much space in our life?” And the brother answered “No, because of course you had to take care of him, but there is one thing that I would reproach you and that would be, that each time that my brother was successful in something, you congratulated him very warmly and talked about it to everyone. On the other hand, each time I was successful in anything you would not even notice it and certainly would not talk about it to anyone. As an example, you never really congratulated me for my results in school”. This mother really regretted that nobody had ever pointed out to her the difference of attitude she had with her two sons.

**Let's have a look at the family caregivers** who are confronted with a family with a disabled child. We, as professionals, are very lucky: we have learned how to cope with disabled children, we know what is good for them and how we have to react or, at least... we are supposed to know. The parents don't have that chance. There is no school where to learn how to be parents. It's already difficult to be good parents with a normal child, it is even more difficult with a disabled child.

Because of this lack, we have to give them information on how to do. But we don't need to be lesson givers. We have to start from where they are and progressively suggest them to modify some attitudes. We have to be very careful because parents are already so hurt by the handicap of their child that they can react very heavily to our suggestions. We have to coax them, to influence them by gentle persuasion. In French, there is a word with no translation in other languages: "apprivoiser"; it's close to tame or domesticate a wild animal. But naturally, you may not say domesticate a family.

Let's take an example. My sister-in-law lives in a house in the woods. She noticed that a racoon came frequently around the house and decided to try to tame it. She tried to give him food but the racoon flew immediately when she went through the door. Progressively, it came closer and after three weeks, it accepted to take the food from her hand. The following day it came with three little racoons because it was a female and now that she had confidence, she brought her children.

For me it's a marvellous image: it takes time to allow somebody to approach us. Remember the story of the racoon when you have to approach a family. As I said before, the parents are hurt and need to be carefully approached. Remember that you have plenty of time before wanting to change something. Remember that before trying to change something, you have to collect information on what the family can do, what they can do and what they cannot do. Never point out what they do wrong: frequently they know what is wrong but they don't like somebody else to tell them. But don't forget to acknowledge each of their successes. They need as much recognition as their children do. But above all, repeat to them regularly that you do see that they love their children.

Last but not least: don't let the burden of your job bring you to a burn-out. You have also to take care of yourself. You are generous but you don't have to become a victim of your generosity. I always say in my trainings: "look at your own comfort; if you are not comfortable, how will you help others to be comfortable". And you also have to care for your own family first.

### **Our family respite "les Quatre Vents" (the Four Winds) in Québec**

Ten years ago, in 1998, the regional authority and the government gave me the opportunity to propose a project to cope with children and teenagers with double diagnosis: mental health problems and behaviour problems.

My first proposition was to create a foster home where they could stay for several months or even years after the psychiatric hospitalization\*. The main goal was to give those children a life as close as possible as the life of other children of the same age. The four pillars on which we built the project where:

- Individualize: each child is taken care of by a care worker and the goal is not to include him in a group.
- Depathologize: (it's a word that I have built) that will say not to put the focus on the pathology: they are just children and not only sick children.
- Socialize: because more often they were desocialized after years of psychiatric intake.
- Working with the family: therefore in each unit, we provided a "parent's room" so that parents could come for one or two days to share the life of the unit and of their child. This facilitated very much the contacts between parents and care givers and was a source

of pride for the children. Every month, a family meeting takes place and every week, at least one telephone call is made. The parents are really our collaborators.

My second proposition came after an inquiry with more than forty social workers. I realized that many families kept their disabled child at home and that they needed help to cope with the burden of a mentally disabled child or teenager having behaviour problems. We decided thus to create a family respite. Therefore we built three studios\*. Luckily enough for us, the center is located in a very nice region, front of a large lake\*. Most of those families are poor and don't have the possibility to take vacations. Coming to our campus is a kind of luxury for them. The context we offer them is:

- The whole family comes for a week-end in a Bed & Breakfast mode so that the child care workers can take contact with them and learn how the family functions.
- After that, the mentally disabled child can come alone for three weekends.
- Again, at the fifth stay, the whole family comes again for a weekend and the cycle starts again. Naturally, the weekends are not every week but every fifteen days or every month and also for a vacation period.

For the foster home, it is not a burden because most of the children who are institutionalized return in their families for the weekend. The rooms are then empty and can be used for the respite. It's not a big expense because we have some children who may not return for the weekend for many reasons and we need thus to have care workers working through the weekend. Thus we don't need to have more staff for the family respite.

The main benefit is that the care workers can deal part of the day with the family, discuss with the parents and sometimes give some advice. There are also shared activities like skiing or swimming. Under this circumstances, a kind of modeling is then possible because parents are able to see how care workers cope with their children. We are not talking about family therapy here: we consider that we are professional care workers and that the parents are natural care workers, thus we are colleagues ! And you don't have to do therapy with a colleague.

**My conclusion is:**

- that every parent has competence, even the worst one, but that one does not always have all the competences one needs;
- that every disabled child has competence even if he or she has not all the competences we wish he or she had;
- that every sibling has a heavy burden even if it does not demonstrate it and that sibling will also develop large competences;
- that every family caregiver has competence but that he has the main duty to take care of himself and of his own family, to do what is needed to feel himself comfortable.

That's what I wanted to say. Thank you!

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