

PREVENTING THE RISK OF ABUSE

THE RISK OF ABUSE IS A VERY REAL ONE. TALKING AND EXCHANGING OPINIONS ON THIS MATTER IS IN ITSELF A WAY OF BEING ENGAGED IN PREVENTION.

by Yannick Besnier

First let me say something about who I am. I'm currently vice president of AFPE (www.afpe.org), an association concerned with professional training in education and social work which operates 3 training centres for social workers in 3 cities in Brittany.

For 11 years I was director of an IME, a medico-educational centre run by the Les Genets D'Or association (www.lesgenetsdor.org). This structure provides assistance for children, adolescents and young adults with mental disabilities and developmental disorders, many of them autistic. It has a maximum capacity at any one time of about 60. Of these, about half are provided with residential accommodation on a weekly or fortnightly basis, while the others attend the centre on a daily basis. Some young people are also hosted on Saturdays and Sundays and during the holidays. This is the case with severely handicapped young people whose violent behaviour renders normal service provision within the family difficult.

I have personally encountered two cases of maltreatment in families and one involving a social worker within the structure, and these experiences have convinced me that the risk of abuse is a very real one and that, alongside help and support for families, a voluntary policy of prevention must be designed and put into practice.

My report is divided into 4 parts.

1. Understanding the parents of a disabled person. Why does the risk of abuse exist with the family?
2. What are the key elements in the interaction between families and social workers? In order to build a policy of prevention within the family itself, what should be accepted and acknowledged?
3. A prevention policy for families, within the IME.
4. A brief conclusion

1. Understanding the parents of a disabled person. Why does the risk of abuse exist with the family?

We know that it is very difficult for parents to accept the birth of a disabled child. It calls into question something that is essential for the happiness of a family: the joy of giving life. Instead of the expected happy event, a birth of a different sort occurs.

The dreamt of event does not take place.

No parent is ready to suffer an injury so insidious, so irreparable. Handicaps are something that happens to others and yet now they find that disability is part of the family. It hits the family like an act of aggression, a scandal, a crime perpetuated by nature against herself. The new born child leaves his/her parents shocked, different, gutted ... The celebration of birth turns into disappointment, sadness and suffering. It seems so unjust.

Happiness has fled, life abruptly darkens, and the doors of the future seem to have shut.

How can you cope? And what can you say to others about this cruel ordeal?

How can you communicate the sense of absurdity, the disillusionment wrought by a birth that has become a tragedy? How can you share what cannot be shared, the experience of a happiness stolen by fate? How do you learn to live with the many and continuous sacrifices it demands and at the same time hope for some degree of serenity?

Faced with these existential problems, it is understandable that parents develop psychological defence strategies, that they look for shields with which to protect themselves and that will enable them to deal with a situation fraught with anxiety and anguish.

Some deny the reality of the disability, others forget themselves and devote their lives entirely to their children, others immerse themselves in the responsibilities of work and associations, and still others establish a self-reliant existence in which the symbiosis with the child goes on getting stronger and stronger.

All of them seek to anesthetize their more painful feelings in order to protect themselves and go on. Despite such strategies and the attempt to distance what is most painful, parents are often exhausted by their child's unceasing need of support.

They have less and less left to give and their defences are eroded.

Everyday parents face heavy burdens and uncertainty about tomorrow.

There is never any relief, they survive with difficulty. They do not have space for themselves, they struggle to keep alive their life as a couple. There is less and less space for other children, for brothers and sisters, because the disabled child takes so much of their time.

For us social workers, it is important to understand this context, because the anguish and suffering that characterize it can favour the emergence of violence - of physical and psychological abuse.

Their children behave in ways which are incomprehensible, irrational, insane. And such behaviour continues without respite, everyday; there is nothing that that the parents can do: it is wearying to the point of exhaustion.

Such repetitive patterns of behaviour would severely try the patience and resistance of anyone ... How can these tensions be avoided? How can you react calmly when what is happening to you is profoundly and intimately unsettling? How can you avoid reacting violently to all this?

2. Key elements in the interaction between families and social workers: what do we have to accept and recognise about the families concerned in order to construct a policy for the prevention of risk within the family itself?

We must

- recognise that the parents of a disabled child bear a burden of suffering that is cruel and permanent.
- accept that they should be able to express it and that they should be listened to.
- recognised that the disability of a child is unacceptable in itself but that this does not mean that the child is not accepted.
- recognise that everyone in contact with a handicapped child reacts deeply with rebellion, anger, anguish, vexation ...
- consider the whole family group with whom we work and the resources and needs of each of its members: children, parents, siblings, grandparents, and even friends and neighbours.
- know how to share the knowledge parents have of their own child, of his/her habits and rituals, as well as their ideas and views. (They know their child much better than we do).
- know how to share our knowledge of disability and of that of the child with his/her parents – of his/her needs and capacities – and recognise what we don't know.
- share and construct projects with them, work together to establish the best modes assistance and support structures, and set up networks of help and support.
- accept that parents can give other parents advice, help and support (peer counselling) that we professionals can not offer.

These elements form an ethical foundation for dialogue and cooperation between professionals, users and their families. They are pre-requisites for the active participation of parents in the education of their child, the corner stones of an educational project in which professionals and parents are involved as partners.

This co-educational road may be long or short; it will go through changes; there will be many meetings of various kinds, individual and collective, with professionals, with other families. It is in these various forums that the members of the family will be able to express not only their desires but also their difficulties, their expectations, their problems, their feelings and their resentments. Such forums are essential for parents as a source of help and support because they provide them with an opportunity to begin to accept the unacceptable.

3. A prevention policy for families. What do we do in an IME?

The service charter given to each family immediately upon insertion of the child in the service (in accordance with legislative requirements 2002-2) specifies the IME's policy with regard to family participation and its current requirements, including the meetings in which parents can participate. Obviously, the principal objective is to ensure that parents have opportunities to express themselves, but not only. The aim is also to provide parents with a means of transforming words into action. Parents are expected to be the real protagonists of the project that concerns their child, and they must know what part they have to play.

Promoting self-expression on the part of the mother and the father of the child, and also of siblings, is a way of reducing parental anxiety and of providing reassurance about how they are doing things and how they relate to their disabled child.

Such a strategy also functions as a way of helping mothers and fathers to express their differing points of view, for example, concerning the future of their child. Such issues can often give rise to tensions and conflict ... and even to separations.

This involves understanding their anxieties and their feelings about, or resentment towards, their child. It means understanding their desire of violence at times when it becomes impossible to communicate, when nothing can calm or appease their son or daughter, when their child cannot sleep and is causing sleepless nights for the whole family. It could even be a matter of trying to understand their wish that their child would die...

It is also important to promote relations with other parents through meetings and through sporting or festive events organized by volunteers, and to encourage them to join parents' associations. The goal is to create a sense of solidarity, the feeling that they are not alone in struggling against disability, and to enable them to discuss different ways of doing things, their difficulties and their sense of guilt.

Talking to others enables parents to realize that they are like everyone else (those who have a disabled child), that the difficulties encountered are the same, that sometimes other people have bad

feelings too, that others are tempted to violence too ... all this reassures, encourages and placates their sense of guilt.

What are these meetings, these opportunities for self expression?

The first meeting at the IME is important. The couple is invited to attend and a lot of time is needed because parents often want to narrate their history and tell the story of their child.

This first meeting takes place with the Director in his office.

Often, parents tell us that the enrolment of their child in the IME means that they have lost hope – hope of seeing their child in a normal school, in normal situations like other kids.

This first meeting is also important because the Director will inform the child's parents of what is expected of them, telling them that their presence and their commitment are essential, and that the involvement of both of them is highly desired. Parents are made to understand that the IME project for their child involves a series of meetings of various kinds and that their participation is important both for themselves and for the life of the structure.

We call the second meeting "the meeting after the synthesis". It is led by an educationalist. At this point there has been time to observe the child, to prepare a report based on the observation and to design a project specifically for the child. The report and the project are mailed to the family 15 days before the meeting so that the child's parents have time to familiarize themselves with its content and formulate their own reactions and criticisms. This is a critical moment because we're informing parents about a project concerning their child and we need to hear their views and benefit from their experience and advice. We have to respond to a multitude of questions from the child's parents and deal with their anxieties. The child is involved in all the meetings, either for the whole duration of the meeting or for part of it, for as long as s/he can remain attentive. The child's presence is certainly important for the child him/herself, but it is also important for parents who do not normally have the habit of speaking of their child in his/her presence, because s/he is disabled and can not understand what you say....

We take advantage of this meeting to also talk of siblings, grandparents, life in the home, neighbours ... and of the future.

Following this meeting, the document called "individual case" is amended if necessary, and sent to the parents for their signature. The project description highlights its objectives, and the commitments made by the professionals and the parents.

During the school year there may be a third meeting if it is necessary. It can be requested by the family or by the professionals involved with the objective of clarifying observations or objectives; participation is not obligatory however.

Another important meeting is that of the social life committee (every 2 months) which is attended by representatives of users (the people with disabilities), families, professionals and management. This meeting is concerned with the functioning of the structure, projects and their implementation, and the problems encountered by each and all. These meetings play a vital role in the life of the structure because this is the only time that all the people involved in individual and collective projects can be found around a table together. It is at these meetings that we decide, together with parents, what arguments of interest to them will be the subject of the evening meetings organized to discuss a particular topic.

There are two topic meetings per year. They are conducted an outside expert on the chosen theme. An outsider is preferred because it is felt that in this way parents feel freer to ask questions and express their point of view with regard to the IME.

The themes chosen over the last few years are indicative of the questions which are uppermost for parents... for example:

- The situation of siblings when there is a disabled child in the family
- The sexuality of disabled children
- How to tell a disabled child about the death of a dear one
- Relationships with other members of the family
- Drugs, why and how
- Care and guardianship after the death of parents
- Relationships with professionals
- The methods used in educating young people with autism
- Violence – of one's own child and that of other young people

Apart from the issue under discussion, the exchanges that take place between the families involved during these meetings are very important, and sort for. They represent an goal in themselves. It is important that when one family asks a question it be answered by another family, that they can talk together about their experiences, that they have an opportunity to recognise that they face the same problems, have the same worries, that their experiences may be different but they are in the same situation, and that despite everything they will manage...

The object of these meeting is therefore to create solidarity between parents and to establish relationships of aid and mutual support.

Answering a question asked by another parent is in itself part of the solution.

It is important to remind families that are not alone in experiencing the consequences of disability. Even if its manifestations are not without shortcomings, social solidarity is essential. It is precisely in this kind of meeting, in front of other parents, that I have heard parents talk about their violent

reactions, their desire of death, their longing to escape or to have free time, their overwhelming sense of helplessness when faced with certain kinds of behaviour or madness...

I have often found that these meetings help parents to express themselves not only during the meeting but also after it. I have heard of parents who have phoned each other, who have met in each other's homes ... of cases in which sharing a means of transport has created an opportunity for discussion.

Meetings of this kind offer parents an opportunity to get over their own suffering through an interaction with others which is healing of their self-image.

Family days are another high point in the life of an IME. They are held two Saturdays a year during the months of September and June.

These meetings aim to foster a better understanding of the IME and to bring together family members and professionals. At these meetings, in the course of which it is possible to visit all areas of the IME, each group and class presents its projects and there are plenty of opportunities for exchange. Our objective during these two days is enable professionals and the families of the young people we assist to spend time together in an atmosphere which is as friendly and relaxed as possible (eating together, going for walks, playing games together etc ...).

Family days are all about meeting parents outside meetings (not all families are comfortable in a meeting around a table and some prefer more informal situations like lunch). Lunch is also a time to laugh, joke, have fun. And this in itself is unusual: normally we are quick to laugh at remark made by a 'normal' young person but less ready to do so at one made by someone who is disabled. Family days also serve to integrate the families of young people who have just been inserted into the IME.

We finance family days through seeking sponsorship.

On these occasions, especially during lunch, I have often heard families talking about the problems they have at home, the spankings that some fathers have given to their children, and the sense of guilt that they have had afterwards, the moments of discouragement, their sense of guilt for having entrusted their son to the IME while they went skiing with the other children. I have heard them talk about being at the end of their tether at weekends or of sleepless nights, of having to get up at night and walk with their child because it is the only solution that they have found ...

I have heard parents giving tips to others, grandparents talking about the difficult lives of their children, brothers and sisters talking about the shame they have felt when their friends and girlfriends come home ..

I have heard brothers and sisters say that they never invite anyone home ... and parents explaining how they lived in seclusion for fear of inviting friends and neighbours ... because sometimes it goes wrong.

Such moments of sharing are what family days are about: they seek to create encounters and promote solidarity. When things are at their worst, families are more tolerant of words spoken by one family to another than those of a professional, however sympathetic and helpful.

By way of conclusion

Talking about their problems and experiences, expressing and exchanging opinions, answering questions put by other parents, narrating their experiences: these forms of self-expression are essential for the parents of a handicapped child.

In my experience the most important things we can do are to encourage exchange between parents, give priority to their experiences, and help parents form informal networks of support and mutual aid.

I have not talked much of maltreatment. We rarely talk of it within official structures. We professionals are seldom aware of violence in families. But we know that the potential for violence is ever present because the concerns, anxieties, and difficulties of coping with disability are factors that weaken the parents and make them fragile.

So what I want to leave you with is that sharing is essential when you are the parent of a disabled child. If we want to prevent the maltreatment of disabled children, this is the road to take. But taking this road together is time consuming because it is difficult to come to terms with grief. Can you ever come to terms with it? All the more reason to talk.

Thank you for listening.

Yannick Besnier
Vice President of AFPE

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