



F.I.A.D.D.A.
Sezione AGAP di Torino

in partnership with



PRESENTS:

Sentiamoci Amici

*three days of sessions of group-work
dedicated to discussion of the experience
of parenting deaf children*

Saturday 28th April – Saturday 19th May – Saturday 9th June 2012

co. Casa Oz - corso Moncalieri 262 Turin (IT)

conducted by Paolo Brusa¹

Introduction.

The participants gathered at the premises of Casa Oz in Turin during three Saturdays between late spring and early summer of 2012.

The meetings were organised by Fiadda Association to enable parents to share their experience of parenting deaf children freely, giving participants full liberty of expression under the guidance of a psychologist.

In the same premises of Casa Oz, parallel to the group-work sessions, specific areas were organized to allow children to play freely in the presence of trained educators.

The aim was to enable:

- parents to dedicate some space to themselves;
- children to play, interact and relate to other children with hearing difficulties;
- hearing brothers and sisters to interact with each other, having the chance to experience a place of encounter and to reflect on the beauty and difficulty of being the “normal” children.

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Participation in group-work.

The group agreed on a few, defined rules: no value judgements; no judgements regarding right and wrong behaviour; recognition that all choices are up to the parents; although sharing of experiences is important, it's important to leave the technical and medical advice to the professionals on whom the families relied.

The meeting attendance was high, though fluctuating: the first and the third meeting saw the participation of more than two dozen of parents, while the second was more "intimate", with the presence of about a dozen parents.

Methodological approach.

The approach is based on the methodology of group-work and of sharing between peers: it leaves parents with complete freedom in terms of what and how to express themselves, taking care to give space to everyone.

The group creates a dimension of togetherness in which participants open the door to a thinking about possibilities, to a personal and intimate dimension of dialogue and shared affection.

Especially in the two most attended meetings, it was necessary to limit the time available for each speaker under a common accord between the participants and the facilitator. Participants respected the time-limits, without interrupting each other, and limited the comments on the various contributions.

However, the smaller group who attended the second meeting, enjoyed greater sharing among the participants, in a more "intimate" dimension which made it possible to talk at a more in-depth level about each contributions.

The group has thus become a space to "be with ...", to get closer to emotions and to imagine the development of a shared project.

Feedback.

The group agreed with the facilitator's proposal to structure the contributions from all three encounters in the form of a collective summary. The aim is to give witness to the richness of experience

recounted, as well as to facilitate the dissemination and the transferability of the initiative to other contexts.

To ensure privacy, the group agreed to collect ideas, comments and experiences: they have been divided by issue into five separate areas, with no indications of the speaker and with no time-references.

Contributions from the participants.

The themes that emerged during the three days of group-work were collected following a progressive logical framework from the outside context to an inside, more intimate and personal world. These are the resulting areas, divided into:

1. external and background experiences, from the diagnosis to the medical environment
2. relations with the familiar context, from grandparents to uncles, other relatives, friends and neighbours
3. own family and the relationship between brothers and sisters
4. the relationship of the couple
5. the individual's intimate, inner world

Thoughts, reflections, feelings and experiences that participants offered to the group all represent an open contribution; as a parent said «... it is important to leave a message to those who are and to those who will face the same problems, so that they will feel less lonely knowing that others have had similar experiences ... ».

1. External and background experiences, from the diagnosis to the medical environment.

The first issue at stake regards the time when parents first face the real situation of their children: it is the moment of diagnosis, which is often a shock.

Many parents experience feel as though they are falling into a "chasm" that threatens to negate the known coordinates of meaning, creating a state of utter helplessness and confusion.

This often means parents engage in an endless cycle of research and hope, trying to deny the reality of the illness.

At this early stage, it is essential to support parents to share their angst: when a time and space to process and elaborate their feelings is offered, opening the way to some relief so that, after diagnosis, parents can understand what it is really happening. In this case understanding is not necessarily linked to acceptance, which may come later on, with great difficulty.

The diagnosis is also the first moment when parents begin to deal with the medical environment, with everything implied by the hearing deficit of their child, with concepts such as disabilities, normality, hearing impaired...².

It is the time for anger: listening to medical expressions of the deficit accompanied by reassurances that "everything's OK" is difficult for a parent to accept, since they know that, from an emotional point of view, there is nothing "OK" about their situation.

Choosing the medical team to trust is a delicate problem and is central to moving forward. Parents must choose the medical team which will support them most, and who are perceived as able to help in remembering that miracles are not of this world, and to help parents to get to the point where «... enough is enough, let's come to terms with it and do something for the future of our children...».

2 Evelyn Glennie gives an enlightening account in "*Disability Essay*": «...It's up to you whether or not to talk of "special needs", "hearing impaired", "handicapped" or simply individual ... By definition, being disabled means that I am not able to do something. However, except for a few minor inconveniences, I am not disabled from achieving anything in my career or private life ... it was not a question of breaking through my "handicap" and then competing with "normal" people. I have never considered myself as anything other than a "normal" person in the first place. I view my hearing impairment ... the injury doesn't define who you are, it doesn't take you out of the realms of being a "normal" person ... In fact it's completely irrelevant to what you can achieve in your work or your life. Like everyone else in society, regardless of my legal status, I am physically handicapped. For instance, regardless of my desire I can never be a professional heavy-weight boxer, a supermodel or a famous tenor ... Like all other people, regardless of any so called "handicap", there are certain jobs I can't do due to my physical attributes. However, I can't excel at hundreds of other jobs because I either don't want to or I believe I am not sufficiently talented. How we categorise ourselves and where we fit into our own framework of understanding leads the vast majority to the belief that they are unable to achieve the highest levels of attainment in their chosen field of endeavour. This a far greater handicap and disability than virtually any physical problem I can think of, with the exception of death!! From politics to theoretical physics and numerous other examples besides, there are people whose careers prove that the biggest handicap is the framework of understanding in which people place themselves, and that even the severest of physical difficulties are at most secondary.»
(ref.: Disability Essay: www.evelyn.co.uk/literature.html)

Parents might come in contact with medical teams that they perceive as rigid, aggressive, with no, or little, attention to the patient.

The fact that the patient is their son or daughter, might lead to an inexpressible rage, leading families to move to services where they feel more accepted.

Once the service has been chosen, parents feel an emotional ambivalence: while, on the one hand, it is reassuring to know that trusted doctors are taking care of their children, on the other, it feels like a continual burden of progressive choices for their children future.

Each parent, and each family, will make the decisions which they feel are most appropriate. Each decision will, in any case, profoundly affect parents. For example, the decision to insert implants or not, implicitly implies that one day parents will be asked to explain to their children the reasons behind their choice, one way or the other.

There is yet another level, which has a huge impact: the choice between one or two implants must be made considering both the family and the clinical situation. When it happens that budget constraints and services cuts³ impact on a choice that will affect the health of a child, it becomes a question of human rights: the constant erosion in welfare and the progressive delegation to families and the private sector means a denial, in fact, of any given right, dignity and care in supporting people and children with different abilities to choose how they want to live.

2. Relationships in the local context, from grandparents to uncles, other relatives, friends and neighbours

A parent is an individual, a partner in a couple, a family member.

It is never easy to discover that relatives, friends and neighbours do not necessarily represent a resource, but that they can bring out anxiety, doubts about choices made and misunderstandings instead.

³ The Italian National Health System provides for all medical and rehabilitation, but the resources are decreasing constantly in terms of availability of implants, hours of speech therapy, educational rehabilitation ...

On these occasions, instead of a space of openness and listening, the wider family context might force parents to «...swallow down their emotions ...».

When the situation is difficult, the choices complicated and painful but necessary because they are felt to be 'right', the weight of the family context in terms of conditioning can foster a sense of guilt.

Parents can learn to empower themselves by recognising that «... it is not my fault ... what I find difficult and painful to face, is something I do for my child, for their brothers and sisters, and for us ... it is not perfect but still I can work on it, that's all...».

Parents should remember what it is the most important thing for a child: to be able to move freely relying on his/her skills, because they have many; and this must not be put into doubt.

It is, in any case, important for parents to feel that they are understood: sharing their own experiences can make a difficult experience a bit less heavy. It can bring back that hope and warmth that might have disappeared when they heard the diagnosis.

3. Relationships within the family and between brothers and sisters

Having a brother or sister with a disability is an unexpected and unwanted event which profoundly affects not only the relationship between the two directly involved; it might also cause psychological consequences on the "normal" brother / sister.

Similarly, when there is a hearing brother or sister, it may happen that parents focus much of their attention and care on the one with difficulties, threatening to "forget" the other child. If and when parents realise that these situations exist, «... you get a sinking feeling...». In such cases, it is essential for parents to take all the time and space they need to find a balance again.

The ability of parents to take full responsibility for the care of their disabled child becomes a key-stone on different levels. On one, it will help the "normal" brothers or sisters to perform the most of their developmental tasks; on a more implicit level, it will help to lift the heavy burden from the hearing sibling of adhering to parental expectations of the lost ideal child.

In the natural process of growth, every child has to face his/her differences. Like any child, he/she will need support, care and

affection from his/her parents, even if this leads them to deal with questions like «...why do I have ears (the implant) while others don't? ...».

4- The relationship within the couple

The relationships within the family and within the couple are put under great strain. Under this emotional burden, the everyday life of the couple and the strength of their bond is severely tested, with the risk of braking up if there is no unity between the partners when it comes the time to make decisions.

Within the couple, there are times when one has to hold on, to stand also for the other, when one has to mourn and pull up the other, even when feeling that «...the soul is squeezed ... and broken up...».

The risk of isolation becomes tangible.

Whenever there is no possibility outside the couple to drain the tensions off, the parents risks the feeling of being «...tired of being patient...».

Other times, especially with some external to support the process of acceptance and adaptation, parents can find the strength needed to reorganize their relationships, safeguarding the well-being of each member of the family.

It is important for groups of parents to get together; despite their difficulties and pain, and try to express their inner feelings, to listen and understand what other parents did in similar circumstances.

It is a sign of strength, and not a shame, to accept an external support to allow an opportunity to calm down, to consider the point of view of their partner as a first step to reunite the couple.

5- The individual's intimate inner world

Being a parent itself evokes a constant questioning of one's sense of adequacy, which sometimes might end up in a feeling that whatever one does, it is never enough.

It is a complex and delicate balance between accepting the serenity of their child and their own hardship; it is a tricky, dangerous and dramatic question: «... if it is enough for them, why not for me? What am I entitled to want then? ...».

Besides the rational awareness on how concepts such as efficiency and normality are relative⁴, it might be painful in western culture to accept any deficit, and the fact that it lasts forever.

The challenge is huge in the daily routine, and it lasts even when children grow up: it is a challenge that changes with age and needs, and that despite the modern technical support such as cochlear implants, it remains, just as deafness will.

Each person carries his/her own internal fragility, which is intimate and personal; this fragility might become an obstacle in acceptance at an emotional level, and sometimes it takes the form of denial.

Despite the fear for the future, or perhaps because of that, parents learn to live taking each day as it comes.

It is an emotional and tiring complex in which each single step simply comes after the former, and before the next, beyond any standardised logic and judgement.

Even if it sounds obvious rationally, the deep awareness that every experience brings and teaches something new is a corner-stone in the construction of the inner structure.

The tricky «...why me? ...» is another question that might arise, beyond rational thinking, and it has no answer. Deafness does not affect the parent who asks the question, but his/her child, however, this question signals the activation of different defences, such as denial of reality, displacement and projection.

Deep down in each person's inner world, it is not written anywhere that parents has to «... accept everything at once ...».

Sometimes, the disability of their children might evolve into some sort of secret, a constant state of unspeakable anxiety, where parents are likely to build a shelter behind and within the disability.

Parents have the strength to form groups that are able to go beyond the normally accepted concepts of disability, so to create a new culture around disability.

A new culture represents a fundamental requisite and opportunity to bring out inner feelings: from a dimension of silence and loneliness to collective sharing, from the single group to other families to promote public awareness.

4 «...don't be scared, be norm'l ...» was a common joke from friends in Berlin

As previously seen, the concept of normality is very volatile and relative. To get back to "normal" parenting, parents should follow their "normal" role: they just have to treat their children as individuals outside any standardised and competitive logic.

Sometimes, it might also help to meet and listen to other people, with older children, who will testify that they have never perceived themselves as anything other than normal; that "what one physically cannot do" has nothing to do with serenity in life; or still, nothing should become an excuse to withdraw from life; and finally, that we all striving to achieve inner serenity without competing or comparison with others.

Anecdotes, pointers, surprising suggestions are always precious to bring in some fresh air, like the tips of those who said that there is also the possibility that deafness allows a possibility to perceive a different dimension of silence, which not given to others.

My thanks goes to Casa Oz for the hospitality; to Turin section of Fiadda Piemonte, for organising the group-work sessions; to the educators who ran the play area; to the children, who were involved in their games, and allowed their parents to set aside some time for themselves; to all parents who participated, freely sharing their richness.

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