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### **Complex communication needs ?**

#### **Special needs ?**

#### **Did you say special needs ?**

I am Geraldine's mother, she is 24; Geraldine has a genetic condition, with learning difficulties, no oral speech.

she is said now to have complex communication needs. She is said to be nonverbal. As a mother of this child, I faced her difficulties to understand, and her pain of being not able to express herself, and I explored alternative communication tools, with Makaton, to help her to communicate.

In fact she only has a few words. But she speaks through gestures, signs, symbols, objects, body language, and voice...She is a happy young lady, she is able to tell almost everything she wants to; this is possible when she is in an adapted world, She has no major issue to communicate as far as people around sign, label, and slow down. When she has to communicate in a non-signing environment, she is like being in a wheelchair, at the bottom of a huge stair, being said "come on, go upstairs..."

I spend a lot of my life to think about my daughter's communication, my daughter's thinking, the way she understands the world, and the tools she needs. My strongest expertise comes from my daughter. As a Makaton tutor, much involved in French Isaac association, I am now used to think about communication, and the special tools children and adults need to communicate.

I am also a baby sign tutor, and a happy grandmother, discovering again and again the magic of a young baby discovering language and speech. These experiences helped me to better understand Geraldine's path towards language.

#### *Problematic, Rational*

I also read a lot, and two books are important to me:

Alison Gopnik, in her "the philosophical baby", compares the growing child to us, well thinking and well speaking adults, and I think that it allows us to use the concept of "developmental age", to consider the needs of children with disability. We can compare children or adults with cognitive disability, with a child having close cognitive functioning.

And Andy Clark, in "being there, putting mind, body and world together", about what is called the embodied and situated mind, shows how we structure our world, to allow us to think, to create, to communicate, to be together.

Looking too at the research on our adult multimodal communication, we can understand where all AAC tools have their roots. We should not link with disability, what is just to be linked to the cognitive pattern, or what is to be linked to human communication.

As everyone, Geraldine needs to understand the world and what is going to happen. She needs to know people's names. She needs to have tools to remember, a life story book. She needs to understand how she feels, and why. She needs to have no pain and to have no fear. She needs to talk, to tell, to read, to sing...to understand and to be understood. Don't you? My daughter has the same needs we all have, and I would not dare to say that my daughter has special needs, or complex needs. During this presentation, I am going to explore basic human needs, mine, yours, theirs, and try to show that we are all sharing the same needs.

People as Geraldine do not have complex communication needs... We share the same communication needs. This will be the core of my defence speech here.

I don't say that they don't need help to be in our world, I don't say they have no disability. I know those too well... She just needs special tools, maybe complex tools, or special friends, or friends with complex skills.

That's all!

## **Communication**

Following Bloom and Lahey, human communication could be divided in 3 parts : the form, that is speech, the content, that is language, and the use, that is pragmatic.

### **The form: speech**

We need to understand, we need to talk and be understood.

Sometimes, it is difficult to understand, and I think that Isaac congress in Portugal is a big deal for a lot of us: two foreign languages. We can feel what our children s'life is: too much words, too fast, too long sentences. In this situation, we need special tools, dictionary, kind people, maybe pen and paper to draw, our hands, body... we are not so far from signing babies, signing children, to be able to communicate together.

Human communication is multimodal. We use speech, voice, gestures, and posture to communicate. We need our body, we need our hands to communicate. We need our hands, our body to help us thinking. Signing with children with cognitive disability is not a strange idea coming from the moon, but just a step sideways in our human communication.

In the form, we should give a place to the children who use pictograms to communicate. Showing pictograms is their voice. As signs are my daughter's voice. We all need a voice.

### **The content: language**

The little Prince is a poetic book, from Antoine de St Exupery, relating the meeting between that little boy coming from the sky, and St Exupery, lost in the desert. the little Prince asks St Exupery to draw him a sheep. And as the sheep is never beautiful enough for the little boy, the man draws a box, and says" your sheep is in the box" and the little Prince says" oh, it is sleeping"

When you know our French poem "the little prince", you may know about the sheep in the box. The sheep in the box is our language: we have to help children to open boxes in their minds for concept such as sheep. And to have a lot of possibilities to open the sheep boxes: the name, the sign, the symbol, a photo, the" baa", the wool, the smell...we are doing the same: we have in mind what we

know; we see what we have in mind; we see what we know (think about your ability to find mushrooms: if you don't know mushrooms, you can't find them, even in a crowded mushroom forest.

It is also the famous awareness test, with the gorilla: you can't see the gorilla, because you don't know it is there.

So are the children with disability: if you don't give them the world, if you don't name them the world, in a modality they are able to perceive, you keep them in a small and empty world.

They need us to bring to them the world. We can't accuse them of ignoring what we are not giving to them: names, and mushrooms, or sheep. That they could hear, see, or touch.

We should forget the question "did you understand? A child just does not know if she understands or not: I am getting deaf, and the birds that I don't hear just don't exist for me anymore. If I have a narrow vision, what I don't see just does not exist. Again, children are like us, we have to make the world exist. To open the world.

We say that they are bad in making choices... are we so good? We say that they don't understand when we ask for their opinion. But we often ask them about things they don't know or understand.

We should also be careful, when we give choice, when we explain, to always start at the child's comprehension level: that is, what she has in mind. Give choice about things the child does not know: it is like I ask you "in Tokyo which museum do you prefer? Suntori or Fukagawa Museum? Or would like to do some Goshinyutu... you just can't answer, because you have never been in Tokyo and that you don't know ... and sometimes we accuse children to be unable to do a right choice! We accuse them to be unable to understand... and to having behaviour problems...

If we explain from what they know, they can understand

Speaking of the world given to the children, Alison Gopnik tells about children attention. Saying that for very young children, world comes to the child and the child can't go to the world: a child attention is driven by the world. It is hard for him to look as we look: to aim voluntarily the eyes as we do. "So, rather than determining what to look at in the world, babies seem to let the world determine what they look at"

Children with disability are often accused of being dissipated, scattered... but this it is the normal way of a young child to be in the world: she has to discover the world. If we consider the developmental age, our children are just in the stream! For those children the sign "look" can be a great help, like an invisible thread, from the children's eyes, to what she is supposed to look at.

**Pragmatic** : It is the way we use language. And with children with disability, I see two major difficulties.

We think that life is bread and jam: and that when a child is able to ask for bread and jam, it's done. Communication is also bread and jam, but not only. Through Hanen program, through Podd approach, we can rediscover the multiples facets of human communication : to ask for, but to tell, to pretend, to express the feelings, to lie, to chat , to think together, to answer , to question... A French psychologist, Isabelle Filliozat, gives a very good image. "You are driving with your husband, he tells you – look! This fantastic car!- you don't answer – oh, non, we have already 6 cars, you had one last week, you won't have it- You can understand that your husband is just dreaming, or admiring. "With

a young child, or with a person with disability, we say" NO, you won't have ... the ball, the cookie, the..." We grant the child to be able only to ask, and to ask NOW. We don't give her the right to tell, to dream, to think, to dislike...

And other difficulty with pragmatic and AAC. We only sign, we only use pictographs when we want to be sure that the child understands and listens. It is like a young mother I had in a makaton training. She told us that her daughters said" oh, Mummy, you only speak Arabic with us to scold us" In this family, Arabic turns to be the law-language. And we must admit that AAC turns often to be the same!

We have to remember that we never teach speech, nor language, nor pragmatic to young children: we don't teach: we spontaneously adjust the way we talk to them, we change our prosody, we use simpler words, we speak slowly, we repeat, we simplify grammar...we catch their attention by being wonderful, exiting, attractive, and they learn. By contrast, we often think we have to teach communication to children with disability; to sit at a table and to teach.... According to Gayle porter, we have to realise that we expect them to use a mean of communication we are not using with them. The 20 mn with a speech therapist are not enough! We should have "communication at any time", as Gayle Porter pleads. And remember that even the better program is nothing if there is no good and alive interaction.

### **And we can explore now other sides of being in the world**

We often say that children with cognitive disability, or with autism, have great difficulties to understanding time concepts.

And thus, we have to make time table, we have to use time timer. We have to explain, and explain what is going to happen, when, with whom... and we sigh a lot, it takes our precious time to build these tools for those complicated children....to print, to cut, to glue...sigh...

As everyone here knows, we don't share that needs....Do we? Here, in our bags, in our iPhone, we have an agenda, we know what we are going to do this afternoon, tomorrow, the next week and during our holidays. We have a watch at our wrist, and we set alarms on our phones...

Another crucial point is memory, and the ability to navigate in our memory. When children with disability are young, we find it easy and obvious to give them life story books, to write in their diary what happened during the day, so they can share their experience at home.

The problem occurs when children grow and get older, teenagers. Then, we hear professionals saying" oh, we won't write anything more, they are teen agers, it is their "secret garden". And the sad, or angry parents have nothing to share and talk about with their children ; Here comes Alison Gopnik again : young children don't have the same access to their memories; the memories are in their mind, in closed drawers; and the question" what did you do at school" is not a key to open the drawer. They need clues. "Do you remember, you had painting...", and there the little one becomes loquacious. This is the same for children or adults with disability, whose developmental age is different from the legal age: if they are functioning like a 5 years old child, and that is high! They need clues...

Alison Gopnik compares exogenous recalls - children's one, to endogenous recall – adult's one. She says "these cued memories are also episodic, but they are prompted from the outside, rather than generated from the inside; the information you remember is really in there, but you could not have retrieved it without the cue. Memory is controlled from the outside instead of the inside."

So they need marks, cues; they need words in the diary, they need photos, videos, and objects.

Recent research shows how language is important for children's ability to build memories. Life events must be shared, and told, and retold, to become memories in mind. It is true for all of us. There is no possible recall without memorization. The life has to be transformed into mind traces, the best way is the path of telling... if we don't give to non-speaking children the possibility to tell what they have been through, it will be very hard for them, to remember it.

Life story books are precious, they allow the children to know where their roots are. We are not who our ID tells we are. We are what we can tell from our story. We, all of us. And, yes, children with disability need life books, and we are creating life photo books, and we have on our Face book wall, our life line... the life story books are a wonderful tool toward others, to share, to read, to become friends.

And speaking of marks, it is once again interesting to look at what we are doing: we take millions of photos, we create wonderful photo books. We film, and even more, we buy souvenirs (and from Lisbon too!!)

So, why is it so difficult to let children with disability gathering objects, precious stones, paper candy, and bright string... to build memory boxes? We are just the same, and we are even worse! We have more money! The world is our external memory

### **The need to visual mark the world**

In the book "being there", Andy Clark tells us how our mind is in our body, and our body is in the world. What he calls "embodied cognition, and situated cognition"..."drawing on the resources of mind, body, and world."

"Our cleverness shows itself in our ability to actively structure and operate upon our environment so as to simplify our problem solving tasks."

We structure our world to alleviate the cognitive load. We try to have our kitchen, our desk well organised, our computer memorizes and organizes things for us. Google is providing answers to our questions. Our cell phones are our extended memories, they even help us to localise where we are.

We put post it on our fridge, we hang empty bag at our door, not to forget to buy milk...we follow quite strict routines when we get prepared in the morning...

And we still consider that only children or adults with disability need visual clues or routines to perform tasks of daily living

The environment is not only there to bring stuff to the brain, as input; but we do use environment to simplify brains' job. Our written tags are just there to off load our memory. It is even taught in training sessions about time saving: write down what you have to do, make lists...

"We use intelligence to structure our environment so that we can succeed with less intelligence. Our brains make the world smart so that we can be dumb in peace"

We need external scaffoldings too. They are part of what we call our smartness.

We have sometimes to visually explain to our children how to get dressed, or how to wash in the shower; but we are also using visually detailed list, recipes, schemas and instructions about how to build a child bed, how to use a tea bag, or what not to do with a new bread toaster

Alison Gopnik recalls us, that growing is being able to use our pre frontal cortex, being able not to rush, being able to inhibit our first move. Some children still behave like younger ones: they just can't help doing what they want to do, right in the moment. But symbols recalling them to remain seated, to speak in a low voice make this possible. We have to explain how to behave, write social stories... Why do we have speed posts on the highways, we know that we have to drive slowly!!

### **Writing words...**

We write, with a pencil or a computer, to help us to think, to store, to organise our mind. And we would not offer the same tools to children or adults with disability, thinking that the only true writing comes through letters!

Clark gives the image of a mangrove: the seed begins to grow, sends roots, which will catch floating earth, and create an island: the tree builds the island and not the reverse. Sometimes ( or often) we hear about some children that "they don't reach the level for AAC", it is useless to provide them signs or symbols, or podd... think of the mangrove... the word, the sign, the symbol turns into a ground for thinking.

if we offer them to write with symbols, to lay their thoughts on paper, we offer them a wonderful gift, we open for them the world of writing, which was considered not for them. They have the same need, just the form is changing.

We think with words, but sometimes a word enlarges and allows our thinking. It is the same with written words: a symbol help the child to think. That can be seen, when using the pragmatic and fantastic podd books. We offer to the child a path to her thinking.

"by writing down our ideas, we generate a trace in a format that opens up a range of new possibilities, we can inspect and re inspect the same ideas... the real properties of physical text transform the space of possible thoughts."

### **We can explore a lot of topics, in our human communication needs**

It is said that children with disability have great difficulties to cope with feelings. But it is mainly because of us. We can't understand their feelings, because it is sometimes hard to light on our mirror neurons. And if we don't help them to recognize how they feel, and why, to build a bridge between the external world and their inner feelings; they won't be able to say how they feel. Are we so bright to understand how we feel? and how to tell others. Sometimes, my husband would say, I have complex communication needs!

And what about pain? Medical care provides visual scales to evaluate pain, why don't we use them with children with disability. We can imagine adapted scales, even for children unable to read facial expressions.

We could spend our day, exploring views about our ideas on children with disability...

Young children have imaginary friends, that help them to grow, and who help them to think. They talk to these imaginary friends. When we grow up, we turn able to have inner dialogue, we speak to ourselves. With words. Children with disability need these friends longer, it has to be seen according to their developmental age... not as a problem.

And now, we reach the most important point in our communication needs: **we need friends.**

When you read books about human language development from our far far ancestors climbing down the trees. A lot of factors contributed to make our language emerge; from standing, running, breathing, freeing our hands for tools and for communication; but one of the most important factor is the human being a social being: we talk to talk to the others. We talk because we are not alone. We talk about rain and sun, we gossip about our neighbours, we talk about triviality and about philosophy... and the children who have a communication disability need to talk for exactly the same reasons.

They talk as belonging to our human world.

And so, they need friends to talk with. And there is maybe the biggest difficulty: their friends need to be able to use specific tools; they need to know how to imitate, how to sign, how to use symbol support, how to podd.

They need to share what a French wonderful man , Jacques Souriau, is calling" cognitive intimacy"; which allows a child to be understood at" half word/half sign/half symbol message". We must be careful and not ask the children using AAC to speak in a better form than we do: we don't speak grammatically correct, we speak with half sentences, we speak to persons able to understand us, because they know us.

If we think again to our little Prince, we can see that our friends have some keys to open our own mind doors. Our history is in our friends mind too. They have the keys too. We are not alone.

We are the ground of their communication, we have to be accessible, we are their better communication tool, as Gayle Porter says , we are " a smart partner operating device"; like between all human.

And there is the spot where I arrive with my daughter: I gave her signs, I gave her tools to remember, to think, to belong to the world. And now, I have to be sure that I give her friends; for after me. Friends with complex communication smartness, friends with love...