A Parent’s Perspective on Supporting and Advocating for her Son

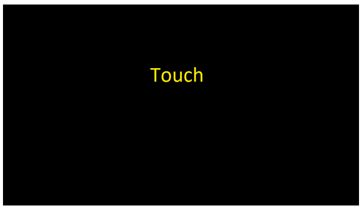
Part 2

Welcome back.

At the end of the first part, I finished by telling you that Fearghas was nearly 20 before I was conscious that his access to the world was limited to the reach of his fingertips. This meant that touch, or the tactile modality, was absolutely crucial to Fearghas for his communication, orientation within the environment and access to information about the world around him.

So, the next thing I needed to understand was the vital importance of touch.

Slide 18



Touch

As babies, my other children knew I was there because they could see and hear me. If Fearghas couldn’t feel me, then he was alone. To my regret I would put him down, safely in his Moses basket, or on a playmat, or in the special chair provided by physiotherapy,

Slide: 19

to get on with jobs around the house thinking I was reassuring him by my voice and the sight of me as I moved around. But without my touch, he was marooned on an island of isolation.

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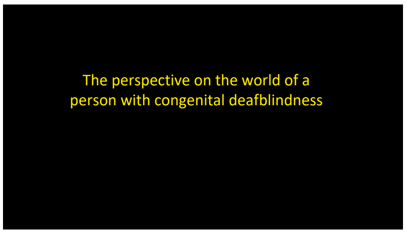
I hadn’t used a sling with my other boys, so it didn’t occur to me to use one with Fearghas. I didn’t understand why he seemed to cry far more than my other boys had. Because Fearghas had hypotonia, that is he was very floppy, I did hold him much more than my other babies but not enough for a child who experiences the world through the bodily tactile modality of touch, movement, etc. I was unwittingly limiting his access to information about the world he had been born into.

My instincts told me things were different, but I had no idea why.

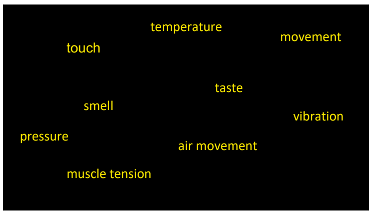
What I needed to understand was Fearghas’s perspective on the world.

Slide 20



The perspective on the world of a person with congenital deafblindness

Slide 21



temperature

movement

touch

taste

smell

vibration

pressure

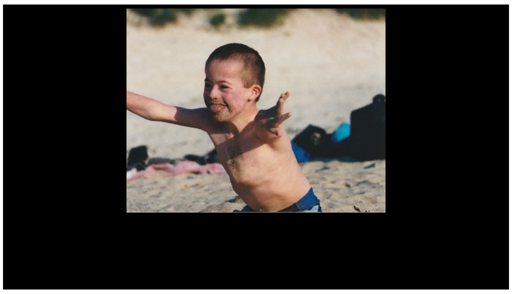
air movement

muscle tension

My son’s primary means of receiving information about the world he had entered was not through vision and hearing, but through touch, taste, smell, movement, pressure, vibration, air movement, muscle tension, temperature.

Here are some examples of what I was failing to see and understand:

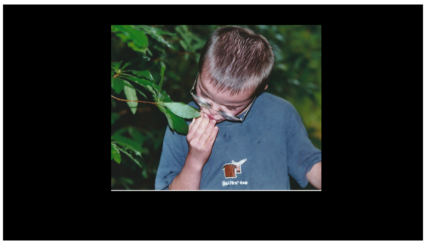
Slide 22



What I saw when we were on holiday was my son really excited to be on the beach.

What I failed to see was him getting information, understanding and delighting in his surroundings through the grittiness of the sand against his skin, the firmness of the beach as he bounced up and down on his legs, the warmth of the sun on his body, the taste of sand and salt in his mouth, the smell of the salty air, the tension in his muscles as he reached out, the air movement created by himself as he moved, the shadows created as he waved his arms around, the temperature of the sand compared with the temperature of the air, and probably loads more. I recognised his pure, unadulterated joy at being on the beach but I didn't know how to use that to help him develop his communication. In short, I didn't know how to "listen" to him or how to help him "talk" to me using his bodily tactile perspective of the world. If I had understood, I would have taken bucketsful of sand and a bottles of seawater home so that we could talk about our day through Fearghas's experience of it.

Slide 23



Here I initially saw my son at risk of choking or poisoning himself by eating a leaf. Then I noticed he was pressing it against his lips and mouth but not trying to eat it. I had no idea why but was curious about it. I now know that he was finding out more about the bush as his eyes and ears weren't giving him enough information. Again taste, pressure, touch, temperature, texture. Had I understood, I would have taken a few leaves home so that we could "talk" about the bush later from his perspective.

Fearghas used his tongue to supplement his impaired vision and hearing from when he was a tiny baby. Whenever close enough, he would lick my eyes and other parts of my face. I didn't know why and just thought it a bit odd. He was, getting to know my face. I very quickly stopped wearing make-up!

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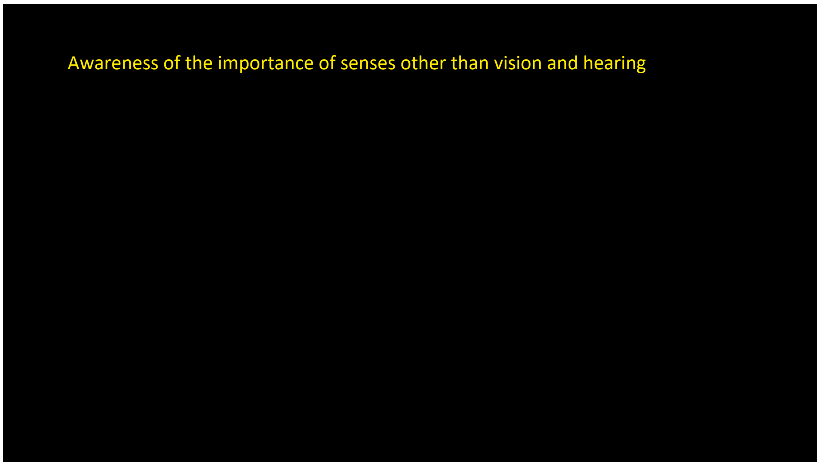
This photo shows Fearghas aged about 21. He is on this particular roundabout for the first time. Fearghas is again using his tongue to supplement the little information that is available to him through vision and hearing, something he still does to this day.

By luck we kept the two big speakers from the HiFi on the floor in the living room. Fearghas’s favourite music at the time seemed to be the rousing music of a full Scottish pipe band. He would always move himself to where you could feel the vibrations from the speaker most strongly. I had no idea why. I just thought it was one of the “cute” things he did.

With knowledge and understanding of what I was seeing, I could have made Fearghas’s world a much richer and more meaningful place.

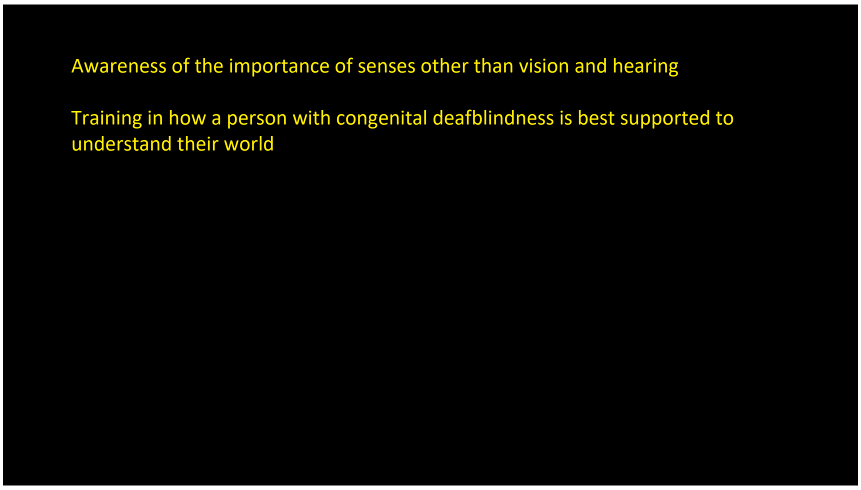
Slide 24



Awareness of the importance of senses other than vision and hearing

So, I also needed an understanding of the importance and function of other senses for a child with congenital deafblindness.

Slide 25



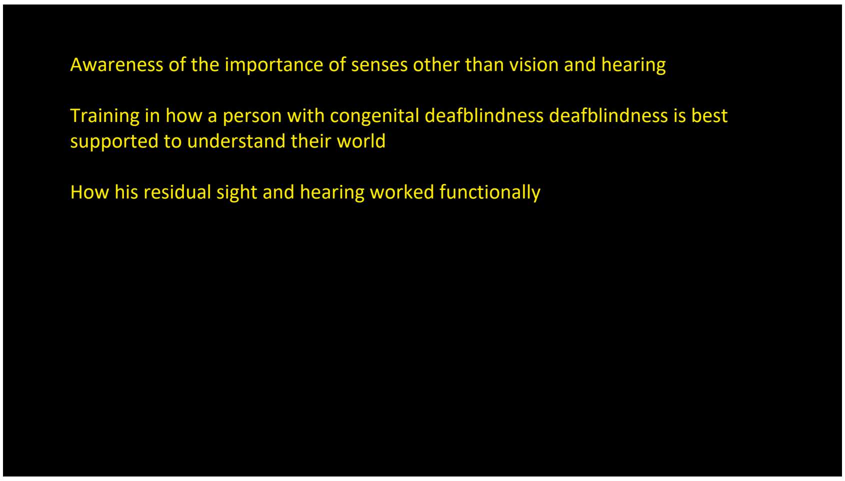
Awareness of the importance of senses other than vision and hearing

Training in how a person with congenital deafblindness is best supported to understand their world

I then needed to know how to use this knowledge to modify the way I did things so that all my actions and communications were meaningful to Fearghas; I needed to meet him in his world, not to try to drag him into mine.

Fearghas has a little residual vision and hearing. In Fearghas’s early and primary school years I knew about Fearghas’s physical impairment of vision and hearing but what I was being told by ophthalmology and audiology consultants didn’t match what I was observing. I therefore needed information about how his vision and hearing were affected functionally.

Slide 26



Awareness of the importance of senses other than vision and hearing

Training in how a person with congenital deafblindness deafblindness is best supported to understand their world

How his residual sight and hearing worked functionally

Things like how CVI works;

the importance of good contrast;

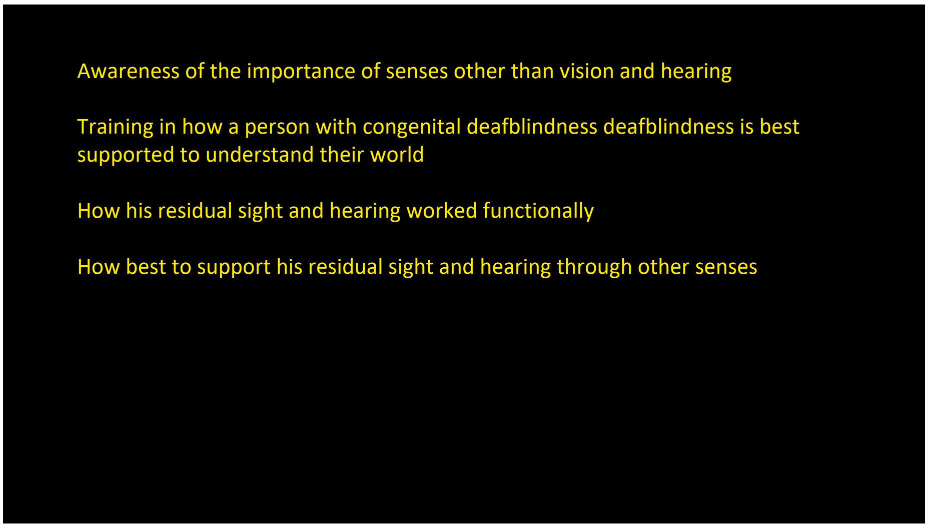
the effectiveness of certain colours over others; luckily I’ve always preferred bold, bright colours; pretty pastel shades were no use to Fearghas whatsoever;

the impact of background noise,

how auditory processing disorder works, etc.

Again, if I got it right, it was luck, not judgment that played its part here.

Slide 27



Awareness of the importance of senses other than vision and hearing

Training in how a person with congenital deafblindness deafblindness is best supported to understand their world

How his residual sight and hearing worked functionally

How best to support his residual sight and hearing through other senses

I needed to know how to support Fearghas's little bit of residual vision and hearing through his other senses, primarily touch.

I lived in a world of not understanding, not knowing, feeling that the support offered was inappropriate but not knowing why, trying to trust the professionals while knowing instinctively that many of them were getting it wrong for Fearghas, asking questions but the wrong questions, and building a reputation for being

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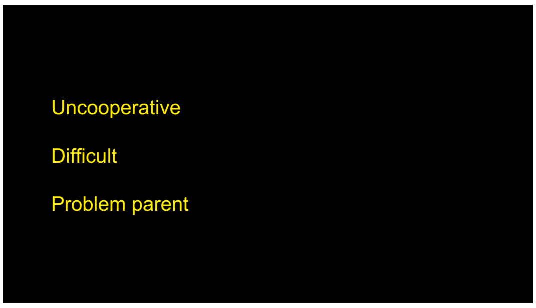


Uncooperative

Difficult

Problem parent

uncooperative and difficult, a problem parent.

Fearghas was adrift in a world that didn't understand him. For example:

A specialist support organisation told me that Fearghas couldn't attend their events without me because they hadn't got the expertise to support him, even as a teenager where the other young people were leaving Mum at home.

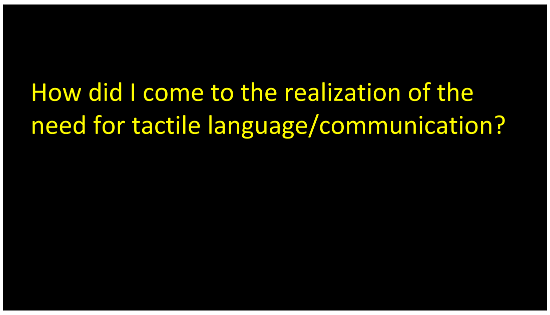
As I said earlier, I had education professionals repeatedly telling me "his sight's not that bad" despite the detailed reports from the ophthalmology consultant.

One day I was summoned to school because of what staff interpreted as "over-sexualised behaviour". Apparently Fearghas kept grabbing out at the T-shirt of a Learning Support Assistant and pulling it down to reveal her chest. What was actually happening, was that Fearghas was kept out of reach of others because of assessments of so-called "challenging behaviour". As a result, if a staff member came close, he would reach out to touch her. Because his sight was so limited, he aimed for the distinct line where the neck of her low-cut black T-shirt contrasted with her pale skin.

With the label "challenging behaviour" attached to Fearghas in secondary school, risk assessments led to him being supported one to one by staff in school and at youth club but being kept out of reach of peers. Outside the home Fearghas was living in a world where he was isolated, lonely, desperately trying to make himself understood but not being listened to, and being constantly misunderstood. When he was about 15, 16, 17, the behavioural team was heavily involved in his support network. Discussions were being had about whether Fearghas's so-called "behaviour" was so out of control that he might end up in a locked ward of a psychiatric unit. This filled me with absolute horror, it was a nightmare beyond comprehension. And I felt completely helpless and ineffectual in my efforts to help my child.

I knew he needed a completely different approach but I didn’t know what shape that would take.

Slide 29



How did I come to the realization of the need for tactile language/communication?

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In 2015, when Fearghas was approaching the age of 18, the 16th Deafblind International World Conference was held in Romania. Sense in England decided they wanted to sponsor a parent to attend. I submitted an application and was lucky enough to be one of two parents selected.

That conference blew my mind. I suddenly felt as though I had discovered a world where Fearghas fitted. He was part of this world, not an outsider. I went to a presentation by Annika Johanneson from Norway and spent most of it with tears running down my face: for the first time ever I heard someone describing a young man who reminded me of Fearghas. And then I went to another presentation where a Danish colleague spoke about a man she supported. Again, I was reminded of Fearghas. After nearly 18 years I had finally found people like my son. But not only that; I was hearing about the importance of touch and communication using the tactile modality.

I was also seeing and meeting people with deafblindness, from all over the world, who were

Slide 30

successfully interacting with each other using tactile communication.

- Successful interaction in the tactile modality

They were active communicators

Slide 31

- Successful interaction in the tactile modality
- Active communicators

with Agency

Slide 32

- Successful interaction in the tactile modality
- Active communicators
- Agency

as they participated fully

Slide 33

- Successful interaction in the tactile modality
- Active communicators
- Agency
- Fully participating

in not only the conference itself but

Slide 34

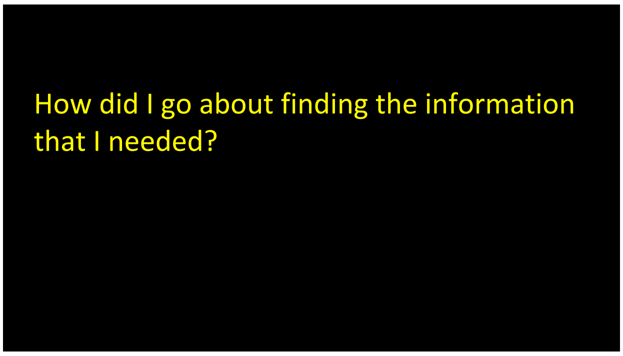
- Successful interaction in the tactile modality
- Active communicators
- Agency
- Fully participating
- Shared experience

the shared, joyful, and exciting experience of all who had come together in Bucharest from the four corners of the world.

I understood very quickly that tactile communication was an enormous key that could unlock Fearghas’s world. I needed to know more. And I needed to tell the people who supported Fearghas. I knew I had to educate myself so that I could play my part in turning Fearghas’s world around.

So began the hunt for the information I needed.

Slide 35



How did I go about finding the information that I needed?

How did I go about finding that information?

I went back to the UK and spoke to teachers, Speech and language therapists, anyone who would listen, about my conviction that tactile communication was what Fearghas needed and what little I understood about it, which wasn't very much at all at that point. No-one in his school or youth club had heard of tactile communication.

At the DbI conference I had also heard about specialist training in Canada for supporting people with deafblindness called Intervenor training. I discovered that there was a much shorter version of it available to professionals in the UK. I found a course and managed to persuade the person running it to allow me to join despite the fact that I was "just a mum". All the other attendees were professionals from over the region.

From then I read what I could find which was fairly limited at the time. Professionals in Fearghas's support network were still not convinced by this "new-fangled", "odd" approach. They were still trying to use the same old approaches and were still meeting with the same lack of success as they had for years. They were all approaches that were suitable if you had good functional hearing and vision but not for someone with congenital deafblindness.

By coincidence a few months after the Intervenor course, in November, 2016, a conference was being held at Groningen

University in the Netherlands for alumni and professionals to celebrate 10 years of the Masters in Communication and Deafblindness. A friend gave me Marleen Janssen's contact details and I wrote asking if I could come along. With her legendary warmth and hospitality, she welcomed me.

It was another mind-blowing experience. I loved every minute and knew I wanted to become part of this world full of people whose life work was to understand people like my son and find ways of improving his life and that of others like him.

Then finally, in 2018 I enrolled on the Masters in Communication and Deafblindness course at Groningen University.

At each step of the way, I went back to the network supporting Fearghas with what I had learned but still it was falling on deaf ears (excuse the very bad pun). People around him still seemed unable to take Fearghas's perspective as a person with congenital deafblindness. And most importantly, they still weren't seeing his bodily gestures and movements as communication and so they weren't listening to him. His movements, gestures and actions continued to be viewed as "behaviour", not as communication despite my best efforts to share the knowledge that I was acquiring.

An example was repeated attempts to teach Fearghas a tactile version of the word "finish" or "finished". When Fearghas was about 18 or 19 and in school, when he was about 21 and in college, and when he was about 24 and in a different college, different teachers and speech and language therapists told me proudly that they were teaching him a tactile sign, using hand-under-hand support, for the word "finished". It involved supporting Fearghas's hands and getting him to follow as they performed a movement in which they crossed his hands and then opened them in a sweeping movement. All were delighted because he co-operated with the hand-under-hand support when an activity was finished. All also reported that he never performed the sign unprompted or unsupported. This was interpreted as Fearghas's inability or slowness to learn. As each new team announced that this was what they were working on, I would ask Why? Over the years, from an early age, I had heard professionals around Fearghas say "Oh, have you finished Fearghas?" as he span his body around from the activity, or moved one arm in a sweeping motion while turning his body in the opposite direction, or pushed the object away, or picked up his favourite toy bears, or simply got up and walked away. Fearghas already had multiple ways of saying "finished" very effectively, in ways that were clearly understood, using his preferred bodily tactile communication. He never used the imposed sign for "finished" because he didn't need it. Sadly, the professionals were so busy trying to impose communication strategies from their hearing and sighted world that they didn't stop and "listen" to what Fearghas was already saying to them, loud and clear.

Another example of the professionals around Fearghas not listening to him and not listening to what I had to share with them is connected with Fearghas's assessment of so-called "challenging behaviour". This is not the current term but was the term used at the time. As I said earlier, it became so severe that Fearghas was in serious danger of a long-term hospital placement.

When in extreme distress, Fearghas would rip his glasses off and punch himself repeatedly in the eyes. This actually led to him detaching retinas in both eyes. The distress could be physical through pain, discomfort, thirst, being too hot, etc. Or it could be emotional distress if something upset him, frightened him, overwhelmed him, confused him, and so on. As I began to understand more about the communication of people living with congenital deafblindness, I slowly came to a realisation about how this serious self-injurious behaviour had come about. As a young child Fearghas had been taught the Makaton sign for “food” which is made by bringing the fingers of the right hand together and tapping them against the side of the mouth. Fearghas didn’t have the fine motor skills to do that so he used a closed fist. He would tap gently to indicate he wanted food. He gradually used it for “more food” and then “more” of anything and eventually “help me with…” something. He had generalised the meaning of the sign in the same way that a verbal child might learn the word “dog” and then for a while call every animal “dog”. I remember a visit to Edinburgh Zoo with one of my granddaughters. She was about a year old at the time and starting to talk. She had a great time spotting black and white stripped dogs, dogs with enormous long necks, dogs with shaggy manes, dogs swinging through branches, dogs with long tails leaping about carrying babies in their pouches! There were dogs in every enclosure!

As time went on, Fearghas would use this sign to ask for help with anything. If support staff missed the sign, he would repeat it; if they missed it again, he would then tap against his temple, first with one hand and then harder with both clenched fists. If he still didn’t get the help he needed and had become distressed, he would then throw his glasses off and punch himself repeatedly in the eyes. Fearghas learned very quickly that this got him attention. Staff would dive on him and try to restrain him using words like “Stop!”, “Hands down!”, “No”, “Don’t do that”. These communicative actions were Fearghas’s way of gradually, and sometimes not so gradually, asking for help with a louder and louder “voice”. Unfortunately, because it was looked at as “behaviour”, not communication, the response was to try and stop him. It was the same as telling a verbal child to “Shut up” or “Stop talking”.

I realised quite early that Fearghas was trying to communicate through these, at times, self-injurious actions. Now if I see his gestures in the first stages as he taps the side of his mouth, I respond with “Can I help you?” or “What’s the problem?” or something similar. Fearghas understands immediately that he has got my attention, that I’m listening and that I’m trying to help him. Living in a care home, it requires busy support staff to be alert and vigilant and on the lookout for Fearghas’s bodily tactile communication at all times. And frustratingly, even now, I still have difficulty being listened to and taken seriously by the professionals around Fearghas.

The issue of being taken seriously and believed by professionals has been going on since Fearghas was a baby. For years I would participate in meetings with education staff, speech and language therapists, behavioural therapists, occupational therapists, social workers, and many other professionals. They would all tell me “You know your son best”. And then when the minutes of the meeting were issued, my input wouldn’t even be recorded let alone acted upon.

The issues were:

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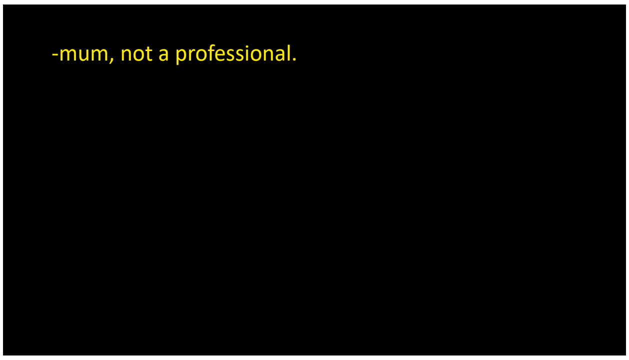
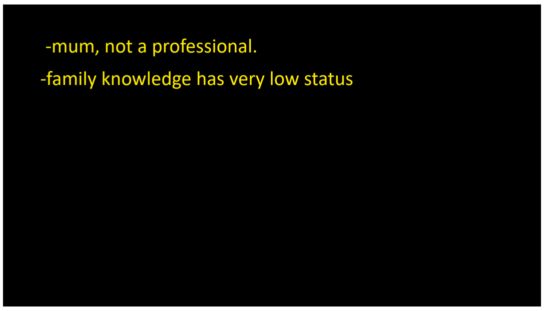


-mum, not a professional.

-I was a mum, not a professional.

Slide 35

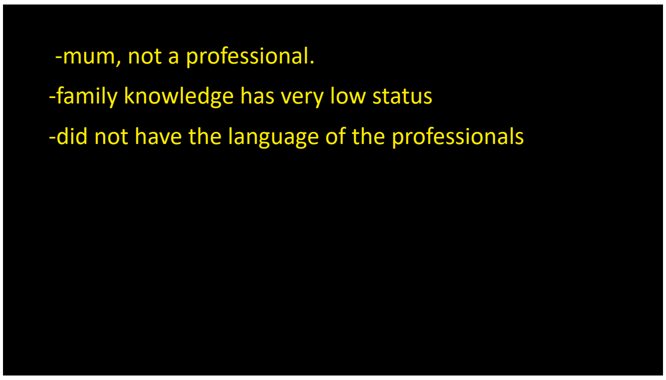


-mum, not a professional.

-family knowledge has very low status

Research carried out by Rosemarie van den Breemer in Norway has revealed that family knowledge has very low status and is therefore not taken seriously. This is a global problem.

Slide 36



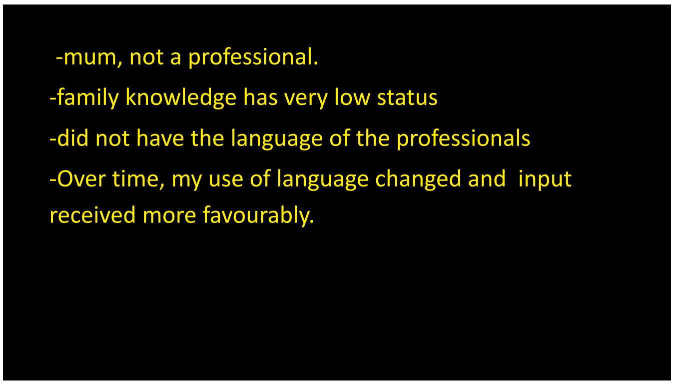
-mum, not a professional.

-family knowledge has very low status

-did not have the language of the professionals

-I did not have the language of the professionals so was speaking as an outsider, not one of the inner circle to be taken seriously as having something worthwhile and useful to contribute.

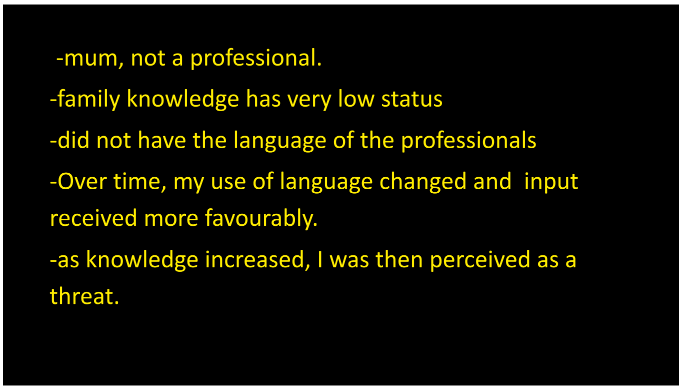
Slide 37



-mum, not a professional.
-family knowledge has very low status
-did not have the language of the professionals
-Over time, my use of language changed and input received more favourably.

Over time, I noticed that as my knowledge grew and my use of language changed, my input to discussions was listened to more favourably.

Slide 38



-mum, not a professional.
-family knowledge has very low status
-did not have the language of the professionals
-Over time, my use of language changed and input received more favourably.
-as knowledge increased, I was then perceived as a threat.

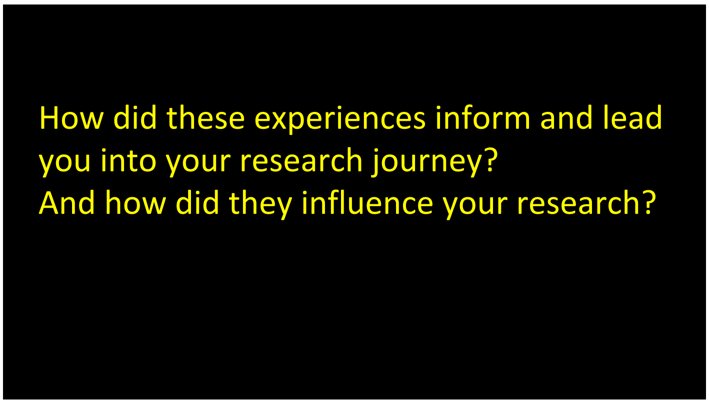
-Another issue that started to emerge was that as my knowledge increased, along with my ability to express myself in professional terms, I was then perceived as a threat.

And even now, I struggle to get the professionals around Fearghas to listen to me and to implement appropriate approaches to support Fearghas as a person with congenital deafblindness in a sighted and hearing world.

The issue of taking parents seriously is, in my experience, still a big problem despite legislation, guidelines, organisational protocols, etc. I have spoken about this and other problems to a number of different organisations and have been told several times that X, Y or Z doesn't or would never happen here.

As I said earlier, I eventually enrolled on the Master's in Communication and Deafblindness course. It made absolute sense to use the experiences I had had in my studies.

So



How did these experiences inform and lead you into your research journey?
And how did they influence your research?

As part of my Master's degree in Communication and Deafblindness I had to do a research project.

Even before I started the Masters programme I knew I had to do something that would improve the quality of my son's life. Otherwise, what was the point of it all?

My research topic was an intervention designed to minimise the risks of social isolation and loneliness in people with congenital deafblindness. Fearghas is a very sociable young man. For his eighteenth birthday, we wanted to invite his friends to join us for a celebration. We approached the leader of his youth club, a person who had known him for fifteen years, and were told “He has no friends; he just does his own thing!” The support workers who delivered this information, accepted the situation as normal and expressed no expectation that it could, or should, be any different. I was devasted: I had assumed that my sociable, fun-loving son had a group of friends like any other young man of his age. This heart-breaking information instantly raised the question of how this had come about. How had this sociable young man, who had spent sixteen years attending educational and social settings where I had expected daily opportunities for participation to be provided, how had he ended up being socially isolated from his peers? This was the first hint that the future I had imagined for my son, as an active participant in a wide and varied social circle of friends, was far from certain. I knew I had to do my best to change this.

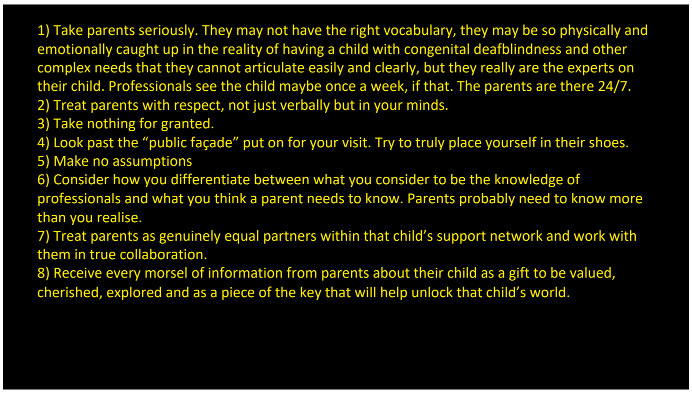
During the masters programme I also did an investigation into the assessment processes that my son had been through throughout his life. It was very revealing in that it helped me understand the origins of the perceptions which professionals had of my son and their predictions of his long-term outcomes.

I have also been an informant to research by Rosemarie van den Breemer in Norway on the status of family knowledge.

My experiences have made me determined that any work that I engage in has to be for the purpose of improving the quality of life for my son and others like him.

Reflection

Reflecting on my experiences as the mother of a young man living with congenital deafblindness, what would I say to professionals in the field?



1) Take parents seriously. They may not have the right vocabulary, they may be so physically and emotionally caught up in the reality of having a child with congenital deafblindness and other complex needs that they cannot articulate easily and clearly, but they really are the experts on their child. Professionals see the child maybe once a week, if that. The parents are there 24/7.
2) Treat parents with respect, not just verbally but in your minds.
3) Take nothing for granted.
4) Look past the "public façade" put on for your visit. Try to truly place yourself in their shoes.
5) Make no assumptions
6) Consider how you differentiate between what you consider to be the knowledge of professionals and what you think a parent needs to know. Parents probably need to know more than you realise.
7) Treat parents as genuinely equal partners within that child's support network and work with them in true collaboration.
8) Receive every morsel of information from parents about their child as a gift to be valued, cherished, explored and as a piece of the key that will help unlock that child's world.

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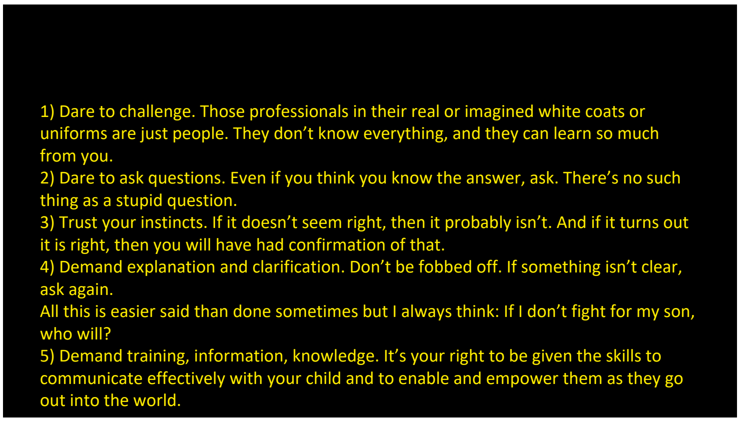
needs to know. Parents probably need to know more than you realise.

7) Treat parents as genuinely equal partners within that child’s support network and work with them in true collaboration.
8) If a parent questions, welcome it with cooperation not judgement
9) Receive every morsel of information from parents about their child as a gift to be valued, cherished, explored and as a piece of the key that will help unlock that child’s world.

And what would I say to other parents?



1) Dare to challenge. Those professionals in their real or imagined white coats or uniforms are just people. They don’t know everything, and they can learn so much from you.
2) Dare to ask questions. Even if you think you know the answer, ask. There’s no such thing as a stupid question.
3) Trust your instincts. If it doesn’t seem right, then it probably isn’t. And if it turns out it is right, then you will have had confirmation of that.
4) Demand explanation and clarification. Don’t be fobbed off. If something isn’t clear, ask again.
All this is easier said than done sometimes but I always think: If I don’t fight for my son, who will?
5) Demand training, information, knowledge. It’s your right to be given the skills to communicate effectively with your child and to enable and empower them as they go out into the world.

1) Dare to challenge. Those professionals in their real or imagined white coats or uniforms are just people. They don’t know everything and they can learn so much from you.
2) Dare to ask questions. Why? When? Who? What? Where? Even if you think you know the answer, ask. There’s no such thing as a stupid question.
3) Trust your instincts. If it doesn’t seem right, then it probably isn’t. And if it turns out it is right, then you will have had confirmation of that.
4) Demand explanation and clarification. Don’t be fobbed off. If something isn’t clear, ask again.

5) All this is easier said than done sometimes but I always think: If I don’t fight for my son, who will?
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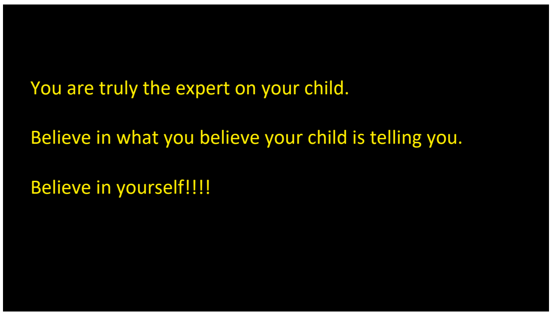

You are truly the expert on your child.

Believe in what you believe your child is telling you.

Believe in yourself!!!!

7) You are truly the expert on your child.
8) Believe in what your child is telling you.
9) Believe in yourself!!!!

And finally,

Way back in 1597 Francis Bacon, an English philosopher, said,

Slide 40

“Knowledge itself is power” (1597, Meditationes Sacrae,). Four hundred years later Kofi Annan, secretary-general of the United Nations from 1997 to 2006, took this further saying

Slide 41

“Knowledge is power. Information is liberating. Education is the premiss of progress, in every society, in every family” (1997, UN Press Release)

As families of children with dual sensory impairment strive to meet their children in their world of deafblindness, the gift of knowledge, information and education will empower these families in the face of opposition and adversity.

As practitioners in the world of deafblindness, the knowledge that families can bring will educate and inform, thus enriching their expertise and practice as they support people with deafblindness.

Working together families and practitioners in the field of deafblindness will become empowered to unlock the door of bodily tactile communication and cast light into an otherwise dark world of potential isolation and loneliness.