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

Part 1

Slide 1: Title

Hello from Edinburgh, the beautiful capital city of Scotland.

My name is Lilias. I have a Masters in Communication and Deafblindness from Groningen University and, to my ongoing surprise, have ended up as a researcher and presenter in the field. This is all thanks to the fact that I am the mother of a 26-year old young man who lives with Congenital Deafblindness. His name is Fearghas and he is the youngest of my three wonderful sons.

Here he is:

Slide 2

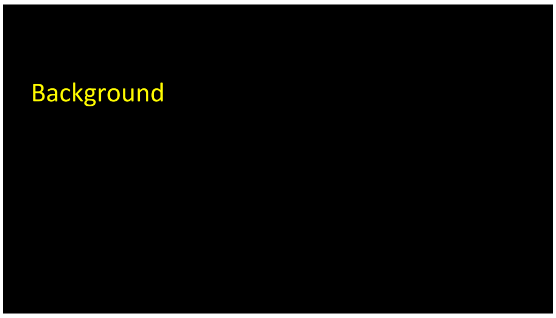
I have been given the privilege of sharing with you today my perspective as a parent who has spent the last 26 years supporting and advocating for her son.

I'd like to make clear at the outset that this is my personal experience of being mother of a child with congenital deafblindness and other complex needs in England in the late 20th and early 21st century. I am not speaking for others although I believe that many people across the world may have had, or are currently having, comparable experiences.

So, that said, I'd like to invite you aboard the rollercoaster that has been Fearghas's and my life from his birth.

This has been a most challenging presentation to prepare for as it has reopened doors to places in my mind that I had carefully locked in order to be able to help both Fearghas and myself come through the battles we have faced from the day he was born. On that day I was told by doctors that I didn't have to take him home from the hospital if I didn't want to. We haven't looked back since.

Slide 3



Background

First of all, some background about myself:

Before having children, I was a teacher. I started by teaching French, German and English in a secondary school but then set off to travel the world. My first stop was Malaysia and within a few days I found myself teaching French with the Alliance Française. After six years, which included working as the English Language Consultant on an English-Malay dictionary project, and teaching English with the British Council for a few years, I then returned to the UK to do a masters in English Language Teaching and Applied Linguistics at Edinburgh University in Scotland. As you can tell I have always had an interest in Communication. Then came marriage and a move to England.

Fearghas was born in 1997, the third of my three children. At that point I had no previous experience of disability of any sort. The pregnancy went well and we weren't expecting any problems. It was a huge shock, therefore, when Fearghas was born with Down's Syndrome. I can remember holding him in my arms and being overcome with the thought that, in this tough world, my beautiful baby was setting out on his life from well behind the starting line.

At the time local protocols around a diagnosis of Down's Syndrome led to immediate referral to a specialist Child Development Centre. From there we were referred to

Slide 4

Community Services
-Paediatrician
-Learning Disability nurses
-Speech and Language Therapist (feeding support)
-Physiotherapist
-Pre-school specialist teacher
-Social Worker

Hospital Services
-Audiologist
-Ophthalmologist
-Heart scan

Our quiet, relatively organised family life, if such a thing is possible with three children under the age of five, was suddenly taken over by what seemed like dozens of professionals coming into our home to offer help and support, and by countless appointments in hospitals and clinics. My initial feelings of shock, fear, confusion, bewilderment at having a child with disabilities became mixed with relief, hope and optimism at all the help that was being offered. But it was also completely overwhelming.

Over the first 11 months a series of other medical issues followed leading to further diagnoses:

The introduction of a dedicated and very determined paediatric nurse and a three-month battle with a new consultant led to Fearghas being prescribed 24-hour oxygen. He immediately started to thrive and was on oxygen until he was eight. We had a month of calm and then Fearghas started to make different strange, sudden movements. Another battle, this time over seven months, and accusations of being a neurotic mother, led eventually to a diagnosis of West Syndrome, a very rare syndrome characterised by a rare form of epilepsy. While this was going on, an incident at home led to me phoning the Child Development Centre in floods of tears. The senior nurse came to the house and after a couple of hours observation, pronounced Fearghas “stone deaf”, a completely inappropriate term but highly evocative. All this happened before his first birthday.

By that time, I was exhausted. As I said, we had a stream of professionals coming to the house regularly and umpteen appointments in clinics and hospitals. And I was getting very little sleep as well as looking after my other two very active boys.

Slide 5

Community services
-Paediatrician
-Learning Disability nurses
-Speech and Language Therapist
-Physiotherapist
-Pre-school specialist teacher
-Social Worker
-Paediatric nurse

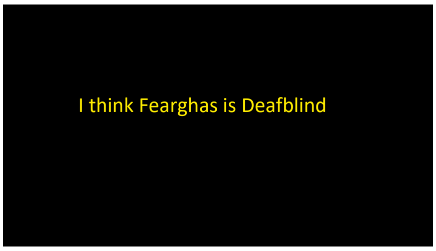
Hospital services
-Audiologist
-Ophthalmologist
-Heart scan
-Paediatrician no 2
-Paediatrician no 3
-Epilepsy services

To the earlier list we added a hospital paediatrician, a paediatrician specialising in respiratory problems, epilepsy services and Ear, nose and throat services. As well as weekly or two-weekly home visits from community services, the different hospital consultants wanted to see Fearghas three monthly at first and later six-monthly. At one point later on, Fearghas was under nine different consultants as well as at least six different community services. And for many appointments we had to travel over an hour each way. There wasn't a lot of time left for just being.

Don't get me wrong: I will be forever grateful for the support that we were given. However, I had been plunged into an unknown world of disability and I no longer had control over my daily life. That was very disorienting and scary. I was in emotional turmoil but trying to keep a calm, loving home for my children and greeting every visitor with a broad smile and assurances that everything was "fine, thank you".

Fearghas was turning out to be quite a complex little bundle, so he was then referred to Sense, a charitable organisation that supports people with congenital deafblindness and other complex needs. He was about 18 months when we had our first visit from a Sense worker. I can remember being out in the garden with Fearghas and her, on a lovely sunny day. She was “playing” with Fearghas (I now know she was assessing him) and she suddenly said

Slide 6



I think Fearghas is Deafblind

“I think Fearghas is deafblind”. I absorbed the word but I had no idea what it meant. And I didn’t ask. There had been so much going on over the last 18 months that I was almost numb with worry, trauma, grief, fighting to keep Fearghas alive at times, trying to juggle two other boys under the age of 5, trying to keep a sense of calm, safety, security, “normality”, whatever that was, while my whole being was exploding with the desire for it all to go away…not my boys but this world I had been plunged into, of doctors, hospitals, therapists, a world where I had lost any sense of what was “normal”, a swirling maelstrom where I had no control, and the worst thing, a world where I felt a complete failure as I was helpless to help my baby.

So I didn’t ask what this “deafblind” word meant; and no explanation was offered. We had regular monthly visits from the Sense worker. As far as I could see, she came to play with Fearghas, and she brought some fabulous toys. But I didn’t understand what I was seeing. I just thought his development was delayed and this would help. As far as I could see any baby would enjoy and benefit from the “toys” she brought with her, some of which she lent us. So I played with Fearghas with these super-duper toys and we had a lovely time.

And then, after a couple of years or so, the Sense worker disappeared, and we were left. We had so much else going on that I didn't chase it. By this time, we were in and out of hospital by ambulance so often that we had direct access to the children's ward rather than going through A&E and triage.

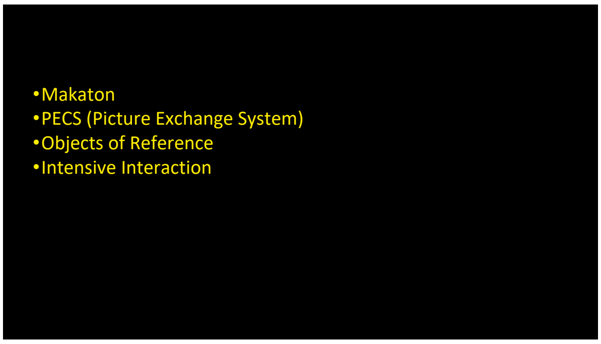
We were seeing an audiologist who never bothered to look in Fearghas's ears. At first, I accepted this as no one had explained what I should expect from the appointments. I was also still in awe of hospital consultants and didn't dare challenge them. Eventually I realised that this wasn't right, so I fought for a new referral.

Fearghas was being repeatedly dropped to the bottom of the ophthalmology waiting list because he was in hospital each time his appointment came round. And when Fearghas did eventually get his vision assessed at the age of three or four, I was told by the optician that he definitely needed glasses, but the consultant didn't want to prescribe because she thought they would be "more trouble than they're worth"! By this time, I had more confidence and was able to challenge the consultant. Another battle fought and then won followed by a fight for another rereferral. I remember vividly the day Fearghas finally got his glasses. We collected them from our high street optician. Fearghas was lying on the floor in the waiting room. The optician bent over him and carefully placed the glasses on Fearghas's face. He stilled, and he looked….and he looked….and he looked….He accepted them straight away and never tried to take them off ….because he needed them.

One paediatrician kept trying to stop the oxygen therapy while he was still having frequent emergency admissions to hospital because his oxygen saturation levels had crashed yet again. I had repeatedly seen my baby nearly die because he couldn't get enough oxygen into him, so an almost primeval instinct kicked in to fight for his life. Another battle; another rereferral. And on and on….

At the age of five, Fearghas went to Special School, that is, a school for children with learning disabilities and other special educational needs. Years later, when Fearghas was nearly 20, I discovered that a specialist report had been written by Sense. This report included assessments of Fearghas's functional vision and hearing and recommended that as a child with congenital deafblindness, Fearghas should have specialist support. It also recommended the approaches that were appropriate to supporting his communication development. However, this report was never included in the paperwork that accompanied him through school and I discovered years later that none of his education staff, or staff in the youth club he attended, had been given the information that Fearghas was a child living with congenital deafblindness. Consequently, Fearghas's Speech and Language Therapist, along with his teachers, introduced various approaches to help support his communication development which were suitable for children with good functional vision and/or hearing. These included

Slide: 7



- Makaton
- PECS (Picture Exchange System)
- Objects of Reference
- Intensive Interaction

Makaton, a signing system based on British Sign Language which is designed to support the development of communication for children with learning difficulties who need help bridging the gap between understanding and producing language; PECS (Picture Exchange Communication System), Objects of Reference, Intensive Interaction, and probably others which I have forgotten. These were all tried and tested with success for children with good functional vision and/or hearing. However, for my son success was very, very limited.

The one approach that did produce positive results was Intensive Interaction. That is a copyrighted name but similar approaches are referred to with terms such as Immediate Imitation. By the time Fearghas was about five or six, he was becoming very withdrawn. He would sit with his head down, focussing on his hands which he clasped in front of his chest. One day I was approached by a teaching assistant in his class, who said she thought Intensive Interaction might work for Fearghas and would I like to go on a course with her. I jumped at the opportunity, desperate for anything that would help Fearghas. It was just a day course. That evening I was bathing Fearghas and, as usual, he was sitting in the bath, clasping his hands in front of him, rocking gently back and forward, his head down. Instead of chattering away as usual, playing, pouring water and so on, I knelt down, very still and silent, leaning on the edge of the bath, and just watched Fearghas. After a little while he made a single sound which I immediately echoed back. He paused for a moment and then went back to rocking. Then he made another sound. I echoed it back and he paused again. He went back to rocking and then made two sounds. I echoed them back; he paused and this time he lifted his head and looked at me. Then back to rocking; then two more sounds which I echoed back. He lifted his head again and this time held my gaze. By the end of that bathtime we were taking it in turns to make sounds, all the time led by Fearghas and he was looking me directly in the eye and holding my gaze, something he hadn't done for a long time. A key had turned in the lock to Fearghas's world. Intensive Interaction is still an important part of Fearghas's toolbox of communication approaches. However, it does have its limitations and there is an ongoing risk that professionals around Fearghas get distracted by the ease with which Fearghas responds to Intensive Interaction at the expense of supporting the development of his bodily tactile communication. More of that later.

But to come back to the other approaches that were being introduced at school. I knew the majority of these approaches were not working. No-one had explained what deafblindness meant or the consequences, so I didn't understand why nothing seemed to be working. That didn't stop me asking questions but rather than opening the door to cooperative and meaningful discussion, I ended up being labelled as a “difficult” parent.

My son lived in a world of seemingly endless assessments by every professional that crossed his path. He was being judged against preset norms. A study carried out as part of my Master's degree in Communication and Deafblindness revealed that standard, non-deafblind specialist assessments carried out in education, by speech and language therapists, and by educational psychologists rely on the child having good functional vision and hearing in order to achieve accurate assessment. This is a worldwide problem. It can result in a mismatch between the support offered, based on the results of official assessments, as compared with the true ability of the child and what that child really needs to meet their needs.

I had repeated battles throughout Fearghas's school and college years. Fearghas would be placed in a class based on his assessment scores but that class that would be below his actual ability level. Repeatedly, I eventually won my battle to have him moved up and repeatedly teachers expressed surprise and delight at how he suddenly started to thrive and make progress again. And this was despite not having appropriate support to develop his communication skills as a child living with congenital deafblindness. My son was perceived as failing to achieve in all areas because his dual sensory impairment was not recognised and taken into account. He was being judged against the norms of a sighted and hearing world, a world that he was never going to fit into.

We lived in the shadow of professionals from education, health and social care telling me over and over what Fearghas was **not** going to do. Following assessments of cognition, I was told Fearghas had Multiple and Profound Learning Difficulties. However, this didn't match the fun-loving, sociable, funny, bright little boy I knew at home. And over the years, with monotonous regularity professionals in his support network would say, privately, quietly, and almost begrudgingly, to me, "He's really smart, isn't he"! I would reply each time with a resounding "Yes, I know!"

When it came to the results of physical vision and hearing tests, other problems arose. Fearghas has no vision, not even light perception, in the right eye. His left eye has

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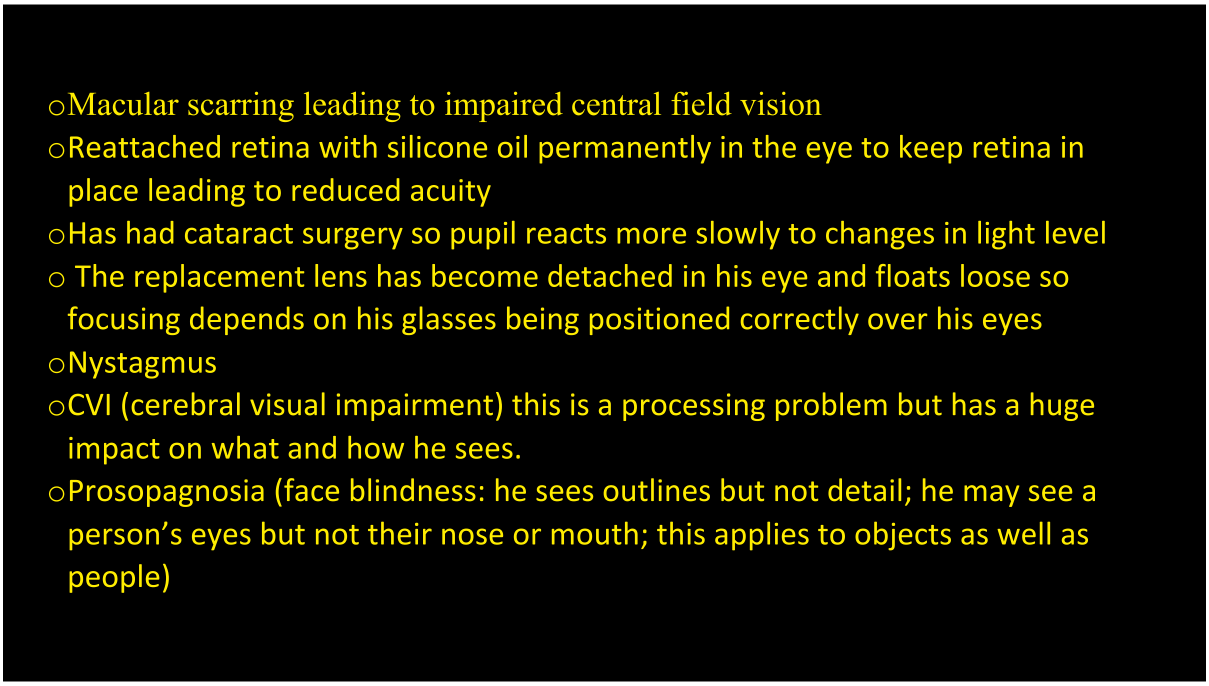


- Macular scarring leading to impaired central field vision
- Reattached retina with silicone oil permanently in the eye to keep retina in place leading to reduced acuity
- Has had cataract surgery so pupil reacts more slowly to changes in light level
- The replacement lens has become detached in his eye and floats loose so focusing depends on his glasses being positioned correctly over his eyes
- Nystagmus
- CVI (cerebral visual impairment) this is a processing problem but has a huge impact on what and how he sees.
- Prosopagnosia (face blindness: he sees outlines but not detail; he may see a person's eyes but not their nose or mouth; this applies to objects as well as people)

Yet despite this wonderful list, education and care professionals have told me very confidently: "His vision's not that bad, is it" and therefore they didn't make the necessary adjustments to accommodate his severely impaired vision because they chose to believe conclusions reached through their own ignorance despite the information available to them. They didn't understand how my "smart" little boy was using muscle memory, shadows, vibration, air movement, tactile memory, and so on, to navigate his world. Hearing this as a parent, having lived through the trauma being told about the reality of his visual impairment, which happened in stages, the trauma of supporting my son through eye surgery, being repeatedly plunged back into the process of grieving for what Fearghas was never going to have or had lost, I wanted to scream every time I heard it. But I didn't, I just smiled and tried to remind them of what the consultant ophthalmologists' reports had said as I gathered Fearghas up and took him back to the safety of home.

I was told Fearghas was never going to do X, Y or Z, for example, I was told he wasn’t going to survive his first year.

Here Fearghas is two or three years old.

Slide 9

then he wasn’t going to survive the following winter:

Slide 10

he was never going to walk:

Slide 11

Slide 12

In this picture you can see the malformation of his ribcage as a result of repeated extreme respiratory distress over the years.

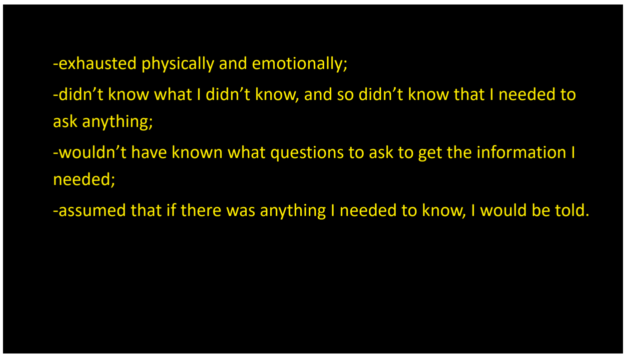
And I'm sure there are other examples that I have buried at the bottom of my memory. He was written off time and time again but Fearghas showed them!

I have shared this detail about the early years of Fearghas's life, not to get your pity or sympathy, but because I believe it is a story commonly found in the early years of children born with congenital deafblindness.

The grief, trauma, sadness, fear and feelings of being lost, of not understanding, of helplessness, are often hidden behind closed doors and what is considered to be socially acceptable behaviour. Weekly visits from a social worker also led to me developing a great fear of being seen or perceived to be failing. I wasn't clear about what her role was and this hugely powerful emotion led to thoughts like: "Am I being judged?" "Am I a failing mother?" "Am I therefore an unfit mother?" "Will I get reported?" "Will someone try and take my child away?" All these thoughts swirled through my mind and led to a highly defensive position of trying to show that all was well to the outside world. Professionals need to consider all this when working out how to approach supporting parents to understand this unfamiliar world and how to take the perspective of their children with congenital deafblindness. If a parent, under such circumstances is saying "I'm fine, thank you. Would you like a cup of tea?", then that should not necessarily be taken at face value or used as a reason or excuse to back away.

So I didn't ask about this "deafblind" word. Why?

Slides 12, 13, 14, 15



-exhausted physically and emotionally;

-didn't know what I didn't know, and so didn't know that I needed to ask anything;

-wouldn't have known what questions to ask to get the information I needed;

-assumed that if there was anything I needed to know, I would be told.

Because I was exhausted physically and emotionally;

Because I didn't know what I didn't know, and so didn't know that I needed to ask anything;

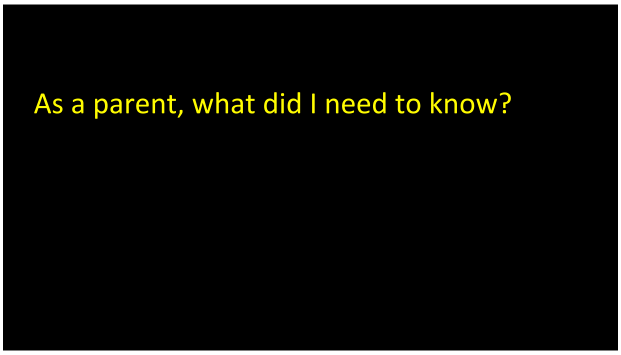
Because I wouldn’t have known what questions to ask to get the information I needed;

Because I assumed that if there was anything I needed to know, I would be told.

How wrong I was!

So:

Slide 16

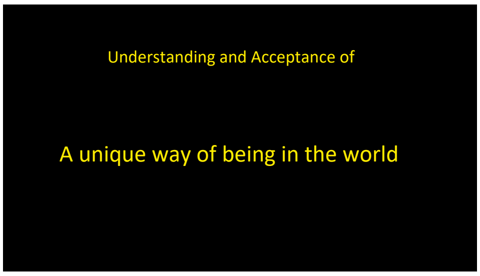


As a parent, what did I need to know?

So, what did I need to know?

Firstly, I desperately needed to understand and accept that my son wasn’t “odd” or “peculiar” or a “funny little thing”, all phrases that I was hearing from random people, from medical professionals and even from education and specialist learning disability professionals. I needed to understand that living with congenital deafblindness simply gave Fearghas a unique way of being in the world

Slide 17



Understanding and Acceptance of

A unique way of being in the world

And there’s that phrase again: congenital deafblindness. It had haunted me for years so what did it actually mean? Forgive me if I’m about to tell you what you already know but this is what, on reflection, I wish I had known and understood from when Fearghas was born.

Then, I needed to know what Deafblindness actually was and most importantly, what the consequences were:

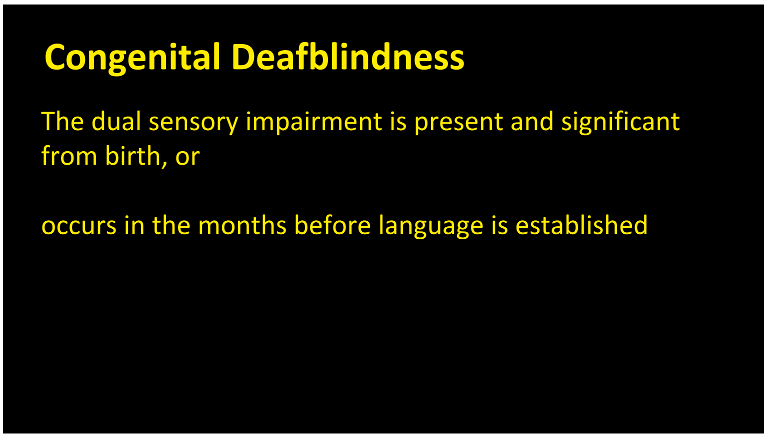
Slide 24

What is Deafblindness?

- a unique disability
- significant combined impairment of vision and hearing
- causes problems in:
    communication
    orientation in the environment
    and access to information

(Rødbroe & Janssen, 2006).

Slide 25



Congenital Deafblindness

The dual sensory impairment is present and significant from birth, or

occurs in the months before language is established

As a sighted and hearing person, I took for granted the ways in which I had access to the world around me through my vision and hearing. I needed to have not just explained, but spelled out in words of one syllable, all the things about my vision and hearing that I took for granted and never even thought about.

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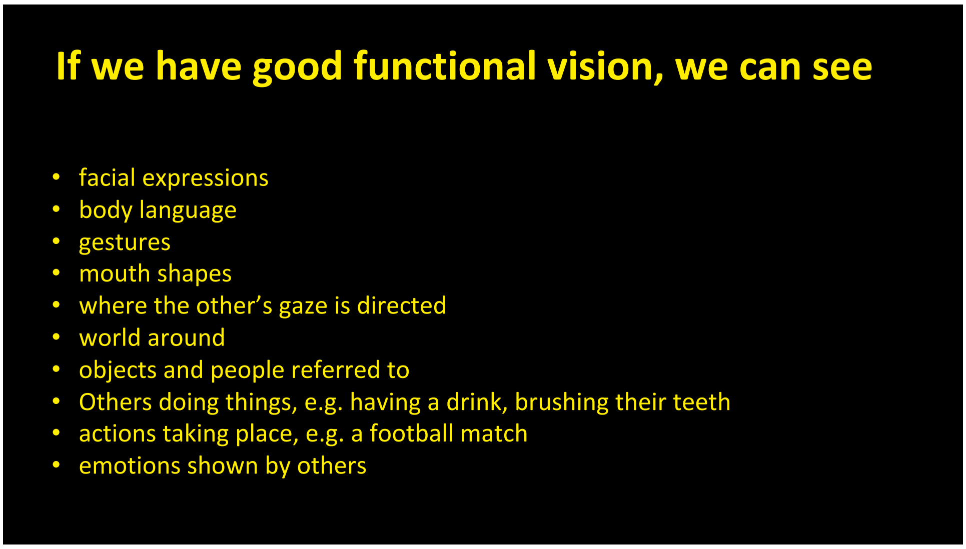


If we have good functional vision, we can see

- facial expressions
- body language
- gestures
- mouth shapes
- where the other's gaze is directed
- world around
- objects and people referred to
- Others doing things, e.g. having a drink, brushing their teeth
- actions taking place, e.g. a football match
- emotions shown by others

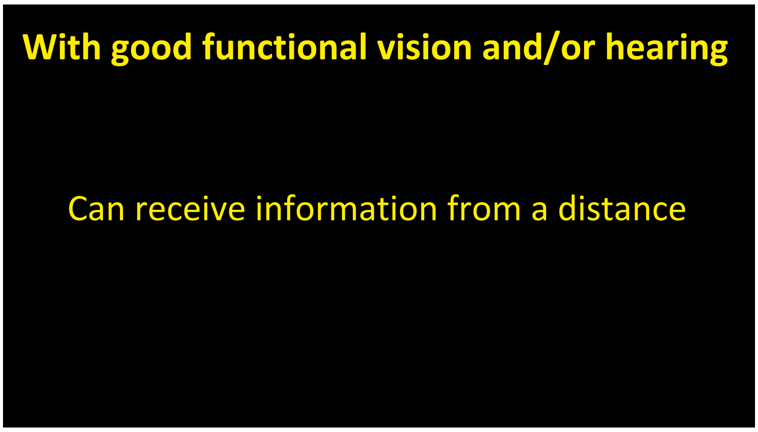
Slide 27

If we have good functional hearing, we can hear

- language/communication addressed directly to us
- language/communication addressed to others (overhearing). (Akhtar, N., & Jipson, J. & Callanan, M. 2001)
- environmental noises, eg a door closing, a car engine, a tap running, someone else coming into the room, birds singing, etc
- Expressions of pain, joy, tiredness, etc
- that others are there
- difference between silence and noise
- others doing things, e.g. eating crisps, brushing teeth
- others engaging in activities, e.g. football match

I needed to have pointed out that through my vision and hearing, I am able to receive information at a distance

Slide 28

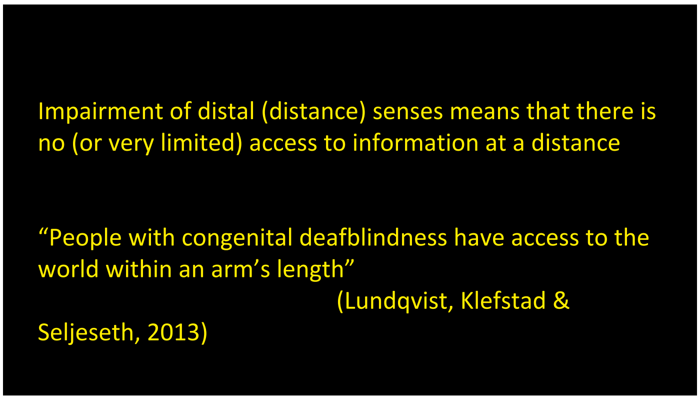


With good functional vision and/or hearing

Can receive information from a distance

And I needed to have explained that if your distance senses of vision and hearing are significantly impaired,

Slide 29



Impairment of distal (distance) senses means that there is no (or very limited) access to information at a distance

"People with congenital deafblindness have access to the world within an arm's length"
(Lundqvist, Klefstad & Seljeseth, 2013)

then you have very limited, or no access to information at a distance. The consequence of that is that "People with deafblindness have access to the world within an arm's length.

So, if you stretch out your arms, just imagine what it must be like for your meaningful access to the world to end at your fingertips!! This is the case for Fearghas and I didn't **consciously** realise it until he was nearly 20.

In the second part I will explore the consequences of not understanding that Fearghas's access to the world was limited to the reach of his fingertips. I will also speak briefly about the relationship between parents and professionals.