

Parent /Carers Story Child with Autism Presented at Royal Manchester Childrens Hospitals

Thank you for affording me the opportunity to share with you some of our families experiences of living with a child who has autism as well as insights gleaned through supporting other families in similar circumstances

‘Hurdles’ the charity of which I am Chair operates in the Bury Borough where there are more than 750 children with a diagnosis of autism, Bury is a small borough, nationally one in eighty children is diagnosed as being on the autistic spectrum. But this afternoon is not about statistics it’s about very real people, their lives and their challenges, the part they will play in your professional lives and your part, for better or worse in theirs.

It is no exaggeration to say that my grandson’s autism has had profound impact on all our lives emotionally, health wise and financial. That said he has enriched our lives beyond measure. Michael is a wonderful beautiful 12 years old without guile or malice. In his mother’s words, we love the very bones of him and if we did not have him we would need to invent him.

Whatever the impact of Michael’s autism on our lives it pales into insignificance when compared to its impact on his life. It is he who lives with the lifelong condition which is all pervasive, insinuating itself into every nook and cranny of his daily existence including illness and hospitalisation.

Autism is defined by a traid of impairment:

Difficulty with social communication

Difficulty with social interaction

A lack of social imagination and awareness.

Communication

Although Michael has neither expressive receptive language and communicates using PECs, a picture exchange system. Other children with ASD may appear fluent in speech but have a very literal understanding of language, others may demonstrate echolalia.

Social Interaction

In common with many children on the autistic spectrum, Michael lacks social awareness and empathy. He has no understanding of other people, or that they too have needs. Even higher functioning children lack this awareness, 13 year old Jacob berated his mother who was immobilised by a back condition telling her 'you could crawl if you wanted to!'

We are blessed in that Michael gives and receives affection unlike many of his peers, but even kisses and cuddles are given on his terms and at times of his choosing. He prefers solitary activities, making jigsaws, looking at picture books or watching Disney DVDs, trampolining or swinging on his garden swing. His twizzer roundabout is a great favourite.

Lack of Imagination

Most of our children struggle to predict what will or could happen next. They have little ability to transfer skills learned in one situation to another and have no understanding of danger. Children with autism are often change resistant and will easily become anxious or fearful. This triad of impairment is only the beginning – the headlines if you like.

Our children are quirky and idiosyncratic full of peculiarities often with present behaviours and rituals, counting, touching etc. Jumping twirling flapping then standing with fingers in both ears, eyes shut tight because the environment is too stimulating and they are experiencing sensory overload.

Over the years we learn to read our children or at least some of their distress signals. Experience teaches us how to avoid situations that give rise anxiety we pre-empt potentially distressing circumstances. We are developing strategies to de-escalate conflict just as our children develop their own coping

mechanisms e.g. shredding paper or flapping to calm themselves. Caring for our vulnerable children, and endeavouring to meet their needs is a full time job, 24/7. It's not the child who demands this it is the condition that requires it. When we say our kids don't do waiting we aren't saying they are more important than anyone else we are saying their inability to understand strange and new situations is such that they become tearful, deeply distressed unable to cope and any change of their being able to receive a service is gone. They are now beyond the point of return and recovering the situation may be impossible. For some children coming down or recovering can take days rather than hours and meanwhile the original problem remains unresolved. Just for a few moments imagine yourself in a foreign country. Everything is unfamiliar and you don't speak the language. Everywhere around you there are people you don't know doing things you don't understand and they are all bigger than you.

Desperately you look around for a sign, a clue something visual to latch onto but there isn't any. Now still in a foreign land you feel ill and in pain. No matter how ill or frightened you feel you have no capacity to communicate your fears or illness. You don't know why you feel like you do, and you can't make it go away. You are so not in control of your destiny, instead you are at the mercy of somebody noticing that all is not well and doing something about it. Nothing is happening so in fear and frustration you bite your hand and slap your face, you bang your head against the wall and people move away. Is he violent? They ask. Welcome to the world of autism.

Our children are in this world all their lives. Their sheer vulnerability and our parental response to this means that we are emotionally wrecked before we reach the GPs surgery.

Diagnosing illness in a non-verbal autistic child is no easy task. Many routine markers, appetite, sleep and eating habits are all erratic in our children at the best of times. Children with autism do not make life easy for you, the medical profession. You are geared up to fixing things, mending the broken and making people better. It's your *raison d'être*. Our broken children do not make for

easy mending, lack of empathy on their part means a lack of responsiveness. You don't get the feel good factor that tells you what you are doing helps. Our children do not make for warm afterglow.

For many children and young people with autism, face to face with new people is often stressful. Many will not understand who you are and what you want. Some will be unable to define what their own needs are. Those who can are at risk of misrepresenting themselves simply because they want to say the right thing.

Others can speak fluently but not understand what you are asking so take things very literally. So if you ask 'can you wash yourself on your own'? the child may respond yes, when in fact they can only do it if prompted at each stage of the exercise. It takes time and effort to understand a child with autism a short attention span and being distracted easily don't help. Our children if verbal may prefer to talk about a favourite topic rather than the issue you are asking them about. Social niceties are in short supply, challenging behaviours can occur particularly where there are also learning difficulties and in all cases our children need time to process information and respond. It isn't helpful to them to have the information repeated as this can cause the processing to have to begin all over again. Many of our youngsters have difficulty knowing who they are, its worth finding out early on how the child likes to be addressed. Most have a single version of their name to which they respond and anything else will not register. One eight year old I know erupts like a volcano if called anything – son, pal, mate, Fred – other than his name – Freddie.

Heightened sensory sensitivities play a huge part in our children's lives. Many are more comfortable using peripheral vision as for them direct eye contact can be intensely distressing and intimidating. They can fixate on small details a crack in the ceiling or a very slight movement of an object in the room, this can render a child oblivious to all else. Changes in floor patterns or colours can cause anxiety about walking from room to room. Continuity of venue and settings can contribute considerably towards a good outcome. Very often our children have acute hearing which makes them uncomfortable with certain noises e.g. hand dryers and very young babies crying. In such cases the child may use a noise of their own e.g. humming to themselves to block it out. Even

the sounds that certain foods make in the mouth can cause deep distress. 6 year old Rain becomes so distressed and inconsolable at the sight of a packet of crisps they are not allowed in his house and he has to eat his lunch separate to other children in his school as they may have crisps in their packed lunch.

Taste is no less of a minefield for the unsuspecting. Children with autism can be especially sensitive to food textures and tastes, some children eat only bland food whilst others craves spicy and strongly flavoured foods not to mention the non edible substances, pencils packaging, baby wipes even clothing. Michael will not tolerate a mix of wet and dry foods, sauces and gravy are definitely off the list. However for him a trip to the park is as good as a visit to a restaurant. He has cast iron stomach and an intense liking of beech leaves, rosebuds, conifers, dandelions and tulip foliage. These are all devoured with gusto but it's not the leaves or the rosebuds that are his passion, it's the dandelion, when we see them in the park he always manages to swipe at least one in spite of our efforts we just have to pray that the dogs haven't been there first!

Touch can produce as many reactions as there are stars in the sky. For some another person's touch can be more than uncomfortable, it can be painful. Haircuts and hair washing can induce frenzied behaviour because it physically hurts. Similarly, teeth brushing. The sensation of snow or rain on the skin can also cause distress.

Conversely other children with autism enjoy firm pressure in physical contact, some have a significantly higher pain thresholds and do not notice or respond to pain.

Some of our children have reduced body awareness and can appear clumsy or accident prone. Co-ordinating their movements can be difficult, for many riding a bike proves impossible. Balance and movement can be particularly problematic for children with autism. Some get travel sick easily, just by climbing the stairs, others enjoy fairground rides that involve spinning and being turned upside down or thrown from side to side at speed. Many use the trampoline almost as therapy.

So there you have it, or rather you don't and we do. These are some of the minefields we negotiate daily as we endeavour to lead our wonderful, quirky

and intensely vulnerable children through a world which is as baffling to them as they can be to us. However, impaired as they are our children are no less human and no less valuable and not less entitled to appropriate care than their mainstream peers. Our children get ill and bleed when cut. They need they deserve your best efforts and they are entitled to every consideration you can give them if it takes twice as long or requires a more complicated procedure so be it. By law they have the right to be appropriately accommodated, morally how can you refuse.

As parents we fight to get an initial diagnosis, then we fight to get a statement of special educational needs, then we fight to get appropriate education, all of this is on top of 24 hour caring responsibilities. Please do not make us have to fight for appropriate medical care as well. We don't want to fight you, given half the chance we will help and support. Sometimes that means you need to follow our lead in determining the whether the child stands or sits for an examination, it means that we need to take the child's temperature rather than nurse. Often the presence of a VCR or DVD player with a familiar film will have a calming influence and assist in processes such as taking blood or giving injections. For a child with autism creams tend to be less successful anaesthetics than sprays. It's not just that the cream feels like a foreign body on the skin to rub off at the first opportunity, its waiting, our children don't do waiting, 30 minutes is a lifetime in which to build stress and provoke self harm. For many children oral medication is a problem. My grandson Michael cannot take oral medication. I do not mean wont I very definitely mean can't. His autism renders him incapable, not reluctant. Just as his brain cannot process expressive or receptive language neither does it tolerate the texture or taste of pills, capsules, potions or powders. After years of devious efforts, masking medicines with drinks – unsuccessful, Michael refused to drink at home for 2 months and even now watches you make his drinks. Hiding things in food – he ate around the tablets or refused to eat the meal, a clinical psychologist recently confirmed what we already knew:- Michael cannot take medicines orally. This has meant that on at least 2 occasions Michael has been unable to access treatment for infections and on one occasion, due to an extreme infection, had to be admitted to hospital for five days for a course of antibiotics that would normally be given in liquid form, to be administered intravenously. I will not begin to tell you the horrors and stress that caused.

We the parents and carers of children with autism live with the fear and knowledge that our vulnerable children will grow up in a society which cares so little for them and places so little value on their humanity that they can starve to death in a hospital bed. How you respond to the needs of our children when they are ill will either feed that fear or help dispel it. The choice is yours, which is a great privilege. Our children don't have a choice.

Mrs G Green March 2011