

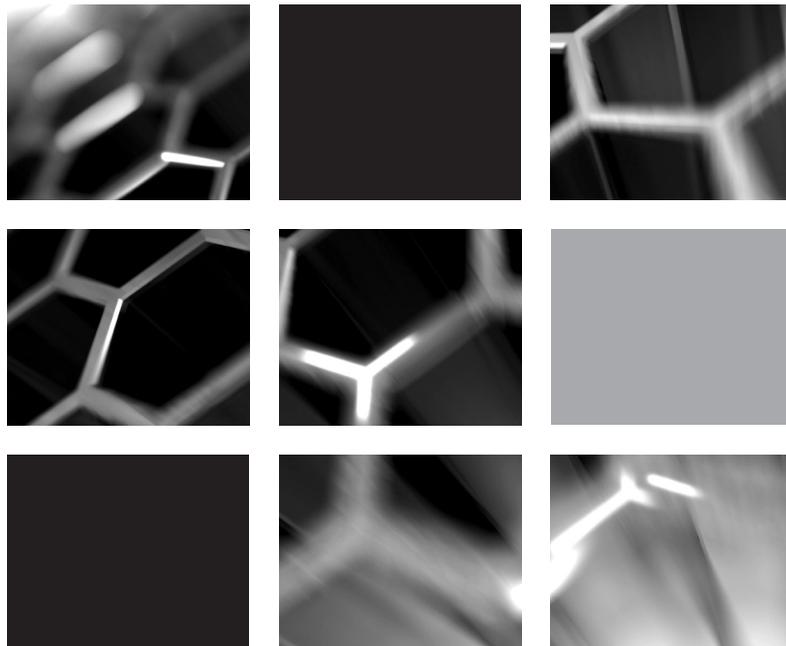


all about people

GAP

CELEBRATING THE
FIRST 10 YEARS OF
THE JOURNAL

Edited by Glenys Jones



Published in partnership with The University of Birmingham
autism.west midlands and Autism Cymru

Within and without autism

Ros Blackburn, UK

GAP Journal, May 2000

An autistic adult's view on some of the whys and wherefores surrounding autism, and a few suggestions on what can be tried to help alleviate problems for all concerned.

Editorial comment

Ros Blackburn is an able woman with autism who displays great courage in dealing with the sensory and social confusion around her. She has an exceptional ability to portray to others how she views the world and why she behaves as she does. Ros has given numerous talks to professionals working in health, social services and education and to parent groups throughout the UK. Using humour and anecdote, she points out the absurdities of many of our social conventions and makes us question so-called 'normal' behaviour. In this paper, she has focused on how autism has affected her and describes the type of support she would very much welcome. Ros identifies a serious gap in current service provision. Many high functioning people with autism have great difficulty in persuading services that they require support, and serious attention needs to be given to this. Ros can be contacted at the address above if you would like to invite her to talk to your service or group.

Address for correspondence:

c/o RAFT, 58 Brisbane Road, Ilford, Essex, IG1 4SL

Initial comment

I would like to stress that this is purely my own individual account. It is my views and opinions on different subjects, my likes and dislikes, what I think works and so on. It is by no means the view of all people with autism.

Brief background history and introduction

From three months old, it appeared that I was withdrawn, isolated and very much in a world of my own. At six months, I was diagnosed profoundly deaf, which later proved to be far from correct. Finally, at a year old I was diagnosed severely autistic, but with average intellectual ability. Now, at 31, I'm regarded as 'high functioning autistic', although I tend to feel that many areas of my autistic condition have remained very severe, while others have almost disappeared completely. I have a very uneven profile of strengths and weaknesses, where often my strengths mask my very real difficulties. In summary, I feel that in many ways my ability quite often proves to be my biggest disability, particularly in the area of obtaining the valuable help

and support I so desperately need as my parents grow older.

In this paper I intend to discuss some of the practices which I found played an invaluable part in my progression from a severely autistic child into a high functioning (albeit still autistic) adult. I'd like to share with you some of my reasoning behind what may appear totally unreasonable behaviour – in other words discuss 'why I do what I do'. And finally conclude by outlining some of the very practical ways in which I can be supported and helped today as an able adult with autism (an area that I feel is somewhat lacking at present).

Question: How has a severely autistic child ended up a high functioning autistic adult? What has happened?

There are several reasons why I've done as well as I have done.

One reason I've done as well as I have is early intervention – I was 'got at' very young. In some ways,

autism is a great big gorgeous, cushy habit and the longer you are left to get set in your ways, the harder it is to get out of it. Another reason is that I had pretty unique parents. I had a mother who was, in many ways, able to turn off some of her natural parenting emotions and instincts. She was able to be 'pig horrible' to her child and, in fact be the cause of her child's distress. Admittedly, I hated it then, but I cannot thank my parents enough now for what they did. I am now able to live on my own (but by no means independently) in my little flat. The nearest I could ever get to autism paradise.

My schooling was also a contributing factor in my progression. My parents were strongly advised to place me in a specialist school as I had very limited speech and severely challenging behaviour (to put it politely). They went against that advice, feeling that my academic needs would be more suitably met in a mainstream setting. They were also hoping that I might learn both behaviourally and socially from what was around me, rather than learn any more 'tricks of the autistic trade'. Both my primary and secondary schools were very small and very old fashioned in style. The classroom setting was fairly serene and ordered, each child having its own desk, rather than shared tables. Teaching materials were put away out of sight, rather than cluttered around the room. Even the decor tended to be pastel colours and plain, rather than bright and over stimulating. In many ways therefore, a much more suitable setting for the easily distracted autistic child to stay focused, rather than the modern 'let's make learning fun' scenario that we are bombarded with today.

Probably the most important and biggest reason, why I have done as well as I have done, is that no excuses whatsoever were made for autism. Making excuses for autism is so futile, so damaging and above all, so wasteful of learning opportunities. I am inclined to say '*Never, never make excuses for autism, but help the person with autism overcome the problems caused by it*'. People with autism cannot learn by generalising, or by learning rules and then applying them to different situations. They need to learn from very specific rules to very specific situations. Although role-play is a very valuable tool, nothing can beat the real scenario, so use it to teach the person with autism the correct way, the real way, rather than the artificial or 'autistic friendly' modified way. I have had to learn everything from table manners to keeping my clothes on in public, to visiting people's houses, greeting people appropriately and so

on. I have got it wrong on numerous occasions. I cannot help getting it wrong. That is all part of being autistic, but it is no excuse. If I am to exist and get along in the real world, I will have to learn and obey the ways and conventions of the real world, whether I understand them or not. This may seem rather harsh and unfair on the person with autism but reality is harsh and quite often unfair. Surely it is even more unfair if parents, teachers, support workers etc. do not prepare the person with autism for reality, but shelter them from it.

Finally, I'd like you to consider how you learn, what motivates you to learn the correct ways? Is it the desire to please others or to fit in socially, to save yourself the embarrassment of getting it wrong or so as not to draw attention to yourself or it may even be to win someone's approval? Now, if you are a person with autism, other people may be of little relevance. A statement such as '*You be a good girl and mummy will be happy*' is totally wasted on me, as I couldn't care whether mummy was happy, sad or indifferent. I don't get embarrassed or self-conscious and I am often totally oblivious to the effects that my actions or words may have on other people. In my case, it was necessary that my parents found other ways of motivating me to learn – ways that did have an impact on me, such as banning my favourite obsession or confiscating particular toys or comfort objects, whether I understood the reasons why or not. This obviously did have an effect on me and in many ways introduced an element of choice that I could control if I chose to.

Question: Why do I do what I do? In other words why do I flick my fingers in front of my face, flap my hands, injure myself, insist on order and ritual and indulge in obsessional behaviour to name but a few?

Once again, there are lots of reasons for lots of things.

To me, the outside world is a confusing mass of sights and sounds. It is totally baffling and incomprehensible. Try watching a soap opera on television with no volume. The characters' actions immediately become sudden and unpredictable since the meaning behind them is no longer clear. Every minute that I am outside my front door I am being bombarded by this mayhem. For an analogy, consider a scenario where you are walking down the street and a large crowd of very rowdy, drunken lads has spilled out of the pub. Because of their

drunkenness, their behaviour is no longer rational and therefore no longer predictable. You become anxious, as you are not sure what they might do next or how they are going to react. You feel threatened by the situation because it is unpredictable and you are no longer in control. This is how the world appears to me most of the time. I am unable to 'read into' people's behaviour or read the intentions behind it and am therefore not able to predict their actions. It comes across as very threatening and frightening most of the time.

I have therefore developed various coping strategies.

In order to create a distraction or cut off between me and 'out there', I will flick my fingers in front of my face. My attention is drawn to my fingers rather than what is going on beyond. I can focus on what is near and close to me and what is predictable and 'me controlled' rather than what is further afield, unpredictable and therefore threatening. Sometimes 'beyond' is so penetrating, that simply flicking my fingers is not a powerful enough distraction in itself, so I may use objects as well such as a piece of paper to flick or a liquid-filled sensory toy, for example. This obviously increases the distraction level and therefore the cut off level is increased too. Sometimes neither of these suffice and I am forced to resort to self-harm. Usually, I claw large chunks of skin and flesh from my upper arms or sometimes my thighs and shins. The pain is so intense that I am totally incapable of focusing on anything else around me. My entire attention is close to me, 'me in me' as I put it. That pain is so intense that nothing else can 'get in'. There is another reason for this as well. It puts me in total control. Rather than 'out there' penetrating and 'hurting' me, it is now me hurting me. If I scratch harder and deeper it will hurt more, if I stop it will hurt less. This perhaps prompts the statement, *'But autistics can't feel pain'*. Yes we can. We may just respond to it slightly differently from the non-autistic. What happens usually when a toddler falls over in the street while out shopping with mummy? The child hurts their knee and screams loudly. What happens next? Mummy drops the shopping bags, rushes over to 'precious little darling', scoops her up, kisses and cuddles and rubs it better. If you don't like physical contact, if you don't like your mother all over you, you keep quiet. If I fall over in the street, I keep quiet. If I'm quick enough I can get up and run and catch up with mummy before she has even noticed that anything has happened. Yes, the gravel in my hurt knee hurts like

crazy, but I don't need the additional 'hurt' of being fussed and 'faffed' about by mother.

Why do I bite the backs of my hands? I used to always bite my hands before we had to go out anywhere. Why? Well what would happen? Mummy would say, *'Don't bite your hand darling'* and push my hand down away from my mouth. So I would do it again straight away. Mummy would repeat, *'Don't bite your hand dear'* and push it away. Although I didn't like mother right in front of my face and I positively detested the physical contact of her pushing my hand away, at least I knew what was going to happen next. Her actions were therefore predictable and less threatening. While she was stopping me from biting my hands, she couldn't be trying to put shoes and socks on my feet or a jacket on me or pile me into the back of the car to take me the unfamiliar route to the shops. (Mother refused to go the familiar route to the shops as she knew that this would lead to further problems later.) If I initiate an action, it is 'me controlled' and therefore predictable. If someone were to burst a balloon behind your back, the sudden bang would make you jump. If, however, you yourself deliberately burst it, you would be ready for the bang and would not get as shocked.

Another big reason for doing what I do is to get a reaction from people that I am ready for, such as asking a question to hear a certain word or phrase in the answer or to re-enact a scenario involving others that I have experienced many times before. This quite often may also be entertaining or it may be to delay or dodge a less pleasant or less predictable issue. I have found that if, when giving something to someone, you handle it very, very gently and softly and then pass it to them very gently, they will take it from you very gently. If, however, you just shove something at someone aggressively they will quite often snatch it quite aggressively. You can also tease them and get their hand to 'twitch' in a brilliant way if you repeatedly keep offering something and then pulling it away as they go to take hold of it.

I used to love chasing my sister around the garden with rose thorns. I would get a thorn between my fingers and then go after my sister with it. I knew that this would make her scream, she would rush off hysterically, screaming and waving her arms in the air. She would race to the back door of the house which she would open so violently, in her haste to get away, that it would

slam back on its hinges and smash against the wall. This used to infuriate my dad, so he would reprimand her. While he was shouting at her, he couldn't shout at me and while he was distracted with her, it meant that his attention was elsewhere so I could get up the trellis on the back wall of the house and onto the roof of the garden shed, another 'no go' area that I was always in trouble for. My mother's face would then appear from the upstairs window to see what all the commotion was about. I had three members of the family all doing exactly what I knew they would do. My mother then learned to say to my sister, *'Look, don't react like that, she's only doing it to you to get your reaction'*. My sister is so good that she used to obey mother and 'stay put'. I then had the added bonus of the sensation of the rose thorn sinking into my sister's flesh. I wonder why we don't get on now!

One thing I really love to do is animate inanimate objects. At home, we had a long bird's feather. I used to love taking this feather and, from a distance, gently touch someone, say on their neck. I used to love to see them twitch and then their hand would come up to scratch their neck and so on. I could never make it last for very long, as I would start screaming and 'flapping about' with excitement. I also used to love making a cardboard box 'quiver' by putting the pet guinea pig inside it and so on. Another reason for doing what I do is for self-amusement. I will tease myself, which in turn excites me. I have a curved shaped toy which when put on the table makes a lovely hollow-sounding noise. I will tease and stimulate myself for hours by starting to put it down but then stopping myself. I also create this same sort of sensation by flicking my fingers at the side of my face, to one side of my vision or by looking at something I really like out of the corner of my eye instead of full on. If something is pleasing to look at, I get enormous pleasure from going to look at it, but then not actually allowing myself to look at it. I love the feeling of excitement and anticipation. Indulging in ritual and routine immediately creates an order out of chaos. It is familiar and therefore comfortable and I can relate to it.

Question: What happens now? How can support and provision be improved for the able adult with autism?

This is quite a difficult subject for me to discuss, as it is very much the 'doom and gloom' side of living with autism and it makes me so desperately upset. It panics

me to death when I think about what on earth is going to happen when my parents are no longer around. It is, however, very much the reality of living with autism.

Although I have done incredibly well, unbelievably well in fact, and have attained quite unimaginable goals, I still remain very disabled by autism in many areas and am therefore still very dependent on other people to have some quite often very fundamental and basic needs met. Although I live on my own, I am by no means independent, far from it, in fact. The reality of living with autism is that at 31 years of age, I am still totally dependent on my now quite elderly parents for all my support needs. While I don't want friends for social reasons, 'cocktail talk' etc, I need people. In fact, I need people more than the average person, as I am not able to decode social signals and pick up on things myself and learn as I go along. I need to be shown, helped, supported or prompted every step of the way in virtually everything I do, but because I don't have friends, I don't have anyone at all to help me with this either.

While I was a child, this was not such a problem. I had one or both parents young and fit and able to help. What's so ludicrous is that as your parents become older and less able to help, so the external support available 'slopes off' at the same alarming rate. While you grow bigger and stronger, your parents grow older and weaker, but rather than the external support being increased at this time, it is for some bizarre reason, actually reduced. While I was a child I had the structure and routine of the school day, various play schemes, clubs and holiday activities, but when you reach that magic age of 19, and enter officially into adulthood, so all these valuable external aids disappear. A more severely disabled adult with autism will no doubt be placed in full time residential care with the various support packages in place. But what of the more able adult? In my experience there is very little provision at all, if any.

What I would dearly like, is real, live human support to do things for me or with me, to supervise or prompt me, to metaphorically 'hold my hand' in new, tricky or unpredictable situations. Someone who can enable me to go to a pub for a drink or to a restaurant for a meal out, help me go to a show, a walk in the hills or even a weekend away. Activities that many just take for granted, but which for me just cannot happen. Financial provision and telephone helplines are quite frequently discussed

when looking into adult services for the more able. Yes, these are important, but they by no means suffice. If someone were to place a sum of money in my hand, that in itself would not enable me to go out and spend it. Likewise, a voice down the 'phone line can give advice and reassure me, but it cannot actually get me across the busy road or help mop up a flood in my home.

Unfortunately, one-to-one care of this kind comes with a pretty huge price tag, if at all, and the average wage, let alone that of a person with autism, just cannot afford it. One ideal set up would be a 'circle' of volunteers based in the local community who could take shifts at being 'on call' for the person with autism should they wish to go out somewhere or should they have a problem, say in their home, and need some practical and readily available help. At present, adult social services provision falls mainly into two categories – learning disability and mental health. Autism is by no means a mental health disorder and the more able adult with autism usually has an IQ above 70 (the cut off for learning difficulty) so does not qualify. Autism is in fact a developmental disorder, a disorder in social interaction and communication, which falls between the existing services into an area where little provision or support has been set up. Many adults with autism remain based in the family home with their parents, since there is little alternative. This is, more often than not, a highly unsuitable placement for all concerned. Those that have ventured out on their own are then totally alone, with little help to fall back on.

This final account highlights the very real difficulties and needs that I have as an able adult with autism.

Recently, I had a very serious accident while trampolining (my greatest obsession!) and had to spend several days in hospital. I was taken semi-conscious from the sports centre directly into casualty and later transferred to the wards. I had nothing more with me than the rather sweaty tracksuit I was wearing and obviously, that was how I remained. A few days into my stay, the nursing staff began to get a bit 'grotty' with me, making reference to my now rather smelly breath. I didn't have a toothbrush with me, so how could I clean my teeth. Next was the fact that I was still wearing street clothes in bed and hadn't changed my underwear for 'x' days. I didn't have anything to change into was the simple reason. *'Can't a neighbour bring some things in for you?'* *'Of course not, I don't even know their names, let alone their telephone numbers.'* *'Well what about a*

friend?' they went on. I don't have any friends, I'm autistic. I don't think they could begin to imagine or even believe my situation, yet autism was written all over my medical records. *'There must be someone'* they went on. Yes, there is – my mother. She is elderly, the full-time carer of my disabled father and lives a 3 hour round trip away. I wasn't able to 'phone her as I had no money with me and was only allowed to make local calls from the nurse's station. I was totally stuck. Finally, when I started feeling a bit better, I was able to get a bit more 'heavy' with the nurses and demanded that if I couldn't 'phone my mother, could they. (Asking politely as I have been taught to do, had absolutely no effect.) The nurses had failed to contact my parents earlier, as they had assumed them to be away. When asked, I had previously said that I was on my own at home, meaning my home. I guess they couldn't believe that I lived on my own, with no support at all. Eventually, my mother was contacted and, yet again, it was down to her that things got sorted.

But what if – what if my parents had been away for a long time or what if my mother herself couldn't physically look after me and what on earth will happen when eventually my parents are no longer around. It doesn't bear thinking about, but it needs to be thought about. I really do feel that some sort of adult provision or support network is essential for individuals with autism who live semi-independently. Why wait for a total crisis to occur and then have to rush about putting together a rather shoddy, make-shift package in an emergency, with little time to work it through and, more importantly, with little time for the person with autism to feel familiar and comfortable with it? The loss of a parent will be devastating enough. Why compound this by thrusting another huge change and upheaval on them in one hit. The parents have lived with autism for 20+ years and can provide detailed and important information on their (adult) child's needs. This is invaluable when compiling a suitable support service and essential when training and preparing the relevant supporters to continue in their role. Why wait until the parents cannot provide this information?

Consider this – autistic children do in fact grow into autistic adults.

Ros Blackburn talks (all over the country) about living with autism and can be contacted at the above *clo* address.