Patricia Howlin (Howlin 1997) has written an excellent book, “Autism – preparing for adulthood” that thoroughly deserved its prize as the winner of the 1997 NASEN Book of the Year Award. It contains practical advice on a range of subjects:

* Problems arising from the triad of impairments
* Education
* Employment
* Psychiatric problems
* Legal issues
* Sex
* Independent living

Like most books on autism it is written for parents and professionals. It is sympathetic to the needs of autistic people and the difficulties and obstacles they have to face in their daily lives. Its emphasis on integration and normalization is much better than the social exclusion and institutional care that used to be the only option for many people with autistic spectrum disorders. It answers most of the questions that parents and professionals might like to put to an expert on autism.

But it has a serious omission. It does not answer the most important question of all, the question a young man with autism asked of his mother.

*“How do I be Corey?”*

Corey’s mom shared this question on an email list. They both gave me permission to share it with you. I do not know the answer for Corey or for anyone else. But I want to use this chapter to explore ways of helping AS teens to find the answer for themselves .

Adolescence marks the transition from childhood to adulthood. In many cultures there is a definite ritual that marks the end of childhood and the beginning of adult life. It may involve tests of physical or mental endurance. Some ceremonies involve pain. They may have a religious significance. But in all these cultures the purpose is clear. The ritual marks a turning point in your life. Once initiated you are ready to learn the duties as well as the benefits of adulthood. In effect you become an apprentice grown-up.

I think that this sort of society would be amenable to young people on the autistic spectrum. As a child there is very clear information about what is expected of you. If you are unable to meet those expectations, society is typically forgiving and there is usually somebody on hand to happily instruct and show the way. When those childhood expectations are about to change to more sophisticated and adult-like expectations, the occasion is clearly marked. You are prepared for it in advance and a new set of expectations follow on from that.

But in places like Europe, North America and the rest of the ‘developed world’ the old ways no longer hold sway. During the teenage years you no longer follow a clearly defined path mapped out by your elders. In fact the opposite is often the case. Teenagers, a word that did not even appear in dictionaries until 1961, are marked out by their conscious rejection of the values and standards of their elders. Their role models are no longer adult heroes and heroines but other teenagers: sports stars, pop idols, fashion models, TV presenters and minor celebrities who are only famous for being famous.

Instead of a clearly defined transition teenagers face a long period of limbo. Adolescence is now a self-contained period in which you look to your peers and within yourself for guidance while resisting the advice of us boring old farts, the ‘grown-ups.’ This may be manageable for most teenagers but I can see how it creates real problems for those who are autistic. Put yourself in the place of a young person with Asperger’s Syndrome (AS)

1. You have always looked to adults for guidance and may feel more comfortable with adults than in the company of other children. But now this marks you out as a ‘geek’ or ‘nerd’.
2. The adults you have relied on are changing. They are no longer satisfied with your well practised responses. And they are no longer as willing or prepared to provide advice on society’s expectations. They want you to ‘grow up’ and ‘act your age’ but they never tell you how.
3. Over the years you have worked out the rules of childhood. Now your peers are changing in ways you do not understand. You are missing the subtle indications of altered social rules and conventions. No one has told you what the new rules are but you are punished by teasing and bullying if you inadvertently break these secret rules that everybody else seems to know about.
4. Worst of all, you are changing as well. The physical changes are bad enough. But then you become aware of the differences in attitude between yourself and other children, differences that place you at a conscious disadvantage for the first time in your life.

The way out for many teenagers is to try and be somebody else. I know how much effort my autistic son, Mattie has put into ‘pretending to be normal.’ But it placed him under a tremendous strain. Like Corey, what he really needs to know is, “How to be me.” At seventeen he is beginning to discover the answer. But this is only since he left school. He used to get conflicting messages from his peers. Some were genuinely trying to help him. But he always had to be wary of those who were trying to wind him up and provoke a meltdown or setting him up for some ritual humiliation. Meanwhile an equally insistent teaching staff placed unrealistic demands upon him to ignore peer group pressure and concentrate on his studies.

Mattie is not the only one. I well recall reading on the internet one girl’s account of how she deliberately adopted different roles. First she copied the good girls and tried to be a model student. Then she got in with a wild crowd and started breaking all the rules. Neither model matched her true identity. In fact she finished up in therapy because she had no idea who she really was. Discovering her autism was the first step on the road to self discovery.

The pressure is always there to conform. But what if you cannot conform because you are autistic and nobody has explained how to conform? So you join the non-conformists, the hippies or the outlaws. You conceal your autism by adhering to a group of outsiders. This behaviour seems to suggest you made a choice when, in reality, there was no choice at all. If you were a person with AS you would find it difficult to work out what other people expect of you. That is why people with AS often join the most tolerant, the least demanding and the most unthreatening teenage sub-culture they can find. Gunilla Gerland (1997) refers to a period in her life when she was involved with a dope smoking crowd who were accepting of her peculiarities because they just assumed that she was as stoned as they were.

On the other hand they may join a teenage sub-culture with rigid rules that are clearly stated and expected, in other words, in groups that lay the rules out there for others to learn and live by; the army cadet force, college fraternity, boy scouts, cheerleaders etc. Either choice, is really no choice at all.

A third way is to ignore peer group pressure because no matter how hard you try to conform you always stumble and suffer ridicule and rejection. Instead you try to bypass adolescence and pass straightaway into the adult world. You will take your lead from adults and be what they want you to be. While this might provide some meaningful experiences, it is far more likely to encourage a lifetime of pretending and therefore, a lifetime of unhappiness. Besides, no one can leap straight from childhood into maturity. Adulthood results from the successful negotiation of the trials and tribulations of adolescence. It is not possible to avoid these difficulties and emerge miraculously ‘grown-up’ on the other side.

Whichever path you choose, you are responding to the biological imperative, “How do I survive?” rather than to Corey’s question of personal identity, worth and purpose. So, given the impossible demands placed on them by peers, parents and teachers, how do we answer Corey’s question? How can we help autistic teenagers to discover who they are?

We can talk to them, explaining as best we can what society’s general expectations are. We can tell them what NTs think they need. But most importantly, we can tell them they have a right to set their own expectations and the right to satisfy their own needs and when we close our eyes at night, we have to hope we all learn to meet somewhere in the middle.

**You are autistic**

First and foremost these young people have a right to know that they are autistic. This is not just about knowing why they struggle in matters that *seem* so effortless to their peers. They also need to know that the rest of us struggle in some areas that *they* take for granted. *‘They’* is the key word here. Probably the greatest boost to my son’s self esteem came when he visited an autistic couple and was able to be himself and be accepted for who he was. Spending time with other teenagers with AS has also helped Mattie tremendously. He has discovered a shared culture. He has also learned that other people with AS are unique individuals like him.

Clare Sainsbury (Sainsbury 2000) makes a similar point in her account of school life. Integration and inclusion are all very well and many young people with AS thrive in a mainstream setting. But there is always the feeling of being special. Spending time with other autistic people gives you the chance to be ordinary. My friend Kalen recently held a successful birthday barbeque. It helped that all the guests were trusted friends who understood her autism and many of them were also on the autistic spectrum. She described to me how it was all so ‘normal’ that she felt as if she was at someone else’s house!

**You are unique …**

It is hard to learn that we are *all* individuals. The teenager with AS has one set of rules taken away with the onset of adolescence and responds by trying to develop and apply a new set of rules to human behaviour. Mattie used to think that everybody was like him. When he realised that he was different he thought that he was unique but the rest of us were all still the same as each other. We were just totally unlike him.

His contact with other ACs has taught him that all autistics have a unique profile of strengths and weaknesses. And he is beginning to learn and accept that NT people he knows are also unique. But the idea that the whole world is made up of individuals is scary. How are you supposed to know how to react with strangers? Best to ignore them and hope they ignore you.

**… and so is everyone else.**

A young person with AS may believe that only he is unique and that other teenagers adopt similar dress codes, attitudes and tastes in popular culture because they are all the same. But one important motivation for this is to hide their individuality. Skinheads are a teenage sub-culture in the UK who favour cropped hair and heavy boots and have a reputation for racism, homophobia and violence. Yet I knew one skinhead who was homosexual and went to gay bars and another who visited Afro-Caribbean clubs because he liked black music and grew prize winning flowers in his spare time!

These lads were pretending to be normal in the context of the inner city environment where they had to live, while pursuing their own dreams in private. They were NT. I cannot imagine a lad with autism maintaining such a double life. The nearest Mattie has come to learning this skill is to pretend to like football because that is what lads do on the streets where we live.

## You have the right to happiness

Another aspect is believing that you are the only one with problems. Mattie was genuinely surprised when I told him that other people lead stressful lives as well. He was amazed to learn that I had problems too. If you believe that you are the only one with problems and everyone else is happy it could make you quite resentful. Mattie with typical stoicism just accepted that his life was supposed to be miserable.

An important lesson for him was that he has the right to be happy. When he misreads the social cues Mattie can be quite stunningly insensitive to other people’s feelings. But the idea of the selfish autist locked in his private world is totally misleading. Mattie and people like him put immense effort into accommodating other people and putting themselves out on our behalf.

The best advice that Mattie got was from Dave, a clinical psychologist who asked him to think about what *he* wanted. Prior to this Mattie had always been encouraged to meet other people’s demands and expectations. Dave was the first person to give Mattie permission to put his desires before our expectations.

## You have the right to privacy

My skinhead acquaintances represent an extreme example of a common phenomenon. Teenagers conform because they have to. It is the price of social inclusion. This does not mean surrendering your personal identity. My teen daughter, Katie has a private life away from her peer group. She does not share everything with them. Some things she only tells her best friend. Others she only shares with her diary. There are even a few aspects of her life that she shares with her parents!

**And so has everyone else!**

Katie has to be very careful about what she shares with her older brother. He has Asperger’s Syndrome and has not yet learned when to keep quiet in front of his parents! Sometimes we have to remind him to be quiet and not share too much with us.

**Honest to a fault**

People with AS are often confused by this. It is not dishonest to fail to tell the whole truth all the time. When you meet someone new and they ask you where you are from you probably tell them the town or the district. You would be foolish to tell a complete stranger your full address. Keeping things private is not the same as being ashamed of them. Certain things about your life are private for your own security. This obviously applies to personal details like PIN numbers and passwords for your bank account. It is less obvious when you are expected to observe different levels of disclosure with different social circles.

One reason for keeping quiet is that other people may misunderstand your intentions. I recently heard from the parents of a young man who, in common with many autistic people, has sensory sensitivities that make him very selective in his choice of clothes. In particular he does not like wearing trousers but will tolerate them in order to leave the house.

But he does not understand that other people do not share his sensitivity so he does not explain it to them. Instead he sees nothing wrong in telling other people that he cannot wait to go home and get his trousers off. Then he asks them if they want to take their trousers off as well!

**Lonely or alone?**

NT folk sometimes struggle to comprehend the difference. They imagine the life of an autistic person from their own perspective as being unutterably lonely. They try to help AS teens get into the swing of things – discos, rock concerts, the dating game. This may be OK for some AS teens for some of the time. But they may not be able to keep up with the relentless pace of their NT friends’ social life.

Once a week Mattie likes to have friends round in the evening. They talk, listen to his music collection, play computer games and surf the internet. We go out for the evening and leave them to it. At first we used to stay out as late as possible. But Mattie prefers us to come home at a fixed time. He likes to have friends in the house. He also likes to know when they will be going and our return is a signal for this.

At first we used to worry in case they were merely tolerating Mattie and using our home as a youth club. But we were pleased that a core group of friends call round for him and include him in their activities outside our home.

Given that ACs do struggle to cope with the social world, it seems a very good idea to me to help them to discover and delight in the private world of their dreams and special interests. People are afraid to indulge someone’s autism in case they encourage them to retreat completely into their private world.

But if the world is so harsh that the alternatives are to retreat or to be broken, then retreating seems eminently sensible to me. I think that respecting the AS right to privacy, to an inner life that is hidden from the rest of us, strengthens people with AS and increases the social bond they have for people who show them such respect. This can make it easier for them to engage with the world.

I know this goes against the old wisdom that you have to constantly battle to drag autistic people out of their introspection and into the ‘real world.’ But it is old and outdated wisdom. You have to work with them, not against them. That means working with the whole person and respecting their right to be autistic.

Following your interests does not have to isolate you. There was a time during Mattie’s early teens when he was isolated, not by his autism but by the behaviour of a gang of bullies who made it their business to torment him. At the time he was interested in railway modelling and I used to take him to a model railway club every week. There he found friends of all ages who were happy to answer all his questions and talk to him about their shared interest. He helped out at exhibitions and was delighted to discover that there was at least one part of the human race outside his immediate family where he found acceptance.

**Conclusion**

Peter Vermeulen (Vermeulen 2000) has put together an excellent resource for professionals working with young people to explain their autism in a realistic but positive manner. Gunilla Gerland (Gerland 2000) has written a very straightforward account that my son says would help with any pre -teen with AS. There is an ever growing number of autobiographical accounts that ACs can turn to for self affirmation. Then there is the Internet with all its web sites, email lists, news groups and chat rooms that offer peer support from fellow ACs. Information and communication technology has made such a difference to the lives of so many ACs that it justifies my friend Kalen’s description of the computer as ‘a wheelchair for autistics.’

But if Mattie and Corey and the rest of the teenagers out there are going to discover who they really are there is no substitute for personal relationships. An important part of who we are is the contribution we make to the lives of others and the feedback we get from them. We all want to feel loved, wanted, needed, appreciated. This aspect of social interaction may be difficult for ACs but it is not impossible.

Most of the time ACs rely on logic and hard work to understand NTs and cope with our behaviour. Brain imaging techniques that are used during exercises to test responses to human faces show that ACs differ from NTs. ACs use a part of the brain typically used for recognizing inanimate objects, the Inferior Temporal Gyrus. In the rest of us, it is the Fusiform Gyrus that is activated during these tests (Cowley 2000). But the most recent research by Karen Pierce of the University of California has found that the Fusiform Gyrus is activated in autistic subjects when shown pictures of their parents.

This suggests to me that (contrary to the popular belief that autistic aloofness arises from the fact that their brains are differently wired) intense emotional experiences may help to shape brain function. ACs have brains that can work in exactly the same way as their NT counterparts. The fact that they do not respond to everybody in the same way just goes to show that their brains are just far more discriminating in the range of stimuli and experience that shape their response. As ever with autism, the actual mechanisms are far more subtle than we first imagined.

It is exciting to think that by helping them to develop close relationships with a relatively small circle of family and friends, we can assist Mattie and Corey and the ACs in all our lives to develop and discover their personalities and answer that question, “How do I be me?”

How important friendship can be to ACs is shown by this letter from a young man on the spectrum to his NT friend. I find the level of self knowledge and the degree of sensitivity he shows for his friends feelings both marvellous and humbling. It is a brave letter and I thank Joel for his permission to reprint it here.

*“Dear Friend,*

*I want to thank you for being my friend. Your presence means a lot to me*

*and I am glad that you have chosen to share your life with me. But, despite us sharing many things, and despite the amount of time we spend together, some things are hard for me to share with you. I'm sorry. But I do want to share them.*

*I appreciate your tolerance. But, even with your tolerance, it is still hard for me to be with you. This isn't your fault - it is my limitation. But, even with very tolerant people, I still have to put tremendous effort into every interaction. It is very stressful, and I never know if I'm doing it right.*

*When I spend time with you, I enjoy it. I wouldn't spend time with you if*

*I didn't. But there are times when I go home upset simply because I can't*

*figure out something about you. If you are upset, I assume it is something that I did but was unable to stop from happening. Surely there are times when you are upset at me and you don't speak, thinking that I will pick up the subtle hint. But, at best, I'll just pick up that you are upset and not know what I did wrong or how to fix it. Other times, I probably couldn't fix it even if I knew what was wrong. But when you are upset at something else - not at me - I still can be upset. Unless I know what is wrong, I can't rule out the possibility that it was caused by myself.*

*There are things I do which I know make people feel uncomfortable. My tics, for instance, are something that I try to restrain when I'm around most people (although that is usually a futile exercise). But, when I'm around you, I allow them to come rather then trying to stress myself out over something I can't really stop. I hope you don't mind. Other things, like my stims, I don't always realize that I'm doing. But when I do, I try to stop most of them whenever others are around. I allow myself to do a few of them around you, but even when I'm around you, I am fearful to do too many of them.*

*There are some things I can't control, like the loudness of my voice. Certainly, I can be loud or quiet when I'm trying to, but I can also be loud or quiet when I'm not trying to. Do you always think about the loudness of your voice? I have to, or even my friends will try to quiet me. But it is a lot of work. I understand the concern when I'm loud in a place where I should be quiet, and I feel bad when you point out that I am being too loud, but it is something I have little control over.*

*There are also some things I don't understand. I've lived nearly a quarter century with the fear that others would discover I don't understand some things, so it is nearly impossible for me to stop faking an understanding when I don't have one. The biggest example is with jokes. I probably don't understand half the jokes that I hear. But I'll still laugh, to cover up my lack of understanding. I'd like to be able to say, "I don't understand," but I don't know if I have the strength to do so.*

*I know you get sick of my endless conversations on only two or three subjects. I know you try to steer my conversation to something that interests you, too, but I don't let you. I'm sorry. But I don't know how to talk about anything else. I wish I could talk about the weather or your landlord or whatever else is important to you, but I don't know how.*

*I also know that I come across as a "know it all" sometimes. It is very difficult for me to not speak when I disagree with you, even if it is just my opinion. I worked hard to reach my opinion and my initial instinct is that you haven't. I know that is often wrong, but it is a hard instinct to suppress. In fact, I do suppress it at great effort much of the time - but I can still annoy you even so.*

*I'm sorry that there are times when you feel bad but I can't console you*

*or be there like some of your other friends are. I wish I could understand what you are feeling, but in those times your thoughts are very different from mine. I want to share something that happened in my day that is important to me, but you want comfort and someone to listen to you. I know that you probably don't care about my trivial thing, but I can't always see what is important - the little thing in my life seems just as important as your hurt. I wish it wasn't so.*

*What scares me is that these are a lot of reasons for you to not like me. Part of me knows that you probably really do like me as a person - otherwise you wouldn't want to spend time with me. But other parts of me are scared that you are doing it simply out of sympathy or obligation, rather then true friendship. I don't think I can read you as well as others can read you, so I can't pick up on the signs that you would be a friend for reasons other then friendships. So I worry about this - especially after I see you and I do something I described above. I don't want your sympathy, I want your friendship! I hope that is the basis of our relationship, but it is hard when you aren't able to know.”*

I have nothing to add to that except to give the last word, as ever, to my son, Mattie.

“My autism is not a problem. It creates problems. But it is not going to go away. I want help with my problems not with who I am. I want you to offer support but do not try and change me into someone else.”

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