

1

Understanding the parental emotional rollercoaster

This chapter looks at the rollercoaster impact of the diagnosis of autistic spectrum disorders upon parents, where expectations change over time, but how encouragement can be gained from apparent adversity.

Living in a social world

The family with autism live in a wider social world. It may seem unfair that this wider population will hold a variety of perceptions about autism ranging from ignorance through a gamut of myths, legends, falsehoods and just occasionally empathy and understanding.

Both authors have spoken to parents over the past 20 years and it is obvious that for many families life with autism can be a lifelong struggle. The family with autism has to make its way in the social world from the time the child with autism is born. For parents particularly, life circumstances can seem extremely daunting and often feelings of isolation and the need to fight tooth and nail to push forward the need for services for their son or daughter become the prime motivators of family life.

Today we are moving into an era where, just possibly, the cause of families with autism is being listened to and felt more by governments and the planners of educational and care services, and therefore more support may be made available than ever before.

2

LIVING WITH AUTISTIC SPECTRUM DISORDERS

This perhaps is a bold statement to make but there is clear evidence in support of this view, as in recent years we have seen significant developments in each of the UK's countries. It may be helpful to very briefly recap on political developments in the field of autism.

In Wales, following substantial lobbying work of ministers by Autism Cymru, the Welsh Assembly Government have been developing a ten-year national strategy for autistic spectrum disorders which, according to Wales' ministers, is due to start in 2007/8 (Henwood, 2003).

Likewise, the considerable lobbying work in Northern Ireland (NI) by Autism Northern Ireland (PAPA) is leading to consideration by the Northern Ireland Assembly of the development of a Northern Ireland Autism Act (Coulter, 2006). This NI charity is also campaigning hard for a NI Assembly-led national strategy for autism.

In Scotland, the Scottish Executive have produced very good working reports on autism, especially *The Public Health Institute Autistic Spectrum Disorder Needs Assessment Report* (Scottish Executive, 2001), and the Scottish Society for Autism is lobbying for the development of a national autism strategy in Scotland.

In England, although there has been no ownership to date by Westminster in the development of a formal national ASD strategy nor indeed any attempt to move forward with primary legislation for autism, the manifesto of APPGA (All Party Parliamentary Group for Autism) sets out the rights of people with autism. In addition, several influential reports have been produced, e.g. *Guidelines for Good Practice* (DfES, 2002); the *National Autism Plan for Children* (NAP-C) (NAS, 2003); and *Psychiatric Services for Adolescents and Adults with Asperger Syndrome and Other Autistic Spectrum Disorders* (Royal College of Psychiatrists, 2006).

Ten years ago, none of this movement at strategic levels existed within the field of autism, so it can be seen that considerable progress has been made by a whole range of large and small voluntary organisations and public agencies alike in inspiring and helping to achieve significant steps forward, based upon foundations laid by the heroic work of parents and practitioners over previous decades. The cautionary note, however, is that the impact of these great strides can only be determined by the way in which they lead to improvements in the quality of life for individuals and their families, and there is a need for serious research to evaluate this effect.

Changing expectations: the parental grief cycle

As parents we do not plan to have a child with autism. Rather, we anticipate having children who, as they grow older, will themselves become self-sufficient and independent, and experience the desire to have their own children, in the same way that we have.

Parents experience a mix of emotions when they are told their child has a disability – especially when that disability is a hidden one, like autism. Parents find that they may have been lulled into a false sense of security regarding their child's development up to that point and now it's a 'double whammy' to find that the perfect child they thought they had does not exist and they must adjust their aspirations and expectations accordingly.

For some parents, who knew instinctively that 'something was not right', there may be relief at getting a diagnosis and being able to put a name to the difficulties they and their child are experiencing. They then discover they can do something about it by finding out about the condition and seeking information and interventions to help them deal with it. This then becomes a coping strategy as much as the temporary withdrawal from the world that other parents employ.

Coming to terms with the reality of what the diagnosis may mean for the family is a grief cycle akin to bereavement and parents need plenty of time and tolerance from others as they move from one stage to another. There is likely to be tremendous shock and denial.

'It can't be true! It's not fair ... why him? ... why us?' The sense of injustice and the anger, guilt and feelings of powerlessness and despair, may overwhelm parents before they finally come to accept their child for who s/he is.

Parents need to know that it is not their fault that their child has an autistic spectrum disorder and learn not to blame themselves for a quirk of fate. They need to give themselves permission to grieve, not to feel they have to 'put on a brave face' all the time and pretend they are not devastated by the realisation that their world will never be the same again and their lives will be altered in unimaginable ways. *It is OK to cry!*

It's a tough time emotionally and nobody from outside the family can really help parents through it. But, as they begin to appreciate their child's unique personality and see some of the positives of having a child who is different – and this may take years – some of the hurt will go away, but never

completely because you still feel the loss of the child you wanted, and planned for, and thought you had.

Understanding the emotional rollercoaster

Natural responses of parenthood

Unconditional love
Bonding
Reciprocity

- Emotion
- Response
- Interaction

Protectiveness
Positive emotions associate with child's development and progress from childhood to adulthood:

- Joy
- Pleasure
- Pride
- Excitement
- Fun

Expectations
Aspirations
Future plans
Growing confidence in own parenting skills
Diminishing responsibility as young person takes on more responsibility for self
Sense of achievement in part played in child's upbringing and development
Feeling of belonging
Inclusion

Disability in the family

Unconditional love tempered by sadness
Bonding process damaged
May be no reciprocity

(Over)protectiveness
Negative emotions associated with child's development and possible lack of progress:

- Sense of loss
- Grief
- Fear
- Anxiety
- Worry

Lower expectations
Lower aspirations
Concerns for the future
Lack of confidence in own parenting skills
Overwhelming responsibility: young person lacks ability to take on responsibility for self
No sense of achievement because child's development is 'different'
Isolation
Exclusion

Parents – the heroes of the autism movement

An important early point for parents of the newly diagnosed child with autism to realise is that they are not alone. They are by absolute right 'members' of a very large movement in the United Kingdom and wherever they should live in the UK there are likely to be other families with autism not very far from them. Quite possibly there will be a local support group

UNDERSTANDING PARENTAL EMOTIONAL ROLLERCOASTER

5

that they can join, and indeed other parents what they can talk to who have been or are going through similar experiences as them.

History speaks for the strength of families with autism and of the successes they have made in moving forward the cause of autism in the world today. It is parents who have played the key role in the development of public awareness and of the development of services for people with autism. During the critical early years of the 1960s, 1970s and 1980s when autism was a condition recognised by very few members of the public (and indeed the medical and social care professions), it was the drive and initiative of parents who almost single-handedly moved forward the development of services for both children and adults with autism. These parents, who started several powerful autistic charities in key geographical areas, should be viewed today as the heroes of the autism movement.

Points to remember

- Experiencing a variety of emotions is perfectly natural for parents
- Expectations are likely to change over time
- Parents need not feel alone; many have trodden the path before