AutismNI
Northern Ireland's Autism Charity

Is Anyone Listening?

A Report on stress, trauma & resilience and the supports needed by parents of children and individuals with ASD & professionals in the field of Autism in Northern Ireland

Autism in Northern Ireland - Is Anyone Listening?

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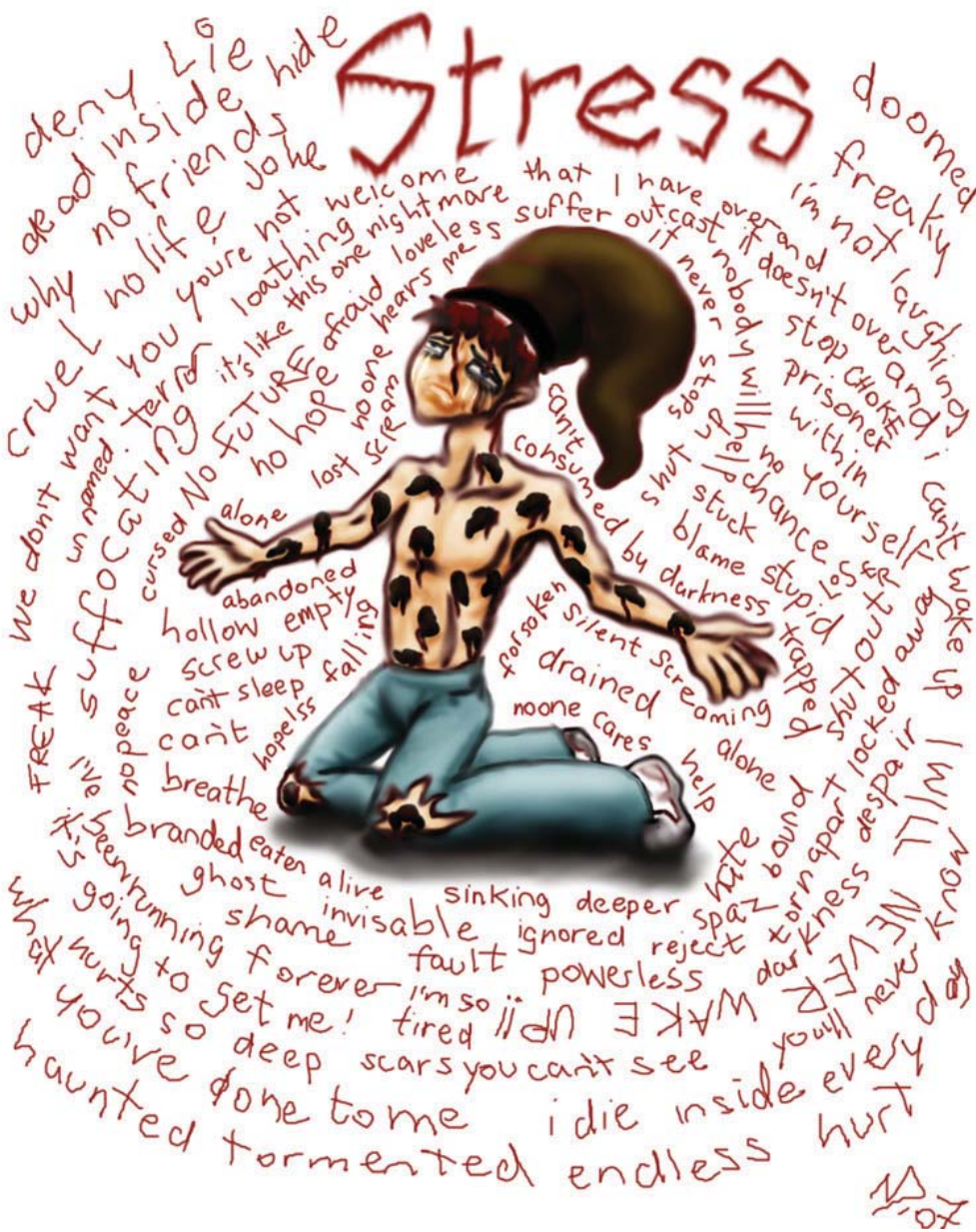
Life with Asperger's Syndrome through the eyes of young adult Natalie...

ACKNOWLEDGEMENTS

We would like to thank the parents and professionals who participated in this study;

- Those parents who showed their courage in opening up to tell of their experiences of pain and loss.

- Those professionals who showed their enduring concern and commitment to the lives of parents and children and in many cases acknowledged their own vulnerability.

- Those parents who are also volunteers working in the field of ASD.

Thanks also to the 'Is Anyone Listening?' Advisory Group and all those who supported the work.

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EXECUTIVE SUMMARY

The title of this study 'Is Anyone Listening?' was chosen as it best describes the feelings of parents of children and individuals with Autism Spectrum Disorder (ASD)[1] who took part in the study. Many feel misunderstood and ignored by society, resulting in experiences of frustration, despair and social isolation with minimal support. Professionals working with families confirm parent's experiences, and identify changes needed.   The study aimed to:

'ASD...it's all consuming, it takes over. You are totally absorbed in it...Nobody understands unless they're living with this. Decision makers don't. If they lived with this, they'd understand'
(Parent North)

- Document the response of parents to having a child/individual with ASD in Northern Ireland, recognising that stress, trauma and resilience among parents are to be expected.
- Consider the impacts on professionals who work with families where there is a child/individual with ASD.
- Be of practical use in terms of policy and practice by identifying supports needed by parents and professionals.

'We're living with a constant feeling of jet lag …. a roller coaster. Worrying and lack of sleep … We are like two zombies'
(Parent East)

The study involved 141 parents of over 300 children, 59 professionals and two adults with ASD. Methods used included focus groups, family and individual interviews, a questionnaire, literature search and a theoretical discussion of the findings.

The study produced startling evidence of how parents experience a continuum of stress from manageable, through to unmanageable and unbearable e.g. over 90% of parents experience significant anxiety, with 57% reporting acute anxiety and panic states. Nearly 65% report illness linked to caring, with over 50% of mothers taking medication[2]:

It has been found that the families of children and young people with ASD experience greater levels of stress than families experiencing any other form of disability (Bromley, Hare, Davison and Emerson, 2004).   Parent feelings ranged from optimism in connection to parenting their child (i.e. *'there's a gift in it'),* through to despair (i.e. *'what do you have to do to be heard?'* and *'Do you have to be found dead in the canal?')* The evidence points to the urgent need for serious listening and serious action - lives can be at stake.

Parents experience marginalisation and discrimination in relation to the wider society.   Parents provided clear evidence that society seems all too often to turn a blind or judgmental eye to the situation without any real or meaningful engagement.

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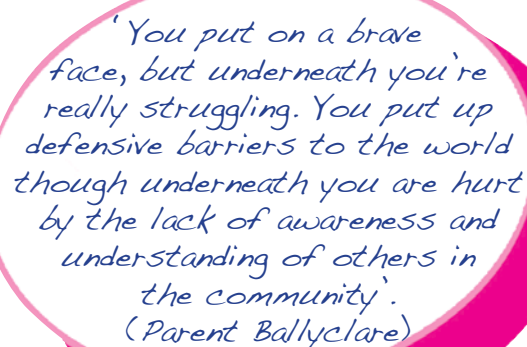
[1]The term ASD is used as the current term that includes the wide range of experiences and conditions associated (i.e. Aspergers) on the Autism spectrum. A full description is given in the Theoretical Framework Section of the study.

[2] Family interviews, further substantiated by individual interview and group evidence
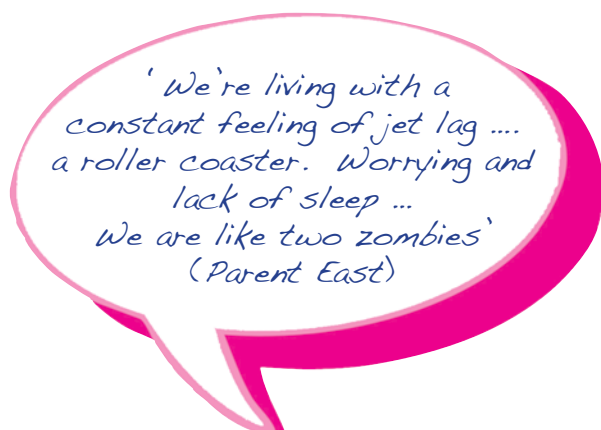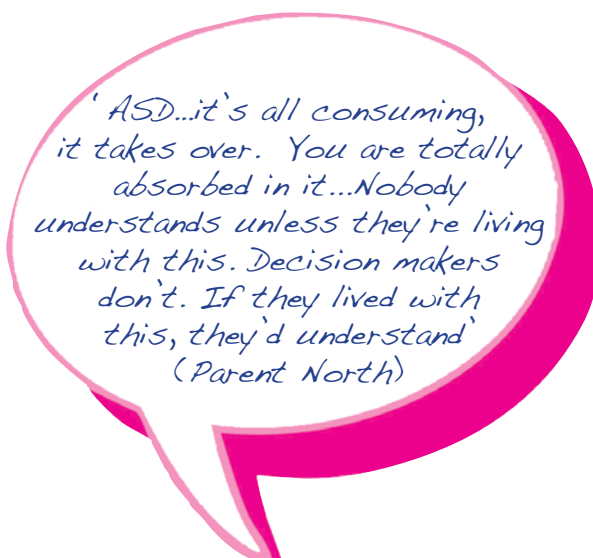
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Professionals are deeply impacted by the work they do with families with a child/individual with ASD. Their quality of life and the work they do is effected by how they perceive their role and the stance they take. The study found that professionals are often caught between the expectations and needs of parents and an inflexible state system. Professionals in the study referred to higher numbers of children with ASD with complex and multiple conditions, an increase in parents experiencing crisis and a willingness to reach for support rather than suffer in silence.
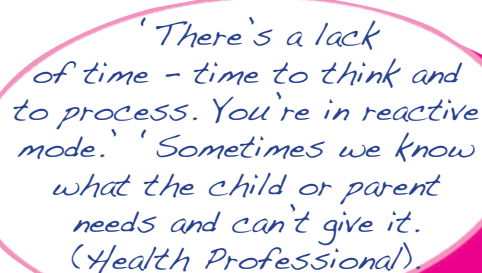
'You put on a brave face, but underneath you're really struggling. You put up defensive barriers to the world though underneath you are hurt by the lack of awareness and understanding of others in the community'. (Parent Ballyclare)

The Section on Professionals:

• Identifies and explores experiences that have not previously been documented.
• Offers a framework for reflection with the intention of supporting resilience and development among practitioners, supervisors, managers and policy makers.
• Records the supports needed to influence policy and practice in the field.

Professionals experience pressure with current ways of working and the allocation of resources:[3]
This pressure is illustrated by the evidence that over 72% of professionals experience anxiety about families with a child or young person with ASD with over 50% experiencing sleep problems due to work related stress. More than 10% of professionals reported experiencing physical and emotional symptoms related to work (e.g. Migraine).

'There's a lack of time – time to think and to process. You're in reactive mode.' 'Sometimes we know what the child or parent needs and can't give it. (Health Professional).

Parents and Professionals are also resilient and find ways to influence. However, research shows that the general growth in knowledge of ASD over the last two decades has not fully translated into awareness and practices that support the diversity of parents needs or provide a consistently strong focus on what supports resilience.
To support the resilience and competency of families and professionals nine key study findings and recommendations apply as follows;

1.   Parenting

The context of parenting a child/individual with ASD in Northern Ireland is highly significant. It is marked by lack of awareness of ASD, lack of investment, legislation and practices to address ASD relative to other countries e.g. Canada, and set against a backdrop of a society in transition from decades of political conflict.

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[3] Resources are being defined as time, money, people, knowledge, awareness, skills, buildings, equipment and anything else that supports the needs of children, parents and workers

Key recommendation
The human rights and equality of parents, children and individuals with ASD are currently not being upheld. The State in partnership with relevant stakeholders needs to lead change by implementing legislation, policy and practices as defined by the parents and professionals in this report.

2. Stress and resilience continuum

The study found that stress, trauma and resilience[4] are strong features of parenting a child with ASD. Parents demonstrated a continuum of stress and traumatic stress responses[5] prior to, at the point of diagnosis and at other key transitions throughout the lifecycle.

Parents of children and individuals with ASD are paying a high price (e.g. physical and emotional health problems, social and financial loss) and require urgent, ongoing action to implement the supports they have identified. Current and future generations should not have to pay this price as illustrated by the additional financial costs of raising a child with ASD, loss of income due to the need to give up work where that was feasible or to try to manage on state benefits. Families in rural areas face additional barriers, including transport and service costs.

Key Recommendation
Care pathways throughout life to reduce unnecessary and avoidable stress and trauma for the child and young person with ASD and their family, with one central contact worker for parents. Adequate support and services for families as identified under supports needed e.g. emotional, financial. (see sections three and four)

3. Marginalisation

Parents of children, young people and adults with ASD experience isolation and marginalisation in relation to the wider community. 85% of parents experienced lack of understanding and support and over 70% were experiencing isolation. Lack of awareness and the social processes of denial, minimisation and distancing, serve to reduce any affirmative recognition of difference - these unique areas need to be responded to so that children and young people, and their parent(s) can reach their full potential.

Key Recommendation
Anti discriminatory measures need to be urgently implemented to include practical initiatives such as the ASD awareness cards as parents with children and individuals with ASD are not in a position to continually work to raise awareness. Training and awareness programmes regarding Autism need to be ongoing, coordinated, resourced and implemented for the wider community.

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[4] These terms are defined in the Theoretical Framework Section of the study
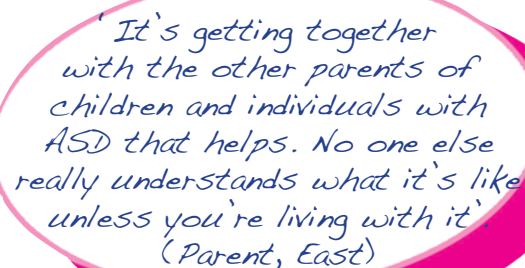
[5] An overwhelming experience related to perceived or actual threat to life shifting the person beyond their usual capacity to cope. A discussion of stress and traumatic stress is in the Theoretical Framework Section of the study

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4.   Group support

Parents have actively responded to stress, trauma and marginalisation by forming parent support groups. Parents across all groups consistently demonstrated that above all and sometimes after years of studying books, listening to experts, and searching the internet, it has been the face to face contact with other parents, the social connection in a mutually supportive group that has in the end made the biggest difference to their quality of life. Parents stated again and again that what had really 'got them through' were the other parents in the group.

'It's getting together with the other parents of children and individuals with ASD that helps. No one else really understands what it's like unless you're living with it' (Parent, East)

The Section on parents is structured around the themes of:
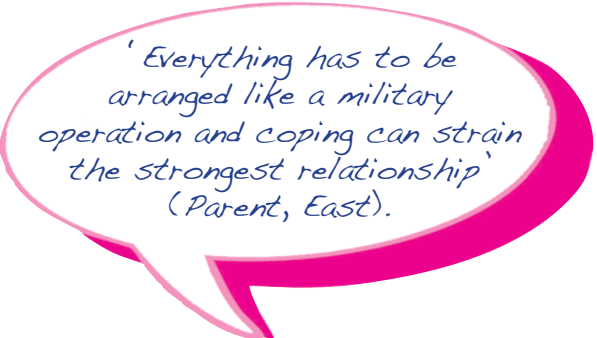
- Invisibility: making visible the child's needs.
- Grouping: how parents organise in groups as a response to stress and isolation.
- Surviving: survival strategies of flight, fight and freeze.
- Developing differently: the losses and gains of ASD from a parents perspective.
- Engaging: social and political engagement from crisis 'lifeline' to 'lobbying'.
- Supports needed.

Key recommendation
Parent support groups need to be fully supported through adequate resourcing given their critical role in supporting parents of children and young people with ASD. Group based support needs to be developed with very isolated parents in small cluster groups, young people with ASD, siblings, and peers of children and young people with ASD.
Family support training models need to be readily available and accessible for the whole family.

5.   ASD is a unique experience for each individual family.

One size does not fit all and unique responses are required that does not separate the family from their hinterland of support. This is exemplified through the evidence of older parents reporting strong anxiety about the future for their adult son or daughter with ASD and asking the painful question '*what will happen to him/her when I am gone*?' Couples are also under immense strain.

'Everything has to be arranged like a military operation and coping can strain the strongest relationship' (Parent, East).

Key recommendation:
Support needs to address the unique needs of the family (i.e. siblings, lone parents, older parents, mothers, fathers, the need for professionals to recognise the complex symptoms of Post Traumatic Stress in addition to ASD in the family, ethnic minority families, young parents). Family support training needs to be tailored to the needs of a range of family members so that they can have the opportunity to explore the issues that are unique to them. eg Sibling workshops, Fathers perspective workshops and Grandparent workshops

6. Crisis point - Do our children and/or ourselves have to reach crisis point before we can access support?

Professionals referred to an increase in parents experiencing crisis, with a willingness to ask for help rather than suffer in silence. Parents across the groups reported that schools and other public services often made parents wait until their child experienced a crisis before they could access support – a reactive and costly approach based on inflexible criteria. Parents are using the law as a last resort and attempting to sort out in Court case by case the unmet needs that have not been addressed consensually between families and statutory services. One solicitor noted a 70% increase in his work in recent years in representing families with a child with ASD.

There was a cohort of parents across all the groups who displayed significant distress at not being in a position currently to fight for their child's rights and needs. When external authorities who are expected to respond do not fully recognise the parents' break point, desperation ensues with painful consequences for parents and their children individuals with ASD (i.e. family breakdown, long term use of medication).

Key recommendation
Adequate awareness and training for all relevant professionals (i.e. G.P's, teachers and school staff), including adequate training, support and supervision for professionals working with parents in ways that help prevent crisis. The importance of training opportunities for parents and carers is crucial in exploring possible strategies and giving a feeling of empowerment through knowledge and skills.

7. Depression and ASD

The rates of depression and use of anti-depressants among mothers of children or individuals with ASD appear startlingly high. The evidence shows that mothers in particular, though also other family members risk labelling themselves and being labelled through mainstream medical and social approaches of what are actually social, political and psychological concerns relating to the everyday care and quality of life of parents and children and individuals with ASD. The prevalence of the long term use of anti-depressants in mothers is a key finding.

Key Recommendation
Family members, particularly mothers need a range of other supports as well as and other than anti-depressants e.g. anti discriminatory measures given lack of awareness and prejudice in the community, group support, and respite.

8. Failure of services

The fragmentation and at times failure of services in the support base of the person with ASD and their family means increased, unnecessary stress for families which also impacts on the professionals who work with families.
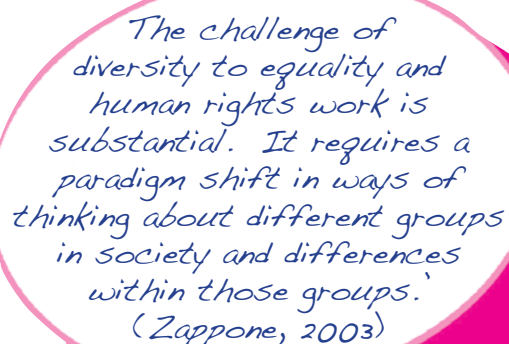
Key Recommendation
Legislation, policy and practices are required to uphold the human rights and equality of families and individuals with ASD with structures that develop integration between services, (i.e. Occupational health, psychology, etc.)

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9.   Desensitisation

Professionals noticed that in the absence of sufficient support: *'over time parents tolerate more and more and become desensitised'*. This desensitisation impacts on parents health and capacity. Professionals also tolerate desensitisation (i.e. disconnecting from themselves and other people) as a way of handling ongoing pressure. The evidence shows that it is not easy to handle intense feelings in others whether that is a child or young person with ASD, a parent or a professional.

Key recommendation
Professionals need adequate training and support to consistently work in ways that develop resilience rather than dysfunction.   Professionals need adequate support to reflect on and deal with their feelings. By doing this, the worker can have empathy and enable others to experience the full complexity of their own feelings in a way that is empowering and not disempowering.

> The challenge of diversity to equality and human rights work is substantial. It requires a paradigm shift in ways of thinking about different groups in society and differences within those groups.'
> (Zappone, 2003)

SECTION ONE - BACKGROUND

1.1   Purpose of Study

Autism NI was formed in 1990 by a group of parents and professionals concerned by the lack of ASD services in Northern Ireland. The mission of the organisation is to 'ensure that individuals with ASD and their carers are valued members of the community'. Autism NI seeks to ensure that people with Autism Spectrum Disorder (ASD) and their carers have access to appropriate services.

It is not easy to be the parent/carer of a child/individual with ASD. There are joyous moments, but there is no denying the challenges parents face, and the toll these take. Parents worry themselves sick, blame themselves, fight continually for services, sacrifice careers, sink into debt, are faced with relationship issues and rage at the injustice of it all. Parents grieve.

Most anyone that works in a 'helping' profession understands the term "burnout". It is something that the statutory and voluntary sector must be aware of and pay attention to. Re-living traumatic events on a daily basis can be very overwhelming and starts to take a toll on even the most seasoned professionals.

This study was commissioned as more and more stress and trauma is being evidenced by Autism NI and partner organisations within the Autism Community. The study aimed to:

- Document the response of parents to having a child/individual with ASD in Northern Ireland, recognising that stress, trauma and resilience among parents are to be expected.
- Consider the impacts on professionals who work with families where there is a child/individual with ASD.
- Be of practical use in terms of policy and practice by identifying supports needed by parents and professionals.

1.2   Study Target Groupings

The study was carried out to raise awareness and create change with and for four main groups:
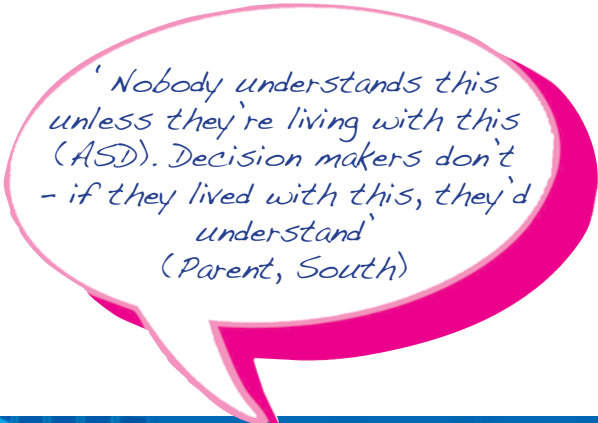
Parents/carers.
Practitioners/professionals.
Policy/decision makers/politicians.
The wider community of concerned adults and young people.

1.3   Rationale and Starting Points

It is important to make explicit starting points (i.e. the continual need to respond to a child with ASD has particular kinds of impact on the parent and their capacity to engage with the wider world), initial assumptions and hypothesis to be tested. Parenting any child

'Nobody understands this unless they're living with this (ASD). Decision makers don't – if they lived with this, they'd understand'
(Parent, South)

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is usually a challenging as well as rewarding experience. Parenting a child with ASD is more stressful and may at times be experienced as 'too much', overwhelming the usual capacities to cope. When a person experiences a sense of overwhelm, various physiological, psychological and social processes begin that need to be recognised and addressed.

(i)   As professionals are part of the community and are designing and/or delivering services, they are also susceptible to the impacts of environmental stress. Exploring impacts is necessary to effective, ethical practice and policy.

(ii)   Parent experiences as well as professionals working close to families (i.e. paediatrician) and those further removed though influential (i.e. manager of services) are included here. The experiences of 'different levels of the system' (i.e. family, organisation) are necessary for change (Nevis and Melnick, 2010).

(iii)   The specific features of the Northern Ireland context must be included:

- Lack of adequate investment throughout decades of political conflict.[6]
- Lack of awareness of ASD in Northern Ireland.
- The lag in service development compared to England, Scotland, Wales and the ROI.
- The transgenerational[7] and intergenerational[8] effects of trauma in this environment.

Lack of awareness and specialist training can lead to a one size fits all solution rather than a child, family and context specific response. While people are resilient, without skillful and timely individualised intervention that respects the strategies people adopt to survive overwhelming experiences and the kinds of homegrown wisdom that have emerged through adversity, organisations may miss the opportunity to support the capacity of people to be active agents in their own lives.

1.4   Research Design

This work emerged from a participatory[9] (i.e. parents decided how to focus the discussion within the study framework), systemic[10] (i.e. viewing the family as a system and exploring how the child's narrow focus impacts on the parent) and holistic[11] (i.e. keeping the bigger picture in mind as well as the particular focus) model. It was also firmly positioned within an equality and human rights framework. Therefore the assumptions in this approach are that people are:
i.   Relational and socially embedded – problems and resources are illustrated in the study and are viewed within the wider context (i.e. the problem a mother has when her child misses the school bus as he struggles to dress himself and the bus driver does not wait the extra few minutes needed).

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[6]Most obviously from 1969 to the Good Friday Agreement, over 3 decades with profound losses and ongoing impacts on families (i.e. Fay, Morrisey and Smyth, 1999; Hamber, 2004; Burrows and Keenan, 2004)

[7]Transgenerational – the unspoken, unexamined and implicit messages and memories we carry that pass from one generation to the next.

[8]Intergenerational - the spoken, available to memory stories and culture transmitted within and between families and groups

[9]A participatory approach takes the view that knowledge is socially generated through observation and participation and the bringing together of different forms of expertise (i.e. learning from experience, using any theory discussed with participants as a tool of consciousness raising, as developed by Paulo Freire, 1973).

[10]A systemic approach describes the way a whole group, organisation, or society is effected by patterns that emerge between the diverse participants

[11]Holistic definition – see section 1.5 of the study

ii.   Influential and vulnerable – the developed strengths and competencies of parents and professionals and what is underdeveloped/emerging are described in this study (i.e. parents influence by setting up their own support systems as they frequently experience lack of help at key points in their child's life at school. There were also some older parents who spoke of their worries about what the future held for their adult dependent son or daughter with ASD, and they were aware of the lack of supported housing and choices regarding care).

iii.   Learning – with adequate awareness and support, quality of life improves and change can occur (i.e. parents become aware of educational support needs and have their child statemented in order to get a Classroom Assistant for their child in school and feel relieved).

1.5   Research Methods

This study has focused mainly on families, groups and organisations. Individual (parent and professional) interviews have been included to deepen the findings and offer readers another lens. Sources include primary research with parents and professionals, as well as a range of secondary sources e.g. literature search, professional journals, websites. A largely qualitative approach was taken with group, family and individual interviews as follows:

- 13 group interviews (126 parents of 277 children) plus two adults who were diagnosed with ASD.
- Three group interviews with professionals (40 professionals).
- 14 family interviews carried out by family support workers. A father of a daughter with ASD volunteered additional personal information. Prior to meeting with families, the workers had a one-day training programme and follow up debriefing focus group with the researcher.
- One individual interview with a mother of a son with Aspergers Syndrome.
- One individual interview with a professional.
- A quantitative questionnaire was used with additional qualitative data sought.
- 18 individual email questionnaires were collated from professionals.

A questionnaire and data capture template (see appendix 2) was developed as a structure for each group and family meeting in order to collate:

(i)   Indicators of stress and trauma and what parents/grandparents or professionals said.
(ii)   Indicators of resilience and what parents/grandparents or professionals said.
(iiii) Supports needed.

The parents, branches and groups were chosen from existing groups to represent geographic spread, political/cultural diversity, and availability to meet. The professional groups were chosen to represent a range of voluntary and statutory workers across Northern Ireland. The study design was influenced by and reflects the importance of:

- Experiential learning – exploring and describing how individual parents and professionals construct their experiences.
- Action research – research which aims to support intentional change.
- Field theory – as a way of noticing and thinking about what influences current conditions (Lewin, 1952).
- Appreciative inquiry – focusing on what is working in order to support development and resilience and not only what is not working.

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- Holism - means that theory grows out of the data so that the work remains grounded in that data, as well as identifying inconsistencies and incomplete understanding. Holistic also means reflecting upon experience in ways that include different sources of data, and that move the researcher towards an appreciation of and inquiry into sensory data and physiological responses; social, emotional and intuitive responses (Barber, 2006). Occasionally, the emotional and physical impact as a researcher meeting with parents and professionals is included as part of the research methods, as 'use of self': '*I look within myself and to my own experience to glean a richer understanding of others'* (Barber, 2006: 24).

1.6   Ethics

For ethical purposes, groups and parents have been anonymised in order to protect the identity of participants. Working with an Advisory Group, an independent supervisor and Autism NI, the meetings with parents included a deliberate focus on resilience, on how parents had continued to keep going through adverse experiences.

This was an important value related to working with prolonged stress and trauma – to ask individuals and groups how they had kept going and continued to survive through challenging experiences. In order to help counter the experiences of acute and chronic stress directly and indirectly related to ASD, the emphasis in each group was on the specific ways people had learned and changed. That is, when sufficient support is available, 'transformation' rather than living in crisis and 'reliving' again and again overwhelming experience becomes possible.

1.7   Social Context & Economic Impacts of ASD

There are a high percentage of children and young people in Northern Ireland, with almost 37% under the age of 25. It is estimated that one in a hundred children in Northern Ireland have ASD (www.autismni.org).

Extensive levels of inequality persist on a wide range of issues. Higher levels of lone parent families, children on the Child Protection Register and children with a disability live in Northern Ireland than in England, Scotland or Wales and half of children in Northern Ireland are poor on the basis of at least one poverty measure, compared to 45% in the rest of the UK, (Monteith & McLaughlin, 2004). '*A Child's Portion' documents the higher levels of need but also the lower levels of spending in Northern Ireland on children and young people – it should be raised to higher levels to meet the identified greater need (Sefton, 1999*).

Knapp found that 'little is known about the economic impact of ASD' (Knapp et al, 2001:7) and that 'the absence of the realistic consequences of ASD complicates planning and hampers policy change'. Knapp and Jarbrink (2001) reviewed spending into the following:

- *Hospital Services.*
- *Medication.*
- *Sheltered work.*
- *Family expenses.*
- *Other health and social services.*
- *Day activities.*

- *Lost productivity.*
- *Living support.*
- *Voluntary support.*
- *Family member's time cost.*
- *Special education.*

They found the overall average lifetime cost of ASD for a person with ASD and a learning disability is £ 2,940,500. The largest percentage of spending for ASD was identified as living support, with the second largest percentage being spent on day activities.

Families of children and individuals with ASD face a range of extra costs, (i.e. replacing clothing, not being able to use public transport, having to adapt the house). Costs can include specialised childcare, additional therapy, food supplements, as well as replacement costs for items that were destroyed by their child. Households with a person, adult or child who receive Disability Living Allowance to meet the additional costs of disability have that benefit included as income with no allowance made for their extra expenditure. Impacts extend into adulthood for families. It is estimated that less than one in six adults with ASD are in full-time employment and a third live without a job or benefits. Many people are forced to rely on family and friends for support *(A Life Less Ordinary, New Philanthropy Capital 2007)*.

Two adults with ASD who participated in the study stated that they had had difficulties accessing relevant education and training, obtaining and maintaining employment. One adult had obtained a senior level administrative post for many years until his employers 'let him go'.

1.8   The Context of Public Policy

Government policy shapes how services are developed and what gets funded. There are a number of state policies and legislation that specify what changes need to happen to bring about greater equality, social inclusion and human rights that are relevant:

• The Autism (NI) Bill 2010, supported by the All Party Group on Autism at the Northern Ireland Assembly, aims to provide recognition for ASD within the Disability Discrimination Act definition of disability. The recognition of ASD as a cross cutting issue is reflected in the Bill which identifies the need to establish a cross departmental strategy for ASD. In addition, there are specific duties linked to equality standards within the proposed appointment of an Autism Advocate. The Disability Discrimination (NI) Order 2006 and the Special Education Needs and Disability Order (NI). 2005 does not include recognition of ASD. This inequality is being addressed through the proposed Autism Bill (NI).

• The Bill of Rights for Northern Ireland enshrines the principles of justice, equality and human rights, which promotes equality for everyone in order to protect the most vulnerable in our society.

• Section 75 and Schedule 9 of the Northern Ireland Act 1998 placed a statutory obligation on public authorities to have due regard of the need to promote equality of opportunity between: persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation; between men and women generally; between persons with a disability and persons without; and between persons with dependants and persons without.

• The Children Order NI (1995) provides a legal framework for the provision of services for a child with a disability and seeks to ensure that 'the welfare of the child is the paramount consideration. Parents with children in need should be helped to bring up their children themselves and such help should be provided in partnership with professionals. Independent living schemes, vocational training and community support to assist children with a disability to live independently'.

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- The Programme for Government – The Northern Ireland Executive has committed itself to working for a healthier, more equal and inclusive society.

- Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09 – 2010/11 (June 2009) This DHSSPS plan states the intention of one Department to promote a coordinated range of services for children, adolescents and adults living with ASD as well as the setting up of a Regional ASD Network Group linked to the broader implementation of *Delivering the Bamford Vision*. The Bamford Vision (2006) aims to improve mental health, resilience and wellbeing, and support the development of therapies for those individuals and carers who may develop, for example, anxiety or depression, though parents and groups did not refer to this indicating minimal change has taken place.

- Our Children and Young People – Our Pledge (2006-2016), is a ten year strategy for children and young people that sets out what will be done by Government. The vision '*is that all children and young people living in Northern Ireland will thrive and look forward with confidence to the future'. 'We will offer support to parents, carers and families to ensure that they are able to take primary responsibility for their children and to assist them with the challenging task of parenting, where this is required. We will also work to energise communities so that they, too, can play a supportive role for the benefit of children and young people*.' The principles of family support services for individuals with ASD and their families informed by the strategic context set out in *Families Matter: Supporting Families in Northern Ireland*, March 2009.

- Every School a Good School: the way forward for Special Educational Needs and Inclusion August 2009, Department of Education. This is a review of special educational needs (SEN) proposing the establishment of a robust, accountable and inclusive framework which identifies the needs of all children, supports those needs and promotes a culture that welcomes diversity.

1. 9 International Legislation and Frameworks

Northern Ireland is currently lagging behind many other countries in relation to both awareness of ASD and legislation and practices to address ASD. There is legislation for ASD in the USA, Canada, Sweden, Australia and New Zealand. Scotland, England, Wales and Denmark have national plans for ASD. Northern Ireland does not yet have adequate legislation in relation to ASD.   Legislation and frameworks that support the need for adequate legislation and policy include:

- Universal Declaration of Human Rights (1948).
- International Covenant on Civil and Political Rights (1966).
- International Covenant on Economic, Social and Cultural Rights (1966).
- Declaration on the Rights of Disabled Persons (1995).
- United Nations Convention on the Rights of the Child (1989).
- United Nations Convention on the Rights of Persons with Disabilities (2007).

Finally, the World Health Organisation (2004) defines an international framework on health and well being and states that there are three main risks to mental health – social exclusion, discrimination and lack of economic participation. Parents, particularly mothers of children or individuals with ASD though also fathers, reported experiences impacting on these three domains that have been identified in Section Three of this report.

1.10 Reflections on Context: The Need for Awareness, Safety and Investment
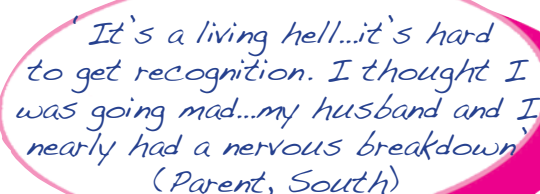
'*A social climate that encourages experiencing and sharing intense social emotions is needed*' (Lichtenberg, 1990:66) The parents experiences exemplified the central tension of trauma '*There's a gift in it*' derived from the experience of one father reflecting on how his life had been transformed through the process of accepting his son as he was - on the 'severe' end of the spectrum. On the other hand, the despairing cry of a mother '*What do you have to do to be heard?*' and a fathers answer based on his knowledge of what happened to a number of parents in his town: '*Do you have to be found dead in the canal to be heard*?' The title '*Is Anyone Listening?*' was chosen given parents repeated experience of not being listened to.

The intensity of parents experiences point to the urgent need for serious listening and serious action - lives can be at stake. Stress and trauma was reported by parents as part of the experience in parenting a child with ASD.

This reflects a need to acknowledge and address the complexity of the impacts of and responses to living with a child with ASD in Northern Ireland. For many adults who are middle aged and older parents, who were children when the conflict began, past strategies of survival had often, with the benefit of hindsight been costly, e.g. living on 'adrenaline'.

The double burden of stress at home and the wider environment, means that difficult circumstances, if perceived as unchangeable, can lead to the involuntary nervous system 'freeze' (Levine 1997)[12] response, immobilising the person and resulting in a sense of 'learned helplessness' (Seligman, 1975) and depression (Abramson et al, 1989; Alloy, 1989; Amirkhan, 1998). Parents of children or individuals with ASD are at risk of depression, stress and anxiety (Boyd, 2002; Lainhart, 1999; Piven and Palmer, 1999; Sharpley and Bitsika, 1997). The findings of this report strongly demonstrate the need to understand and address the complexity of ASD in a transitional post conflict society.

> '*It's a living hell...it's hard to get recognition. I thought I was going mad...my husband and I nearly had a nervous breakdown*' (Parent, South)

The tension or ambivalence between the need to speak out and the need to keep silent (Herman, 1992) is at the heart of all traumatic experience. Speaking out about stress and trauma is not easy. The need to build structures that support safety is illustrated by the range of strong feelings and visible signs of distress (i.e. tears and signs of high levels of frustration and exhaustion with parents stating that they felt on 'automatic', 'permanent on'/unable to relax', and/or not 'getting a nights sleep for years').

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[12]The 'acute stress response' – known as Fight-or-Flight-or-Freeze response is a medical term of defining a biological phenomenon of a human mind in which if a person is suffering from a stress of any kind has adrenaline that will cause him to either fight it, flight (escape from it) or freeze (halt -do nothing, sometimes staring state in which a person is confused and unable to think of something).

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SECTION TWO – THE THEORETICAL FRAMEWORK

This study is informed by a number of theoretical influences and reflections. The data from parents and professionals informs the theory, while the theory provides a structure for the study that will be described largely under the following headings:

1. What is ASD?
2. Stress, resilience and ASD.
3. Depression and ASD.

'Conceptual frameworks can contribute to the visibility/ invisibility of people'. (Zappone, 2003)

SUMMARY OF THEORETICAL INFLUENCES
ASD - History of ASD, scientific, general, self definitions & social model of 'disability' or 'diff-ability'
STRESS AND TRAUMA - Selye (1956), Danielli (1998), Levine (1997), Herman (1992) Bloom (1997) Rothschild (2003)
LOSS, GRIEF AND MOURNING and CHANGE - Kubler Ross(1969), Worden (1991), Parkes (1996), Herman (1992), Melnick & Roos (2007) Bonanno (2009)
RESILIENCE AND DEVELOPMENT - Individual, families, group, systems, Oaklander (1978) Lichtenberg (1994), Karpman, (1968) Shub and Audet (2007), Herman (1992), Bloom (1997), Gaffney (2003) and Beisser (1970)

2.1 What is ASD?

The term 'Autism'[13] was first used by Swiss psychiatrist Eugene Bleuler in 1906, to describe behaviours in people who seemed to consider everything going on in the world around them as related to themselves. Leo Kanner (1943) developed this to describe and name a pattern of behaviour he observed in a small group of young children, which he termed early infantile Autism. Asperger (1944), wrote about another behaviour pattern in older children and adolescents, which, though different in detail, was similar to Kanner's accounts.

Autism Spectrum Disorders (ASD's) are the fastest growing neurobiological conditions in the world. ASD is lifelong and complex and creates social and emotional vulnerabilities for the child, young person and their family. ASD is not a learning disability or mental illness, though other conditions can co-exist alongside ASD e.g. Epilepsy. ASD is estimated to affect about 1 in 100 people, and is more common in males at a ratio of at least 4:1. Approximately 300 children are born every year who will receive a diagnosis of ASD in Northern Ireland and rates of increase in the last decade are 400% (www. autismni.org).

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[13]In Chinese the word Autism is 'gudu zhang' translates as 'the lonely illness', the term 'Autism', comes from the Greek word 'autos' meaning 'self'.

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ASD is characterised by three main difficulties in the development of:

- Social relationships,
- Communication skills, and
- The presence of unusually strong narrow interests, repetitive behaviour and an aversion to changes in routine (www. autismresearchcentre.com).

ASD is referred to as a pervasive developmental disorder reflecting its impact across various areas of functioning. The cause of ASD is a subject of intense debate and is based upon limited research, resulting in inconclusive debates about the impact of genetics, environment, diet and vaccines. The term Autism Spectrum Disorder (ASD) is used because ASD varies from person to person and will be used throughout this document. Around 25% of people with ASD will have an accompanying learning disability. Some people with ASD will have average or above average intelligence, they are likely to be diagnosed with Asperger's Syndrome (www.autismni.org).

The essence of a diagnosis of ASD centres around 'the capacity for relatedness' (Audet and Shub, 2007), with people with ASD 'dropping into their own worlds' and out of the everyday world of interaction (Levy, 2007): 'Life is like a video, I watch'. Mind-blindness can be described as an inability to develop an awareness of what is in the mind of another person and is the opposite of the capacity to relate, to feel empathy (Simon Baron-Cohen, ASD Research Centre website).

Individuals with ASD may engage in behaviours that are potentially disruptive to family life such as aggression, self-injury, impulsivity, hyperactivity, temper tantrums and obsessional behaviour. Children usually develop an array of obsessive behaviours as a means of self regulation such as rocking back and forth, stimming[14], and hand flapping in an effort to stay alert and calm.

The 'triad of impairments' (social, communicative, and repetitive) along with the energy bound up in attempts to manage sensory experience limits the person's capacity to explore the environment and engage in mutual relationships. Children or adults with ASD do not recognise the overall pattern or picture, the 'gestalt' first, but rather many parts that are often not connected. Therefore, what can be tuned out and tuned into can feel out of control and overwhelming, and meaning and synthesis is made in unusual ways.

While diagnosis is very important for most parents, classification, as developed by the Diagnostic and Statistical Manual or the World Health Organisation (ICD, 2007), differs radically from the meanings given by those young people and adults with ASD who sometimes question the idea that ASD is a 'disorder' and propose that an inclusive dialogue on the meaning of ASD should be considered. This debate falls within the context of a more ideal world where differences are accepted and respected.

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[14]Self stimulating repetitive behaviour that it is done alone without any interaction or eye contact with others such as staring at a wall, repeating lines from a favourite film or lining up blocks and knocking them down.

2.1.1 Social Model

The social model of 'disability', developed some 30 years ago, proposes that policies, procedures and practices are the 'problem', rather than individual impairments of function (Shakespeare et al, 1996). How society responds to the combination of social barriers determines the isolation or inclusion. As other conditions may be present with ASD (e.g. sensory integration problems, seizures, sleep problems, depression and anxiety which seem to give rise to behavioural and other problems), close relatives are also often at risk of social exclusion, not least due to how neighbours and friends respond.

2.1.2 Self Definitions

Those children and adults with ASD, are increasingly entering the debate on definitions. For example,
• Jackson (2002) uses the analogy of a sound equaliser with different inputs in relation to the three main areas impacted by ASD - imagination, social interaction and communication, each being at different and unique levels: *We are all amazing in our own way .....I just have a grasshopper mind...* '(Jackson, 2002:189, 21)

• 'ASD' is one word for a 'fruit salad' of conditions. These conditions usually result in a range of voluntary and involuntary behaviours, in a combination that is unique to the person. (Donna Williams, who has ASD, www.donnawilliams.net).

• 'If you are on the Autism spectrum you learn differently, from 'typical' people'. Wendy Lawson (2009) is an international author and speaker who has ASD and advocates the term 'diff-ability', different ability to 'disability'.

The wider international field of ASD is marked by competing approaches that frequently adds to the distress of parents. These approaches range from diet, drug treatments, horse therapy, behavioural and other methods. Parents spoke of the amount of hours pre and post diagnosis spent reading, searching the internet, seeking 'treatment' or a 'cure'. Some parents have formed links with others using the internet. However many parents in the study have had bad experiences using the Internet.

Parents and professionals both state that while there is increased general knowledge about ASD through popular and scientific media, including the internet and films such as Rainman (1988), Mozart and the Whale (2005), and Snowcake (2006), as a society we have not yet reached the 'tipping point'[15] of awareness.

'you're working all the time with high expectations of parents wanting an instant fix' (Health Professional).

'At first you look this and that up and its all telling you your child will never, never, never do this or that – it's total overload and meltdown. You come to realise after reading and searching for years that it's other parents that get you through. You learn it by living it' (Parent, North)

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[15]Tipping points are 'the levels at which the momentum for change becomes unstoppable. Gladwell (2000) defines a tipping point as 'the moment of critical mass, the threshold, the boiling point', as ideas, messages and behaviours spread like viruses.

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2.2   Stress, Resilience & ASD

In this sub section, there are four main points based on the evidence gained from parents and professionals:

(i)   Stress and traumatic stress are features of parenting a child with ASD in Northern Ireland.

(ii)   Resilience is relational and not only within the individual.

(iii)   How parents are supported matters, and likewise how professionals are supported matters to quality of life.

(iv)   Taking a proactive approach as a parent of a child with ASD and as a group of parents makes a positive difference

'There's so little help, it's like banging your head against a wall." (Parent, East)

The phenomenon of stress was a focus of the study and was a major feature of the parents accounts e.g. '*You worry about the future, you worry about summer times and worry about the loss of respite care and services. You don't know if his condition is going to worsen or improve*'. The 'acute stress response' – known as **fight, flight, and freeze** response was first described by Walter Cannon in 1929. He found that animals react to danger or perceived threat with a general discharge of the nervous system, priming the animal for fighting or fleeing/flight[16].

'You begin to recognise the danger of the expert and giving up on your own authority. Professionals need to be listening to parents.' (Parent, South)

'if they don't give us the services we need, they'll have not only the children on their books, they'll have parents and the whole family as well (Parent, North)

The approach taken to resilience in this study is to emphasise both the vital role of the personal nervous system and the ***relational*** aspects of the nervous system in overcoming challenges and adversities, whether externally or internally generated. That is, it is what happens *between* people that supports resilience, rather than regarding resilience as something that is only inherent in a single individual.

This approach avoids the kind of individualising and pathologising, that increases the risks to families through lack of awareness, ignorance, trying to change or 'fix' others, prejudice or/ and discrimination of the kind that parents report in this study, leads to isolation and preventable lack of well being.

'I walk as if I've a thick skin, but I don't... Now I don't want to talk with anyone who doesn't have a child with ASD. There's a real them and us' (Parent, East)

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[16]Biology of the stress response - an event, perceived as a threat or a stressor, is relayed to parts of the brain and the person becomes alert and may attempt to fight or to escape. Seyle (1956) identified the physiological responses to change, an adaptation which consisted of 3 stages: first, the emergency or alarm reaction which prepares the organism for immediate fight or flight, then the resistance stage in which many of the physiological changes associated with the alarm reaction are reversed, and the organism has increased resistance to the stressor. The final stage, exhaustion occurs when the body's ability to deal with stress runs out. Stress, is linked to externally difficult living and working conditions.

What supports inner and interpersonal resilience[17] is a central focus of this study as: *'it takes a healthy field to foster and maintain healthy individuals across their life span'* (Lee, 2004:337). Taking this interconnected approach to resilience, means noticing the nature of patterns repeating as well as emerging between parents with a child(ren) or individuals with ASD and the rest of the community.
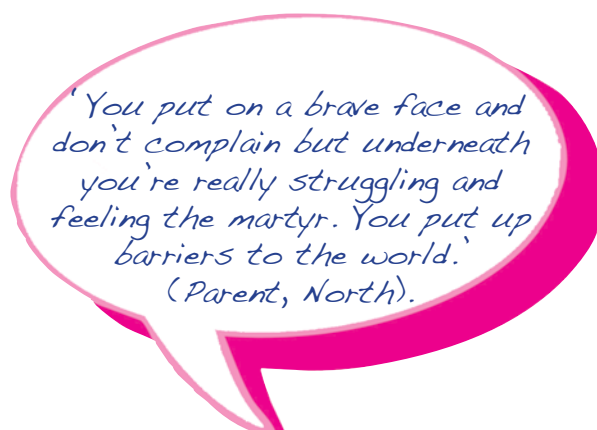
Resilience is both an internalised and externalised process and as evidenced in the section on parents accounts, this can only be addressed by mobilising different levels of system e.g.. personal, family, community, organisational.

Fleischman, (2005) found that this form of mobilisation is 'a survival strategy for parents assisting them in improving their own mental health and also for helping their child with Autism'. 'Having an internal locus of control benefits families' – this includes: positive reappraisal (e.g. growing as a person, finding new faith, rediscovering the important things in life, being inspired to be creative); confrontive coping (e.g. effective fighting for what is wanted, expressing anger to the cause of the problem, letting feelings out somehow and taking chances) and seeking social support are all beneficial as coping styles while escape and avoidance were not' (Dunn et al, 2001). 'Learned optimism' (Seligman, 1998) is at the heart of a proactive approach of mobilisation. Parents spoke of the continual stress they were under and the different strategies adopted in handling this.
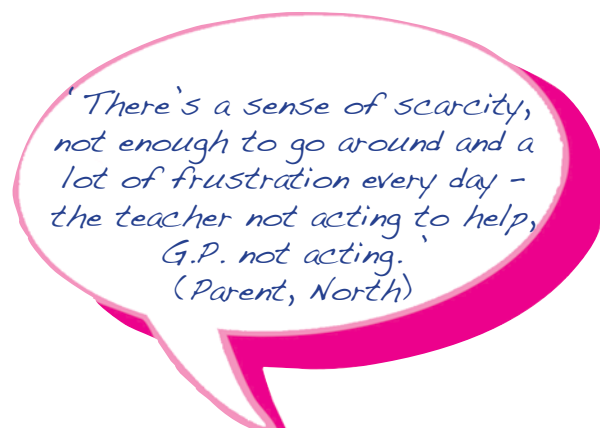
The individual and family interviews, as well as the group based research with parents and professionals provide clear evidence that parents are on a continuum experiencing three main levels of stress, traumatic stress, and trauma which are manageable stress, unmanageable stress and unbearable stress / unresolved trauma.

2.2.1 Manageable Stress

Stress results from any demand on the body and is a normal part of life and helps us feel alive except when the demands exceed perceived or actual capacity (Selye, 1956). Where the situation of chronic frustration goes on and on, as parents reported, particularly at key developmental transitions in their child's life and given other life and family events (i.e. death of a parent, illness of a parent and additional caring responsibilities, growing older, loss of a partner/support system), the capacity to keep rising to meet needs is threatened and the next level of stress kicks in either temporarily or chronically.

> 'You put on a brave face and don't complain but underneath you're really struggling and feeling the martyr. You put up barriers to the world.'
> (Parent, North).

> 'There's a sense of scarcity, not enough to go around and a lot of frustration every day – the teacher not acting to help, G.P. not acting.'
> (Parent, North)

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[17] Resilience is defined as all the ways people survive and keep going through stressful, adverse circumstances. Resilience can be seen as an outcome and a process, as 'a set of qualities or processes that enable a person to make use of internal and external resources and as a capacity that brings a good outcome' (Hill, Stafford, Seaman, Ross and Daniel, 2007).

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2.2.2 Unmanageable Stress

Unmanageable stress is a more extreme form of stress related to shock which causes hyper arousal in the body's nervous system, making it possible to fight, flee or freeze in response to real or perceived threat. This type of stress happens after exposure to incidents and events that result in a sense of being overwhelmed, intense feelings of terror and fear, helplessness and loss of safety, loss of control and fear of physical or psychological annihilation. Symptoms include nervousness, sleep disturbance, nightmares, changes in appetite, difficulty concentrating, depression and anxiety. These responses can be considered normal for up to several weeks/two-three months (Rothschild, 2003).

Traumatic incidents can include one off shock events (e.g. car accident) as well as the ways in which we adjust to daily, chronic stress and a sense of overwhelm in the nervous system following one off events.

'It's just one thing after another. I'm on medication for depression and I haven't had a decent night's sleep for years'(Parent, North)

2.2.3 Unbearable Stress / Unresolved Trauma

When the symptoms continue for months or years after an event is over, PTS or Post Traumatic Stress Disorder (PTSD) may apply. Where the symptoms are the result of a series of events, Herman (1992) has developed the term 'complex PTSD'. Unresolved trauma, makes the autonomic nervous system highly unstable as hormones flood the body to prepare for muscular action in the form of flight or fight (Gleitman, et al., 2004) [18].

By this point, life becomes unbearable and in the absence of other supports, parents use longer term medication for depression in order to suppress feelings deepening the 'freeze'[19] response, may become desperate and/or one or both parents may wish to leave the stress of the family (i.e. flight) or experience suicidal thoughts. One father spoke about others who had threatened to take or had taken their own lives - '*do you have to be found dead in the canal before they do anything, is that how far you have to go?*' (Father)

Prolonged stress responses may result in chronic suppression of the immune system and parents spoke about chronic
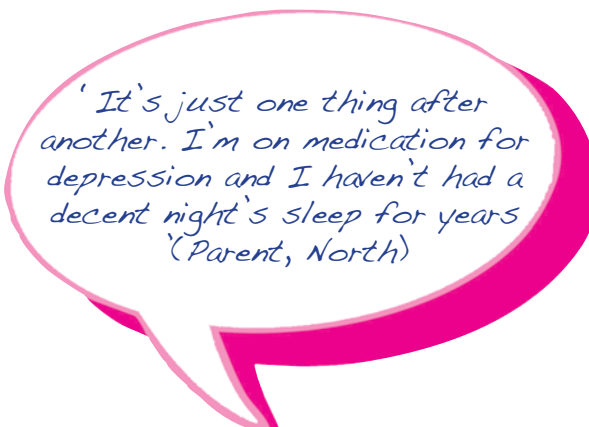
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[18]Acceleration of heart and lungs, flushing, loss of colour, or both, digestion slows down or stops, general effect on the sphincters of the body, constriction of blood vessels, dilation of blood vessels for muscles and flow of nutrients (i.e. glucose and fat) for muscular action, inhibition of tear ducts, inhibition of the lacrimal gland (responsible for tear production and salivation), dilation of pupil, relaxation of bladder, evacuation of colon, loss of sexual desire/potence and inhibition of erection, loss of hearing, tunnel vision/loss of peripheral vision, acceleration of instantaneous reflexes, shaking

[19]It appears that the more the nervous system is dysregulated, the greater is the tendency to move into freeze. Freeze can also be related to depression and is the nervous system operating in shut down, conservation mode. Scientific evidence affirms that we have extraordinary strategies for transforming too much stimulus in order to survive, though at a cost. A regulated nervous system can shift easily from high arousal and alert, and from relaxed, neutral, into rest and withdrawal. A nervous system that is not regulated (an unsupported dysregulated nervous system) given too much stimulus and demands, cannot discharge the energy when needed and has a hard time letting go. The hormones triggered by the stress response make people with dysregulated nervous systems feel both primed to react and exhausted at the same time, as if both the brakes of the car were on as well as the accelerator (Levine, 1997). This results in the 'freeze' response (i.e. 'scared stiff', 'caught like a rabbit in the headlights') and is an automatic, unconscious reaction that occurs when mammals face an overwhelming threat. It is an effort to save life and the reaction is not overridden by the neocortex (i.e. our intentional, thinking self). This type of freezing can cause trauma symptoms long after the danger has passed and people can go into freeze and not be aware of it

illnesses (i.e. stress induced diabetes, lower back pain, allergies, chronic exhaustion) - '*Trauma puts the primitive brain into a state of constant activation. The result is impulsive, automatic reactions, which alternate between frenzy, withdrawal and immobility/paralysis.*' (Foundation for Human Enrichment). '*I'm mesmerised by ASD. For years it was a secret, then it had to come out because I was a wreck*'. Post traumatic stress and chronic traumatic stress syndrome (Herman, 1992) involve high activation/hyperarousal, catastrophic interpretations of bodily sensations as well as underaction/hypoarousal and exhaustion.

'Me and my husband thought we were going to have a nervous breakdown. We nearly did and thought we'd have to put our son into care. If it wasn't for the other parents we would have.' (Young Parent East)

Parents offered substantial evidence of situations that were experienced as so overwhelming that they felt like they had no choice but to take extreme measures, sometimes pulling back from the brink due to the support they received from the parents support group and parent workshops.

2.3   Depression and ASD

Mothers spoke of their concerns regarding their own experience of depression, and mothers and fathers also stated their concerns in relation to their adolescents and young adults. Depression symptoms are best understood as a continuum from mild to severe and parents experienced a wide range of symptoms on this continuum. Fatigue is the defining feature.

One parent's group provided evidence of how the music[20] and drama peer support groups they had set up for young people with ASD had increased personal and social development. The consequence of the absence of these creative groups in the past was also noted, with '*those young people suffering more mental health problems than the young people with access to peer groups*' (parents who set up peer support for young people).

'Everything revolves around her...you feel guilty all the time – are you doing enough? (Parent, East)

'I'm exhausted all the time and I can't sleep at night' (Parent West).

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[20]Porges (1995) discoveries regarding the autonomic nervous system brings both an understanding of how the experience of depression develops and how the human voice and sound can be used to support social engagement in children and adults with ASD.

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2.3.1 Loss, Grief, Mourning and Change

There was strong evidence of the features of grief and mourning in the experiences of parents ranging on a continuum from seemingly obvious and brief to prolonged and complicated at different life transitions (i.e. '*I was devastated. I stayed in the house and bawled my eyes out for a couple of years*'). Grief accompanies any experience of significant loss, and is the suffering that accompanies mourning as a necessary process and expression people go through in learning to adjust to loss and keep living. The process is unique to each person and family and no two people or families are the same, no matter how similar they may appear: '*we need more support for people's differences not less' (Mother, East)*

'We've all come through change and it's still happening. Crisis comes and goes at different stages...My husband and I went through many grieving processes. I realised that my perception and impression was wrong about my child, and I also grieved about that. We're stronger now...... there are a lot of obstacles at every transition point.'
(Mother, North West)

The stages or phases model of grief are widely used as a road map to support mourners through the confusion and pain of loss, and in an attempt to bring more clarity to the experience. Denial, anger, bargaining, depression and acceptance (Kubler Ross, 1969); numbness, yearning, disorganisation & reorganisation (Parkes, 1996); accepting the reality of the loss, working through the pain of grief, adjusting to the change, and emotionally moving with life (Worden, 1991).

Some authors place emphasis on our instinctive resilience and capacity to creatively adjust (Bonanno, 2009), while others point to the possibility of prolonged and complicated grief depending on unique individual social and personal histories, including histories of unresolved trauma and loss, and the responsiveness of the social context.

2.3.2. Resilience as Self and Group Regulation

The term resilience comes from physics whereby a resilient object bends under stress instead of breaking. Another way to describe resilience is self regulation. The most natural way to gain resilience is in experiencing many positive interactions, including the mend and repair of interactions between parent and child. Resilience is not to be confused with will or strong will, as in pushing or driving oneself through life. It gives us that capacity to respond easily to changes in our circumstances. It helps us to let things go and move on as we are hardwired to survive. Without resilience we tend to become stuck in old patterns - *Resilience, is a body based state that largely depends on the health of your nervous system. A healthy, resilient nervous system moves easily and rhythmically between stimulation and letting go/discharge (Levine, 1997).*

'it was support from the group that really got me through'
(Mother, Mid Ulster)

Herman (1992) and Bloom (1997) propose that our greatest strength and resource is in our social connectedness, in being 'part of' a group rather than 'apart from' (Gaffney, 2003). Both authors emphasise our human need for spaces of protection and reflection, 'sanctuary' in groups. These are groups where people can explore their own responses to events without fear, tell their histories and stories in ways that promote safety, learning and connection with each other, and restore influence and authority as parents and concerned adults, in ways that support the resilience of the next generation of children and young people.

2.3.3 Resilience and Well Being in Professionals

Three theories have emerged from the study with professionals that seem most relevant are described in this section. The drama triangle (Karpman, 1968), the paradoxical theory of change (Beisser, 1970) and the framework for professionals developed by Lichtenberg et al (1994) that builds on Karpman and Beisser, has been used in relation to the evidence given by professionals that:

- Parents in their frustration and desperation are at times looking for a 'cure' e.g. '*there's high expectations of parents wanting an instant fix.*'
- How professionals respond to the expectations and needs of parents e.g. '*the need to make snap decisions that impact on families.*'
- How professionals are supported and how services are organised influences both resilience and stress e.g. '*how to keep going under ongoing and increased pressures.*'

Beisser (1970) following a personal illness that left him profoundly physically disabled developed a widely known theory of change that states that change occurs when *people become more fully what they are, not when they try to become what they are not.* That is, change does not take place through coercive or persuasive attempts by the individual or by another person to change her/him, but can take place if people take time and effort to become aware of their investment in current positions.

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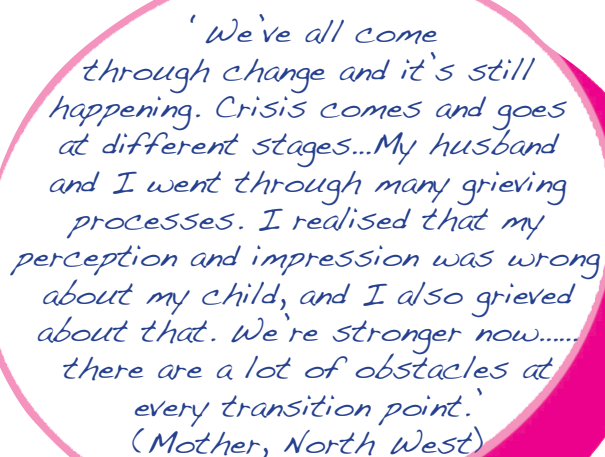
SECTION THREE - PARENT ELEMENT OF THE STUDY

3.1   Fighting For Everything

A parents comment, 'We've had to fight for everything' is at the heart of the experience for parents with a child with ASD[21] as parents recognise that how their life is currently neither inevitable nor unchangeable: '*No is never an answer. I tell them if they don't help us, you'll have both parents and children on your books not just children. It will cost you more. I was timid and quiet at the start....It's advance and regress with your child the whole way' (*Mother in rural group).

This section provides evidence of the lengths parents have gone to, the personal price they are paying, as well as the gains made.   Parents have achieved many gains in relation to their child/individual with ASD, though they have done so with little support and so the gains have cost them enormously. This section also alludes to impacts on personal health and their quality of life (i.e. back pain, immune system problems, tension and exhaustion).[22]

This is illustrated in this section and in the findings from the family interviews which show startling indicators of stress:

- Over 90% of parents experience serious sleep difficulties, exhaustion and fatigue (i.e. needing to get up during the night for years, often more than once). Almost one quarter of parents report fear of physical injury from their child or young person with ASD.
- Parents experience marginalisation and discrimination from wider society.
- Over 70% of parents reported feeling isolated with 85% reporting lack of understanding and support from the community.
- Stress and trauma range from manageable to unbearable are strong features of the experience for parents of children/individuals with ASD at key transitions through the lifecycle.
- Over 90% of parents experience anxiety, 80% of parents feel overwhelmed and helpless on a regular basis with 57% reporting acute anxiety and panic states. Nearly 65% report illness linked to caring with over 50% of parents on long term medication.

The section is structured around five headings, based on themes that have emerged from meeting with the parent groups:
(i)   Invisibility: making visible the child's needs.
(ii)   Grouping: how parents organise in groups as a response to stress and isolation.
(iii)   Surviving: survival strategies of flight, fight and freeze.
(iv)   Developing differently: the losses and gains of ASD from a parent's perspective.
(v)   Engaging: social and political engagement from crisis 'lifeline' to 'lobbying.'

Two personal accounts by a mother of a boy with Asperger's and a father of a girl with ASD are included. Finally, the supports parents need are identified.

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[21]It is important to note the deep frustration and concern expressed by parents in at least two groups about consultations and research, not receiving feedback as well as lack of impact in terms of change and services (i.e. being asked 'again and again about needs with no services following'). Parents made it clear that they need action.

[22]Local research (Autism NI, 2003, 2010; PEAT, 2007), found that the impacts on the family are: Social limitations, Continual stress, strain, lack of sleep, Constant supervision and having to plan ahead, worry about the future, embarrassment, hurt, devastation, financial worries – may have to give up employment, Lack of appropriate services, insufficient support, psychological and emotional difficulties, including impact on marital/intimate relations, restriction on personal interests and activities and problems for siblings.

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3.2   Introducing the Groups

Between April and December 2009, the researcher met with 13 parent support groups or branches of Autism NI throughout Northern Ireland, a total of 128 parents of 277 children. Each meeting lasted between one and two hours and was held round kitchen tables (2), in community and church halls/centres (8) and special schools (2). The groups met in the following urban and rural geographic locations outlined Figure 1 which shows the branches and support groups across Northern Ireland.
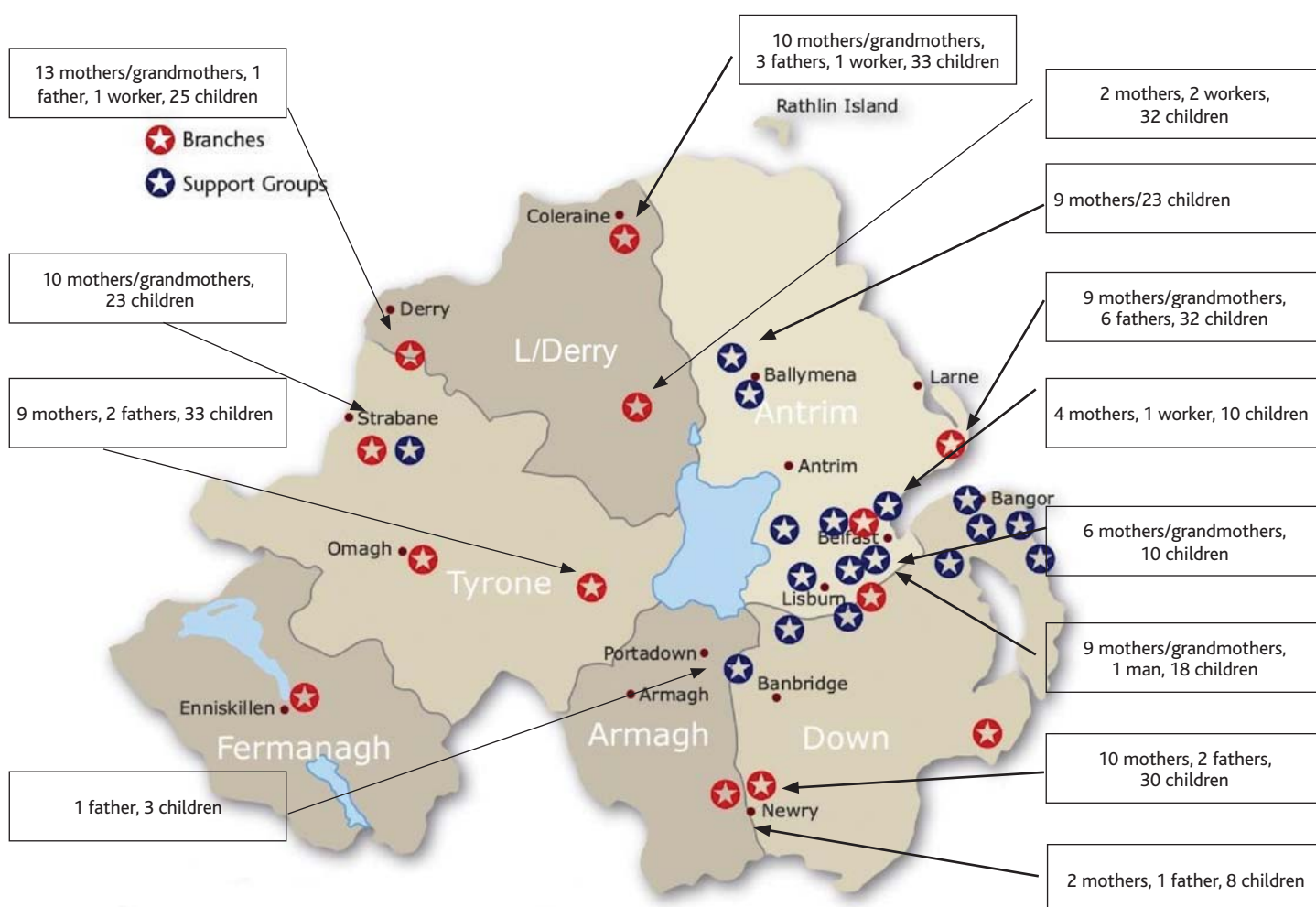
Figure 1 *Location's for Meetings with Parents in Study*

In the groups parents told how they had gone to incredible lengths to:

- Discover their own unique child, to learn what ASD means as s/he develops, and to support their child's development.
- Try to protect their child from the risks that are often a feature of ASD (i.e. unaware of danger, accident prone) and to access whatever support they could.

- Create mutual support alongside other parents in the parent support groups and to lobby socially and politically for their child, family and other families.
- Keep going within a frequently high stress home environment as well as an unpredictable political and cultural environment, (marked by transition from political conflict and the ongoing impacts at the levels of the individual child, family, community and state).

Parents state that they are under immense pressure and urgently need support:

> '**We**'re living with a constant feeling of jet lag ....a roller coaster. Worrying and lack of sleep ...We are like two zombies...Often she rises from 2.30am clapping her hands. My daughter needs constant supervision; she has no awareness of danger. There's constant mopping up the floor, dressing her, washing her, helping her feed, changing wet beds, using incontinence pants....Sometimes it hits you like a brick. You're cleaning and training an 18 year old. Thankfully most of the time I don't compare her to any other young person though I do think what could she have become...Not many people can cope when you tell it like it really is... If we don't have dinner strictly between 5.00-5.30pm she is banging her head. Bedtime needs to be rigid also. When she has bad PMT it lasts for 10 days and her noise level rises to that of an ambulance. She can't tell us why she's upset. As a parent you are sucked into isolation and the rigidly structured world of Autism. We can't be spontaneous. Everything has to be arranged like a military operation and coping can strain the strongest relationship. We need regular and suitable respite to experience normal life.' (Mother, Autism NI event launch 2009)

Meeting with the groups of parents from April – December 2009, the researcher noticed and was impacted by the emotions and thoughts expressed. These include exhaustion, anger, overwhelm, frustration, despair, confusion and sadness as well as inspiration, clarity, wisdom, humour and optimism. Fighting for recognition and against marginalisation[23] was strongly present in the lives of parents. Despite the everyday strain and stress that is usually involved in parenting a child with ASD, and despite progress over the last two decades, parents still experience the need to go to extreme lengths to get support for their child at different points of development.

At the same time, parents offer mutual support and encouragement with and for each other and value the tradition of being available to each other through hard times. As one father said in response to a mother at a point of crisis, *'around here the door of the house is the best door'*.

Victimisation? - while the term 'victimisation' may seem controversial in relation to the parent-adolescent relationship, the experiences of some parents with a young person or adult (and occasionally a school age child) on the spectrum bears similarities to such experiences of deep vulnerability. Nearly one quarter of parents reported fear of physical injury. One mother spoke of the intimidation she and her husband felt when her adolescent son went into a rage e.g. fear of violence, destruction of household items, shouting and slamming doors, threats, frequently refusing to let go of the remote control

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[23]Marginalisation- the experience of being pushed to the edge of mainstream society resulting in different opportunities and rights including cultural, social, political and economic opportunities

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of the television. *In other words, oppressive[24] experiences likely to lead to intense feelings of helplessness, vulnerability, loss and anger within and between the person, close relatives and friends* (Lichtenberg, 1994).

Lichtenberg et al (1994) proposes that people need to be supported to experience and work through the intense feelings (i.e. isolation, fear, helplessness, shock, anger, guilt, and self criticism) as well as the capacity to experience influence and to have the complexity of experience witnessed without judgment. Strong feelings of anger, guilt and fear can be particularly difficult feelings for people to work through (Lendrum and Syme, 1992), and are three of the most common feelings parents experience across the groups. '*I want to walk out the door. I can't stand it. Keeping to the structure 24:7'* (Parent North).

At times, the experience of being a parent seemed related to feeling trapped, in a stressful, inescapable experience similar to 'captivity' (Herman, 1992), and was one challenging aspect of the experience described by some parents. More than one-third of mothers in the groups spoke of depression and of being on anti-depressants[25]. This rose to nearly 60% in home based family interviews. This finding means that mothers in Northern Ireland are at greater risk of depression than the international finding of DeMyer (1979), who found that mothers of children with ASD appear to be the most affected member of the family, with almost one-third showing depressive symptoms. Lainhart (1999) noted that fathers of children with ASD are susceptible to low moods and this correlates with the findings of this study.

Levine (1997) proposes that focusing on how people manage to survive through one off or prolonged experiences that carry the risk of overwhelm is essential to supporting resilience. The belief that one can make a difference as a parent helps avoid falling into a state of depression (Seligman, 1975). Keeping going through such experiences promotes growth and development. Recognising the transformative aspects of the experience with sufficient social support appears to be central to parenting a child with ASD in the developmental life cycle.

3.3   Theme One: Invisibility - Making Visible the Child's Needs

'Autism is a hidden condition'
Across the groups, the invisibility of ASD was raised as frequently distressing. Parents often manage by *'putting on a brave face'* in order to survive while largely hiding the extent of their hurt. A distress can arise from the experience of being with their child through difficult ordinary times, for example, tantrums at the shop, but also from the lack of understanding and support from neighbours, family, friends, and professionals:

'*You put on a brave face, feel like a martyr not complaining but underneath you're really struggling. You put up defensive barriers to the world though underneath you are hurt by the lack of awareness and understanding of others in the community. One person looked into the pram my daughter was in and started calling my daughter 'a dummy'. I was so shocked I didn't answer'*

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[24]Oppressive – a state of being burdened/weighed down, the systematic exclusion and undervaluing of individuals and groups by other individuals and groups resulting in different and unequal conditions. Internalised oppression is when members of marginalised groups hold an oppressive view toward their own group, or start to believe in negative stereotypes of themselves

[25]This finding indicates that mothers in Northern Ireland are at greater risk of depression than the international finding of DeMyer (1979), who found that mothers of children with ASD appear to be the most affected member of the family, with almost one-third showing depressive symptoms.

Society seems all too often to turn a blind or judgmental eye to the situation, either ignoring the child and the parents stress, or judging the child and/or parent as somehow 'bad', and the parents as not doing their job e.g. inadequate parents. The wider community seems to judge the situation from afar without any kind of real and meaningful engagement – '*nobody in your family believing'*. The sense that '*no one's listening*.'

This social disconnect brings parents the experience of 'embarrassment', 'isolation' and 'fear' of going out, often resulting in a vicious cycle of further withdrawal, and a deepening sense of invisibility, rejection, objectification and marginalisation. Increasingly restricted lives, narrowed worlds and social exclusion, become normalised for parents: '*Nobody believes you. They see my child as spoilt and say that to me. If you lived with my son you'd understand. It's hard work. We don't get out*.'

3.3.1 Invisibility to Visibility: First Noticing Something is 'Wrong'

Gradually noticing that something was 'wrong' as their baby developed, was a deeply worrying time for parents, full of confusion, needing information and needing to know what to do – '*You have to label to get the help you need.' 'There's a need for diagnosis otherwise you are seen as a neurotic mother'*. Across the groups, parents stated that the stress of noticing something was 'wrong' and achieving a formal assessment and diagnosis, was a time of significant anxiety and stress.

There was a wide range of responses from parents: (i.e. with parents waiting many years for formal diagnosis and parents feeling guilty for not noticing earlier).

Child, parent and system responses included:

Responses re: Child	Responses re: Parent	Responses re: System
My daughter seemed blank, not registering much	The biggest stress was the point of diagnosis when you hear the words aloud, Autism. It's a shock	It took ten years to get him diagnosed
He didn't cry for 3 days after he was born. He stared.	It was really hard to know what to do	We had had to go elsewhere to get the diagnosis and were told mild to moderate Autism. It was and is actually severe e.g. he's still wearing a nappy to bed. You were sent home with a leaflet...
He'd no reaction to anything	Relatives called him a brilliant baby. He'd all the symptoms from birth when I look back on it and it was very stressful	Sometimes it's put down as mental health problems, sometimes learning disability. It's confusing...They didn't tell me what level my son was.
He slept a lot	When I was told it hit us hard, came out of the blue.	Professionals aren't giving straight answers or breaking down what is actually meant by what they say. They never have the time of day
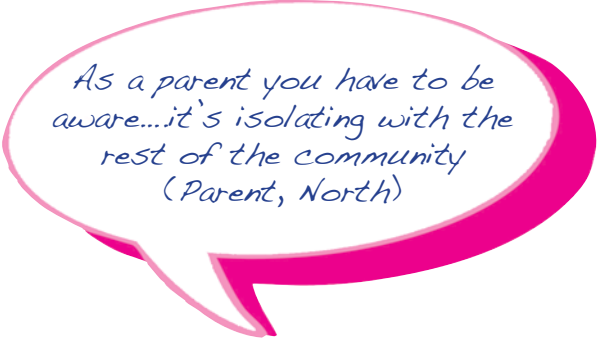
While there was a range of responses from systems with parents praising individual professionals who were genuinely supportive, there were also examples of '*professionals not believing/not engaging with you when you first notice something is not right.'*

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The experience of ASD as a difference that is not visible, leaves parents and young people feeling not understood and ignored by society, often resulting in experiences of frustration and social isolation with little support. This occurs in the following contexts:

As a parent you have to be aware....it's isolating with the rest of the community (Parent, North)

(a)   The family and extended family.
(b)   The community, including shops and employers.
(c)   Statutory services.

One parent described *'feeling embarrassed due to lack of awareness in public... Autism is a hidden disability. I've a fear of going to the shops in case he has a tantrum as people don't understand and criticise'*. The prevalence of prejudicial attitudes and actions indicate that while there has been a significant growth in knowledge about ASD this has not resulted in an overall growth in awareness sufficient to bring about sustained change -'*People are ignorant, they stop coming to your house.'*

Parents reported difficulties getting support from others in the community, in shops, in public services and within the family circle.

Denial in the family is really hard...old school approach, there's nothing wrong with you (Parent, South)

You feel like nobody is really interested, there's a façade, so you keep up a front (Parent, South)

Some parents stated that their own uncertainty, lack of confidence, self doubt and gradual recognition, combined with lack of other professional or family support to verify concerns, had resulted in lack of early intervention. Futagi and Yamamoto (2002) found that generally the earlier a child was diagnosed, the sooner the parents came to terms with and accepted the diagnosis.

This study finds that each family situation needs to be addressed uniquely. Families spoke of wishing to remain outside the formal system of State support and to make their own decisions (i.e. deciding to home school 'high functioning' second child in the family who was developing ASD traits and behaviours following a very negative experience of state 'support' with their first child). This demonstrates the importance of providing real choice in terms of specifically tailored services for parents.

3.3.2   Invisibility and Age

Parents were not able to access diagnosis in Northern Ireland 20 plus years ago and were often advised to go to England for assessment. Older parents reported waiting many years to get help.

After working extensively over prolonged periods on behalf of their own children and children in general with ASD, it may be viewed as shocking that in our relatively wealthy society, older parents of individuals with ASD are carrying the care and are left worrying and anxious about the future of their adult son or daughter.

Middle aged parents experienced the loss of family support and exhaustion from caring responsibilities as they often care for their own ageing parents. Young mothers are more likely to be parenting alone, at greater risk of living in poverty and experience acute anxiety. Young lone parents reported a range of ways of handling the experience, including '*staying in all the time, trying to make the house safe*' for their child, self criticism and self medication.

3.3.3   Invisibility and Gender (see also 3.5.4)

As only 1 in 4 people with ASD are female, parents stated their concerns for their daughters: '*Girls can often mask their Autism'*. This is the basis of a debate led by Tony Attwood that the actual number of females with ASD is higher than current estimates[26]. More than one third of the mothers in the groups acknowledged experiencing depression and taking medication. While fathers also experienced low moods they were less likely to take medication or become as isolated as mothers. Adolescents and young adults with ASD are at risk of anxiety and depression according to parents and professionals in this study.
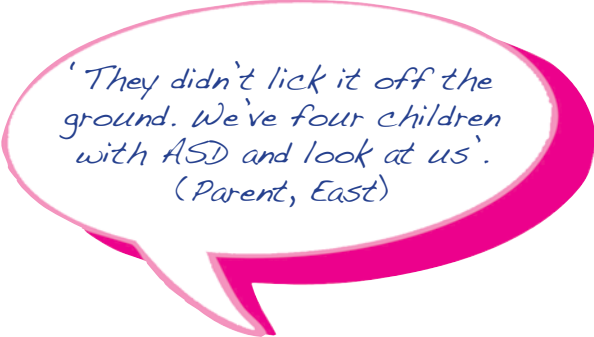
3.3.4   Invisibility Within

As ASD is a wide spectrum, occasionally parents expressed feeling marginalised even within the group. There were two main issues identified. One was due to their child's additional medical conditions or minimal speech.

The second issue was where parents recognised that both or one parent had ASD traits themselves.

3.3.5   Invisible: Post Traumatic Stress and ASD

Professionals and parents spoke of the complexity of ASD in this context. This is illustrated by the awareness for one mother of noticing similar 'traits' in her son and in her husband. The invisibility of posttraumatic stress[27] and transgenerational[28] trauma in the community can mean that in a small minority of instances ASD may be a partial diagnosis of a complex phenomenon. Lack of awareness and support in relation to the impacts of PTS, could mean a complex combination of traumatic

'*They didn't lick it off the ground. We've four children with ASD and look at us*'.
(Parent, East)

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[26]www.tonyattwood.com.au

[27]Posttraumatic Stress - severe anxiety disorder that can develop after exposure to any event which results in psychological trauma

[28]Transgenerational – the unspoken, unexamined and implicit messages and memories we carry that pass from one generation to the next.

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impacts on the child and family - '*People have been through so much here already'*. Those parents in the groups who viewed themselves as having 'ASD traits' may also be describing this complexity.

3.4   Theme Two: Grouping - How Parents are Connecting

A key finding is that parents across all groups consistently demonstrated that above all and sometimes after years of studying books, listening to experts, and searching the internet, it has been the face to face contact with other parents, the social connection in a mutually supportive group that has made the biggest difference to their quality of life.

What stands out is the power of parent groups to function as a literal 'lifeline' to support parents through times of stress and crisis on the one hand, and on the other to mobilise and take action as social and political lobbyists influencing State policy and practice. These polarities can be represented in grid form as:

Vulnerability	Stress/trauma/crisis/'stuck'		Influence
	What happens when we die? e.g. Worry about my adult son, health concerns in parent	How will my son survive? Live independently? e.g. Stating needs re semi independent. housing, not getting it, having to push and push to be heard	
	Risking being seen, dialogue in the group, being heard and taken seriously	Joining with other parents to lobby	
	Support/integration/change		

The above grid illustrates how parent support groups provide a safe space for group members to integrate difficult experiences. To shift from vulnerability to influence, and from stress, trauma and crisis to gaining support for change.

Of the 13 groups involved in the study, new members joined two of the groups, couples were present in several urban and rural groups, and fathers were members in eight out of the 13 groups. Each group acted to look after its members by providing refreshments, information, resources, training opportunities and discussion on future events.

One group began after two mothers of children with ASD whose houses were back to back discovered what they had in common while chatting '*over the garden fence'* and went on to form a parents group together.   Substantial evidence was found of the capacity of parents to form groups with the support of Autism NI, to provide mutual support to one another in the following ways.

3.4.1 Meeting Parents in Similar Circumstances

This study has found that parents had an experience of 'containment' (Bloom, 1997). A place where feelings could be safely experienced, explored and challenged in the group which held a wide range of attitudes, awareness and skills: '*The group is a lifesaver. This is a lifeline for me... they accepted my wee one's as they are. This group, keeps me going...and the friends I've made because of this'*.

3.4.2 To Identify Unmet Needs

The full range of needs identified by parents in the meetings have been summarised at the end of this section under Supports needed e.g. '*I need to learn new skills to soothe my daughter and to communicate. She's minimal communication, rocks back and forward and flops.'*

'Forming a group and keeping going even if people come and go. The only support we have is each other. I'm not alone'
(Parent, North)

3.4.3 Meeting Needs at a Local level

Examples of the wide variety of needs addressed included:

'Fighting back together against cut backs. To learn and develop as a group of parents. Sharing information. Getting in different speakers. Lively discussions and debates in the group on what ASD means and what needs to change, on strategies that work and don't work with Service providers, on what intelligence is, on medication, temper and aggression, use of movement, breathing, calming and gym balls with adolescent. I'm here to learn, to understand the way he thinks. I've learned about oral development, motor skills.'

3.4.4 To Celebrate Achievements and Socialise

Examples of activities organised by the groups for the children, young people and parents included *swimming, horse riding, judo, drama, trips away together as families.*

Groups members worked in various ways reflecting the developmental process of a group within the meetings. Moving from initial beginnings and joining (i.e. confluence), acknowledging and addressing difference (i.e. conflict), increased co-operation and intimacy (i.e. differentiation). Groups may need support at any point in their development.

Groups are essential in reducing the isolation of stress and trauma (Herman, 1992), decreasing the tendency to individualise and pathologise experiences and increasing well being. The parent group members were involved in the following:

• Focusing on what they shared in common (i.e. similarities in raising a child with ASD). Joining and being 'a part of the group' (Gaffney, 2003).
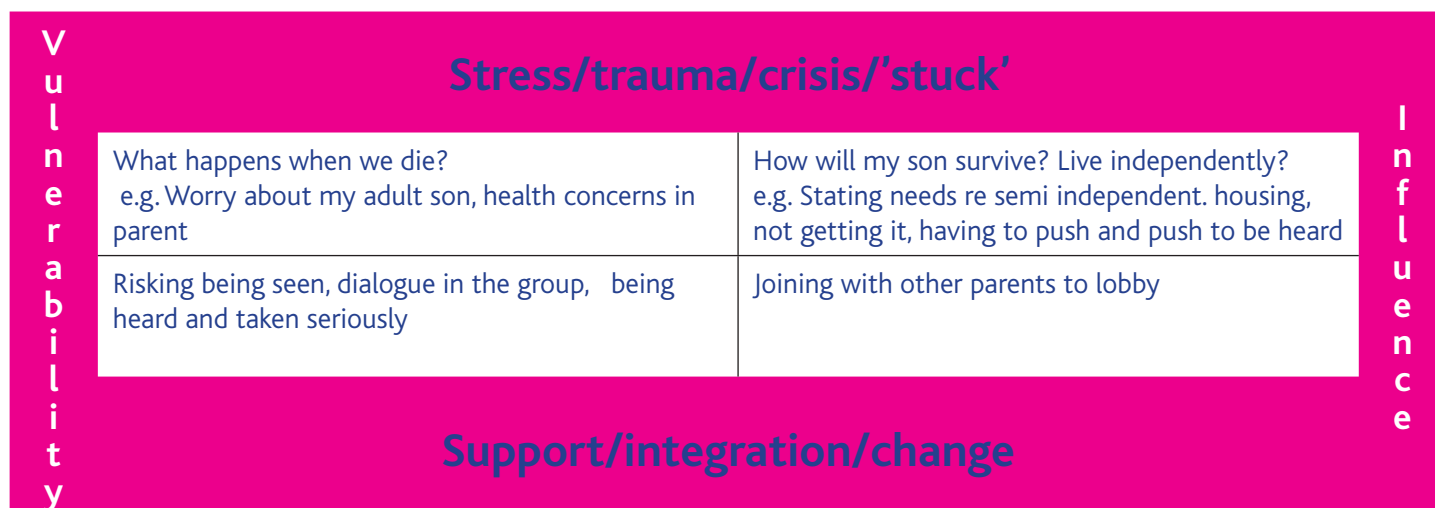
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- Expressing a sense of belonging (i.e. relating the history and recent achievements of the group with pride and strength of connection).
- Identifying or/and discussing differences (i.e. being a parent of a dependent adult, different approaches to schooling/ medication, recognising those outside the group who couldn't attend for various reasons such as ill health).
- Co-operating and working closely together (i.e. organising future events, speakers, learning from each other, campaigning).

In most of the groups there was at least one member of the group expressing tears and others in the group offering consolation. Tears may be viewed as one indicator of the depth of feeling that can be contained and expressed in the groups.   After a short period, someone in the group related a supportive experience or story and moved the group into a different experience:
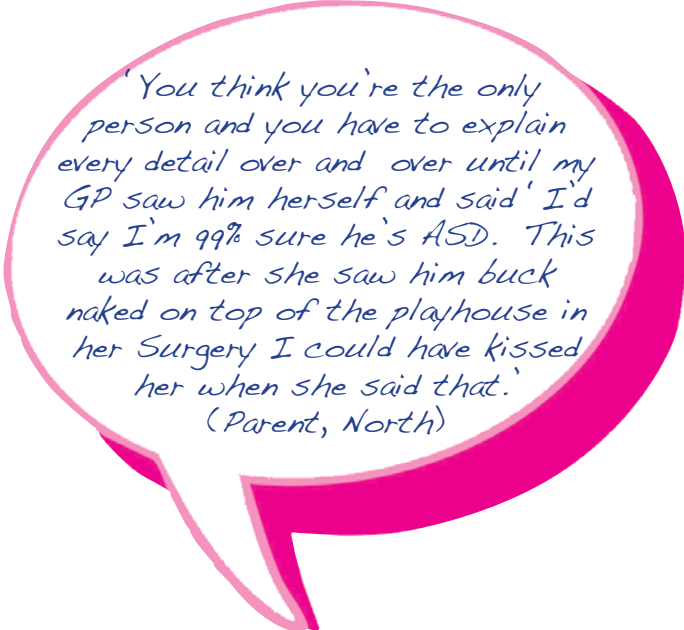
The power of the group is unique as an environment for three main tasks:

- To establish safety.
- To act as witness to parents experiences of loss.
- To support connection and the rediscovery of a sense of purpose (Herman, 1992).
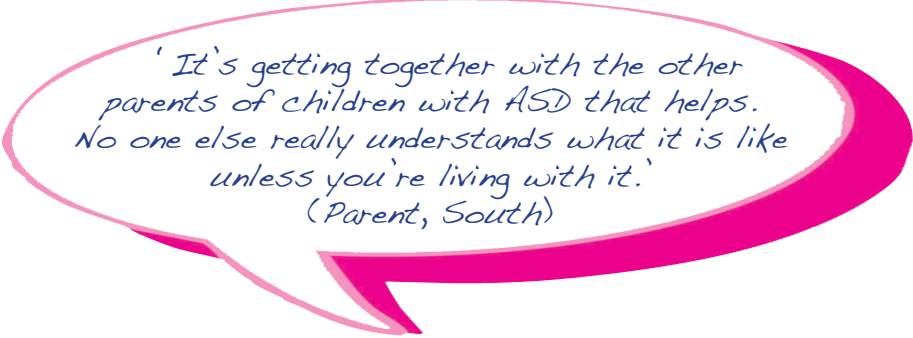
Parents stated again and again that what had really got them through very difficult times were the other parents in the group.

3.5   Theme Three: Surviving - Survival Strategies of Flight, Fight and Freeze

When a person experiences continual pressure as something that is inescapable, coping strategies will develop both in and out of awareness, ways of living and complex physiological reactions to stress over prolonged periods. Parents described different types of functioning on a daily basis through constant stress. This took three main forms of flight, fight and freeze.

'You think you're the only person and you have to explain every detail over and over until my GP saw him herself and said 'I'd say I'm 99% sure he's ASD. This was after she saw him buck naked on top of the playhouse in her Surgery I could have kissed her when she said that.'
(Parent, North)

'It's getting together with the other parents of children with ASD that helps. No one else really understands what it is like unless you're living with it.'
(Parent, South)

3.5.1 Flight

There were many examples of flight – both actual and where the idea of flight was both an illustration of desperation and an exploration of possibility:

Actual flight/a family member leaving - '*Some families don't make it. The constant stress is too great. Usually it's the father who leaves but very occasionally the mother leaves the home, her children. There was one mother we know who did that a couple of years ago. It's rare in mothers. It happens. It's tragic for that family...we try as a group to support each other, but some parents don't even get out to the group. They're the most isolated.*'

Other kinds of flight e.g. emotional management by numbing the range of feelings as a way of keeping going and maintaining parenting under pressure:

3.5.2 Freeze & Breaking Point

Parents experience of distress and despair at unchanging, unbearable stress to the point of fleeing life itself, can be seen as an attempt to both fight and flee - '*Some parents have gone as far as to be suicidal... do you have to be found dead in the canal before they (the relevant authorities) do anything*'. There was a subgroup of parents across the groups who displayed significant distress at not being in a position currently to fight for their child's rights and needs, and who believed that certain professionals (i.e. teachers, G.P's or social workers), had not fully recognised their feeling overwhelmed and beyond coping.

When external authorities are expected to respond, do not fully recognise the experience of overwhelm, in other words the parents 'bottom line' or break point, desperation ensues. One mother who was very visibly distressed and in tears in the group stated: '*I've told her (social worker) I can't cope and I need more help again and again... (tears)*.

' We're near all on anti-depressants here. I haven't the energy. I wear black, black, black. We get on with what's thrown at us and learn to accept our lot.' ' I feel like running out the door. I just can't take any more....' (Mother, agitated and visibly distressed)

'Your nerves are wrecked' 'at times I hurt myself.' (Mother)

' We'd a near nervous breakdown...we even thought we'd have to foster him out. I thought I was going mad.' ' It's total overload and meltdown.' (Mother)

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She doesn't hear me no matter what happens or what I say. She just keeps telling me I'm coping.....and I'm not. What do you have to do to get heard in this town?' 'It took something to go wrong before others realised' One parent who felt desperate and threatened suicide was then offered services - 'Is that how far you have to go?' (Father)

When neither the voluntary and involuntary flight nor fight responses solve the situation that is experienced as a threat by the person, the instinctive, biological life saving and involuntary nervous system human response of 'freeze' results: '*The sense of imminent danger or impending doom associate with an urge to escape, this is the essence of trauma: the urge to escape coupled with the perception of not being able to*' (Levine, 1997:9). Herman (1992) found that outside of war veterans, women and children are at greater risk of 'freeze' and these findings endorse this.

3.5.3 Fight

Parents related many accounts of:
- Fighting for recognition.
- Fighting for support at various transitions and crisis points in the life of their child. This included the desperate last resort of using the legal system (i.e. taking the education authorities to Court in order to get the educational support needed for their child/young person with ASD).

One mother described her son's experience of being prevented from doing Physical Education by a teacher, then being teased by some of his classmates. Her son lashed out and was expelled from the school. No one realised until later that he had exploded as 'all his grief' about his grandfathers death had 'got locked in' and then erupted. The Education Board backed down before the case reached court and offered many things. However, the mother declared '*We all paid the price for that fight, including our other children at the school'*.

 The ongoing stress of the need to fight to have the child and parents needs recognised and to rise to meet the challenges of family life with other children, other life events and bereavements, also means increased levels of conflict and strain on the couple relationship. One father said '*Our family is just about together. We've been through hell as a couple and many marriages don't make it. My wife is on anti-depressants.'*

3.5.4 Gender and ASD

The evidence shows that mothers in particular, risk labeling themselves and being labeled through mainstream medical and social approaches which tend to:
- Individualise – view problems from the point of view of the 'individual'.
- Pathologise – find out whats 'wrong' and 'missing' (i.e. deficit approach).
- Medicalise - treat the manifestation of what is seen to be 'wrong', the obvious symptom (Burrows and Keenan, 2004, 2006) of what are actually social, political and psychological concerns relating to the everyday quality of life of parents and children.
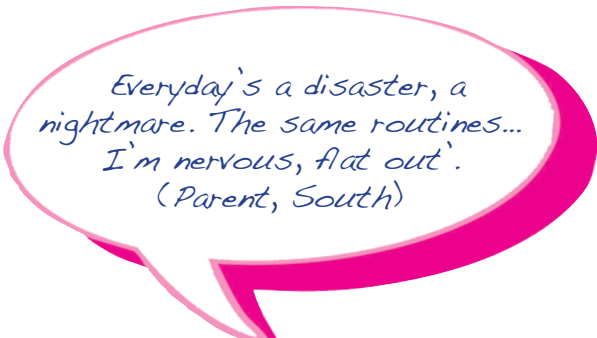
One way this cultural tendency to individualise, pathologise and medicalise emerges is in blaming mothers, parents and/or indeed the child or adolescent with ASD. There is a long history of detached experts speaking of 'refrigerator mothers'. This term was coined in the 1950s as a label for mothers of children diagnosed with ASD and similar conditions, and popularised by Bettelheim (1967). Mothers were blamed for their children's different behaviour, which included speech difficulties, self-isolation, and rituals.

The term was based on the now discredited assumption that ASD behaviours stem from the emotional frozenness of the mothers. As a result, many mothers of children or individuals with ASD suffered from guilt, blame and self-doubt from the 1950s to the 1970s and beyond when the prevailing medical belief was assumed to be accurate. Most studies now demonstrate that ASD is a very complex condition with a genetic component.

However, the strength of mothers in tuning in to their child's needs and seeking to address those needs, appears to have a high price in terms of guilt and depression. The judgment of failure, and scarcity, as the experienced consequence of perceived failure (i.e. not enough time, attention, etc.) is illustrated by the frequently held view that 'I can never do enough.' This judgment, culturally and self imposed, of not being or doing enough relating to mothering the child with ASD, the other siblings and the other social roles required was a significant feature in the groups.

Where women could afford to, many had given up jobs or changed their work in order to 'do enough' at home, though this often increased isolation. Other women's choices were restricted to scraping to make ends meet on State benefits, or juggling work and family life. Many of the women in marriages and partnerships expressed concern about the impacts on their relationship. Young mothers across the groups were more likely to be parenting alone and to experience depression and panic attacks.

Depression can protect people from unbearable feelings by numbing and cutting off feelings in order to keep going. There was substantial evidence of mothers turning their anger inward against themselves rather than risking further frustration and/or criticism. The prevalence of the long term use of anti-depressants in mothers is a key finding.

Everyday's a disaster, a nightmare. The same routines... I'm nervous, flat out'.
(Parent, South)

There is consistent international evidence that mothers experience greater personal impact than fathers (Sharpley, Bitsika and Efremidis, 1997; Seltzer, 2001). Women and mother/grandmothers also formed the majority of members of parent support groups backing up a UCLA study (Taylor, et al 2000) that confirms that social support reduces stress, and that women are inclined to 'tend and befriend' and connect with each other to relieve stress, while men tend to 'fight or flight' at times of acute stress. Gray (2003) found a difference between mothers and fathers in terms of the personal impact of their child with ASD.

For fathers according to Gray, the most serious effect was in relation to the impact on their wives/partners who were also more likely to give up work or work part time, where possible. There are clear findings in this study that fathers are deeply impacted, though express the impact differently (i.e. fathers may be more likely to leave or distance themselves from the family, though one father gave up work.

A key finding is that group members help each other handle their difficult feelings and turn them back into outward oriented, productive action. Where men were present in the groups, the fathers sometimes challenged and supported mothers to recognise their limits, even though the mothers desire to want to do more for their children, including the other siblings in the family, often remain.

One father as well as participating in the family interviews wrote of his experience and generously offered this powerful account.

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3.5.5 A Father's Experience

'Frustration is the key part in our life,
(Father, West)

Once my daughter gets over to sleep she is usually fine.

At times however she would find it hard to get over to sleep and would shout out and make loud noises. This disrupts my other children.

Frustration is the key part in our life.

It is hard to watch your own daughter try to do things, but is not capable.

On the one hand you want to step in and help her while on the other hand you wish and hope she learns to do things herself. As I get older I worry more for the future.

I worry that if anything happens me or my wife, what will happen to my daughter – who will look after her? How will she manage? What about the financial side?

In the earlier days, following diagnosis was really hard.

I did not know what to do to help and did not know where to go for help.

There was little support and at times you just wanted to shut yourself away from everyone. I really felt and still believe, that no one really understands what it is like to live with a child with ASD unless they have one themselves.

People make it so obvious with stares and sniggers particularly from children of the same age. This lack of understanding annoys me and sometimes makes me mad.

At times like these I just want to get to the comfort of our own home – comfort eating helps in the short term but the feeling of helplessness never goes away fully. Thankfully I have never yet had to resort to medication. I take comfort instead in a close knit family home life. Having a child with ASD in the house affects the whole family.

The other children feel at times as if they take second place as it comes over as if the child with ASD 'always gets her own way'! This can lead to arguments in the house and it's a difficult balancing act to try to allow everyone to do their own activities.

My wife would have an increased burden as my daughter with ASD relates the female issues only to my wife – personal hygiene and general welfare leave my wife drained, both physically and mentally and this has a knock on effect on our relationship. At times we don't have the same quality time with each other unless we arrange leave from work on a morning to grab a coffee or something to chill out. Sometimes it feels as if life is passing you by.

On the positive side, having a child with ASD lets me see what it must be like for hundreds of families throughout the country who are dealing with similar or worse issues – I have looked at the side of believing things could always be worse. On good days my daughter is still an innocent and loving teenager and is very open with her feelings. She helps me appreciate the simple things in life. I now take one day at a time as I do not know what the future will hold for her. Even though it is a worry what she will do as she grows older, I try to just take it a step at a time.

3.6   Theme Four: Developing Differently - The Parents Perspective

The evidence shows that ASD is a *different developmental experience* from 'typical' or expected 'normal' development, involving not only the individual child, but also their siblings, the parent(s), family and wider social system. Focusing on the reality of different development means acknowledging and accepting difference thereby building resilience, rather than assuming one developmental path against which others can be measured and judged.

The unique development is illustrated through:
·   The experiences of the parent support groups.
·   The experience of one mother.
·   Reflection on the 'cycle of experience' as a theoretical tool highlighting the impact on the parent-child relationship.

Behaviour problems in children and adolescence are strongly associated with increased parental stress (Lecavalier, Leone, and Wiltz, 2006).   Parents in most of the groups described a vast array of visible behaviours that their child displayed that they found stressful, and/or that they sometimes struggled to make sense of like those examples in Table 1 below. Parents urgently wanted support to understand and to respond to their child or adolescent in ways that promote well being and development.

EARLY YEARS	SCHOOL YEARS	ADOLESCENSE	ADULT
Rituals and repetitive behaviours (e.g. squeaking, flapping, banging)	My child's withdrawn, spaced out, lives in room though responds to his daddy	Not knowing about gender differences – hitting girls	Noticing differences from peers – e.g. not living independently, no girlfriend
He didn't cry for days after birth	He's breaking things every day	Aggression - he tries to push us around	Opens the door to anyone
No recognisable speech, repetitive sounds, loud pitched screams	He can't wear certain things	Can't focus in school	Can't leave him alone
Minimal verbal communication, speech delay, rocking, flapping	He's bouncing about like a toddler in the body of an 8-9 year old	His language is appalling	Regression – steps forward and back
He knocks his head off walls	His way of coping is to line up objects and wreck them again and again	Very sensitive (e.g. to sound)	✓
Bumps into things, constant accidents	He knows he needs to climb into a cubbyhole to calm himself	Sleep problems	✓
Staring, no reaction	Same routines	Obsesses	✓

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EARLY YEARS	SCHOOL YEARS	ADOLESCENSE	ADULT
She won't let me touch her	Seeing my child not be able to join with others is heartbreaking	No sense of danger	✓
He bit a relative	Big issues with attention	Wanders off	✓
No imaginative play going on	Never wanting to be in the wrong	Won't speak	✓
You would think that my son is plugged into the mains. I have to stay with him. You're exhausted dealing with the problems Autism brings and you give up the fight. My son could stay up all night and the next day and the following night	Different development – he didn't register his granddads death for a long time. When our rabbit died he began to make sense of death	He hurts himself, very competitive, tunnel vision....he's petrified, fear of what might happen, he's not communicating	✓
My son talks and talks. He doesn't know when to stop	The children and young people have problems with their emotions	Screaming, telling you to fuck off, in your face...	✓
My child not being able to join with others	Takes it out on me if bad day in school	High pitched screams	✓
He has strange eating patterns and that puts me under pressure	Wearing nappy to bed	Bullying and being bullied	✓
He has tantrums at the shops	Running out of the school gates	I remove sharp objects	✓
Can't stand loud noises	Sensory issues	Fuzzy head, stress	✓
No sense of danger – I've to lock the windows and doors. I'm really concerned	She's very critical of others, it all has to be on her terms. She's very demanding and lots of fear and anxiety	Grinding jaw, pain, naïve, doesn't know the social rules	✓
She screams and screams every time we get into the car to go drive my other children to school	He's a high IQ but needs his bum wiped. They (teachers etc) assume he's so smart he's learn to do other things	Has to win – gets to do things his way	✓
He burns himself on hot things and doesn't notice	He self harms if he gets aggressive as then he dislikes himself	Regression – moving forwards in learning then forgetting	✓
Fascination with water, splashing, lights	Gets really distressed and confused in shops	She self harms when she has her periods	✓

EARLY YEARS	SCHOOL YEARS	ADOLESCENSE	ADULT
He was constantly running away. We'd to lock all windows and doors	He didn't address me as mum until he was 7yrs then he said I love her not you. He wants to talk and hasn't the ability, there's frustration	He lets it build up rather than say what's annoying him, he's tormented and the so is the rest of the family	✓
Sensory issues	He'd thump you	She eats and eats	✓
Regression – moving forwards in learning then forgetting	Locks doors, can't use handles	Suicidal ideation and attempts	✓
✓	Doesn't see consequences	Anxiety and depression	✓
✓	Clever though doesn't understand	He implodes and explodes, he's very cross with himself	✓
✓	Has fantasies about killing things	He blames	✓
✓	Shouting in shops	✓	✓
✓	Difficulty swallowing, eating problems	✓	✓
✓	Pushes head of our baby to stop the baby crying	✓	✓
✓	Says no to any change	✓	✓
✓	Being the butt of class jokes	✓	✓

Table 1 *The Array of Visible Behaviours*

Parents also gave many examples of critical and unsupportive reactions. Reactions that serve to mirror the disconnection, dissociation, isolation and loss of contact that is already being experienced by the child/young person and parent: '*I walk as if I've a thick skin but I don't. People are ignorant and I feel devastated. They say, thank God my child's not like that, they're purely judging you, especially when you're out shopping. I stare back sometimes. If you get cross, they're winning.*' (Parent, North)

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3.6.1 A Mother's Experience

What follows is a description by a mother of a young person with ASD of key milestones with her son from birth to late adolescence. The experience was told in a naturally poetic form. What support parents need from her perspective concludes this courageous personal account.

- The journey with Autism is an evolutionary journey.
- The positives and negatives
- The drip, drip of the journey
- He was my youngest
- I'd a very difficult birth... labour for three days
- The shape of John's head, was flat
- After a few days he developed an infection, he was passing blood, needing an antibiotic
- He was very different, very young
- At six weeks old I couldn't take him out in the pram
- He just screamed, aware of every change in temperature
- At home, we call that 'making strange'
- It was difficult to leave him with anyone
- He wouldn't settle   He didn't sleep
- We felt trapped with that
- He was two and a half before we got one whole night of sleep
- Four years before he began to sleep through the night
- He didn't crawl, he shuffled on his bottom
- Grew very fast, seemed too big, his head looked large
- He was fascinated with adverts on TV
- Dancing to the Guinness advert
- Everywhere he saw and heard that
- He hurt himself with that dancing, doing that over and over and over again, as if he couldn't stop
- His speech was delayed
- He made strange when I came home
- It took ages for him to come round
- His dad was at home with him
- There was something different, not right
- Always clumsy, constantly running up to casualty with breaks, sprains, in plaster
- The Health Visitor kept saying to me 'it's just because he's the youngest'
- At age five he'd a full investigation

- I was sleep deprived as I couldn't leave him with anyone
- Felt like a treadmill
- We were in an intense bubble with occasional referrals for speech and language
- Nobody put the pieces together and we were unable to
- I knew in my gut he was different
- Obsessed with certain food and very into TV.
- ' Stimming`[29] with his hands when excited or anxious
- And walking on tip toes at the same time
- He was very intelligent, doing things like CPR on his dad when lying down
- Way ahead in some ways, though poor with language
- Aaaah when he wanted something, or he took you by the hand
- Advanced in counting,   Instant.
- P1 was ok, P2 there was an incident in class
- I asked for him to be assessed if he's that awful
- The teacher said, I can't integrate him within the class
- An Educational Psychologist assessed him
- Found him very high on some things, very low on others
- She seemed to be telling me something and not telling me
- What are you really saying? I thought
- She recommended assessment by a Paediatrician
- I suddenly asked - are you saying my son has Autism?
- I don't know where that thought came from
- She said he's showing signs similar to other children with Aspergers
- Within six weeks he had an appointment with an Occupational Therapist and Speech and Language Therapist
- And the Paediatrician then diagnosed him with Aspergers Syndrome,
- Dyspraxia -weak muscle tone, poor co-ordination, motor deficits
- We had went on the internet for information and it seemed very bleak
- I was convinced he did have Aspergers and my husband was the opposite
- I had access to people in the work I was doing, very child development focused
- I was relieved and terrified and it all happened very quick and not quick enough
- At diagnosis you want an answer straight away
- It's like referral for a lump on the breast
- You're desperate to know what you are dealing with

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[29]Stimming - a repetitive body movement that is stimulates one or more senses. The term is shorthand for self-stimulation.

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- And all you can do is wait
- Saying to your family and you don't know enough to tell them
- You look for something to hang it on
- Genetics? It was like an implosion in the relationship
- Looking at each other to blame, the straw that broke the camel's back
- We separated the week before the diagnosis
- There was a lot of distress
- The loss of the hoped for child and relationship
- We saw the Paediatrician monthly a few times then were left to our own devices
- John got Occupational Therapy for a while for co-ordination and muscles
- Though the O.T. couldn't connect or motivate John
- He wouldn't co-operate
- His eating was restricted, he had issues about the textures of food
- He gagged on a pea or a bean
- My life became more and more restricted in terms of doing things and going places
- I rarely went out, as John would have kicked up a fuss
- Both before and after the diagnosis
- He'd only eat certain things – everything revolved around him
- My older kids resented him – 'You let him away with murder'
- They saw the impact on me – they had empathy with me, not him
- I was just existing, juggling work and child care
- John had a full-time classroom assistant after diagnosis and special needs statement at age 8
- He was bullied in Primary School, he perceived it as bullying
- He took a huge dislike to one boy
- Fell out with the teacher at times
- Walked in to the Headmaster regularly
- Everyone knew him, girls looked out for him, he was cosseted
- Secondary school turned him down
- Legally they couldn't refuse him, yet they did
- We were left and it became a battle between the Board and School
- We got a solicitor as nothing was shifting
- A Judicial review
- The school backed down but there was no classroom assistant
- They weren't prepared and we'd to rush him in
- Then SENCO rang to say he was behaving psychotically

- We tried to get his needs recognised
- If my ex hadn't had him three nights a week, I couldn't have worked.
- Anger and exhaustion, we tried everything
- The Board accused us of damaging him, the only option seemed to be residential school in England or stick with the school so we decided to keep going
- He was physically ill – we kept information from him and protected him
- He started collapsing – everyday we were getting calls to come and get him Meetings in the school then a lull for a month or two
- He got very distressed and tried to walk out of school a couple of times
- He got more and more worked up. We had to physically carry him from school out to the car and he took a long time to come round
- The school solution was to ring us to get us to take him home
- Rather than work with his idiosyncrasies
- Forcing a square peg into a round hole
- The school was a treadmill and he was angry/blaming us for keeping him there especially me. It was awful, felt like no other choices
- Then he started talking about killing himself
- A lot of teachers were very fond of him
- But there was a lack of flexible thinking, they were treating him as a nuisance
- Rather than recognising the distress he was in
- Then they removed him from the school
- All came to a head about his mental health
- I spent days on the phone getting support
- The G.P. put him on diazepam and rang me every night and he got an urgent referral to a psychologist for a year and a half
- He also got melatonin as he wasn't sleeping
- He was angry with me due to his high anxiety and I couldn't fix it
- He blamed me
- Over time I realised I was becoming depressed and on anti –depressants
- I felt like running away
- He was out of school for a month and a half
- I was on suicide watch with him
- I got him a placement in a new school and this school approach was so open and and willing to experiment and try different things
- A breath of fresh air but it didn't stop the crisis
- Things would go down very quickly for John

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- He was lethargic, trying to strangle himself, suicidal
- We'd told him his diagnosis at age 8
- But the underlying distress was that he didn't accept himself
- And he got into more and more denial in secondary school
- He accepted the dyspraxia but not Aspergers
- The impact of adolescence was huge
- The sense of a square peg trying to be squeezed into a round hole
- Things were very intense with him from age 11 on until last year
- We were on survival and my other kids were left to get on with it
- One moved to my parents, another moved in and out, was withdrawn
- Seven years ago I started heavy smoking/'stress sticks' and my health has suffered – Gynae problems, eczema, hair loss, weight gain. Chronic and acute stress
- Chronic pain, constant bleeding, eating pain killers, surgery
- People don't really get it
- Even my partner, friends, or dad
- At times its not healthy – I'm very tuned into my son
- It's intense, I know it before he shows it   I get worn down
- His dad and I are building his skills for independence
- I get my head showered three nights a week
- It has to be at his pace as nobody is as stubborn as someone with Aspergers
- You've to work with or give up and work with and give up!
- I feel bullied by him at times, he's very reactive, high paranoia
- I'm walking on eggshells
- I can't go head to head with him, I need to go in by the back door`
- He goes from 0-90, like the features of domestic violence and trauma
- My skills and understanding have helped, otherwise I'd have more self doubt
- It's been surviving not thriving, becomes a way of being
- It's been rocky, horrendous and I feel lucky
- I don't know how others get through
- Scariest is the next stage into adulthood
- I want rid of the difficulties, not him
- I appreciate his quirks and personality
- Hardest is that your children will grow up and grow away and want to be independent
- You have to live with the pain of not being able to protect him
- It's terrifying as your reserves are low as a carer by this point

Some typical needs of parents/carers which the study found included;

- Time for yourself, healthy escapism and breaks.
- Personal therapy.
- Getting glimmers of shared experience.
- Boundaries –

> 'my mantra is 'know your limits' –
> many parents don't and they are 'do, do, do'. Don't get sucked into the
> drama – learn to be able to hold stuff – we slip into reacting versus
> sitting with and being reflective of our own capacity
> (Parent, East).

3.6.2 The Cycle of Experience

The 'cycle of experience' is one lens for exploring development, what can occur to interrupt development and how that impacts on all involved (Zinker, 1978).
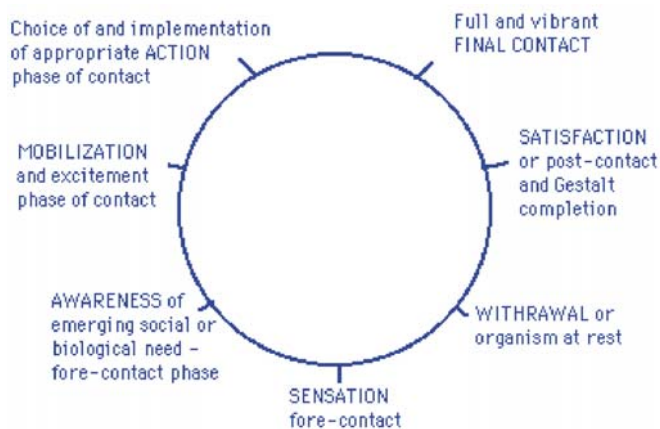
Figure 2 *Zinker's 'Cycle of Experience'*

Figure 2 represents how the 'cycle of experience' occurs over and over in daily life at an intra and interpersonal level, with possible interruptions at any point, leading to dissatisfaction, unmet need and unfinished situations/dissatisfaction, and/ or to satisfaction and growth.   In the **Sensation** phase we look at what we currently see, hear and feel. (Fear, my child is touching a hot object). At **Awareness** we are looking at what we are going to do (to stop her from hurting herself). In the **Mobilisation** phase we are preparing for the coming action or getting ready to move. Then we take Action and remove her from danger. At the **Final Contact** phase we process the experience.

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In the **Satisfaction** phase, we reflect on the experience and at **Withdrawal** we have completed the experience. Consider one parents experience with her young child with ASD and how at any moment another event may occur:

- A mother hears the sound of the school bus driver tooting the horn to pick up her child with ASD for school.
- He has been slow in getting dressed that morning and is running a little behind. The bus driver toots the horn impatiently.
- The mother tries to get her son out on time and as she opens the front door a couple of minutes later notices the bus driving off.
- Her son is inconsolable at missing his school bus and spends most of the day in a state of distress, impacting on his mother's sense of herself and her capacity to do what needs done.

Development is the developing boundary between the child and their environment (McConville, 1995), and relies on awareness and action in the whole context or field[30] of t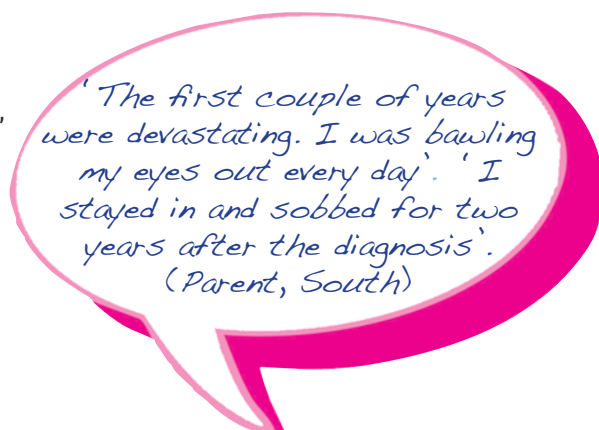he child. This begins with someone noticing the unique needs and potential of the specific child and the actions of the child (i.e. attunement).[31] As the parent or concerned adult begins to notice difference (i.e. unusual behaviour and an absence of an expected behaviour), an experience of increased stress occurs in recognising the need to expend additional efforts to discover and respond to the child's developmental difference.

3.6.3 Difference, Loss, Change and Development

Parents described experiences of grief when they first noticed their child's difference, at diagnosis and beyond at key transitions (i.e. entry to primary school, transition from primary school to secondary, adolescence and young adulthood, death of a relative). Grief accompanies any experience of significant loss, and is the suffering that accompanies mourning as the necessary process and expression we go through in learning to adjust to loss and keep on living.

While each parent and family's experience of living with ASD is unique, the general features of grief, sometimes prolonged or complicated grief[32] and resilience were apparent in the groups -

'The first couple of years were devastating. I was bawling my eyes out every day'. 'I stayed in and sobbed for two years after the diagnosis'. (Parent, South)

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[30]Field theory was developed as a way of understanding the behaviour of individuals, groups, organisations and societies and is defined by the way different forces push and pull in different directions and influence each other in mutually interdependent ways (Lewin, 1952). The relative strength of each force of any field determines the characteristics of that particular field as well as the possible/probable actions of any part of that field (Gaffney, 2003). Individuals are seen to behave differently according to the way in which tensions between perceptions of the self and of the environment are worked through as we each participate in a series of unique though connected 'life spaces' (i.e. family).

[31]'Attunement' is the attitude and ability to pay close attention using all of the senses, and 'join' the child in some way while also holding a sense of separateness, thereby supporting change and development (Audet and Shub, 2007).

[32]Complicated grief - feelings of disbelief, loss and anguish continue on

'I felt so much grief....the Irish myth of the changelings[33] really sums up ASD. You've a sense of putting your quiet child to bed one night and the next morning waking up to someone else - squealing, flapping, spinning, you name it, endless strange behaviours'.
(Parent, North)

Parents described:

Shock and disorientation	Panic	Guilt
Sadness, crying, keeping a stiff upper lip	Hopelessness	Fear
Muddling through and keeping going	Helplessness	Depression
Making contact with others, strengthened relationships		Despair
Physical activity, creative activity, deepened spirituality or religiosity		
Planning for the future		
Acceptance/relief/integration	Anger	Anxiety
Story telling, witty characterisation, wisdom tales		Loneliness
Yearning, pining	Humour	

Frequently within the supportive group context the parent's experiences flowed from painful and serious to playful and light. While there is increased knowledge about ASD and a resilience oriented approach among many parents (i.e. '*You value difference'*), the general lack of ongoing responsiveness of state services tasked with supporting parents, means that parents are leading the drive for increased awareness and change at considerable cost to their own physical and emotional health.

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[33]In Irish and worldwide myth & legend a child believed to have been exchanged by fairies for the parents' true child

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3.6.4 Costs

Parents spoke about the additional financial, the often hidden, costs in raising a child and young person with ASD, with the additional loss of needing to give up work or work part time and loss of income. The difficulty making ends meet was felt most acutely by lone parents who represented approximately 45% of families in the study. The destruction of household items and the need to spend on specific items was an additional burden on the family budget. Prejudicial attitudes by some staff can make the experience of applying for Disability Living Allowance stressful for parents. Parents spoke of needing to spend a long time on the phone in order to get State services resulting in high phone bills. The overall experience in relation to finances was often highlighted as a huge concern

'Families have their heads just above water.' (Parent West)

Families in rural areas face additional costs including difficulty accessing free or low cost services, transport costs and time spent travelling. Public transport is rarely a safe option due to public attitudes and unpredictable attitudes. Some children and young people with ASD are calmed by the motion of the car, 'he loves the car', and the costs of running a car where seen as prohibitive for some families. Families on small farms face additional problems accessing financial support: '*You get scored off from support as we have a farm – little money, but you're meant to hack it yourself* '

There were many examples in the groups of other losses in terms of social relationships, roles and identity as outlined in Table 2 below.

Family	There's a lot of lone parents due to stress of ASD, I've no fall back now I'm a lone parent. I've less family support now my parents are elderly, caring for both children and elderly parents. My family doesn't want to know and I don't have the energy to explain to other family members.
Siblings	There's constant conflict in the house. Bickering between the children 'One child diagnosed and my other child's not but has similar responses. She screams and wails in the corner. She can't communicate and says no to any change unless it's on her terms. She doesn't like school and screams every time we get into the car...I feel guilty. My other children have lost out due to the need to focus on my son.'
Fathers	Struggle to hold value in a wider society where the focus is often external - on status, freedom to travel, going to hotels, not on caring for my son.
Mothers	Guilt, can't do enough
Couples	Often one person is trying to cope and the other is in denial. There's conflict coming to some acceptance. Some couples don't make it
Shops	Shop assistants not understanding . Not going out for fear of tantrum and people's reactions
Schools	The bus driver's assistant just flings him (son) onto the bus. I can't stand that. They're not caring - I'm exhausted. It's a battle. They (school authorities) keep saying we've to wait to find out what level he's at before he can get help.
Professionals and other Public Services	There's a sense of scarcity, not enough, it takes so long to get anything
Employers	Many mothers reported leaving work in order to care for their child and one father leaving a 'top job' to care for his son while his wife continued working. My employer 'let me go'. Giving up jobs due to inflexible management

Table 2 *Parent Losses in Terms of Social Relationships, Roles and Identity*

Parents were concerned about the crisis oriented approach to public services and provided evidence of schools and other public services making parents wait until their child experienced a crisis before they could access support. This was viewed by parents as a reactive and costly approach based on inflexible criteria.

3.6.5   Evidence and Illustrations of Resilience

The study clearly demonstrates that parents are also resilient. Nearly 90% of parents stated that they felt empowered, at least at times. 'You have no choice, you have to become empowered to survive'.   Nearly 80% felt valued within the family and had developed new skills because of ASD. Over 70% of parents had a sense of purpose in relation to being a parent of a child with ASD.   While crisis points were experienced, parents also spoke of what they were doing that was working with their child. This included acceptance of their child as s/he is and trying out a range of other therapies:

> 'Being open to complementary therapy and other supports to help (e.g. head massage, acupuncture). Touch, hugs, massaging his feet and back, buying a special shaped cushion where he can sleep'.
> (Parent, South)

Oaklander (1978) aligns with this finding in relation to her internationally renowned work: '*the more the children came in contact with themselves, their senses, their bodies and the more self-discovery that took place, the calmer these children became*'.

Building resilience relationally, as a result of being with others was evidenced again and again in the stories parents told and illustrates the move to satisfaction within the 'Cycle of Experience' described earlier in this section. One example was from a mother observing her son's distress as they entered a busy, packed shop in her town on a Saturday, rather than insist on the task, she accompanied her son out of the shop and walked with him until he was calmer. When they returned and tried again twenty minutes later, the shop was less packed and her son was ready and willing to go ahead with the shopping.

This kind of strategy that parents typically adopt is confirmed by an internationally renowned author: '*When the brain becomes disorganised,...think of controlling the sensory input from the environment to help organise the brain...Because we cannot see a sensory integrative[34] dysfunction, it is easy to forget....Make sure that your expectations for your child are within the capacities of his particular nervous system*' (Ayers, 1991:162-163)

This is further illustrated by two fathers who spoke of their experiences of trying many different activities with their sons until they discovered what their sons truly enjoyed doing, then joining them in that activity (e.g. running, playing with trains). One father found that joining with his son's deep interest or 'obsession' in trains every Saturday was a way of

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[34]Sensory integration involves the many parts of the nervous system working together so that a person can interact with the environment effectively and experience appropriate satisfaction (Ayers, 1991)

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experiencing mutually satisfying contact. Another father encouraged his son to gradually stay a little longer watching a movie at the cinema so that eventually father and son were able to watch a full movie together from beginning to end, feeling satisfied with small steps over time.

The patience and persistence shown in these examples indicates a commitment to holding optimism in the process rather than focusing on any kind of set or fast outcome. This openness to the child, and the parents willingness to change their expectations is validated by studies on resilience - *Expectations appear particularly important in promoting resilience... resilience develops through the positive use of stress to improve competencies (Frydenberg, 1997)*.

These are inspiring findings as parents navigate and value their relationship with their child/individual with ASD and are affirmed by Oaklander (1978): *'Begin where the child is. Stay with him. Take cues from him. Be alert to his process and his interests.....bring him back to his self awareness over and over by providing many sensory activities'* (Oaklander, 1978:275)

The type of willingness to focus on where the child/individual is with their ASD is further endorsed by internationally renowned practitioners: *'The objective (with Autism) is to improve the sensory processing so that more sensations will be more effectively registered and modulated, and to encourage the child to form simple adaptive[35] responses as a means of helping him to learn to organise his behaviour' (*Ayers, 1991:130*).*

Parents helped each other to regulate their feelings – the sometimes intense expression of painful emotion with storytelling, laughter relating funny incidents with their children, looking out for each other and interaction in the group. Parents gave many examples of resilience – how they had transformed their experiences over time: *'I got no help from the Government so I do Reiki, a meditation and massage group for the kids. You've got to feed their possibilities.'* The process of increasing awareness through contact with the child, other parents, supportive workers, family and friends brought increased satisfaction.

3.6.6 The ASD Experience

Gains	ASD makes you less selfish. Determination to do whatever it takes, to do the best I can as a parent. Realising this is a lifelong condition and to take the best from him. Accepting this. The feeling we can work round it. Accepting difference and finding ways to live with and sometimes laugh about. Recognising different development. Using his 'obsessions', fitting into their world. Seeing strength – my son is big and bold. They are who they are! Straight forward! Noticing when he achieves something. I like that he still likes tactile support, holding hands with me.
Learning	Initially it was what can I do to 'fix' it, just because he doesn't speak doesn't mean he's not intelligent. Cooking – make it interesting for me and my son – making shapes, smiling faces, making it fun – it's fun, never a dull moment with ASD.
Personal growth and change	I'm a different person now. Less judgmental now. I'm like a consultant now tuned in, though concerned about who will do this when I'm older. More patience than I used to have...calmer. Personal boundaries and putting limits on what I can do/looking after myself. More assertive.

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[35]Adaptive responses are an appropriate action in which the individual responds successfully to some environmental demand. Adaptive responses require good sensory integration, and they also further the sensory integrative process (Ayers, 1991)

Recognising the need to change	I was doing too much for my son, I needed to step back. Realising I had an unrealistic template, and needed to get my husband involved. Contact and learning- asking questions, interest in adolescence and transitions, development, learning about impacts on whole family, interest in the family, curiosity and desire for more awareness (e.g. what impact on my other two children as our life was focused so much around him).
	Exploring mental health issues, challenging self criticism/unhelpful messages of not being or doing enough, unrealistic ideals that reduce esteem and confidence (e.g. perfect parent, perfect house, perfect relationship, etc). Relief and 'Aha' moments – Autism can protect the person in some ways
Humour and stories	E.g. death of family rabbit and death of grandparent – will grandad be buried in the garden with the rabbit? Humour in the group about the five year old described by professionals as 'non verbal' saying 'no way' in different situations. Our marriage is stronger now
Investing time	Taking time off work to walk in the hills with my son, checking he's OK. Walking up country lanes. Noticing and appreciating professionals who are helpful. Holding value and worth regardless of adult peers, recognising the superficiality and limits of seeking status/wealth Being part of the group. Counselling. Taking each small step at a time. Each thing that comes up dealing with it, not dealing with two things at a time now
Pushing, standing up for ourselves	Fighting, focusing anger, strategy. Political work, placing responsibility on Government, planners, property developers, etc . Going out (e.g. to concert). Meeting in a parent's house for a social night. Step father who is more supportive than husband was. My sister helps. More patience, joking between a husband and wife. Joining his world. A like-minded person to talk things over with and reassure you you're doing the best you can.

Parents reported that the experience of being a parent of a child with ASD can be transformative and that gains can be experienced as a parent. They gave many examples of their own unique summarised learning or wisdom.

' It's a mixed blessing, Autism. There's a gift in it. You become a better person, you're enriched. You accept and understand other people's failures; you're more willing to give. You want to give; you've more empathy for anything and everything on the planet. They open up the world to us and we then have to open to them'.
'You have to develop emotional strength e.g. my son isn't invited to parties.
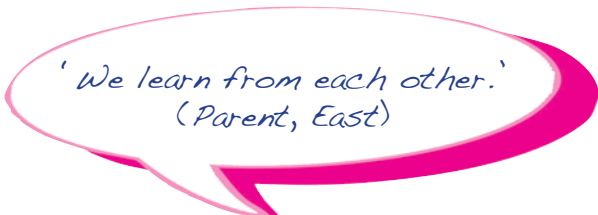Rationally you accept this, emotionally it's really hurtful.'
(Parent East).

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3.7   Theme 5: Engaging[36] - Social and Political from Crisis Lifeline to Lobbying

'I'm a political animal now.'
(Parent, East)

The shift from isolation and frequent self blame towards recognising that parenting a child with ASD is a shared responsibility means that parents viewed their problems differently. This represents a move from disconnection, 'being apart from' others, to becoming 'a part of' and connected to a support group (Gaffney, 2003). From this base of support, the parent groups moved out towards engaging other groups and organisations as well as developing their own sense of group expertise.
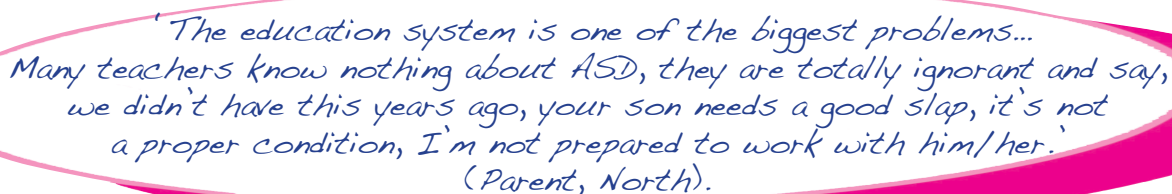
'We learn from each other.'
(Parent, East)

The social and psychological process of change from isolation at the level of the individual parent, to becoming a member of a group, to further social connections and activities was described in the groups. Parents described changes in their lives as they experienced enough support to be able to focus their frustration socially and politically. A number of parents had changed direction feeling 'really drawn' to work with children and a 'deep interest and empathy' in special needs, children and individuals with ASD and their parents – 'I could just see her in me'. This increase in empathy is evidenced by more than 90% of parents with a child/individual with ASD reporting more awareness and respect for difference and diversity as a result of their learning.

Another mother had become a volunteer: '*Volunteering with an organisation and taking courses...as before I was very alone with living with ASD, even within my own family. It makes a big difference to have more information, support and contact. I feel more empowered and instead of focusing on what I can't do, I see progress.'*

Parents in all the groups with primary and secondary school age children referred to negative experiences and considerable difficulties with the education system at different points of their child's life:

'The education system is one of the biggest problems...
Many teachers know nothing about ASD, they are totally ignorant and say,
we didn't have this years ago, your son needs a good slap, it's not
a proper condition, I'm not prepared to work with him/her.'
(Parent, North).

Challenging the school, moving school, and taking the school to court following exclusion of their child were among the strategies parents adopted.

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[36]'Social engagement' is a critical factor in resilience and is being studied by researchers at the University of Maryland with children with ASD in order to stimulate behaviours such as listening, looking, facial expressions and vocalizations that support social interaction, using music at frequencies associated with the human voice, (Porges, 1995). Tomatis first discovered a way of using music to help singers then children with ASD based on his idea that hearing is the root cause of a variety of problems. Social engagement is a key aspect in reducing stress and supporting self regulation of the nervous system.

Engagement at the local community level where multiple forms of ignorance, fear, prejudice and exclusion may manifest was also a significant feature of parent's strategies to resist exclusion. Two mothers spoke of how they had encouraged and supported one another by challenging neighbours who had allowed the other children on the street to exclude her friend's child. While one mother had felt disempowered and resigned, her friend, also a mother of a child with ASD, decided to knock on each door, hand the neighbours a leaflet about ASD and engage them in discussion about the impact of leaving a child out of everyday play on the street.

Another lone mother set up a support group in her community with the other mothers, while dedicating herself on a daily basis when her son came home from school to try out different, creative ways to help him learn to identify and express his emotions:
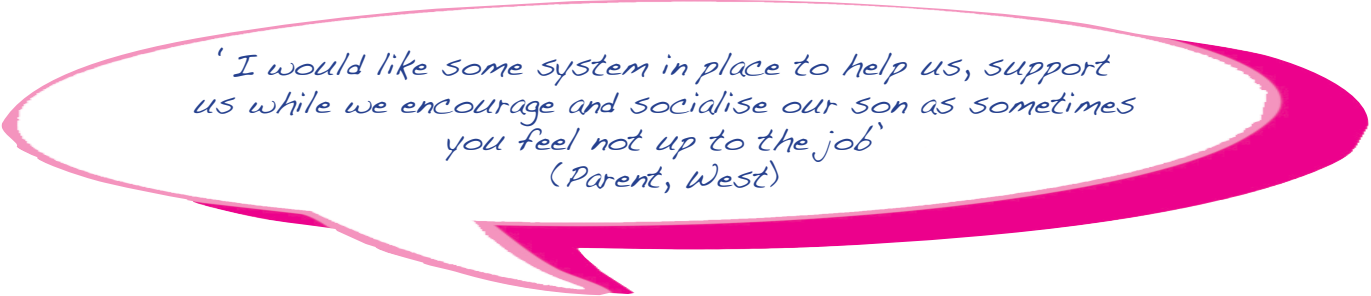
> ' I used to be frightened of his aggression, that he'd stab me...
> I'd hide the kitchen knives. Now I know he needs structure and no
> distractions. I've learned to stop talking to him and not ask him how his
> day was at school. I do sit down now and talk with him about feelings.
> Use pictures. He's learning how to care.'
> (Parent, South)

Parents became strategic by identifying the source of problems as a political matter: *'knowing this is a long battle. Taking each small step at a time'.* Fighting cut backs, lobbying for services, resources and fundraising, going to the High Court, contacting the Education Minister, meeting MLA's to tell them what strategies are needed and to lobby for legislation on ASD and finding ways to work with the State, were among many ways parents had become activists and advocates for their children.

The organisation and compartmentalisation of services into child, adult, speech and language, psychology, etc, makes life for parents 'very hard work' and recognising that this current 'fact' of life is neither inevitable nor unchangeable:

> 'No is never an answer. I tell them if they don't help us, you'll have
> both parents and children on your books not just children.
> It will cost you more.'
> (Parent, South)

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3.8   Findings: Supports Needed as Identified by Parents
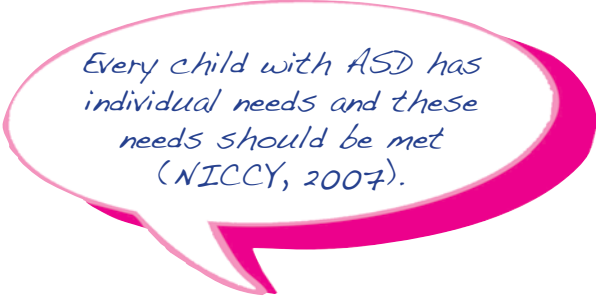
> 'I would like some system in place to help us, support us while we encourage and socialise our son as sometimes you feel not up to the job'
> (Parent, West)

This section has been compiled using data across the 13 parent groups, the family group interviews, and the individual interview. Parents are clear about the changes that need to happen. The postcode lottery of services was raised by parents as an issue that needs to be rectified.
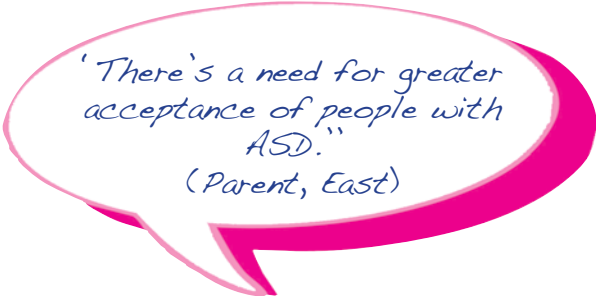
> Every child with ASD has individual needs and these needs should be met (NICCY, 2007).

The study identified the following as needs that require to be met:

3.8.1 Human Rights and Equality Needs

•   Parents of children and individuals with ASD have a right to a review of legislation and to be recognised and included (i.e. within disability discrimination legislation). Adequate legislation in relation to ASD is necessary. Anti-discrimination measures are needed to create a supportive environment for the child, young person, individual with ASD and parent/carer.

•   The lack of awareness of ASD and years of under investment needs to be urgently addressed.

•   The complexity of ASD and the transgenerational impacts of trauma need to be fully identified and addressed if as a society all our children are to be supported to fulfill their potential.

•   Private business has a major contribution to make in raising awareness among all front line workers in shops/service industries in order to decrease prejudice and discriminatory actions.

> 'There's a need for greater acceptance of people with ASD.''
> (Parent, East)

•   Information, education and early intervention.

•   Parents and all relevant professionals need awareness training regarding ASD.

•   Good timing - getting the help needed when it is needed e.g. at the time of this study, the average waiting time for assessment was coming down from 18-24 months, though parents have described the anguish involved in lengthier waiting times. However there is a fear that if the waiting times are reduced, that there is no or little investment in early intervention so the situation could be worsened.

- Assessment and diagnosis - Parents need early intervention, pre diagnostic and follow up support, use of other tests to identify a wider range of intelligences, emotional support given likelihood of shock at diagnosis and difficulty taking information in at this time, clear information and guidance on the specific needs and abilities of the child

- Information on local and regional services and how to access services.

- Choices in terms of services as not all parents currently trust State services.

- There is a need for awareness, education and support on the use of medication for children, young people and adults (i.e. anti-psychotic drugs, Ritalin, anti depressants) and alternatives.

- There is a need for ASD awareness raising cards for parents and young people to hand to others (i.e. in shops when the parent hasn't time to continually explain)

3.8.2 ASD: Parents, Children with ASD and Professional Needs

'I need support for my anxiety and sensory assessment for my child as he's overeating but there's no one to do this'
(Parent East)
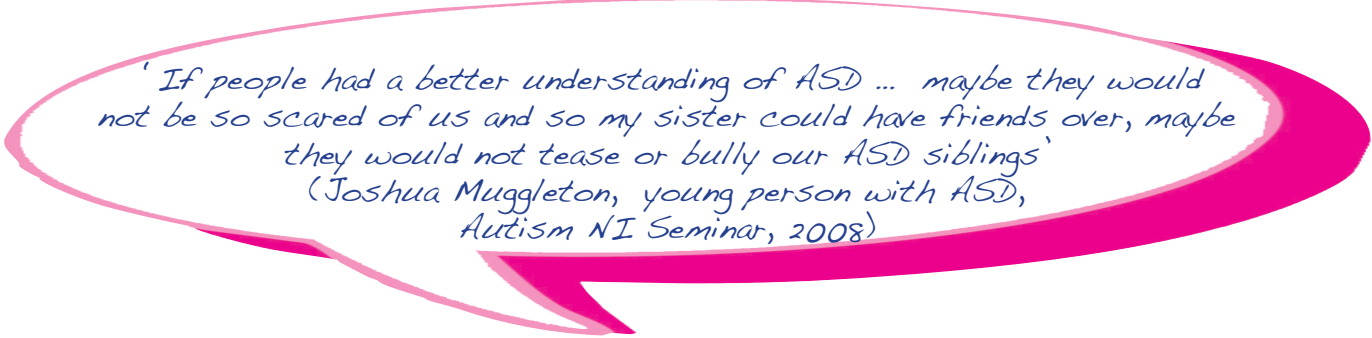
- Parents experience a strong need to be listened to as the primary 'expert'/authority on their own child/young person with each family situation addressed uniquely.

- As children with ASD frequently experience no sense of danger and/or other distressing behaviours, children and parents need a range of specifically tailored and ongoing supports to help keep their child safe and promote development (i.e. nursery and primary schools need to have secure fences).

- Parents clearly identified the need for personal support at different points of crisis or transition including when experiencing acute and chronic anxiety.

- Education, training and support needed includes: sensory integration issues, supporting verbal skills, understanding unusual behaviours, aggression, fight, flight and freeze behaviours, sleeplessness, screaming, developing boundaries that can work for child and parent, new skills to communicate with their child, learning about the nervous system and handling overwhelm, awareness of the impacts of ASD on the whole family.

- 'Age sensitive' support for parents is necessary e.g. older parents with an adult dependent son/daughter as well as young and lone parents.

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- Parents need awareness raising and training for other family members as they do not have spare capacity to keep trying to describe the problems over and over while handling an already challenging situation

- Prolonged and complicated grief in parents needs to be recognised as this can lead to psychosomatic pain and ill health. Adults may require specialist support or/and group and/or individual therapy.

3.8.3 Adolescence and Sibling Support Needs

'If people had a better understanding of ASD ... maybe they would not be so scared of us and so my sister could have friends over, maybe they would not tease or bully our ASD siblings'
(Joshua Muggleton, young person with ASD, Autism NI Seminar, 2008)

- Young people with ASD can be at increased risk of anxiety, depression, and intense self consciousness around their felt difference in relation to peers. They may benefit from strong school support, peer support, group work and other relevant creative interventions.

- Bullying has been identified as a significant feature e.g. bullying others within the family and/or being bullied outside of the family.   Support for the young person, family members and peers is required (i.e. skills in personal and interpersonal boundary awareness and maintenance, support to communicate and contain intense feelings of vulnerability related to difference, and to experience their capacity to influence others).

- Sibling support was identified to include peer support groups and sibling workshops. Sibling behaviour can sometimes mirror that of the child with ASD causing further stress for each family member.

- Activities for children and young people with ASD to include summer schemes that are staffed by well trained professionals. Music, drama and activities that support connection and personal development. I.T. and media based developments have a particular appeal to young people on the ASD spectrum and need to be made accessible and available.

- Groups for young people to build peer support and prevent emotional and mental health problems. These groups can evolve as a political and lobbying forum for young people to articulate their needs.

- Peers need to be made aware of ASD and how they can make a positive difference. Examples of good practice cited are teachers educating and discussing ASD openly in the classroom.

- Therapeutic support for children, young people and/or their parents may need to be made available to those who need it, when they need it by well trained and skilled professionals who have the relevant skills and training.

3.8.4 ASD: Young and Older Adult Needs

'There's a need for ongoing support beyond 18 years, and not being cut adrift'
(Health Professional)

- Integration between child and adult services.

- Young people need a range of relevant supports to prepare for the future e.g. emotionally, vocationally, socially.

- I.T. needs to be made available to young adults to support their connection to others. There were examples given by parents of how I.T. can be used to build social connections locally and internationally.

- A range of arts provision is essential to promote the development and interests of children, young people and adults with ASD (i.e. movement, sensory, visual, musical, drama activities that support the development of an integrated, competent sense of self).

- Independent and semi independent supported housing is required. Government, Planners, Housing authorities and Developers need to set aside land and plan for supported housing schemes for young and older adults with ASD. There is a dire need for funding for day placements for adults with ASD who would benefit from this as well as other forms of residential support.

3.8.5 Gender and ASD Needs

- Men and women appear to experience different responses to ASD. There are distinct gender patterns emerging that need to be researched, explored and addressed in order to support the leadership, resilience and flexibility of the family system.

- Mothers are at risk of depression and a range of other health impacts. Support needs to include respite/time out, opportunities for social contact, supportive employment practices. Anti-depressants are readily prescribed for mothers in Northern Ireland and other forms of support urgently need to be made available.

- Women report change in terms of increased assertiveness, increased empathy and social skills when gaining the support of the parent group.

- Men generally find it harder to seek help and emotional health problems may go unrecognised and unaddressed e.g. one third of fathers were said by mothers to be in denial in relation to the full impacts of ASD. Work with fathers at an early point of diagnosis may help prevent later problems. Fathers want to know the best action they can take for their child, in order to take a lead in discovering the unique interests of their child and joining their child in that activity. Interventions to support fathers with their feelings about ASD and their child are likely to support fathers

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and the family. The different approach of some fathers appeared to support mothers to stand back in the groups. At least a third of mothers found their partners more distant stance unsupportive in the absence of other support. The increased risks of depression for mothers need to be addressed within a relational context.

- Girls with ASD are more hidden in the population and need specific support. An ASD brain is sometimes described as 'an extreme male brain' (Baron-Cohen, 2002) because stereotypical male traits are present though exaggerated. 'When men seem aloof, absent-minded or self-centered, they more easily get away with it and can still be integrated into society. Not so for girls and women' (www.girlswithautism.com)

3.8.6 Couple and Lone Parent Support Needs

- Mothers identified a strong need for support for the couple and the intimate partnership/marriage given the additional strains experienced. Around a quarter of mothers expressed concern for their relationship and stated the need for therapeutic support and/or respite. This is likely to help prevent or/and help resolve unhelpful polarisation on gender lines and to strengthen parental authority. More than a third of the parents interviewed stated that they knew of marriages/partnerships that had been broken by the range of cumulative stresses. Others found their relationships had grown stronger. The group is a support for couples where they can both attend if they can gain access to child care. The strain on lone parents, particularly young mothers is immense and needs to be addressed.

3.8.7 Respite – Urban and Rural Needs

- Respite is needed when the extended family group is less available and accessible to parents as a resource for additional child care and general support, or in instances where the extended family is itself a source of stress and judgmental attitudes due to lack of awareness and prejudice. Without respite, parents lose out on social connection and are at risk of isolation, exhaustion and associated health and social risks.

- A centre where children/individuals with ASD can go to provide respite for parents and a different experience for the child/adult could be a partnership of public and private funding, with no families excluded on the basis of finances. Other flexible options to enable respite that meet the parents need for accessibility and suitability are necessary particularly for rural areas.

3.8.8 Group support – Parent Needs

- The branch and group support set up by parents and Autism NI and self organised by parents as a mutual support is valued deeply and is universally experienced as a 'lifeline'. Resources to support group development and group activities are needed, including linking to other groups to learn and share experiences and develop skills.

- Isolated parents – extending support via small cluster groups at different times is needed to reach out to 'very isolated' parents.

- Lone parents - child care support is needed so lone parents can attend parent group meetings and groups can expand to day time meetings to include parents who cannot get to evening meetings.

- Parents benefit from well facilitated support groups on particular themes of interest to the group.

- A range of family support training/workshops tailored for the whole family and extended family.

3.8.9 The Need for Responsive, Secure and Accountable Public Services

- A strategic approach to services that are accessible across all areas, fit for purpose and co-ordinated so that parents do not need to 'chase' professionals when already under pressure (i.e. Occupational therapy, speech therapy, psychology and other relevant professionals working effectively together).

- Improve the assessment and diagnostic process.

- Lifelong support - Child and adult services need to be integrated so parents are not left 'starting out all over again' during this transition. Services to support adults are necessary.

- Central contact - one central professional contact rather than needing to 'run round four to five different professionals'.

- Awareness, support and training in ASD for all professionals working with and for children and young people (i.e. General Practitioners, Teacher training Classroom Assistants and other School staff, drivers and drivers assistant, policy makers in education and health).

- Social service support needs to be accessible without a diagnosed learning disability.

- Parents and carers need to be given priority for health services (i.e. not to be waiting weeks for a dental appointment with severe toothache when caring for a child with a disability).

3.8.10 Education System Needs

- All schools need awareness of ASD. Changes needed in the education system include: the need for all staff to have knowledge, awareness, skills and training on ASD, not moving children up a year before they are ready, not waiting until a child is in crisis before intervening due to uniform procedures of assessment and statementing.

- Some teachers are unaware (i.e. 'he needs a good smack' or 'ASD isn't a proper condition'). Relevant support in and out of school is required. For example, parents identified:

'help with school',
'help with homework',
'he can't concentrate in school or cope with the work',
'I don't know what level to be pushing to',
'He was held down, in a room on his own and that is not right',
'someone to watch my son doesn't wander off'.

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- Nursery and Primary Schools need to be physically safely secured so that children cannot run away.

- Children have also benefited from a move into mainstream and the needs of each individual child must be paramount in decision making.

- The Statementing process needs to be clearer and a range of tests used that support both identification of a broader range of abilities and support for parents at home in putting this knowledge into practical application with their child.

- Flexible use of well trained Classroom Assistants e.g. some children need one to one whilst others could share.

3.8.11 Financial Support and Cost of Caring

- The higher cost of caring for a child with ASD was highlighted with families losing income due to the need for additional expenditure and caring. Clear information on state funding and additional supports are needed so that all parents who need it can access what they are entitled to, including support for respite.

- Families who are self employed (e.g. farming families) face barriers to accessing financial support due to capital assets that are not available to the family.

- Disability Living Allowance has supported some families. Parents found the forms difficult and failing to take into account the full needs of their child and the family. Prejudicial attitudes by some staff can make the experience of applying stressful for parents. Guidance notes in relation to ASD are required for staff, clarifying the status of ASD as a disability.

SECTION FOUR - PROFESSIONAL FINDINGS

4.1   Between a Rock and a Hard Place

This section documents the experiences of professionals. The study found that professionals are caught between the expectations and needs of parents and children, and an inflexible State system. The notion of 'cure' or what's 'normal' in relation to children and individuals with ASD can place unrealistic expectations on both parents and professionals and do not seem to serve children, young people and adults with ASD.   Professionals in the study referred to higher numbers of children with complex and multiple conditions, an increase in parents experiencing crisis, and a willingness to reach for support rather than suffer in silence.

The research underpinning this section:
•   Identifies and explores experiences that have not previously been documented.
•   Offers a framework for reflection with the intention of supporting resilience and development among practitioners, supervisors, managers and policy makers.
•   Records the supports needed to influence policy and practice in the field.

The factors that professionals viewed as significant are organised under five key themes:
•   The field of stress and trauma in ASD.
•   Developing support: a practice and policy framework.
•   Recognising needs: the context of ASD.
•   Reorganising: building resilient families, professionals and organisations (includes an individual interview with a senior professional).
•   Supports needed for all those concerned with progressing a practical path forward.

Professionals experience pressure with current ways of working and the allocation of resources.

> 'There's a lack of time – time to think and to process. You're in reactive mode.' 'Sometimes we know what the child or parent needs and can't give it.
> (Health Professional)

This pressure is illustrated by the evidence of professionals that:
Over 72% experience anxiety about families with a child or young person with ASD with over 50% experiencing sleep problems due to work related stress. Nearly 40% of professionals experienced a lack of understanding of the impacts of ASD work and unsupportive responses. Over 30% experience exhaustion related to work. 5% of professionals have

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experienced physical injury, 5% of professionals have experienced verbal abuse, and 17% of professionals have experienced physical injury and verbal abuse.

In relation to work with ASD, over 10% of professionals feel isolated and experience physical and emotional symptoms related to work (i.e. headaches, migraines).

There is clear evidence that the professionals who participated in the study are impacted by the systems they work in and the parents and children and individuals with ASD they work with in a variety of ways. While there is increased knowledge about ASD and basic service provision, professionals recognise that parents, children and individuals with ASD are paying a high price for the current situation. This also impacts on the well being of workers.

How workers perceive their role in the relationship with parents impacts on the working relationship. This is elaborated in this section with a framework for understanding the different strategies professionals adopt both with and without awareness in relation to parents (Lichtenberg, 1994).

The evidence shows that where professionals experience a supportive environment, an empathic, strengths oriented, and empowering relationship can emerge between parent and professional based on good contact, present need, trust and autonomy. Where there is insufficient support for professionals, less competent support will be available for families and professionals will also suffer.

4.1.1 Introducing the Groups

Between April and December 2009, there were three focus group meetings made up of professionals from across Northern Ireland:

- One regional organisational focus group in Belfast.
- One interagency professional focus group in Ballymena.
- One family support workers focus group.

Total number of professionals: 39, one Volunteer worker
Gender: 37 Women and three Men
Area: regional spread

There was also an individual interview with a Professional in a senior role, and 18 questionnaires returned from a range of professionals including: Principal of School (1), Educational Psychologists (2), Clinical Psychologists (2), Paediatrician (1), Paediatric Occupational Therapist (1),Social Worker (2), Early Intervention and Diagnostic team (3), Manager (2) Family support (1) Unknown (3).

4.2 Recognising Needs: The Context of ASD

> 'It's good to be acknowledged and that it's not just one side (i.e. families). The opportunity to speak like this is really important and something we don't do. This feels open... and like something is going to happen with this research'
> (Heath Professional)

Professionals identified a range of forces that work against the recognition of needs e.g. fragmentation between services, not knowing what others are doing, competition for and allocation of resources, increased workloads and expectations.

Professionals recognized the following (4.2.1 to 4.2.3) ;

4.2.1 Complexity and ASD

> Delivering a pervasive and lifelong diagnosis to parents is difficult. Parents can have difficulty coming to terms with the diagnosis, then not turn up for appointments and not follow through with the advice given.'
> (Health Professional)

Professionals stated that families are usually in shock and find the information they provide hard to take in. Professionals struggle to be clear as there can be *'a lot more going on than ASD'*. Parents find professional jargon difficult, and workers were aware that families often referred to difficulties gaining responses from professionals.   In addition to the difficulties of diagnosis, other areas requiring investigation and action are:

- Complex conditions e.g. dual diagnosis: learning disabilities, ASD and other conditions e.g. 'differentiating ASD from early onset of psychosis when developmental history is not available.'

- The last forty years of political conflict was seen by one group of professionals as representing complexities that complicate how parents and professionals recognise and respond to mental health issues and ASD because of certain similar features of complex Post Traumatic Stress (Herman, 1992) which can exist alongside other clusters of syndromes. Where the abnormal has been normalised over many years, it seems inevitable that there will be levels of complexity.

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- 'Language and communication' difficulties e.g. growing number of ethnic minority families, undiagnosed ASD or mental health problems in the parent.

- Concern for siblings in the family whose needs and rights can easily be overlooked.

- Concern for how adolescents are given a diagnosis of ASD at this vulnerable developmental age and recognition of the need for training and support for parents and workers (i.e. the sense of injustice is very strong for the young person and the parent).

- One legal professional stating that his work had increased by over 70% in the last few years in relation to providing legal support for parents of children and individuals with ASD in taking court cases, indicating that needs were not being addressed in other more consensual ways.

- There were fewer professionals from Education participating in the study, although parents stated that they experienced significant barriers where the child faced problems or exclusion in the school system.

4.2.2   Interventions in Relation to ASD

The differing agenda's and ways of intervening in relation to ASD was seen as creating a climate of working with continual uncertainty, with the 'face to face situation with the family as unpredictable'. The tension between working to recognise the actual diverse needs of families on the one hand, and an organisational culture focused on targets, the concept of 'balance' and mandatory administration. There is evidence from professionals of the difficulties in large bureaucratic systems which 'lack strategic direction, clarity of roles, and pressure on resources and time'. On the other hand, professionals in community and voluntary organisations experience different kinds of stress.

'Being a lone worker, using my own personal mobile is worrying in terms of health and safety and privacy.' (Health Professional)

4.2.3 Culture: Parents' Awareness and Knowledge Contributing to Change

Professionals identified change in parents from an attitude of 'not making a fuss, not making a show of yourself' and 'not taking anything from anyone else'. The culture of organisations was described as creating stress due to policies and practices that included caseloads that are too large, feeling under pressure and as one professional put it entering '*a type of mother role that you get into in the work place where you do everything'*. While the competency of multitasking was well developed, workers recognise that 'there's no culture of boundaries' and this impacts on their own health and practice.

The above factors can *'lead to confusion, anxiety, lack of consistency and continuity, contradiction and confusion'* and need to be addressed.

4.3   The Field of Stress in ASD

One interagency meeting of professionals across Northern Ireland focused part of the meeting on the stresses parents face from the point of view of professionals, and showed a range of awareness that confirms the evidence given by parents. The group included the following professions – family support workers, educators/trainers, speech and language therapist, occupational therapist, children's service planner and management, senior practitioners, psychiatrist, pediatrician, psychologist, and lawyer.

4.3.1   Stress: What Professionals said about Stresses for Parents

The stresses identified by professionals further validate many aspects of what parents said in the previous section.
There are layers of social isolation, frustration and exclusion of parents and of children and individuals with ASD

S h e l l s h o c k e d after diagnosis   Negativity or/and unsupportive extended family
Families being made to jump through hoops

Change and transitions – fear of change   Lack of trust and empowerment
Communication is a problem – lack of information especially for families coming from other countries

Being between a Rock and a Hard Place   There's more going on than Autism for families
Families struggle with professional jargon and difficulties gaining responses from professionals

The large number of professionals involved can lead to anxiety, lack of consistency and continuity, contradictory and confusing information

Vulnerability around making choices for services.   Biased information
Gaining access to services, knowing how to access, there are inconsistencies the number of appointments and meetings

The education system is difficult for families   Navigation of the statementing process

LAST RESORT, Desperation use of the LEGAL SYSTEM to challenge exclusion

Vulnerability to the notion of a cure Management and impact of behaviours on family life-siblings-physical and mental health (e.g. sleeping, eating, behaviour in public)

Siblings coping with the child with ASD is a problem

Families lacking confidence – need for support and to teach strategies   Learned helplessness in family

The complexity of grief - Grieving for the loss of the child 'who could have been' and seeking a cure

Impact of media – sources e.g. internet   Spousal relationships – strain

Financial pressures (e.g. having to give up work, cost of private interventions)

Barriers to work and earning money can be a problem. There are benefits to working though and this can be lost when family stressed

Respite services and support for families often difficult to access

Holidays are a difficulty – families needing respite and summer schemes being thin on the ground

Change and ageing - access to family support and changes – ageing grandparents, fear of the future and death of parents themselves   Parents undiagnosed ASDs and/or mental health problems

Over time parents tolerate more and become desensitised

Gender issues e.g. 'men may be more freaked at diagnosis' & subject to peer pressure

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4.3.2 Boundaries and Expectations

Professionals listed a range of challenges in relation to the boundaries of their work: that families used them as a '*sounding board for all of the family issues and problems'*. This indicates the need for clearer role definition and support.

Indicators of stress: Professionals

The increasing rate of diagnosis and expectations of parents and organisational culture

Being between number crunching and best practice and a lot of restriction in the system

Inconsistent procedures within and across agencies, too large caseloads, waiting lists, eligibility criteria for access to services

Confusion about line management structure, role not understood or valued, how resources are used and limited resources, Changes to team, change or role, extra management responsibility

Meeting difficult deadlines, cutting waiting lists, staff vacancies, lack of specialists, no cover for staff when sick, on maternity   tendency for managers to focus on negative feedback from service users

Attitudes in society and the effort required to make change, under pressure and more likely to enter a role like a mother role you get into in the work place.   Doing everything, you're enmeshed in your own work and there's a difficulty bringing people with you.

We don't convey enough of what we do and the spread of what we do

The pressure of part time work also impacted and the ethics about responding to people that means workers

Feeling guilty for holding back, There's no culture of boundaries, its the bottomless pit of unmet need approach and then roles go

We all do everything, multitasking, Feeling overwhelmed and helpless seeing parents in need and not having the resources to respond.

Crisis telephone helplines , sense of stress in work due to their felt need to respond quickly, the sense that it never stops

GUILT the familiar feelings of being at a loss battling with agencies such as education and not enough support available when families need it in health agencies

Stress supporting inexperienced staff, vulnerable as a lone worker, increased demand, micro management, lack of inclusion of staff in management decisions that affect their role

Needing to put aside other work to deal with the immediate in 2 seconds flat,

So much comes in and there's deadlines, Working in the evening, unknown venues. Bureaucracy and administration, difficulty contacting other professionals, the need to make snap decisions

Feeling overwhelmed by the difficult situations families have to face on a daily basis, the transition from work to home, its hard to switch off and let go. Outbursts of physical aggression from people with ASD and challenging behaviour

I've come off phone calls literally shaking. It's a very lonely job…you need more supervision. The big issue is behaviour, parents want to know what to do families so stressed they can't take in what you're telling them. Lack of equipment and residential support. Sometimes carers don't co-operate and I worry about the situation

Being a lone worker, using my own personal mobile is worrying in terms of health

Professionals working directly with parents identified difficulties at times in recognising and responding to the level of risk. Examples included a parent phoning at a point of experiencing suicidal thoughts - '*a key question you're asking yourself is, is the threat real or perceived?'*

- Being the 'first port of call' when a parent is or feels in crisis is challenging work as there is no set time to the phone call. Professionals described the experience of being 'triggered' (i.e. physiologically and emotionally impacted) by the parents' experiences. For example, that the desperation as well as the hope that some families are experiencing meant '*the need to watch what you say, your own nerves are jangling'.*
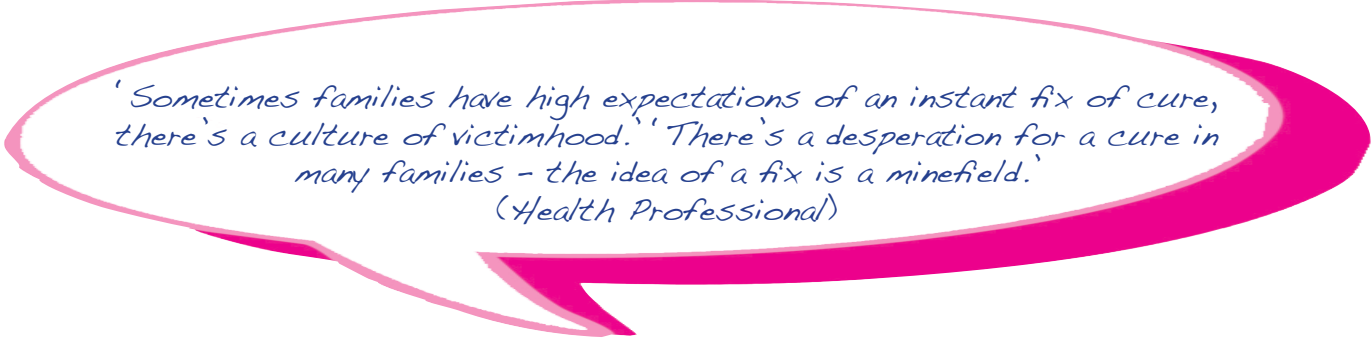
> '*Being a lone worker, using my own personal mobile is worrying in terms of health and safety and privacy.*'
> (Health Professional)

> '*When you go into a family you are bombarded, all these things fired at you, sometimes it's overwhelming seeing people in need and no resources'.' Feelings of helplessness are hard to bear – you can't provide for what parents want.'' It's a very lonely job...you need more supervision'' The big issue is behaviour, parents saying tell me, show me what to do'.*
> (Health Professional)

- Going to visit families in their home was sometimes experienced as difficult

- In one geographic area, workers estimated that there were high numbers of lone mothers using the service (70%) who stated to workers that the father left the family due to high levels of stress (i.e. the child screaming). '*In turn, the lone mother experiences a lot of anger and gives it to me as the worker'.* Workers reported difficulty working with the intense feelings of self or/and other blame, helplessness and despair in unsupported parents, indicating a clear need for increased support for workers.

- When the desperation of parents is viewed as 'negative', professionals need more support (i.e. peer, supervision, and training). For example, professionals saw 'the ultimate negative feedback as the use of Courts when other avenues had failed'. 'Negative' is both a perception and a judgment. The use of Courts by parents as a last resort can be seen as a positive action.

The descriptions of professional's experience of stress, echo parents stress and trauma, and can be described as mirroring or resonating with the experience of the child and the parent in the absence of sufficient support. If workers have not worked through their own experiences of vulnerability, they are likely to get caught up in the parents distress, and distance themselves from the parent (i.e. 'disaffected other' position) or alternatively, minimise the personal responsibility of the parent, the 'emphatic rescuer' position (Lichtenberg, 1994) or in other ways be less effective e.g. 'only providing a space for parents to vent.'
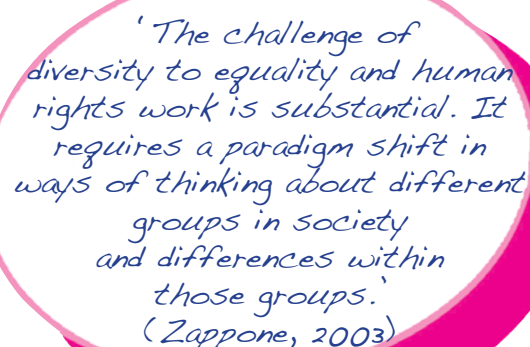
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4.4   Developing Support: A Practice and Policy Framework

'Sometimes families have high expectations of an instant fix of cure, there's a culture of victimhood.' 'There's a desperation for a cure in many families – the idea of a fix is a minefield.'
(Health Professional)

The evidence shows that it is not easy to handle intense feelings in others. Lichtenberg (1994 states that professionals and concerned adults in general, need support to reflect on and deal with their own feelings. By doing this, the worker can have empathy and enable others *to experience the full complexity of their own feelings in a way that is empowering and not disempowering.*[37] Fear is a human response to the unexpected and all experiences of helplessness includes some aspect of self blame in the form of e.g. *'I should have…,' or 'if only I had.'* When professionals encounter the self blame in parents they respond in three main ways influenced by their awareness of unexpected loss and how they handle that in their own lives:

1.   The 'empathic helper' is able to stay with intense feelings without needing to stop or alleviate these feelings prematurely. This worker will be able to meet the parent as authentically as possible and to support the person to explore and come to terms with all the influences that are creating intense often out of awareness feelings. When workers can fully accept and contain their own painful experiences and feelings, these become a source of understanding and support to be able to establish and maintain a healthy separation, connection and clear sense of self in relation to the person.

2.   The 'disaffected other' joins with those social norms that suggest individuals are in control of our lives and destiny and reduces our common need to depend on others in our human vulnerability. This lets the wider system leave responsibility with individuals. Mistakenly, 'professionalism' may be seen as being withholding, critical, rigid and bureaucratic.

3.   The 'emphatic sympathiser' becomes a rescuer to avoid feeling weak in the face of overwhelming forces. By endeavouring to feel capable and powerful this worker may try to 'fix' or 'cure' other people's lives, to deny their own feelings of being oppressed or dominated, and to retain a sense of influence at the expense of the person experiencing helplessness who may remain vulnerable.

'The challenge of diversity to equality and human rights work is substantial. It requires a paradigm shift in ways of thinking about different groups in society and differences within those groups.'
(Zappone, 2003)

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[37] Herman (1992) refers to the need for professionals to be an 'ally' and not a 'neutral' bystander/a 'disaffected other' or a 'rescuer'. That is, to remain as witness to the child's and parents experience in all its complexity without judgement and blame, while remaining connected to the person and to respond in ways that support empowerment.

4.4.1 The Need for Reflective Practice

The need for 'reflective practice' - to meet other professionals in regular peer forums, teams, and meetings across roles, disciplines and organisations at different levels of system was identified by all professionals. Peer support, supervision, training (internal and external), research and other forms of professional development were recognised as essential. *'Continuing opportunities for training and improvement are needed.'* Developing new skills was identified as central e.g. using visual schedules.

Professionals referred to valuing their own self knowledge and awareness, e.g. '*what you learn yourself along the way*.' This included knowing when it was important to stand back, when to confront or to 'absorb like a sponge' and also to know what expertise parents bring to any discussion. The danger of getting 'hooked in' was acknowledged with workers emphasising the importance of life experience. Having 'fewer expectations of people with ASD while holding hope', and becoming 'more creative, and aware of and ready to give up any prejudices' was identified by workers.

4.5   Reorganising: Resilient Professionals and Organisations

The professionals in the study were interested in resilience and the findings show that:
Over 80% of professionals feel a strong sense of purpose in working with families with ASD and feeling valued by families. Over 75% have developed new skills and have increased respect for diversity as a result of their work with ASD. Nearly 70% feel empowered in the work they do and feel part of a team. More than 60% of workers notice positive changes in the families they work with and feel satisfaction in supporting change.

The need to 'recognise what's out there and in this room' by learning to 'stand back' and 'have a framework' for responding to parents was identified by the groups as essential in first seeing, and then building strengths. This enables professionals to position themselves as an 'empathic helper', to optimise strength and resilience e.g. between parent - child, parent - professional, professional - organisation, organisation - State and Government.

Resilience: Professionals comments included;

> Common philosophy and vision in the organisation, supportive policies and resources.
>
> Passion to learn and developing skills.
>
> An understanding of support and the complexities of ASD.
>
> Negotiating boundaries and expectations (e.g. handling high expectations of families, and working with as people often expect instant results).
>
> Realising 'it takes time'.
>
> Recognising limits - stepping back with families, and in life generally.
>
> Team support – working in a team that can openly question and debate, good supportive relationships with colleagues, ability to delegate to a competent team.
>
> Multidisciplinary working, Inter Board ASD Group, membership of Regional Groups.
>
> Diplomacy.

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Job satisfaction from seeing empowerment in people and actual feedback – the children and adults who make good progress, the parents who appreciated the work, feeling appreciated.

Training, well trained staff, ongoing development of knowledge and skills e.g. *'there's a thirst for knowledge going on and finding more and more that's interesting – that keeps you going'* and ' There is an interest in what promotes resilience and for knowledge that helps me look after myself. ' The continuing opportunities for ongoing training and service/knowledge improvement e.g. sensory motor skills has been helpful.

Having a framework for prioritising needs with families ie.g. I see different levels, have a framework for understanding and working, an imaginery triangle that helps me meet the family – I ask where's the difficulty? Where's that coming from? A deep understanding develops when you keep at this.

Changing ourselves e.g. I'm more direct, empathic, pragmatic.

Putting your own stuff in perspective – there are others worse off.

Learning relaxation and other skills. Trying body awareness activity – open to new ideas e.g. the nervous system settling.

Negative feedback from families. Recognising that sometimes we focus on the negative more. One needs to put it in context/perspective. There is a need for the team to discuss problems with each other. There's a lot of support here and in the office. Humour - a lot of humour and release.

Supervision and clinical supervision.

Specific advice from regional ASD Advisor.

Professionals stated that they often found the strategies used to support resilience in themselves and in parents harder to recognise than the stresses due to the cultural tendency to focus on 'what's wrong'/ pathology and react on that basis. Not recognising change was seen as stressful.

'There's change and people don't always notice. They say there's nothing out there. Professionals also carry this attitude of saying there's nothing out there. This can become a kind of victim identity. They don't want to recognise the changes, feel hard done by, and shout from the rooftops that this is hopeless. People get stuck and the system itself creates these attitudes.' 'I've been working 23 years and it's stressful if we don't acknowledge how much we have moved on'.
(Health Professional)

4.5.1 The Challenge of Thinking Differently and Thinking Long Term

This interview is from the perspective of a senior professional in a Health and Social Services setting. She provides a brief overview of the context, history and changes in ASD Services in one Trust area and her learning on how to influence systemic change. The observations of the needs of workers, confirms the evidence of professionals in the focus groups.

4.5.2 Context

The DHSSPS Independent Review of Autism Services 2008 and the subsequent Autism Spectrum Disorder (ASD) Action Plan 2008/09 - 2010/11 are the overall context for the work.   Each Trust is required to set up a specialist ASD to implement the Action Plan in their area, with a co-ordinator to help lead new ways of working and better outcomes for individuals and families. A regional ASD Network Group and Reference Group with Subgroups will provide a framework and determine the way ahead[38], with parents and service users involved at all stage and levels.   Much of the initial work has been around the care pathway for children from initial referral for assessment and diagnosis to early intervention. The aim will be to ensure a robust pathway which also includes transition from child to adult services, based on a 'whole life' approach, with appropriate support at all stages for the individual and long term family support.
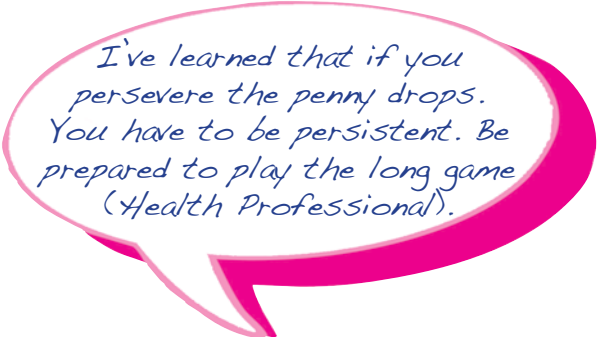
4.5.3 History and Changes

I have worked in children's disability for many years, increasingly using community development and partnership working as a way of promoting social inclusion and integration. The numerous projects were all evaluated and seen as successful by all involved. Until the last few years, parents' experience of 'respite' was largely through overnight care for their child, but the development of new services such as Saturday Clubs from 10am-4pm, and various supported social, sport and leisure opportunities, helped parents to feel these options provided the breaks they needed, whilst also giving their child positive experiences which would promote their personal and social development. Developing a wide network of contacts and partnerships with a broad range of agencies was essential to the effective delivery.   Also, having a team member dedicated to this developmental work was critical to its success. It's about thinking differently

4.5.4 Change and Challenge

There is now a burgeoning cohort of children with Aspergers Syndrome. Previously, services were developed for   children with ASD and a learning disability, as there was clearly a lot of need for these children and families. However, the numbers of children without a learning disability has rocketed in recent years and families are struggling and asking for support. Trust Disability Teams (in social work) have knowledge and experience of ASD but not the resources to respond to this new need. Some families were referred to family support teams, however, this has not always been helpful as staff in these teams generally don't have an understanding of ASD.

You need to put up with a lot in the meantime and keep on message, raise the profile and be credible. There is a lot of pressure on teams in relation to Asperger's Syndrome – there has only been half a social worker per locality for this new and growing population, but no recurring funding even for these posts. The study I was involved in was effective as it had an impact among senior staff.

I've learned that if you persevere the penny drops. You have to be persistent. Be prepared to play the long game (Health Professional).
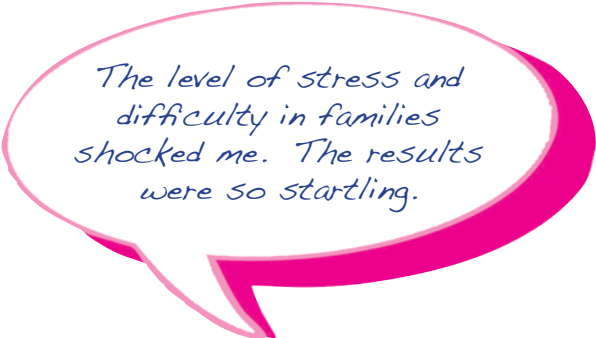
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[38]The five key themes within the action plan are to change the way people receive care and support, make services work better, to invest in training and awareness raising, set up good communication and information channels and ensure that everyone works effectively together

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It informed a better understanding of this population, informed the debate, and it was forwarded by Southern Health and Social Services Board and to those involved in the Independent Review.

The level of stress and difficulty in families shocked me. The results were so startling.

It was not possible to do this study and walk away so I invited key agencies to come together along with some parents. We discussed the issues and the difficulties children and young people with Asperger's Syndrome experience. We wanted to respond in a concrete and practical way.

There was a need to accommodate the different agendas of the various agencies involved. We decided to set up a Saturday Club, specifically for children with Asperger's with significant support needs. There was a huge amount of work in doing it – a lot of time and effort into planning and understanding to get it right, with an operational sub-group involved in its development and delivery. There was 10 sessions initially, then another four sessions and a DVD made by the young people as a means of influencing future developments. An inter-agency and parents event was organised to showcase the model to senior staff across the various agencies and it was very well received. A voluntary organisation is now running the project, and for some of the children, their experiences allowed them to feel confident enough to move on to other clubs and community opportunities.

One of the positive outcomes of the project was that parents met with each other, got to know each other and decided that they wanted to set themselves up as a support group. They now meet regularly and organise social events.

The key findings of the study were;
- It was tough for families who for the most part did not have access to support services.
- Children with Asperger's Syndrome are self aware, do not fit in, are unable to relate appropriately to peers and others, have poor self esteem and are desperately lonely and isolated. All were in mainstream education but often subject to bullying. Many do not have the skills to cope.
- Many boys were physically aggressive - often targeting mother and siblings.
- They have difficulty managing their emotions - getting angry very quickly without the skills to modulate this.
- Mental health difficulties for some young people (e.g. depression, anxiety, obsessional compulsive disorder) and CAMHS involved with many.
- Mental and physical health problems of the parents – 49% in the study had mental health difficulties and 50% had significant physical heath difficulties.
- The rate of relationship breakdown is very high.
- Mothers' life chances are compromised and most are on benefits.
- Mothers often experience guilt in relation to the other children in the family, yet this is the only way to survive.
- Family life is skewed as mothers are often caught up with the child with ASD. Siblings can suffer.
- Children and young people are often poor sleepers and so they and their parents are often exhausted.
- There's usually very limited support from family and friends (as they don't include the child with ASD) so life gets narrower and narrower.

4.5.5 Workers on the Ground

> It's very difficult for some workers as it's your job to have an in depth understanding of the family and to try to respond, it's a big responsibility. Some situations are so complex and sometimes you don't see big improvements, therefore there is a feeling of helplessness. As a professional you see tough things e.g. families falling apart, a mother crying through the whole interview. It keeps you very grounded. As a worker you see that the siblings can suffer, their lives can be abnormal due to the levels of aggression. Those children shouldn't be going through that, yet what do you do? Not having enough services is difficult and at the same time we've come a long way e.g. parental feedback energises you to do more. Most difficult area of this job is negativity. (Health Professional)

> This kind of influencing didn't come easily. (Health Professional)

Supports needed for workers:

- Workers on the frontline need to be valued and people higher up need to be in touch with what's happening. We're not good at that though. I've learned to showcase, to do the best I can, and to use my influence. You have to in order to bring about change – to change thinking and add resources.
- Workers on the ground need good managers who understand the work and acknowledge their contribution
- Workers need to be emotionally mature, to have found their own way/life experience. The work is too difficult a burden for young and inexperienced staff to deal with the level of pain and angst. It's not easy to deal with and walk away, leaving families in very difficult circumstances.
- Good relationships within the team to support you through difficult times.

> 'People are presented as a homogeneous group and differences are ignored. This can lead to marginalisation' (Zappone, 2003)

> 'over time parents tolerate more and more and become desensitised'. (Health Professional).

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Supports needed for families;

- Support for siblings as they can be adversely effected
- Parents health – there's a need for more to be done due to the significant physical and mental health problems (e.g. chronic exhaustion) and that needs to be looked at: *I was taken aback by the parents health.*

'I'm not feeling connected with other professionals doing ASD work. We're working alongside each other rather than with each other'. (Education Professional)

4.6   Findings: Supports Needed as Identified by Professionals

This study shows that growth in knowledge over the last two decades has not translated into practices that support the diversity of parents needs or provide a consistently strong focus on what supports resilience. Professionals noticed that in the absence of sufficient support:

This desensitisation impacts on parent's health and capacity. This study found that professionals also tolerate desensitisation (i.e. disconnecting from themselves and other people) as a way of handling ongoing pressure with negative consequences for workers and families

State and organisational interventions needed:

'There is a need to be aware of the big picture and not only your own view point'

- Legislation, policy and practices are needed to uphold the human rights and equality of families and individuals with ASD e.g. structures that develop integration between services.
- Clear structures, roles and supportive management.
- Equality and diversity.

The differences raised were:

- Gender – interventions to support mothers in effective leadership in the family will support children.
- Ethnic minorities – the growth in ethnic minority families mean that changes are needed to ensure social inclusion. A range of support need to be implemented (i.e. cultural awareness, translators, information in other languages).
- Older children and adolescents need to be prepared for diagnosis and offered follow up sensitive to their developmental needs.
- One key worker parents can contact. '*Research for more than 20 years has shown that children with a disability and their parents would find it easier to deal with health, social services and other agencies through a single, 'key' worker. Yet multi-agency key worker services are still only available to less than a third of families*. (JRF, 1999).
- Improved 'care pathways' through life are needed to minimise unnecessary stress for parents.
- Less bureaucracy, paper work and good I.T. support 'so that we have time to support families as needed'.

'Currently, we give diagnosis then little follow up. Knowing whether families get follow up or not impacts on our levels of stress.' (Health Professional).

4.6.1   Interventions Needed

Awareness and skills   *'We don't usually think in terms of resilience – we think in terms of the problem'*

- Expectations and engagement –'*Realising we can't cure or 'fix' and learning to respond without creating dependency is essential'.* '*Many parents don't remember what happened at the diagnosis. They are in shock'.* Given what is now known about shock and its impacts on the capacity to learn (Levine, 1997), professionals need adequate training and support to support the competency and authority of parents from early intervention onwards. Follow up multidisciplinary services need to be made available after diagnosis.
- Having a framework for working with the diverse needs of parents in order to prioritise work and respond to the unique needs of the family e.g. recognising what kind and level of support families and workers need.

Professional training and supervision needs include;

- External and in service, continuous professional development e.g. Teachers should be trained in Autism awareness and intervention at training colleges' (Principal).
- Working with high levels of distress (i.e. strong feelings of despair and helplessness in parents, tantrums in children with ASD).
- Team and peer support - 'trusting each other then families can trust us', informal meetings, days away and not working in isolation. Not asking for support was seen as a risk, while 'peer support is protective.'

4.6.2 Learning, Training and Ongoing Development

Self care and self awareness was identified as essential and included:

- Developing the skills of relaxation.
- Being open to new ways of working.
- Learning more about the nervous system e.g. *'experiencing my own self regulation and resilience'*.
- Recognising boundaries and learning to 'step back', having a realistic perspective on what you can do, including a work life balance - The key for parents and for us is feeling you are not on your own'.
- Noticing change and knowing that you are making a difference: Seeing a change in a child... Seeing families become more settled when they see change in their child.
- Receiving feedback, acknowledgement and appreciation from families. The sense of satisfaction and integrity when families become more empowered and develop the knowledge and skills needed.

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4.7   Cultural Change and Resilience

A culture of disempowerment was seen as having been institutionalised within the system itself with the focus on 'what's wrong' and the problem rather than the abilities of children and parents (i.e. the approach to diagnosis).

4.8   Political Conflict and the Complex Impacts of Loss, Trauma & ASD

There was an interest in transgenerational trauma in families among professionals who began to identify what usually remains unspoken and invisible, and it seems vital that these impacts are recognised, addressed and gradually transformed - *'The interlocking of integrity and trust in caretaking relationships completes the cycle of generations and regenerates the sense of community which trauma destroys.'* (Herman, 1992: 154)

SECTION FIVE - CONCLUSION 'TOO HIGH A PRICE'

From the extensive evidence of parents of children and adults with ASD and the professionals who work with them, the following conclusions apply:

- Parents and their children with ASD are paying a high price (i.e. physically, emotionally, socially and financially) and require urgent, sustained action to implement the supports they have identified.
- Unique responses are needed as every child, young person and adult with ASD and their family is unique.
- The context of parenting a child with ASD in Northern Ireland is marked by lack of awareness, investment, practices and legislation to address ASD.

This report highlights the personal suffering of parents and their children with ASD who do not meet the norms of society, and how parents have organised in groups to support each other and their families. Professionals have also clearly identified the impacts of their work and refer to the higher numbers of children with complex and multiple conditions, an increase in parents experiencing crisis, and their increased willingness to reach for support rather than suffer silently.

Parents and professionals know what they need and these needs can be summarised under three key headings:

1. Prevention – Information and services need to be organised in ways that prevent problems becoming crises, with the exhausting need to continually advocate as individual families while already under pressure.
2. Protection – Anti-discriminatory measures are necessary. There is a legal requirement for all public bodies and those contracted to deliver public services to ensure they assess their policies and practices with regards to equality, human rights and diversity issues. Currently, ASD falls outside the required definition of disability.
3. Provision - Parents need to experience an adequate provision for their child with ASD throughout the life cycle in relation to safety, development and well being.

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SECTION SIX - APPENDIX

6.1 References

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6.2 'Is Anyone Listening' Data Capture Template (Parents/carers)

Name of group / Area	
Date	
Section 75	
No's of children in families	
No's parents/carers	
Workers/volunteers	
Expectations of group	
Research indicator	1 Stress, Grief, Trauma 2 Ill – health 3 Indicators of resilience/survival strategies
General comments	
Evidence in response to questions	1 What parents said 2 Observations: 3 Significant interventions
Further actions required	What By whom By when

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