



Autism in Northern Ireland - A Hidden Community

A Report on an Effective Family Support Model

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April 2010

In association with the



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Executive Summary

This report examines the Autism NI Family Support Service and provides evidence to illustrate the effectiveness of this intervention for families after a diagnosis of Autism Spectrum Disorders (ASD) has been given. The service is unique in that it has been created from evidence of need in Northern Ireland from both parents and professionals and it is founded on the principal of working in partnership with Health and Social Care Trust teams. The service provides a continuity of care for families from the point of diagnosis. It is staffed by a team of parent specialists who have personal experience of ASD and who are locality based.

The report highlights the work of the University of Ulster who were commissioned initially to assess the level of Family Support available across Northern Ireland and build an understanding of need unmet. Subsequently, Autism NI launched three pilot Family Support Services and this report also draws on the findings of those pilots to date.

It also set out to:-

- Carry out a situational audit of Family Support Services in Northern Ireland.
- Examine the uniqueness and impact of the service during the pilot phase.
- Explore and record learning from this phase of the service development.
- Provide recommendations for future working practice.
- Evidence additionality beyond the service remit.
- Examine whether or not the service provides value for money.

The key findings of the study were:-

- The Autism NI Family Support Service was formed during a period of significant change within Health and Social Care and other public services.
- That it provides a flexible and timely response to complex and varied need.
- That having parents in the role of formal supporters enables them to use their specialist knowledge and expertise to support other parents to become more effective, empowered and knowledgeable, and increases the family's capacity to respond to and represent the needs of their child/individual with ASD.
- The service presents significant value for money.
- The service offers an innovative response to the unmet need of a hidden community of families affected by ASD within NI which will only get larger as diagnostic services improve throughout the region.

From all these perspectives, the evidence gathered leads to the conclusion that the service needs to be developed across Northern Ireland to provide for a synergy in practice, an integrated community development model and a needs led service.

1. Background

In 2007/ 2008, the University of Ulster carried out a review to provide a strategic plan for Autism NI in relation to its remit for Family Support Services. This work involved gleaning the views of parents and professionals on what they felt constituted a coordinated Family Support Service to feed into and respond to the needs of families with children/ individuals with Autistic Spectrum Disorder (ASD).

The recommendations from the review were incorporated into the Autism NI Family Support Service which first came into practice with the Western Health and Social Care Trust (WHST) pilot funding.

The needs identified included:-

- Better local support.
- Up to date information.
- The commissioning of an alert card for young people.
- More services and information for adolescents and their parents i.e. on sexual health and relationships.

As subsequent Trusts followed suit by commissioning the service it became evident that there was a need to evaluate this new form of service. As with all public funding it is vital that any service is scrutinised for effectiveness and value for money. As this was an untested model of intervention it was even more important to examine the model's impact, it's flexibility in responding to changing need, it's application in a variety of settings and the outcomes from it, primarily on parents and carers.

1.1 What is Autism?

Autism is a Social and Communication Disability, not a Learning Disability or a Mental Illness. It is a disability which disrupts the development of social and communication skills. The term Autism Spectrum Disorder (ASD) is used because ASD varies from person to person. Around 30% of people with ASD will have an accompanying learning disability. Some people with ASD will have average or above average intelligence and they are likely to be diagnosed with Asperger's Syndrome. Regardless of an individual's level of functioning, all individuals with an ASD will have problems in the areas of Social Communication, Social Skills and Social Imagination.

ASD affects more males than females and latest research states that one person in every hundred has an ASD. In Northern Ireland this corresponds to 20,000 individuals and families living with ASD. In fact, the numbers of individuals with ASD now exceeds the combined total of known individuals with Down's Syndrome, Parkinson's Disease and Multiple Sclerosis. ASD can be diagnosed by the age of three, although some children are diagnosed earlier and some people may not receive a diagnosis until their adolescent or adult life. There is no known cure, but with appropriate education and support people with ASD can be helped to live their lives with as much dignity and independence as possible.

Research suggests there is no single cause but that there is a physical problem affecting those parts of the brain that integrate language and information processed from the senses. ASD has a physical origin, not an emotional one.

1.1.1 Sensory Difficulties

Individuals with ASD may also have unusual reactions to sensory stimulation. Some individuals show a hypersensitivity to stimuli – e.g. can hear lights buzzing, cannot tolerate touch, fascinated with spinning objects, must smell everything while others display hyposensitivity to stimuli – such as a high pain tolerance or acting as if deaf.

A person with ASD may be fascinated with a piece of shiny paper or may spend hours rocking or watching objects twirl. In general these types of reactions are providing some sort of sensory stimulation for the individual.

1.1.2 Variability of Intellectual Functioning

There is a wide range of functioning within which individuals with ASD can fall. Individuals with ASD can be severely impaired to the extent that they are unable to use speech meaningfully or to perform independent living skills, or they may be functioning in the above-normal range of intelligence. Some people with ASD go to university, and have a career, may get married and have a family.

1.1.3 Uneven Development Profile

People with ASD have an uneven development profile which means they are able to function in some areas at levels perhaps higher than their overall level of functioning. For example, a five year old with ASD may be reading books at a Primary 4 level while his self-help skills are at his own age level and his social skills and understanding of social rules are very low.

1.1.4 Difficulties in Sleeping

Some individuals with ASD have trouble falling asleep or require only a few hours of sleep each night to function. This can be extremely difficult for parents/carers who often sleep in shifts to provide care and ensure safety.

1.1.5 Asperger's Syndrome

Some individuals may receive a diagnosis of Asperger's Syndrome (AS). AS is considered part of the Autism Spectrum. Key features include;

- Individuals with AS may have average or above average intelligence.
- Individuals with AS may not have experienced a delay in language development as children but may have had an unusual language development. This can manifest e.g.in individuals being very talkative from a young age and using language expected from an older person.
- Individuals with AS may be very clumsy and poorly co-ordinated.
- Individuals with AS may be very talented in a certain area and excel in this, but have real problems with practical tasks and organisation.

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It is important to remember that AS is not 'mild' ASD. Lorna Wing (Burgoiné & Wing, 1983) described the main clinical features of AS as:

- Lack of empathy.
- Naïve, inappropriate, one-sided interaction.
- Little or no ability to form friendships.
- Pedantic, repetitive speech.
- Poor non-verbal communication.
- Intense absorption in certain subjects.
- Clumsy and ill-coordinated movements and odd postures.

This list of features is not exhaustive, nor is it totally inclusive of all people with Asperger's Syndrome. How AS or an ASD affects individuals varies from person to person. The severity or degree of that effect can vary considerably and each person needs an understanding of how their ASD affects them in order that they and others can support them effectively.

1.1.6 Need for Family Support

The first part of the study carried out by the University of Ulster (UUJ) during 2007/08 included interviewing a range of professionals from education, health and social services working in the field of ASD.

In relation to professionals, it was found that;

- 100% felt that Autism NI were best placed to provide formal training for families and other family members e.g. grandparents due to the unique access and support provided by them.
- 94% felt that the Voluntary Sector would be best placed to provide a telephone helpline service to give advice and support to families who needed it.
- 94% felt that Voluntary Organisations were best placed to provide information and advice about ASD and services in general.
- 94% felt that Multi Disciplinary Teams and Autism NI were best placed to provide guidance and interventions for families with a child or individual with ASD.

- 94% felt that guidance and intervention for families needed to be increased if the needs of families were to be met.
- 94% felt that Autism NI was best placed to organise meetings for parents to discuss issues of concern to them.
- 83% felt that support groups were best placed to provide support and guidance for families who were experiencing difficulties.
- 83% felt that support for the extended family needed to be increased if the needs of families were to be met.
- 83% felt that Pre and Post Diagnosis advice was needed if the needs of families were to be met.
- 65% felt that Voluntary and Community Organisations were best placed to provide information and advice about ASD and services in general.
- 65% felt that Autism NI were best placed to provide counselling, support and guidance for families who were experiencing difficulties.
- 52% felt that support and counselling for families after diagnosis needed to be increased if the needs of families were to be met.

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What the Professionals said

"Families are not being made aware/ not knowing what is available."

"There is not enough services/staff; discrepancy/there is disorganisation of services between Trusts."

"Families are not being made aware/ not knowing what is available."

"There are unclear pathways through organisations/services and insufficient resources to meet ever increasing need."

"Parents need to be ready to access support."

"Getting a diagnosis/right level of counselling etc. is key"

"There is a lack of communication."

"Either a service is not available for families or families are denied access because the child/individual has ASD e.g. social work support."

"There is a lack of specialist dedicated services including key working and co-ordinating packages of care."

"Lack of specialist staff within the statutory sector to field the range of interventions required; waiting time directives are causing resources to be directed to diagnosis not intervention."

"Extra staffing and finances and resources are needed to support families."

"There is a lack of provision for families."

"There is a shortage of resources and a lack of skilled/experienced professionals."

"Lack of joined up services; lot of service localised around Belfast."

"Parents are dealing with diagnosis and understanding their child/individual may have access to supports but not able to use them at that time without effective support"

"There is a lack of knowledge regarding what is available."

"Families struggle to come to terms with diagnosis. They feel guilty and struggle to cope with the wide range of emotions which can adversely affect relationships. Problems also arise from so much attention being given to the individual with ASD - other family members feel neglected. Appears to be a Post Code lottery of services with Belfast being the pivotal area."

"Families need "hands on" support often, not academic advice. They need people who will come into their homes and offer practical support."

"Needs to be flexible-one size will not fit all."

"There is a shortage of resources and a lack of skilled/experienced professionals."

"This is a top priority. Direct intervention is not effective when families are not supported or able to deal with or understand diagnosis."

"Services lack capacity (waiting lists etc) to provide level of input required."

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"Families are not being made aware/ not knowing what is available."

"Families that don't avail of services don't get relevant information & often miss out on helpful information. Families should receive information on services, what they offer & permission sought to give their names to Autism NI soon after diagnosis."

"We need to work in a more collaborative and multi disciplinary way."

"Managed skilfully families adapt well to changing demands placed upon them."

"Need to focus on adult parent needs."

"Keep going-continue to seek views of professionals as well as families."

"Family Support groups are invaluable but also need to be guided by appropriate individuals in a constructive manner-not as an "opportunity to attack professionals" as can often be the case."

"Better communication is needed between all agencies to prevent duplication of services and to encourage better carry over to input/ therapy/intervention."

"Co-ordination across other support agencies/ network needed."

"Better prompting of services available for families."

"Be cost effective."

What the Parents Said

"We need Literature to use as guidance in future situations."

"There should be Siblings workshops - have been run in the past. We should continue to do this."

"Put pressure on Professional bodies to provide more help/ support."

"Support meetings must be more regular as it also helps to talk to other parents for advice and general conversation about your child."

"Respite care, summer schemes and after schools clubs are needed."

"More adolescent, sex and sexuality info and Family Support locally."

"Practical support in the home - someone to assist when trying new things etc."

"Increased access to services such as O.T."

"We need empathetic and knowledgeable support, not target driven academic efforts."

"Training and Support - practical stuff is essential."

"Increased networking between parents."

2 Development Process of a Family Support Intervention

In 2006 the model of Family Support developed by Autism NI that is now being delivered in three of the five Health Trusts was created. It was forged from the combined understanding of what support families needed, when they needed it, what structures existed within Northern Ireland Health and Social Care systems and how it could be effectively integrated into those systems, and what the demands were on services from rapid identification and diagnosis.

It was also developed on the bedrock of a 20 year history of partnership working within Northern Ireland between Autism NI and Health providers and Educators. Autism NI was created by parents as a mechanism to develop support services for their families through partnerships, awareness and knowledge. Since the 1990's Autism NI has introduced key training programmes in diagnosis and interventions to Northern Ireland specifically designed for professionals. True to Autism NI's history of pioneering pilot projects and embedding those projects within existing services the model of Family Support that operates today came into being.

2.1 The Northern Ireland Context

Autism NI originated in 1990. At that time there had been several decades of political unrest and conflict. The general community in Northern Ireland was more focussed on surviving the trauma of violence and finding some degree of normality on a daily basis. Yet at the same time many families were struggling with children, adolescents and adults who were presenting with a range of challenging behaviours and vulnerabilities.

These individuals struggled to fit within the existing diagnostic criteria for the range of conditions and disabilities. At that time there was little expertise or collaborative working within this area in the Health Service in Northern Ireland. Unfortunately some individuals were referred to Mental Health, some fitted within Learning Disability, others were dismissed as being badly behaved and defiant and some parents were blamed for the behaviours of their children. Elsewhere in the UK, diagnostic criteria emerged for Asperger's Syndrome through the work of Lorna Wing, Judith Gault and others. Greater awareness of ASD was growing during this decade and increasing numbers of professionals began to receive training in assessment and diagnosis.

A number of concerned parents and professionals came together and began to meet, initially in Lisburn. Some parents had an ASD diagnosis for their child/individual, others had labels that did not seem totally accurate and all were striving to get help for their children in isolation. Many professionals at the time were recognising these difficulties and realising that families were overwhelmed and the existing services were unable to respond to their needs. These parents and professionals came together to form PAPA (Parents and Professionals and Autism), later to become Autism NI.

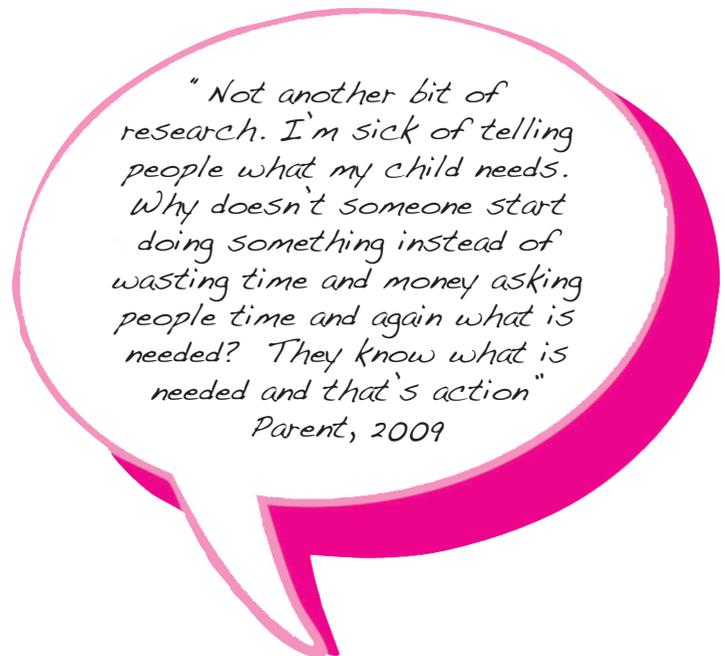
Many of the professionals who were working with these families and their children were being challenged in their practice with the presenting difficulties of individuals and the gaps in provision to support these families. These professionals were largely working in isolation and had few opportunities to broaden their knowledge or link with contemporaries in similar situations. By forming a partnership based organisation PAPA was focused on working in partnership with both parents and professionals harnessing their combined voices to strive for services for individuals affected by ASD.

From the early days when PAPA raised funds to purchase books on ASD and donate these books to local libraries, the goal was to increase access to knowledge, supporting parents to support their children and to lobby and raise awareness of

a very complex and unique Spectrum of disorders. PAPA developed links across the world bringing knowledge, training opportunities in diagnosis and proven interventions to meet the need of both professionals and parents. Subsequently the professionals created a Diagnostic Special Interest Group (renamed the ASD Diagnostician's Forum (NI) in 2007) to unify practice and the knowledge base within the statutory sector.

In later years as can be seen from the journey in Figure 2.1 overleaf, through both the political lobby by parents for services and the rapid growth in numbers being diagnosed, some change began to happen. But it was slow progress and the Review of Mental Health and Learning Disability (The Bamford Review, 2007) illustrated what many people affected by ASD felt, that there was lack of understanding or recognition from decision makers within health and education about this complex condition. The Bamford Review recommended putting ASD into Mental Health programme of care. Yet ASD is not a mental health condition. ASD also didn't fit readily into Learning Disability as there was a threshold for services for IQ's above 70, which many of those diagnosed would have, leading to no access to services for those with IQ's above 70.

There also was no mapping of rates of diagnosis or demographic trends. Anecdotally numbers coming through from Health and Education was obviously on the increase. No one could say for certain how many individuals in Northern Ireland had a diagnosis of ASD and no one could say whether in the short term or long term the need for services for this community of interest would increase dramatically, remain stable or decrease. Without identification, Health Boards did not see or recognise what was happening on the ground and they certainly couldn't plan or prioritise service development to meet huge growth in need. Parents knew by their difficult experiences that waiting times for assessment or interventions were getting longer and longer, with some parents in the Western Health and Social Services Board (WHSSB) area waiting up to five years for an initial assessment appointment.



The alarming rise in numbers of individuals with ASD has been referred to as an 'Autism wave' moving through our schools (DENI Task Group on Autism, 2001) and as 'Tomorrows Big Problem' in the social care field as cited by Morgan, 2002 in the Review of ASD Strategies and Practice, Autism NI, Nov 2006.

In 2005 the Southern Health and Social Services Board and now SHSCT, launched a Children's Autism Strategy. In 2006 the Western Health and Social Services Board and now WHSCT, launched an ASD Strategy. In 2007 the Northern Health and Social Services Board and now NHSCT launched a Framework for Autism. In 2008 an Independent Review of Autism Services was carried out on behalf of the Minister for Health, Michael McGimpsey. In its findings it stated "The Review Team recognises the lack of ASD services across N. Ireland, particularly services for older adolescents and adults." Independent Review Of Autism Services, 6 May 2008.

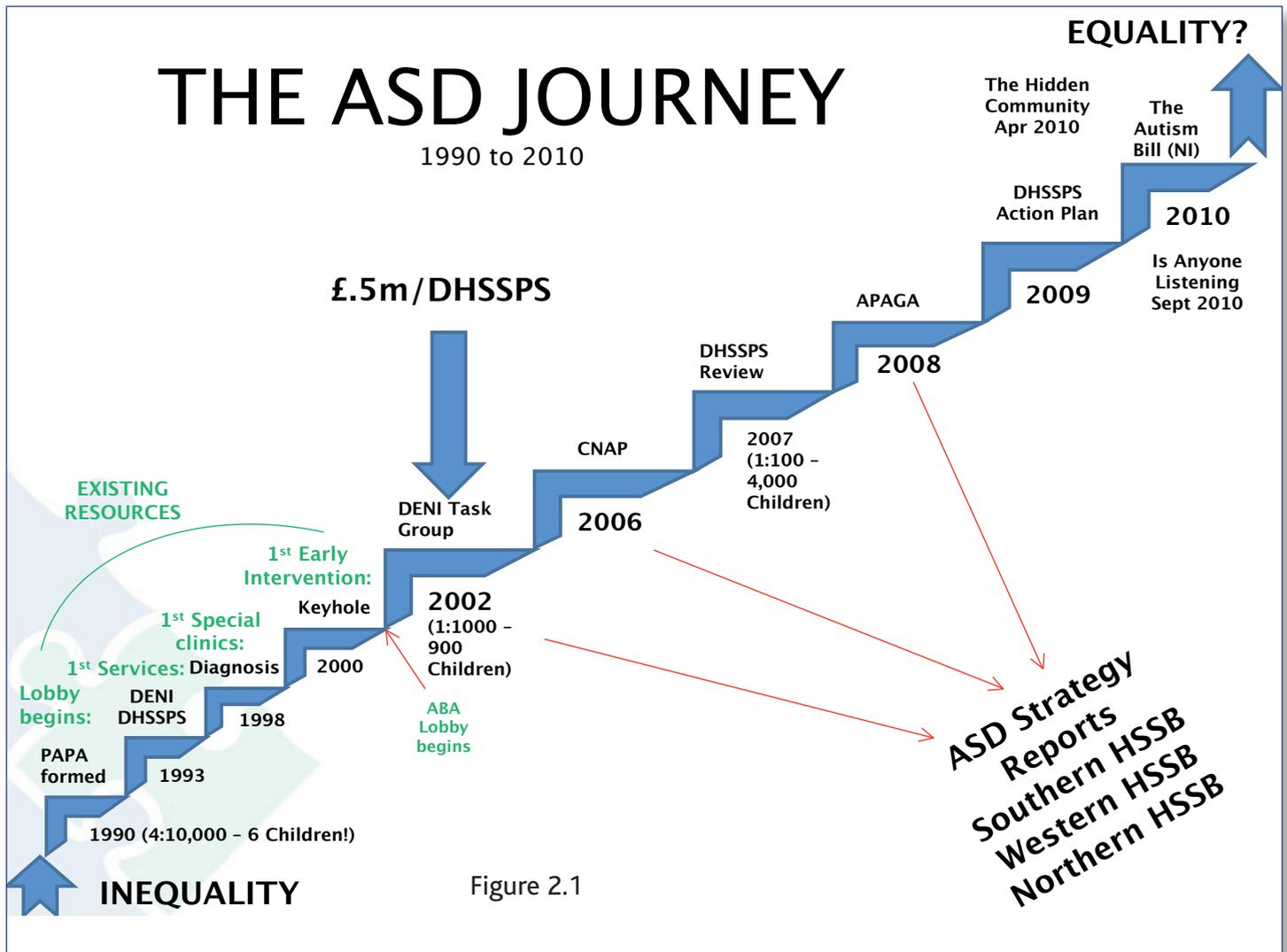


Figure 2.1

In 2009 an outcome of that Review was the formation of the Regional ASD Network (RASDN) which by 2010 has still to become fully operational. During this time the Department of Education (DE) Northern Ireland and the Department of Education and Science (DES), Republic of Ireland announced a joint education initiative at Middletown. This proposed Centre of Excellence is still to become fully operational.

These separate strategies and separate agendas potentially duplicate and miss out on being truly responsive and engaging with all those affected by ASD and are observed by parents in the study as being knee jerk reactions to political pressure and the groaning weight and volume of demand.

"If I was a parent I'd be angry too. Targets for intervention are set but you have to question the quality of what can be provided and what is tailored for the child or just meeting a target date"
Professional, 2009

By 2010 parents of children with ASD have been 'consulted out'. There is a feeling of research fatigue and many parents are critical at the slowness of Health and Social Care and Education to think, act and respond strategically and in unison to the needs of individuals with ASD.

Many professionals were and many still are at breaking point, with services stretched to the limit, waiting times getting longer, unrealistic targets being set for assessment and intervention and they are on the receiving end of parent's frustrations.

Lack of joined up thinking and strategic planning across sectors is deeply frustrating for parents in the study. They have become disillusioned and despondent and wish for help to happen more quickly. The situation has been exacerbated by the period of recession, the Review of Public Administration, the Dept of Education's SEN/Inclusion Review 2009, and recent instability within the Stormont Assembly around the Policing and Justice debate.

During the last decade there was also the introduction of the Special Educational Needs and Disability Order NI (2005) and the Disability Discrimination (Northern Ireland) Order 2006 that all failed to recognise the unique needs of individuals with ASD in Northern Ireland. As a result bodies such as the Northern Ireland Commissioner for Children and Young People (NICCY) commissioned Young People with Asperger's Syndrome - Review of Needs and Services 2007. NICCY, the Children's Law Centre and the Equality Commission all report receiving high numbers of calls from parents with children with ASD because the existing services, systems and legislation does not afford protection to their children rights and entitlements.

Increasingly parents are making formal complaints to Health and Social Care providers. In 2008 Autism NI formed the ASD Equality Forum which includes NICCY, CLC, Equality Commission and Disability Action. Increasingly test cases are being developed to address the inequality in provision for this community of interest.

Autism NI, because of its interest and concern about these issues recently was accepted onto the new Public Interest Litigation Service (PILS) panel. It remains to be seen whether these combined concerns will materialise into change. But the fact that these bodies recognise the uneven playing field of disability highlights the levels of stress parents must be and are under. The implications of this inequality have a legislative dimension and the All Party Assembly Group on Autism (APAGA) is committed to bringing forward legislation. APAGA is supported by a range of voluntary agencies and Autism NI provides the Secretariat.

2.2 The Model of Family Support

The Northern Health and Social Services Board's ASD Strategy Document 'Colouring Lives' (2008) recognised a number of promising developments within the voluntary sector that have not been adopted or mainstreamed to the degree that might have been expected. It suggested that there would appear to be scope to invest in such initiatives in order to begin to develop a more balanced continuum of provision. Autism NI's Model of Family Support is grounded in community development principles. The aim is to empower parents to be more effective in responding to their child/individual's needs, in the first instance post-diagnosis, and on an ongoing basis. Each team is based in a Health and Social Care Trust area and consists of one Autism Resource Officer (ARO), (usually a full time post) and two or three Parent Liaison Officers (PLO) (usually part time posts).

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The ARO implements the Family Support Service in their Trust area by supporting and building confidence within families and communities. The ARO works closely with and takes referrals from the Assessment and Diagnostic teams and relevant transition teams, links individuals with ASD and/or family members with relevant statutory and voluntary services, provides family members with 'signposting', knowledge, training, support and an opportunity to make a difference in the lives of individuals with ASD and in relation to Parents, of their children, families and communities.

The ARO is provided with support and supervision by the Family Support Development Manager at Autism NI. There is also peer supervision sessions and group sessions.

The PLO assists the ARO to implement the Family Support Service in their Trust area. The ARO will refer ongoing cases to the PLO.

The PLO is provided with support and supervision by the ARO. There is also peer supervision sessions and group sessions. In the early days of recruiting it was relatively easy to recruit the Autism Resource Officers but it was more challenging to attract parents to the role of Parent Liaison Officers. It was thought that parents were reluctant to take on part time work given their complex care commitments at home and the pilot nature of the service. However recruitment in late 2009 and early 2010 has shown a rapid growth in interest in the posts and the challenge has been in selecting as opposed to attracting parents to apply.

The referral process is outlined in Figure 2B overleaf.

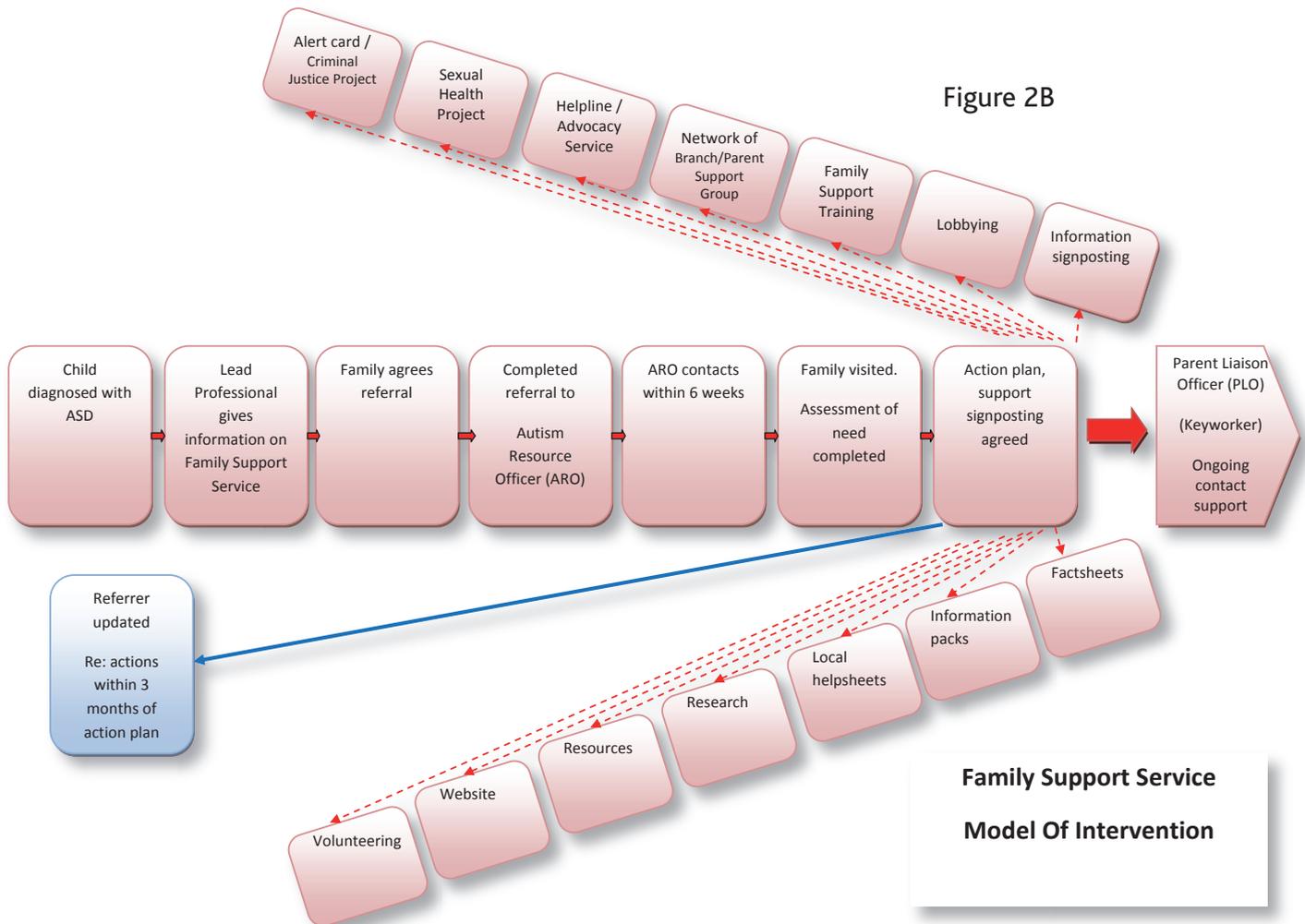
2.3 The Challenges Facing the Family Support Service

The development of any new service inevitably brings with it both expected and unexpected challenges, particularly when the timing of that development is set within a fundamental process of change and re-structuring. During 2008 and 2009 the Review of Public Administration was implemented. This brought about critical change within the structures of Health and Social Care in Northern Ireland. It also brought about, and is still involved in, significant change and re-structuring within Education in Northern Ireland. The impact of such change is often that decisions to implement new initiatives or services are put on hold, priorities shift, and funding decisions can be complicated.

The Family Support Model was created to respond to the needs of families with children post diagnosis. The "Colouring Lives" (NHSSB 2008) report suggested that once assessed, 'if children with a diagnosis of ASD are not in receipt of core services, the demands on Paediatric Medical Services are significant from discharge from the Diagnostic Service. Parents often have no other source of advice in relation to management strategies; at home and in school; as well as concerns for the future'.

2.4 Training Provision

One recruitment criterion for the post of Parent Liaison Officer is a minimum of 3 years post diagnostic experience as a parent of an individual with ASD. Whilst parents who are successful at interview have a range of skills and knowledge in relation to ASD and diagnosis, there are always new areas to develop knowledge. In recognition of this ongoing development need Autism NI put in place a range of training opportunities, to enhance the skill base of these officers.



2.4.1 Internal Induction Training

As part of their induction training, Family Support team members complete training on a range of topics such as:- Child Protection training, Committee training, Family Support Training i.e. ACCESS, Grandparents, Fathers, Adolescence, Social Skills, Autism and You, Sibling Workshop, TEACCH, Keyhole (pre-school training package), Fundamentals of Autism, Lone Worker training, etc.

2.4.2 Partnership Training

Working in partnership has required that all staff participate in key internal training within the Trust to which they work. This has been vital for a number of reasons; not least that staff are often based within Trust premises and need to know basic Health and Safety Policies and Practices. Having two partners operating two separate systems has meant working on shared areas to develop protocols of practice that merge well with each other. Some examples of Health and Social Care Trust training that Family Support team members have availed of include First Aid, Legal Issues, Health and Safety and Data Protection.

2.4.3 Further Training

In the early days of the development of the Family Support Model, Autism NI recognised the need to further develop parents employed as officers within the service. In 2009 a Training Needs Analysis was carried out which identified priority areas for training. This included Listening Ear training, Mental Health Awareness, Handling Difficult Calls, Managing Challenging Behaviour, Sensory Integration, Computer Training, Planning and Evaluation, Lone Working, Presentation Skills, Dispute Avoidance and Resolution Service (DARS), benefits and sources of funding for families, Trauma Workshop etc

3 The Model in Action

One of the unique aspects of the Model of Family Support is that it is home grown. It is a Northern Ireland model based on what families in Northern Ireland said they needed. It is set within an organisation that is indigenous to Northern Ireland that is of the community and created by the community.

At the core of the model is the partnership with the Health and Social Care Trust teams and there are growing and prosperous links with Education. Autism NI has a long 20 year history of partnerships with Health Boards, Health Trusts, Education, other ASD organisations, and other voluntary disability groups. All too often models of support or intervention are brought into Northern Ireland and imposed on the community here as if a 'one size fits all' concept works. Northern Ireland is a community that has particular needs, stresses and strains, structures and legislation. This model recognises that uniqueness.

The model was created by parents for parents, based on a 20 year history of organic growth in training, research and responding to the growing population of the ASD Community of Interest.

The model is steeped in the principles of community development and utilises the specialist skills, knowledge and understanding of parents who live daily with the impact of ASD on their children. It utilises specialist locality based knowledge of what exists within a geographical community, the who's who of local professionals and changing structures, the variety of different protocols and services, the voluntary sector bodies (many of whom are unique to Northern Ireland), educational structures and the vagaries of Northern Ireland legislation.

It is a home based model service that is built upon consent for referral by the parents who have had a recent diagnosis for their child. It has a time bound commitment to make contact with a family who have been referred within 6 weeks of that referral being received. This is at a critical time of upheaval and distress following a diagnosis of ASD.

During the initial home visit an Assessment of Need is carried out. This is an extensive assessment of the whole family's needs and identifies areas where action needs to happen.

An Action Plan is drawn up, a key part of which empowers parents to take on tasks to address their needs. This builds the confidence of parents to respond to their own situation and reduce their reliance on others. The Action Plan strikes a balance between areas where actions will be carried out by the Autism Resource Officer (ARO) and areas allowing for parents to take a certain amount of initiative at this point. Receiving a diagnosis is often traumatic for parents and it is possible for parents to feel paralysed and not know what to do next. The Action Plan attempts to enable parents and help them with this stage of their journey with ASD.

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Several visits later when the Action Plan is completed the family are then linked to a local Parent Liaison Officer (PLO), who keeps in contact with them and who is available to them if they have new needs or issues arising from key transitions, developmental stages or new behaviours. The PLO also links the family with local support groups, keeps the family informed of new initiatives in their local area and keeps them informed of consultations, reviews or strategic developments in ASD in Northern Ireland.

If there is no local support group and a cluster of parents become interested in setting up a support group the PLO works with the families to identify premises, publicise the group, and insurance cover and a start up grant is organised for the group via Autism NI.

If a parent needs advice or support attending meetings, SEN Reviews, appeals, tribunals etc the PLO can help them locally or put them in contact with the Autism NI Helpline and Advocacy Service.

The complex nature of Family Support is recognised within the Model. The presenting issue within families is ASD. But having an Assessment of Need and a friendly face to talk to inevitably brings up further family needs and issues, many of which are complex in themselves.

Families are under enormous amounts of stress and daily pressures and crises are common. Burrows (2010) noted one parent's dilemma 'Most stressful are other people – going out, facing Doctors, teachers, even family. Nobody wants to listen, other kids snigger and laugh. His problems aren't that noticeable yet other kids seem to look at him. They seem to sense his difference. Neighbours leave my kid out. I'm still bitter about that. You can't make them understand...I just shut my door.'

Whilst McKinney & Peterson, (1987) found that parents who have children with ASD endure more stress than parents with non-disabled children and parents of children with other disabilities, Bouma & Schweitzer, (1990) highlighted heightening negative health outcomes like depression and marital dissatisfaction with having a child/individual with ASD in the family. In addition, mothers of children with ASD report less parenting competence, less marital satisfaction, and less family adaptability than mothers of children with Down's Syndrome or mothers with typically developing children (Rodrigue, Morgan and Geffken, 1990).

The role of the Family Support team is to identify the needs and signpost families where needed. Common Issues range from child protection, mental health, domestic violence, bereavement, benefits, and interventions that impact on siblings, and lack of understanding by grandparents.

It is vital that Family Support Team Staff are supported in their work to manage their own stress levels and respond effectively. Regular line management support is provided, and there is a management team available for crisis support when needed. Case supervision is also provided to explore with each member how their practice is progressing and identify gaps in knowledge or provision. Teams are brought together regularly for peer supervision enabling resources and knowledge to be shared, increasing effectiveness and supporting relationships. This also brings a regional perspective to the work enabling a cross fertilisation of ideas and enhanced practice.

Ongoing training needs are responded to through Autism NI's in-house training function and the identification of external training where appropriate. The partnership relationship with the Health Trust means that training available for Trust staff can, where appropriate, be made available to the Family Support team.

The partnership relationship with Health Trust staff means that complex cases can be shared, advice sought and child protection issues responded to appropriately. In some situations the ARO has been able to connect with a family that has not been co-operating with social services or diagnostic services, enabling confidence and understanding to be built and engagement with statutory services to happen.

On occasion parents have disclosed child protection issues to the Family Support team, when previous engagement with statutory services has not been able to pick up on these issues. Whilst these cases are relatively rare, given the volume of families receiving the service, they illustrate the effectiveness of partnership working where family issues can be responded to effectively within the voluntary/statutory partnership.

4. Research Methodology

The University of Ulster were commissioned initially to assess the level of Family Support available across Northern Ireland and build an understanding of need unmet. Subsequently, Autism NI launched three pilot Family Support Services. The report draws on the findings of these two areas of work.

The main emphasis of the pilots was to focus on a qualitative assessment of the impact of the Family Support Service during the pilot stage in each Health and Social Care Trust area. Evidence was gathered about the impact of the Service via individual family interviews, evaluation forms, and verbal feedback to Autism NI direct from parents/carers. A number of professional interviews were carried out and verbal feedback to Autism NI direct from professionals was collated. Seven Branches/Support Groups, from the pilot areas, were consulted about the effectiveness of the service.

The statistical data was gathered from reports to funders as each team established within Trust areas embedded the service. A research study day was also held with all the Family Support teams coming together to reflect on their activity and to evidence the impact from a joint staff and parent perspective. 12 of the 13 staff within the Family Support Service are parents of children/individuals with ASD.

Interviews were also carried out with key Autism NI personnel to evidence the impact internally within the organisation.

5. The Current Service

Figure 5A gives an indication of the issues addressed by the Helpline/Advocacy Element of the Service during the period April until December 2009. Education, Behaviour Management, Benefits, Listening Ear and adult diagnosis are amongst the most popular issues.

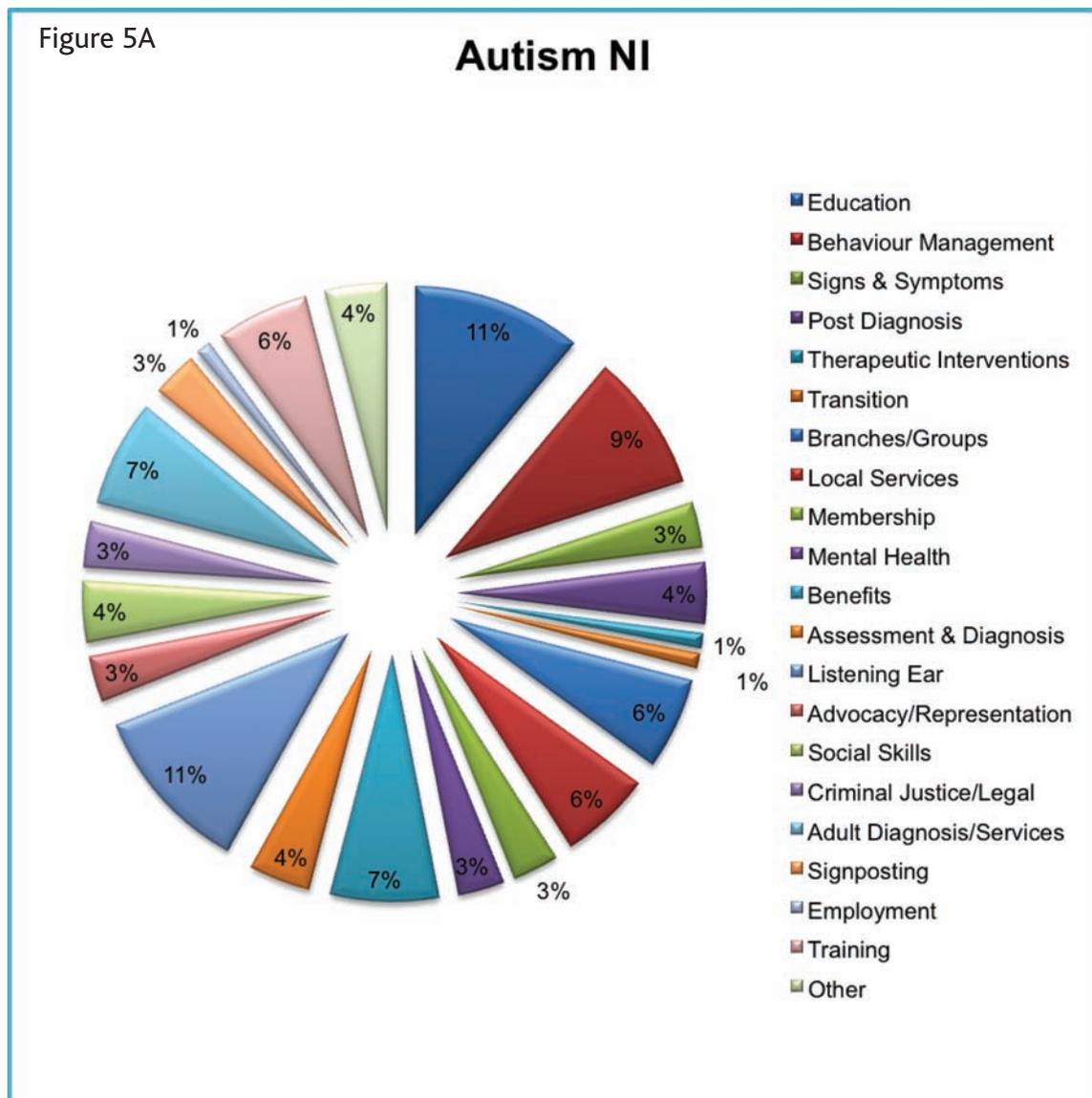


Figure 5A Range of Issues Addressed

The majority of calls require at least three areas of follow up action. The most time consuming is Benefits, specifically Disability Living Allowance which can last on average 3.5 hours just on completion of the form. Then follow up is required if appeals are being submitted or tribunals attended.

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5.1 Numbers of Families Supported

The following diagrams outline the work in each of the three Trust areas that the service is currently operational and the numbers of families involved.

Western Health and Social Care Trust (WHST)

In the WHST there is one ARO and two PLOs. Fig 5B illustrates that from initial referrals and home visits that follow on contact with families is significant. Families are saying they need ongoing support and the reassurance that someone is there, if and when they need it.

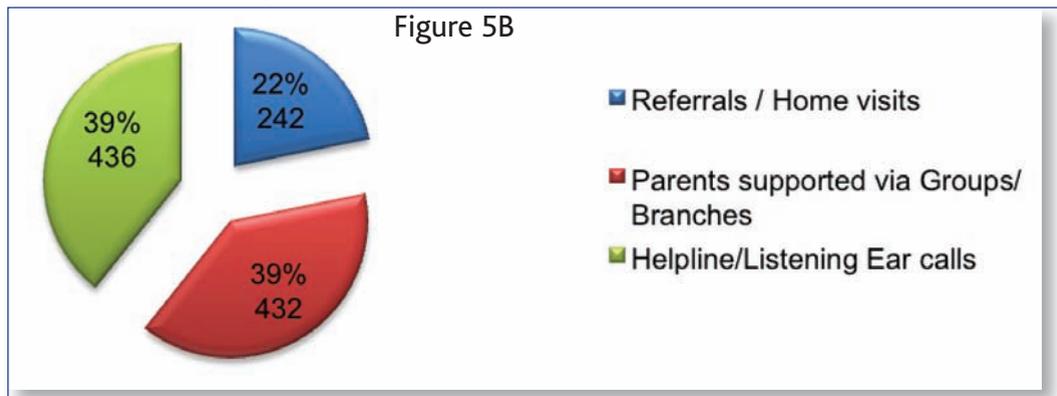


Figure 5B Breakdown of Services in WHST April to Dec 2009

South Eastern Health and Social Care Trust (SEHSCT)

Fig 5C shows the breakdown of the work carried out by the SEHSCT Family Support Service from August 2009 – December 2009. It reflects the initial start up of the service which includes the creation of four new parent support groups, which greatly extends the reach for support for families.

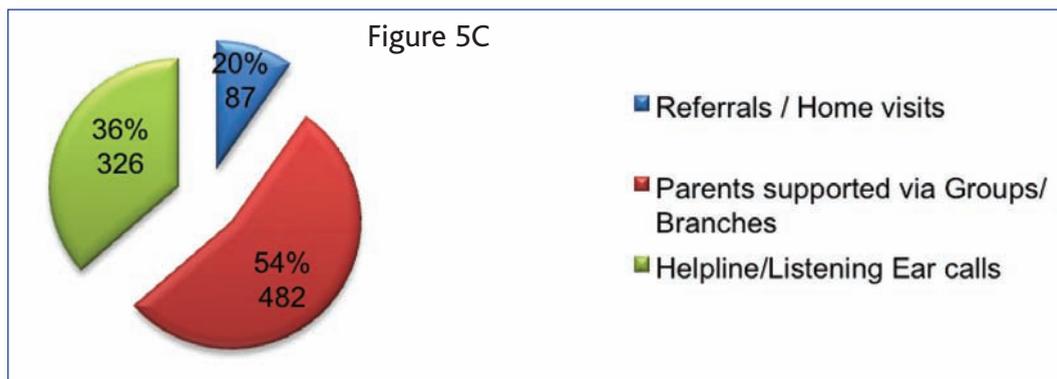


Figure 5C Breakdown of Services in SEHSCT Aug to Dec 2009

Northern Health and Social Care Trust (NHSCT)

This is a breakdown of the work carried out by the NHSCT Family Support Service from Apr 2009 – December 2009. It illustrates the difference of having a part time Autism Resource Officer (20 hours per week), as opposed to a full time post as in the other two Trust areas, to the balance of type of contact.

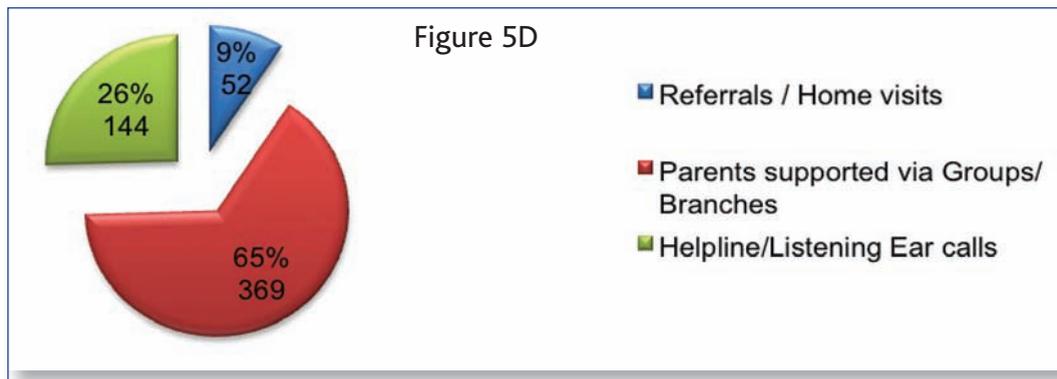


Figure 5D Breakdown of Services in NHSCT Apr to Dec 2009

5.2 Internal Additionality

There have been many achievements and much progress through the pilot of this service, many of which were made in response to need and were NOT in the remit of the original plans or funding applications. Some examples include;

- Having a breadth of knowledge throughout the team informs and supports the role of the Helpline Service in responding to complexity of family needs.
- Statutory services are better informed about needs and are able to respond more effectively in service development.
- Factsheets have been developed creating access to information that parents not in receipt of the service can benefit from.
- Autism NI has examined and is continually enhancing the functionality of its website in providing Northern Ireland relevant information that is more family orientated and relevant.
- The Family Support team is creating Help Sheets to further empower local parents with knowledge of who to contact and what support is available to them at a local level. This enables families to access information and support when it's relevant to them beyond the post diagnostic stage.
- Feedback from parents via the Family Support team has lead to innovation regarding the training needs of families. The Autism NI Training Department has established new workshops and are developing further workshops that are targeted to what families are saying they need.

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- The work of the Family Support team is letting parents know what should be available to them, i.e. their rights under equality legislation. It is informing parents of their rights, supporting where appropriate a parent's right to highlight an injustice, how to complain, what action they can take as citizens to effect change for themselves and others in their local area.
- More families have engaged with Reviews and Consultations than previously. This increases the opportunity for real change to happen that is meaningful and not damaging to families with a child/individual with ASD.

5.2.1 Development of Fact Sheets

During 2009/2010 it was found that a range of common issues were arising which needed support from within the Family Support teams and/or the Helpline Service. It was recognised that a wide knowledge base existed within these teams that should be utilised by parents, professionals or extended family members. A Fact Sheet topic list was developed with contributions from all Family Support team members. Currently a range of 15 Fact Sheets are being published, with a further 15 topics identified for development in the coming months.

This Fact Sheet range includes Recent Diagnosis, Home Education, Living With Autism, Guide to Disability Living Allowance, Autism and DLA, Hints and Tips for Behaviour Management, Guidance on Selecting a School, Education and Statementing, Obsessions and Ritualistic Behaviour, How To Cope with Christmas, Holidays and Autism, Sibling and Autism, The Needs of Siblings, Parent Fact Sheet, Fathers Fact Sheet, and Mental Health and Asperger's Syndrome.

5.2.2 E Bulletin

ASD is often an extremely isolating condition with families finding it difficult or impossible to engage with services due to the impact on their child/individual with ASD. Also many families live in rural areas and using public transport can be difficult with a child/individual with ASD, therefore reaching families, keeping them informed and connected with developments that are ASD friendly or political developments in the world of ASD is vitally important. The Autism NI E Bulletin was developed to keep families connected via the internet. It is a family focussed Northern Ireland based publication that is contributed to by many readers. It currently has over 2500 subscribers to this free service and is made available to all families in receipt of the Family Support Service. Past issues are available on the website www.autismni.org.

5.2.3 Criminal Justice

Autism NI has been to forefront of awareness raising and partnership working with the Criminal Justice system in Northern Ireland. Autism NI is a member of multi agency steering groups on learning difficulties and specific learning difficulties chaired by the Northern Ireland Prison Service and commissioned by Paul Goggins, Minister of State for Northern Ireland. There are a range of subgroups which are looking at diagnosis, assessment, policy and training.

Autism NI actively contributes to the training subgroup discussions which are currently addressing appropriate training options for a range of professionals within the Criminal Justice System. The subgroup involves a wide range of agencies both from the statutory and voluntary sector working together to improve the situation for individuals with learning disabilities, specific learning difficulties and Autism who may come into contact with the Criminal Justice System.

Autism NI has delivered training to the emergency services and the Legal/Justice sector. The training is underpinned and reinforced through the use of a range of Autism specific awareness resources such as posters for targeted locations and information leaflets alongside an ongoing awareness campaign. Part of this ongoing work over the last two years has been training for the Probation Board NI, PSNI, the Judiciary, the legal professions, and the Youth Justice Agency. Over the next year we intend to work closely with other emergency services such as the Northern Ireland Ambulance Service and the Northern Ireland Fire Service.

Many families who are linked to the Family Support Service have reported accusations of anti-social behaviour, intimidation and threats involving their children within local communities. This partnership between Autism NI and PSNI has enabled the Family Support team to seek appropriate help and intervention from the PSNI for those families affected.

5.2.4 Alert Card

In 2008, Autism NI piloted an alert card in the North West for use in circumstances where the Emergency Services and PSNI may come into contact with an adolescent or adult with ASD.

The Pilot, carried out in partnership with the Western Health and Social Care Trust, Autism Initiatives and local PSNI, and working with 39 young people and adults with ASD found that 32 cardholders produced the card. Although, only one of the cardholders was in a situation where they produced the card to the PSNI, it had been produced in a range of other settings for example, to shop assistants on 32 occasions, to security guards on 16 occasions and to teachers on 16 occasions. It may well have been the use of the card prevented a situation escalating or deteriorating into a potentially criminal justice situation.

The cardholders also gave examples of when they had to use the card:

“When I had to apologize for losing my temper”
“When something happened to me I was able to show the card so I can be helped”

The Pilot indicated that the card has proved to be useful in a number and range of different stressful situations.

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Late in 2009 (following further consultation with Autism Cymru and Autism West Midlands who have in depth experience of the alert card) this project expanded to the whole of Northern Ireland and is now available free to all families including those linked with the Family Support Service. Up until publication of this report another 70 people have been issued with the card and as awareness grows it is anticipated the numbers will also.

The alert card offers a degree of reassurance for parents and enables young people and adults to have more independence, as parents know the emergency services and PSNI have access to emergency contact details for each person with ASD who carries the card.

Currently, the card has a contact number for Autism NI and another person who is known to the cardholder who can be contacted by the Emergency Services. There are dedicated people at Autism NI who respond to a call in relation to the alert card. However, plans are already afoot to provide a secure web based resource which will allow for 24/7 enquiries which extends the usage and flexibility of the card further.

5.2.5 Sexual Health

In 2008, Autism NI developed a Sexual Health Project funded by the Department of Health, Social Services and Public Safety and evaluated by the University of Ulster. This project is delivered in collaboration with a range of relevant organisations such as Health Promotions Agencies, Brooke Clinic, Family Planning Association YMCA, Contact a Family and Autism Initiatives. As well as developing training for parents and resources that are ASD specific, this work has enabled families to have their child/individual's behaviours understood more readily. One example was where a child was suspended from school and social services were informed that the child was exhibiting signs of sexual abuse. Upon investigation, and with understanding gained from the Sexual Health Project, a referral was made to Occupational Therapy where it was realised that the child had a range of sensory issues which resulted in the behaviours that the school had witnessed.

5.2.6 Family Support Training

Autism NI has a long history of Family Support Training, which has included ACCESS workshops for parents post diagnosis, Grandparents Workshops, Fathers Workshops, Sibling Workshops and Autism and You (for extended family). The Family Support Service has been able to signpost families to training in their local area and has gathered information regarding needs for such training, which has resulted in greater take up and access to places on workshops and targeting delivery of such training in key areas of need. The Family Support Service has also been involved in identifying other need for Family Support Training and the Autism NI Training Department are currently developing a range of new Family Support Workshops based on the areas identified.

In 2009, Autism NI delivered Family Support Training to 1391 parents, 256 children/individuals with ASD and 262 siblings.

5.2.7 Helpline and Advocacy Services

Autism NI has operated a Helpline service for a number of years, albeit an ad hoc service that had no additional resources to develop it. As a result of the development of the Family Support Service, resources have been secured to begin to extend this service, including the establishment of an advocacy element. Many families supported through the Family Support Service have benefited from advocacy support in relation to benefits tribunals and appeals, education appeals and reviews, and housing issues.

The Family Support Team have been gathering data on the numbers of parents experiencing difficulty with Disability Living Allowance applications, where lack of understanding of ASD frequently leads to parents being turned down for this entitlement, having to undergo appeals and tribunals and often having their entitlement reduced as their child/individual gets older. Autism NI is recognising the equality issues within DLA decision making which has led to scrutiny of these decisions and are beginning to collate evidence to challenge perception within DLA that for example ASD improves as the child/individual gets older. This is a direct result of working with families in local areas where evidence of these types of issues can be gathered and test cases prepared.

" I never would have thought that that visit from Mary would have lead to me getting involved in the SEN Review. I might have heard about it happening but not have realised it affected my child in any way. When I went along to the meeting about this I didn't think I would say anything because I was so nervous. But I found myself saying how this would have a negative effect on my daughter and I felt brilliant afterwards when I felt I had done my best to give her a voice in this review".

Parent, 2009

5.2.8 Volunteering

As more parents experience the benefits of the Family Support Service many wish to get involved in ASD in a variety of ways that help others. More and more parents are now volunteering through their local parent support groups or branches, organising social activities for children/individuals with ASD and their siblings in local areas, assisting with the Helpline, getting involved in lobbying events and becoming active in their local areas. Volunteering has long been recognised as providing benefits to both the receiver and the giver.

" I now help out a couple of times a week and it gets me out of the house. Before I was sitting at home worrying about my son and his future, getting more and more depressed and taking antidepressants. Now I look forward to each week and the challenge of helping others"

Parent Volunteer, 2010

Through these opportunities to help others, parents are finding confidence, gaining in skills and knowledge and feeling positive about making a difference for other people.

Figure 5E



Figure 5E Breakdown of Autism NI Branches and Support Groups in Northern Ireland April 2010

5.2.9 Parent Support Groups and Branches

Since the Family Support Service started, nine new Support Groups and a new Branch have been supported. For key contacts of a Branch/Support Group contact Autism NI on 02890 401729.

In the NHSCT area there have been four new Parent Support Groups. In the WHSCT area there has been one new Parent Support Group and one new Branch, with two more groups planned during the summer of 2010. In the SEHCT four new Parent Support Groups have been created. This increase in Support Groups and Branches in local areas means that parents supporting parents becomes more accessible; it illustrates empowerment in action; it enables a community of interest i.e. ASD, to adopt community development principles and put them into action; it reduces dependency on services for families

and leads to greater knowledge and understanding via support from parents with children at all ages including adults, gender and experience of services and interventions.

Burrows (2010) found that Parent Support Groups in Northern Ireland countered the experiences of acute and chronic stress directly and indirectly related to ASD by focusing on the specific ways people had learned and changed. When sufficient support is available, 'transformation' rather than 'living in crisis and reliving again and again overwhelming experiences' becomes possible.

5.2.10 Political Lobby

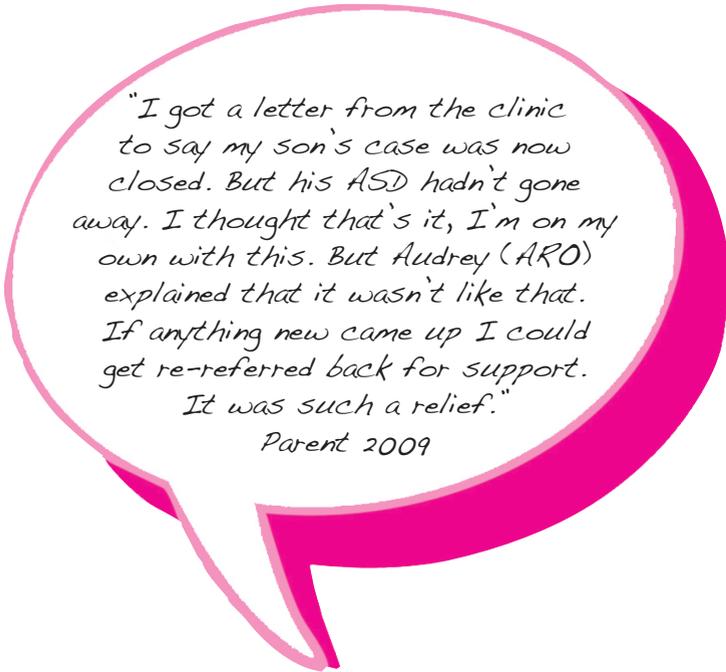
Autism NI has a long history of parental involvement and engagement. Since the development of the Family Support Service more parents are engaged as members, as volunteers, as parent representatives on various structures within the organisation such as, Autism NI's Executive Board and in local branch committees and parent support groups. This increased reach to parents and families has meant that more families have been kept informed of changes within ASD in Northern Ireland, changes that have a direct effect on their child/individual and their families. There have been increased responses to key consultations such as the Department of Education's SEN Inclusion Review 2009.

5.3 What Makes this Service Unique?

The Family Support Service is unique in how it relates to other aspects of Autism NI's services and ethos; how after much trial and evaluation it dovetails with statutory services, supports at key stages i.e. post diagnosis, transitions, life stage development etc. In short, this organic service is unique as it is built on the principles of Community Development, Volunteering, Self Help, Empowerment and Participation.

6 Impact on Statutory Services

Statutory services have been able to be more consistent in responding to a family's needs when a diagnosis is made. Many professionals who responded in the initial part of the study suggested that they have limited time with parents and would really like to be able to offer more support. Now, with the Family Support Service in place in three Trust areas, those families going through assessment and diagnosis have follow up support in place. It must be stated that there is a bottomless pit of need and this service is only resourced to meet a small quota of that need, but nonetheless the support is beginning to widen its reach and include more and more families. The Family Support model is flexible enough to be expanded in an extremely cost effective manner to meet the increasing need due to the accelerating prevalence of ASD in Northern Ireland.



"I got a letter from the clinic to say my son's case was now closed. But his ASD hadn't gone away. I thought that's it, I'm on my own with this. But Audrey (ARO) explained that it wasn't like that. If anything new came up I could get re-referred back for support. It was such a relief."

Parent 2009

Many families have engaged with a range of consultations that have happened since the Family Support Service came into being. Some professionals feel that having an ARO as part of their team has meant that families are less polarised and understand more the restrictions on services and why for example, a child is signed off after a period of time. Previously families felt rejected and that their child was being forgotten about. The Family Support team are able to reassure parents should they need intervention again, how they can go about it in the confidence that their child remains known to the service.

In the West a series of ASD "Clinics" have been set up with a range of professionals, with the ARO in attendance. Families can drop in for advice or support about a particular issue that would otherwise have necessitated referral to the specialist ASD clinic or that they would be left to cope with on their own.

As part of the Family Support Service, training for both professionals and parents has been delivered to meet gaps in services and knowledge. For example, in the WHSCT area a series of challenging behaviour workshops were delivered in 3 different locations because parents identified the need and lack of access to the behaviour team in their area. In the NHSCT area Sensory Integration workshops were delivered to respond to need for more awareness and knowledge identified by parents. Working collaboratively with Trusts and having an 'evolving to meet need' training function, the service can respond and deliver creatively in areas of need.

The Health Trusts are also able to get good feedback on parental experiences of the assessment and diagnostic process. They have been able to develop resources to assist parents with this process and develop new ways of working that supports parents more effectively.

7 Summary and Recommendations

7.1 Key Research Findings

- All Health and Social Care Trusts in Northern Ireland need to have this model of Family Support Service in place. Many families' needs are being neglected in areas that do not have this service.
- The areas that do have this service in place need to expand the capacity of the teams to meet growing need and demand.
- The consistency across life stages and the integrated cross sector model put this model of Family Support Service firmly within the Key Worker practice model and the priorities of the DHSSPS "Families Matter" Strategy.

7.1.2 Learning

- The Family Support Team has found that both parents and professionals can be so focussed on what is wrong with a child/individual's behaviour and trying to fix it, rather than trying to understand it. Sometimes a different perspective is all that is needed in helping to understand what the child/individual is communicating about their emotions or their environment.
- It is vital to use key knowledge about a family to communicate and show interest in their particular life story. Families reported that they are dismayed at constantly having to repeat their story. Having appropriate information and showing an interest communicates respect to the parents and enables them to feel like human beings and not just a statistic or an 'Autistic Family' but a family with a child/individual who happens to have ASD. It was found that showing a genuine interest in their situation by for example using a child/individual's first name or remembering the name of their school, or the names of siblings or enquiring about other family members had a positive impact on the family unit.
- When working with families with multiple issues or challenges, workers can often feel guilt about referring on to other agencies or supports. It is important to remember that there are capacity issues. Over focussing on one family means another family is losing out on support.
- There can be desperation from parents and professionals to fulfil all their expectations, which may not be realistic. It is important to focus on what the service is capable of helping with and outline what is not its remit. We need to be clear what we can and cannot do.
- It must never be assumed that parents have adequate knowledge about what service they are being referred to. Many parents don't understand acronyms such as SENCo, (Special Educational Needs Co-ordinator) and many parents don't understand the different roles of the variety of professionals they may meet. Parents often do not understand why a professional is seeing their child/individual with ASD and what the goals of an intervention are.
- Many Trust professionals are relieved they have something to offer families with the Family Support Service, but this does not negate the need for statutory services to compliment the work of the Family Support Service.

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- When supporting parents it's never just about one thing. Complexity of ASD means it's about multiple issues i.e. behaviour, trauma of diagnosis, trauma of living with ASD, constant reactivity needed by parents, the emotional turmoil of ASD, the frustrations and desperation re: lack of services/help, the lack of understanding by others, and it can also be the complexity of the strain on the family, the multiple issues that families face as families e.g. housing, relationship breakup, violence, abuse, needs of siblings, extended family difficulties, etc.
- Services for families with a child/individual with ASD need to have a focus on the mental health and well being of parents. Supporting parents supports the child/individual, and the family.
- Professionals need to talk to parents on their level, realise the complexity of living with ASD and the additional complexity of multiple family issues and needs.
- Parents have specific needs from the point of referral for services. This is when parents can start to fall apart. They need information and support at this time to help them understand the process and the implications. They need preparation support for the final meeting when a decision has been made regarding diagnosis.

7.2 Internal Recommendations

- Autism NI needs to develop information on Frequently Asked Questions (FAQs) and make this available via the website, the E Bulletin and other means. This will share the increasing knowledge gained by the Family Support team in their first few years in existence to a wider group of parents.
- Family Support teams need to develop localised help information sheets about services available in their area.
- More local parent support groups are needed. These provide a valued and vital connection for parents at a local level at times and locations that suit more parents.
- Volunteers on committees in branches need more training in their roles, focussing on recognising the needs of all the members, focussing on how to support more effectively and how to engage more effectively all parents in the activities of the branch.

7.2.1 Role of Branches/Support Groups

- Branches and parent support groups provide a vital, much needed support mechanism for parents at a local level.
- Different types of groups are needed for different types of needs. In particular there is a growing need to increase the numbers of groups and branches and to connect them to a hub of accelerating knowledge, resources and support.

7.2.2 Parent in Professional Role (Parent Liaison Officers PLO)

Advantage: opportunities to meet parents while out shopping, dropping off children to school, sharing information, the PLO becomes known locally and parents will approach the PLO in informal settings, professionals will contact them for information and knowledge.

Disadvantage: too readily available/hard to manage boundaries and switch off when not working, guilt about not being constantly available for other parents, exhaustion of listening to the emotions of other parents, its and emotional drain on the PLO as a parent.

When discussing a 'hard to reach' family with a professional, the PLO said she was also a parent, to which the professional replied "Well that's how you will get in with that parent, I know she needs to speak to another parent – that's how you will get over the door"

7.2.3 Mixed Expertise within the Team

Having mixed expertise throughout the team expands the breadth of knowledge available to respond to the complexity of family needs and experience to draw on.

7.2.4 Neglect

Families are experiencing professionals making decisions and plans for their child/individual with ASD but some of those professionals don't understand ASD or the complexity of it. Some professionals don't know the services that exist and are unable then to inform parents or refer parents where appropriate. Statutory agencies more often focus on the child/individual with ASD, whereby the Family Support Service can focus on the parent also. They can ask 'what about you'.

"After diagnosis most parents are in shock, they're emotional, they go into fight, flight or freeze mode." Autism Resource Officer

7.2.5 Reactiveness

Challenges arise when last minute meetings, reviews, tribunals take place. The Family Support team is often expected or needed to react and be there with little time to plan or prepare. This impacts on support for other families and brings capacity challenges to the team.

7.2.6 Reaching Forgotten Families

This service has been found to connect most effectively with lower socio-economic groups in the most disadvantaged wards within the three pilot areas.

"It is both exciting and challenging reaching forgotten families, but dreadful that there is so much neglect. This service supports 'invisible people' in their own home and helps them become visible again." Parent Liaison Officer.

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7.2.7 Mapping What Happens In Different Areas of Northern Ireland

- The Family Support Service has been able to uncover neglect of some families needs and make services aware of this to effect change.
- The Service has uncovered a lack of basic provision in some areas and has worked to highlight these and present solutions.
- The Service has found that the IQ threshold of 70 remains a barrier to services for many families.
- The Service has also uncovered dedicated professionals willing to push the boundaries of their remit, professionals who understand the pressures that many families are under. They have worked with professionals who struggle to grasp the complexities of ASD, but who are willing and keen to learn.
- The Service has found that as it has grown and developed many professionals who were previously suspicious and reluctant to engage, are now seeking the Family Support team out to draw on their knowledge and to respond to families they are working with. One professional said to an Autism Resource Officer "Thank goodness we've something else to offer families".
- Some professionals have found that they are constrained by their position and have turned to the Family Support Service to help raise injustices for families and to find ways of helping them challenge the lack of provision families they are working with are experiencing.

7.2.8 Parents as Specialists

- Having parents in the role of formal supporters enables them to use their specialist knowledge and expertise to support other parents to become more effective, empowered, knowledgeable, and increases their capacity to respond to and represent the needs of their child/individual.
- The uniqueness of this service is that it captures specialist knowledge and makes it available to others, particularly those with greatest need to tap into that specialism, those parents at the beginning of their journey with ASD.
- Parents as professionals enables parents who are referred to the service to experience an empathic understanding of their situation, reducing isolation and invisibleness further, and helping parents cope in their situation.

7.2.9 Partnership in Practice

- Some professionals have a level of acceptance of the role of the Family Support team, some are glad of having something to offer parents and some call on the team to help them in their role.
- Some professionals don't understand the role or the service because it is so far removed from their role with families.
- The more connected a Family Support team is with the local Health and Social Care teams the greater the effectiveness of the service.
- In some instances an ARO has been able to connect with a 'hard to reach' family enabling Trust staff to gain access and provide support when previously they have found it impossible to get over the door.
- Some child protection issues have been identified as a result of the Family Support team intervention which proved a positive outcome for all.

7.2.10 Connecting with Parents

- Family Support team interventions with families mean that parents are talked to at their own level. It is never assumed that parents have all the knowledge they need about roles and acronyms used.
- An Autism Resource Officer (ARO) can pick up on what is said and also what is unsaid by parents. They have lived it and are still living it and know the effect on parents and other family members. They can ask the questions that others overlook. Often the focus of professionals is on the child/individual with ASD, and the needs of other family members are forgotten or overlooked.
- Enabling parents to open up often depends on your approach and your first reaction. Often parents ask and wonder what the ARO is there to do. The ARO's response says 'I'm here for you'. Knowing what is often not said and communicating an understanding of that makes a connection with parents that they can feel. It encourages a more open response by parents because a Family Support team member communicates understanding through their personal experiences. They know what to look for and how to identify when a parent is overwhelmed, distressed, or struggling. Professionals are often target driven or time limited with parents. They may not have the time to see what lies behind what a parent is saying. Their response may be more about quantity rather than quality.
- Professionals sometimes do not understand the parent's attempts to tell them they are not coping. One parent described how she was telling her social worker she wasn't coping and the social worker kept saying 'Not at all, you're doing great. You are really good with your child'. The parent felt she was being told to shut up and not share her real feelings, which then came out during her time with the Family Support team.

- Parents feel that many professionals get their knowledge from a book. Family Support team members live with ASD and they know that one size doesn't fit all when it comes to strategies and services. Team members are more readily accepted by parents and trusted by them because they are parents themselves.
- Parents often have expressed fear about telling statutory professionals the truth about their situation. They are fearful of the professional 'taking their child from them' and they don't open up. With a parent professional worker they feel more able to be honest and forthright about their situation; they don't have the same fear that they might have with for example a social worker or Family Support worker from the local Trust. By explaining the role of a social worker, the sort of help that might be available and helping parents realise their need for help some of these fears can be addressed and children's needs protected.



7.2.11 Lack of Consistency of Services

- The Family Support team has found that there is inconsistency of services for families in some local areas. It appears that the family that shouts the loudest gets more for their child/individual with ASD than the child/individual with greatest need. Some families are not prioritised because of their child/Individual's needs while other families get services that are often not needed. In some areas Children's Pathway planning is able to address this more effectively and duplication or unnecessary intervention is avoided.

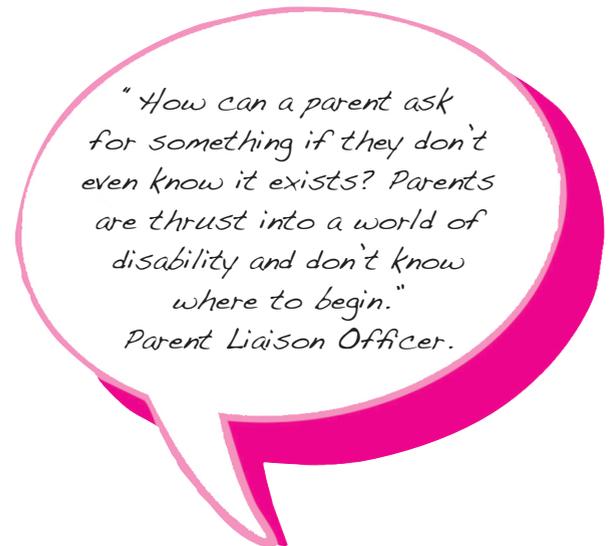
7.2.12 Empowering Parents

- The Family Support team have found that parents often get negative messages about their child/individual from diagnosis onwards. They are more often told what their child/individual cannot do from Health and Education professionals. This is contributed to by what parents need to do to access disability benefits, because they have to represent a negative view of their child/individual. This often feeds a sense of loss of what their child/individual can be. Having parents as role models can represent a more positive view of ASD. They can find out that their child/individual still has potential. The Family Support team can show through example what their child/individual may be capable of. They can often represent hope to parents.
- The Family Support team have found that parents often disengage with strategies that professionals have recommended because they don't understand the context in which it might help. They often feel disempowered, doubt their own ability, knowledge and capacity to effect change for their child/individual. Families need to feel empowered and to be supported to recognise their own value as a parent.
- The Family Support Service can also bring humour. They are able to laugh with the parent at incidents they have experienced with their child/individual. They can connect with the parents at their level and through humour help parents put incidents into perspective.

- By being role models, the Family Support team can communicate to families that it is possible to get through their problems and that they can face the challenges they are dealing with.
- The Family Support Service has found that parents often don't know what services or support exists out there.

7.2.13 Continuity of Support

The Family Support Team provides for a continuity of support at various stages of a child/individual's development into adulthood. They are available for support when a family encounters new issues they have to deal with in their journey with ASD. Once the initial support intervention is completed by the Autism Resource Officer the family is passed to the Parent Liaison Officer, who remains as a key worker for each family, contactable to the family at any future date. They maintain a database of families, ensuring any news about service development in the local area or significant reviews effecting children with ASD are passed onto families.



7.2.14 Value for Money Service

The Family Support Service consisting of a Full Time Autism Resource Officer with three part time Parent Liaison Officers (16 hours per week) costs around £55K to £60K per year. This provides for the officers on the ground, mileage costs, ongoing training, resources and the support of the management team within Autism NI.

As can be seen from the SEHSCT example Figure 5C on Page 26, the first three months of this service cost approx £12K to £15K. The service provided 87 Home Visits, supported 482 parents to Branches and Support Groups and responded to 326 Helpline/Listening Ear Calls. This is a new and evolving service. As it develops, Autism NI in partnership with key agencies involved will evaluate, monitor and continually improve the model. This report 'Autism in Northern Ireland - A Hidden Community, a Report on an Effective Family Support Model' and the upcoming trauma research report 'Is Anyone Listening' are needs led documents and their findings will be incorporated into the Family Support Service to enhance and improve practice. These documents have been made possible by funds raised by Autism NI.

Appendix 1

Case Study 1 (Parent Liaison Officer)

"Mary is a single parent of a five year old boy called Tom who attends an MLD primary school. On my first visit to Mary she reports that Tom is happy in school. When I asked Mary how she was coping with Tom at home, she said that at home his behaviours were very difficult to manage. Mary also disclosed that she herself was on anti depressants and though she has a little support from her disabled father there was no support from anyone else. She confided that Tom's father has never had any contact with her. She is living on income support and tax credits. Financially she was really struggling with only £20 a week left after she had paid her rent and debts. Mary has applied for DLA which has not been processed yet. I also gave her an application for The Family Fund.

I gave Mary advice on ASD strategies and Support Groups in the area, the training provided by the local Trust; however I felt that Mary wasn't engaging with any of my suggestions.

After agreeing to come back and visit Mary a second time I left with a sense that she was struggling to survive financially. She also gave me the sense that she was very isolated, alone and had little understanding of Tom's difficulties and how she could help him.

On my second visit Mary appeared the same, very calm but on this occasion I felt she wanted to talk. I asked her about Tom's behaviours. She admitted that his behaviours were more extreme and vicious than before. He verbally and physically abuses her every day. I asked her how she coped with this. She informed me that she just left the room and let him misbehave. She told me she could not cope with him anymore and that her G.P. wants her to be admitted to hospital for assessment for her long running depression but she has no one to leave Tom with. Mary then shared that she had been drinking heavily, a ½ bottle of Vodka at least twice a week and she would nearly do anything to get the money to buy it, it was the only release she had.

I advised Mary that because she had shared this information with me I would have to refer her to my Designated Officer because of potential child protection issues concerning her alcohol intake. Mary agreed to this measure and stated that she was aware that she could not cope anymore and didn't want to keep trying on her own, that she was lonely and wants help from whoever was able to provide it.

I believe that Mary told me about her drinking as a cry for help.

Mary's case was reported to the Gateway team that day and the team said that they would contact her that day and arrange to visit her the next day.

It is important that the Family Support Service follow up with families and build up a relationship of trust and on a personal level to follow your instinct of how you felt when you finish your visit."

Case Study 2 (Autism Resource Officer)

"In my first visit with Jackie I found her very upset throughout the two hours meeting. She cried relentlessly about Michael, her eight year old son, his diagnosis of Asperger Syndrome and his behaviours in the home. He was being extremely physically violent and verbally abusive towards her. Jackie admitted she was frightened of him as she did not know what he would do next. She felt no-one would believe her as he behaved well in school.

I gave Jackie support and reassurance and told her that because of Michael's behaviour I felt it was necessary for her to speak to the Speech and Language Therapist who was starting to work with Michael. It was important that she make the Speech and Language Therapist aware of the problems in the home and to see if she could refer Michael to other services to support Jackie and Michael.

On my second visit I found Jackie still weepy but coping a bit better. Jackie told me that the Speech and Language Therapist had referred Michael to a Psychologist for one to one intervention. The family were also referred to the Developmental Intervention Service and structures were put in place to support Jackie and Michael.

On this visit I was able to talk to Jackie about Asperger Syndrome and the complexity of the condition. I was able to offer support to help her manage his behaviours, e.g. a time timer, and to help her understand the importance of working with the schedules set up with the Developmental Intervention Service. I gave her some information about behaviour management strategies as well as information about the Parent Support Group in her area and literature that would increase her understanding of Asperger Syndrome.

Jackie came to the Support Group however she was still concerned and didn't believe the interventions and strategies would help. We gave advice and encouragement at the Support Group meeting and I decided to visit her at home a third time. This time the Parent Liaison Officer (PLO) for the area accompanied me.

On this visit I saw a great change in Jackie. She appeared more in control and instead of reacting to Michael's behaviour she has started to reflect on it. She said the Psychologist intervention was working well and she believed that she herself was mentally stronger and was able to reinforce positive routines and behaviour strategies. She herself understands Asperger's Syndrome better and can help Michael with his difficulties. Michael himself is more aware of his difficulties and strategies have been put in place to try and support him through stressful and anxious times.

Jackie believes the time timer was a 'God send'. She said the difference it made to Michael, his homework, as well as his ability to cope with change and waiting was enormous. This change benefited the whole family.

Jackie still attends the local Support Group and the PLO and I keep in touch with her through Autism NI's listening ear service for continued support."

Case Study 3 (Parent Liaison Officer)

"A parent of a fifteen year old boy with Aspergers approached me to talk about her sons difficulties. John, as a child, was diagnosed with ADHD, but his mother felt as he grew older that there was something more going on.

John was diagnosed at eleven with Aspergers Syndrome. John's mother had told him about his diagnosis and briefly outlined the condition. She now felt he was ready to be given more information. I gave her a copy of "What is Aspergers Syndrome – and how will it affect me?" John had a younger sister and I suggested a sibling workshop and watching a copy of the Rory Hoy DVD. She attended the workshop. The whole family also watched the DVD and straight away saw the connections with their son and brother. This gave them a better understanding of what they were dealing with.

The mum had applied for Disability Living Allowance (DLA) several years previously with no success. She had not appealed this as she felt she was not entitled to benefit. When we discussed her previous application I realised her own lack of knowledge about her son's condition had meant she hadn't put sufficient information on the form to explain her son's additional care needs. I advised her to send for forms and gave her assistance in completing these. An award was granted for middle rate personal care and lower rate mobility. The mother was delighted and described me as a miracle worker. This opened another door as the mum was now entitled to claim carer's allowance. The financial difference this made to the family was immense.

John had a lot of interests, one being War Hammer. This financial support enabled John and John's mum to arrange a taxi to War Hammer club and piano tuition. The family didn't have access to their own transport and John had no social outlets prior to this. It also helped with respite care through Crossroads the Caring for Carer's Organisation.

The Family Support service opened a new door of hope and both the mum and dad benefit from monthly parent support meetings and events organised by the service. The parents said "if only this service had been available years ago".

Case Study 4 (Autism Resource Officer)

"I provided a listening ear service to a distraught single parent who has four children. The eldest two boys had been diagnosed with ASD. Jack and Colm were at opposite ends of the spectrum. Jack had Asperger's Syndrome with poor social skills while Colm had classic ASD with a learning difficulty. The mum felt total isolation and did not know to deal with them individually.

Jack was about to make the transition from primary to secondary school. I provided information, hints and tips around school selection. I was able to give a parent's perspective on findings on the school. Jack also had sensory issues and so I advised the mum about the Anne Laure Jackson workshop on Sensory Integration, organised by Autism NI. This helped the mother and grandmother to understand Jack's sensory issues better. I also advised the mum on other suitable courses.

The younger boy had behavioural problems and was extremely demanding. The mum had little time to herself and needed a Carers Assessment done. The mum didn't know what this was and I explained. She didn't know she was entitled to this. I put her in touch with the Health and Social Care Trust ASD Link worker who dealt with complex cases to do the assessment.

I helped the mum complete two DLA forms which resulted in higher rate personal care being awarded for one of the boys and middle rate being awarded for the other. In addition, both were awarded lower rate mobility allowance. The mother attends the support group where an ongoing listening ear is provided, as well as information on the Family Fund. Books on ASD have also been lent to the family from the Family Support team library."

Appendix 2

Quotes from parents

"When my son was diagnosed I left the clinic and cried the whole way home. I cried constantly for about a week. I didn't know what to do next. I was left with this devastating news and not one professional contacted me afterwards. I was devastated and looking back I can see that this was wrong. What I needed was someone who knew what was happening to help me through my grief and loneliness. How could I tell my family, I didn't know what I was talking about? How could they help me, they never knew anything about Autism?"

"Audrey sat with me, cried with me, and talked about why I was feeling like that. I thought I was going mad. Just having someone there who's been through it, who understands, and who can help me see what I need to do next was so good and just what I needed at that time. My son now has a mother who is more confident, and who knows that if she doesn't understand anything or comes up against obstacles that Audrey is there for me, at the end of a phone, and can help me through it"

" When I talk to Mary I know she understands what I'm saying, even if I'm finding it hard to put into words what I feel about my son and what he needs. Mary says something and it just captures what I'm trying to say. I don't feel I have to justify what I think and feel to Mary, she just gets it"

" After my daughter was diagnosed we were just in shock. We didn't know how to help her and we had no idea if we were treating her the right way. Linda spent time with me in my own home, listening and helping me understand what we had just been through and what might lie ahead. She was able to give me some hope about the future. Now I can explain to my husband what Linda explained to me"

" When I go to an appointment with my daughter it's all so rushed. I feel guilty for taking up the consultant's time. And I feel I'm asking stupid questions. Sometimes I feel I should know more, but I don't know how to find out. If I don't know how to ask for something, how can I help my daughter? I feel like a failure all the time."

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The report was supported by the Ben Clark Foundation



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