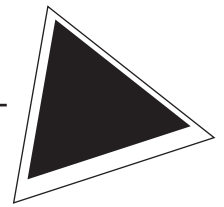


# COLOURING LIVES



## A Strategy for Autistic Spectrum Disorder



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In line with our Communicating Information Well Policy, the Northern Health and Social Services Board is committed to making information as accessible and equitable as possible and to promoting positive and meaningful dialogue with local people.

## **ALTERNATIVE FORMATS**

In an effort to make information as accessible as possible, the Strategy for Autistic Spectrum Disorder (ASD) has been produced in large print.

The Strategy can also be made available in the following alternative formats:

- ◆ Large Print (size as required)
- ◆ Computer Disk
- ◆ Audio tape
- ◆ Translation

For an alternative format please contact:

The Patient/Client Information Services:

**Telephone Number:** 0845 7626428

**Textphone:** 028 2531 1001

The Strategy for ASD can also be found on the Board's website at:  
[www.nhssb.n-i.nhs.uk](http://www.nhssb.n-i.nhs.uk)

**ADDITIONAL COPIES** can be obtained by contacting:

Social Services Directorate  
Northern Health & Social Services Board  
County Hall  
182 Galgorm Road  
**BALLYMENA** BT42 IQB

Telephone Number: 028 2531 1216 or 028 2531 1000

Fax Number: 028 2531 1236 or 028 2531 1100

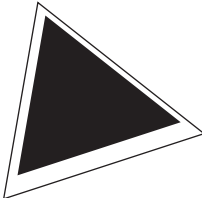
E-mail: [socialservices@nhssb.n-i.nhs.uk](mailto:socialservices@nhssb.n-i.nhs.uk)



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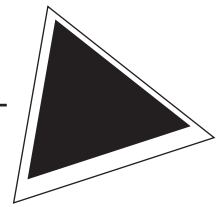


**“Autism is a persistent condition that appears in childhood and affects crucial areas of a person’s development including communication, social interaction and creativity”.**

**All Party Assembly Group on Autism**

**The cover design for this document is based on parents’ observation of the impact of ASD which was shared during the consultation. It was described as “taking the colour” out of life due to its impact on social interaction and communication. This thought has underpinned much of the motivation for producing this strategy and in particular the capacity and potential for sensitive service development to help bring back “the colour” into people’s lives.**





## FOREWORD

The term Autistic Spectrum Disorder (ASD) describes a range of conditions which affect the lives of many individuals and families throughout Northern Ireland. Whilst for some people the impact may be relatively mild, for others it can create major problems in social and family functioning.

Awareness of ASD has increased significantly in recent years and, in particular, since the beginning of the new millennium. However, the enthusiasm and commitment with which this has been promoted has not been translated into significant service development with Health and Social Services.

This may be due, in part, to the relatively weak statistical information and the fragmented nature of the arguments being advanced on behalf of this population. On the other hand, there has been a measure of resistance, or at least lack of acknowledgement within the statutory sector, to the fact that if the needs of people with ASD are to be adequately addressed, greater consideration needs to be given to specialist service design and remodelling.

Commissioning health and social care requires an ability to recognise changing needs within our population, to respond appropriately and imaginatively,

when these find expression in new ways. There is a growing sense, at all levels within Health and Social Services, and indeed in other agencies as well, that we may be near to a 'tipping point' in relation to addressing ASD in a more explicit and proactive way.

This document attempts to anticipate how this might best be achieved:

- by bringing together as much information as possible available to the Board;
- by providing an objective analysis of what this tells us;
- by sharing this in turn with a much wider range of interests; and finally
- by identifying a list of prioritised actions which we feel would make a major contribution to creating a coherent, equitable and responsive service to people with ASD and their families.

-----  
**Kevin P Keenan**  
**Director Social Services (Acting)**

# 1. INTRODUCTION

## What is Autism?

Autism is a life long disability which disrupts the development of social and communication skills. The causes are, as yet, unknown but are likely to be complex and there is no accepted cure at present. The term Autistic Spectrum Disorder (ASD) is used because Autism varies from person to person, however the majority of people do not have a learning disability. Those who do not have a learning disability, but who have an ASD, are likely to be diagnosed with Asperger Syndrome.

ASD is a hidden disability; individuals with ASD do not have particular physical characteristics. This lack of visible disability accompanied with the varied and complex presentation of ASD, can cause significant problems for them, their families and for service planners and professionals who must respond to diverse need.

Regardless of a person's level of intelligence, individuals with an ASD will experience difficulties in how they perceive the world and will have problems in the areas of:

- social interaction;
- communication; and
- flexible imagination/flexible thinking.

Research suggests there is no single cause but that there is a

physical problem affecting the areas of the brain that integrate language and information processed from the senses. Individuals will also experience problems with their sensitivity to sensory stimulation. These can be the cause of distress and behavioural problems.

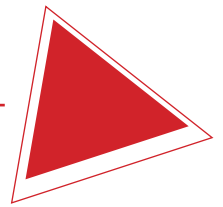
## Diagnosis

ASD varies from person to person and is most likely to be diagnosed in childhood, however, some people do not receive a diagnosis until their teenage or adult years. The average age of diagnosis for Autism is 5.5 years and the average age for diagnosis of Asperger Syndrome is 11.3 years.<sup>1</sup>

Diagnosis of ASD should be made by a multi-disciplinary team. In Northern Ireland many practitioners have received training in specialist procedures for children and adults who are difficult to diagnose. ASD affects four times more males than females regardless of racial or socio-economic status.

## Terminology

There are various terms used to describe ASD. Autism is the umbrella term commonly used for ASD with a learning disability and Asperger Syndrome to describe individuals with an ASD and average or above average intelligence and who do not have a learning disability. Other terms



that are used include: Autistic traits, high functioning Autism, Autistic tendencies and more rarely, Kanner's Syndrome or classic Autism. Throughout this document the term ASD will be used unless it is important to differentiate between individuals who have Autism and an associated learning disability, (ie an IQ of less than 70) or those with Asperger Syndrome who have no cognitive impairment but face enormous challenges in social interaction. There is a third very significant group that do not fit into these classifications but to whom the term ASD can be applied. The needs of these individuals often fall outside the remit of many statutory and voluntary agencies.

### **ASD - The Local Perspective**

The significantly increased awareness of ASD since 2000 has highlighted the need for a more focused and integrated response to the needs of the people and families affected by it. Progress to date has been slow and is outlined in more detail in the next section of the report. In recent years, however, the original narrow definition of the ASD remit has:

- widened beyond learning disability to child and adult health and mental health;
- encompassed children and adult services; and

- recognised the need to address housing and employment issues.

There is a need to consider a more specific focus on planning and developing services for people with ASD on a collaborative, inter-agency basis. The proposed changes in the delivery of public services which are envisaged in Northern Ireland provide an opportunity to consider how these challenges should be addressed. This document is an attempt to bequeath a coherent prioritised and shared vision for the shape of future developments in the new Northern Health and Social Care Trust (NHSCT) area which will promote fairness and balance and help those involved in, and committed to, ASD to have direction and clear objectives.

## 2. CONTEXT - PHASES OF DEVELOPMENT

The previous section of the report referred to the increasing profile of ASD in recent years and the factors which have provided the impetus for producing this document. In order to explain the proposals outlined later, it may be helpful to provide a brief overview of developments within Health and Social Services to date, to identify the drivers for change, the milestones, the developing alliances and also limitations which have got us to where we are today.

### **The First Phase - Establishing an Identity**

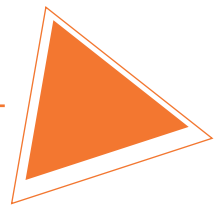
ASD began to impact on service planning in the Northern Health and Social Services Board (NHSSB) and its former Trusts in the early to mid 1990's, partly due to individual families approaching agencies in their search for therapies or interventions which seemed to offer significant benefits to people with the condition. At that time, lead responsibility lay within the Learning Disability Programme Planning Team - a situation which was replicated in the other Boards and Trusts at that time.

In the absence of specialist services, it was largely left to individual 'champions' to pilot particular approaches on a local level alongside the vigorous promotion by Autism NI (PAPA) (Parents and Professionals and

Autism) of TEACCH (Treatment and Education of Autistic and related Communications-handicapped Children) which was a programme of intervention developed in America that helped families and other carers to adopt a structured approach to therapeutic interventions. It was largely through the combination of professional and parental enthusiasm that local initiatives began to develop the distinctive informed grass roots commitment that was to begin to challenge and change views about ASD.

This found explicit expression in 2000 in the former Homefirst Community Trust (Homefirst) with the establishment of a multi-disciplinary Autism Assessment and Diagnostic Service (AADS) through the provision of some additional funding for Psychology and Speech and Language Therapy (SLT) input. The catchment area and client focus were initially limited and the linkages with Child Development Clinics (CDCs), Child and Adolescent Mental Health Services (CAMHS), Educational and Clinical Psychology and Learning Disability Services were poorly developed.

This also coincided with the first tentative developments in the former Causeway Health and Social Services Trust (Causeway) where parents with an interest in



Applied Behaviour Analysis (ABA) found expression through PEAT (Parents' Education as Autism Therapists) which had grown from an academic base at the University of Ulster.

By the end of this stage, ASD was on the map but there was no sense of a broad vision or of having moved beyond a relatively local perspective.

### **The Second Phase - Testing, Building, Influencing**

Whilst this initial burst of energy helped to establish ASD as an issue for both Education and Health and Social Services in particular, this was reinforced in the next phase by a number of other developments:

- the influential Diagnostic Scoping Study undertaken by Autism NI (PAPA) and University of Ulster in 1997/98;<sup>2</sup>
- the provision of short term funding for a number of ad hoc, rather than co-ordinated, training initiatives;
- the piloting and development of early intervention family support services such as the promotion of ABA by PEAT, the Keyhole Project by Autism NI (PAPA) and initiatives such as the specialist STARS playgroup in Kilrea;

- the establishment of an authoritative research base within these islands on the types of service models/therapeutic responses;
- the incremental building of a political 'constituency' for ASD;
- the increased profile of Autism in the Republic of Ireland;
- increasing awareness both locally and internationally of the complex and unique presentation of ASD; and
- changing and increasing prevalence rates worldwide throughout the late 1990's and into the new millennium.

One of the most obvious deficits was in terms of the lack of meaningful funding to take forward the learning and the increased awareness was leading to calls for a more strategic approach to be adopted.

### **The Third Phase - Recognition and Resources**

The beginning of the next phase of development was the publication, by the Department of Education (DE) in April 2002, of the Task Group Report on Autism.<sup>3</sup> This was the first example of decisive 'ownership' of many of the implications of ASD by a major statutory body and it was immediately recognised as an authoritative source document but development of the links with Health and Personal Social

Services (HPSS) and other agencies would take time.

This document helped provide the stimulus for the first co-ordinated investment of dedicated, recurrent funding in ASD services. It paved the way for the requirement for Health and Social Services Boards (Boards) to work with the North Eastern Education and Library Board (NEELB) in producing a joint paper in October 2003 in response to the first formal planning statement about ASD by the Department of Health, Social Services and Public Safety (DHSSPS) as outlined in their 'Priorities for Action' in 2003/04.<sup>4</sup> This had been anticipated at a seminar organised by the NHSSB in October 2004,<sup>5</sup> following the initial allocation, to prepare for future funding. It built on the work of the Boards, referred to above, by identifying incremental investment priorities. Unfortunately, a second allocation, which had been originally indicated, failed to materialise in 2004/05 as ASD slipped from the policy agenda. This was disappointing as DE and HPSS had begun to align their investment decisions in a more meaningful way.

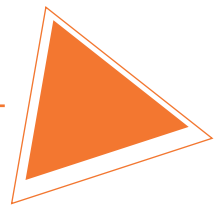
During this stage, professionals and carers had been faced with hard choices and having to recognise that in order to address the needs of people with ASD in

a significant fashion, a coherent, agreed plan was needed. Commitment and objectivity needed somehow to be reconciled.

### **The Fourth Phase - A Policy Solution**

The ASD constituency has, however, been resilient and the disappointment was tempered by an awareness of the potential benefits which might accrue from the Review of Mental Health and Learning Disability (2006)<sup>6</sup> which had been initiated under the leadership of the late Professor David Bamford. It seemed to hold the promise of addressing the interface between these Programmes of Care (POCs), the issue of lead responsibility and placing ASD more firmly within policy considerations.

It is probably fair to say that, for many lobbyists and service providers involved with ASD, the Review has not lived up to expectations, not least because of the initial proposal to place ASD within the Mental Health POC. After much campaigning by the ASD community in Northern Ireland, this was changed, leaving a legacy of anxiety regarding the future planning of ASD services in Northern Ireland. However, the Review's recommendations still have significant potential for advancing the agenda as evidenced



by the Ministerial announcement in September 2007 of a regional Review of Autism Services. Despite these difficulties, it appears to have contributed to another allocation of funding and, in time, to the development of a regional, strategic paper on services for ASD. Whilst preparing to inject additional resources into the system, there is a need to take a broad view of what needs to be done. The messages coming out of the current stage of development are that it is time to:

- plan and shape a system for a diverse and complex population and not on a case-by-case basis;
- plan along the spectrums of chronological age and intellectual capabilities;
- acknowledge the unique complex and heterogeneous challenge of ASD;
- exploit the scale of investment and skill already locked up within current services;
- involve clear accountability, measurability and impact; and
- plan a more co-ordinated inter-agency and inter-sectional basis.

The current Review of Public Administration (RPA), which will include significant changes in how many public services are planned and delivered, may provide an opportunity for more co-ordinated and integrated planning of ASD services between HPSS and DE. It may, in turn, provide a basis for promoting a greater level of involvement from organisations committed to the provision of housing, transport and leisure to begin to develop a more comprehensive and sensitive response to the needs of people with ASD.

### 3. PREVALENCE AND NEEDS

In order to respond effectively to the needs of people with ASD, it is necessary to have some understanding of the prevalence of the condition and the variety of needs generated by it. Organisations such as HPSS and DE tend to have relied on two different sources of information to date in trying to tailor their responses appropriately. The first of these lies in clinical and academic research data and secondly in the operational information collected by services. Both of these have not been without their problems.

#### Research/Academic Studies

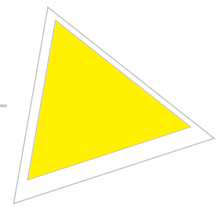
The earliest UK prevalence study, in 1966, suggested a prevalence rate of 4.5 cases of Autism per 10,000 of the general population.<sup>7</sup> However, published rates subsequently have been higher, as the understanding of a spectrum of Autistic Disorders has increased. Wing and Gould's study of children with a learning disability in 1979, also reported an Autism prevalence rate of just under 5 per 10,000 population.<sup>8</sup> They also found a further 15 per 10,000 children whom they identified as, although falling short of a diagnosis of Autism, showing some evidence of the 'triad' of

autistic impairments and therefore fell within what we would now refer to as 'the Autistic Spectrum'. The total ASD prevalence among children with a learning disability reported by Wing and Gould was approximately 20 (ie 5+15) per 10,000 individuals.

As far as children who *do not* have a learning disability are concerned, Ehlers and Gillberg, in their 1993 survey of mainstream children (IQ 70+) in Gothenburg, Sweden, reported that 36 per 10,000 children had Asperger Syndrome, and a further 35 per 10,000 could be placed elsewhere within the spectrum of Autistic Disorders.<sup>9</sup> The total ASD prevalence among children *without* a learning disability reported by them was approximately 71 per 10,000 individuals.

By aggregating the respective prevalence rates derived from these two studies, one arrives at an overall rate for ASD, among children of all levels of intellectual functioning, of 91 (ie 20+71) per 10,000 of the general population. The breakdown of these children can be summarised conveniently by way of a simple 2 x 2 grid representing both IQ level and level of ASD symptomatology.





#### **Full Symptomatology (ie meeting the criteria for either Autism or Asperger Syndrome)**

<b>5</b> (per 10,000)	<b>36</b> (per 10,000)
<b>Within the Learning Disability Range (IQ&lt;70)</b>	<b>Outside the Learning Disability Range (IQ 70+)</b>
<b>15</b> (per 10,000)	<b>35</b> (per 10,000)

#### **Partial Symptomatology (ie within the ASD spectrum, but not meeting the criteria for either Autism or Asperger Syndrome)**

It should be noted that, whereas the general expectation will be for the level of a child's ASD symptomatology to be related directly to the degree of impact on his/her daily living, ie the more ASD features that are present, the greater the expected impact on the child's day-to-day functioning, this will not necessarily be the case. Some children whose symptoms are such that they do not fulfill the criteria for either Autism or Asperger Syndrome may still experience very significant limitations in terms of their daily lives.

Whilst a number of more recent studies have suggested even higher prevalence rates (eg Baird et al, 2006,<sup>10</sup> have estimated the figure to be as high as 116 per 10,000), other academics (eg Lilienfeld and Arkowitz, 2007,<sup>11</sup>) have urged caution in the interpretation of such figures, pointing out that it is not clear whether the reported rise in prevalence rates indicate a

genuine increase in the number of ASD cases, or better assessment practices and/or a broadening of the diagnostic criteria that are used.

Given the ongoing lack of precision about the true prevalence of ASD, the figure presented earlier, of 91 cases per 10,000 of the general population, would seem a reasonable basis from which to estimate the number of individuals with an ASD throughout the local population. Certainly, it is very close to the figure of 1% cited by Baird et al (see above).

Such studies clearly contribute to the ongoing debate about the need for change but they have had little impact on service planning because of the difference between prevalence and presenting need. They have not been sufficiently sophisticated to identify the scale and variety of needs of the population.



If one applies the regional estimate identified above to the population of the NHSSB/NHSCT, the rates per District Council would be as outlined in **Table 1**. The figure of over 4,000 does not correlate with any known or suspected population in contact with current services. In order to develop a more fine-tuned response to ASD, there will have to be a resolution to the scale of this discrepancy and to eligibility for, and access to, services. There should be 992 children and young people with ASD in the NHSSB/NHSCT based on the prevalence rate. However, from the most recent information available in the period

from 2003 to 2007, approximately one third (ie 387 children) are known to have received a diagnosis (**see Figure 2**).

### Service Data

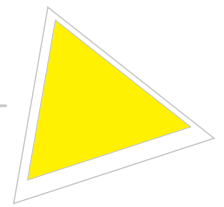
The following sections illustrate this dilemma by attempting to gather information about need and/or demand in order to assist the process. An immediate problem which contributes to the inconsistent nature of the data is that the needs of many people with ASD, even if not diagnosed or identified as such, are being met within a range of non-specialist services. A relatively small number

**Table 1: District Council Population and Estimated Numbers of People with ASD based on Prevalence Rates in the NHSSB/NHSCT**

District Council	Total Population	Estimated Prevalence based on 91/10,000 ratio	0-17 Year Old	Estimated Prevalence based on 91/10,000 ratio
Antrim	51,510	469	13,354	122
Ballymena	61,352	558	14,423	131
Ballymoney	29,225	266	7,304	66
Carrickfergus	39,715	361	9,523	87
Coleraine	56,718	516	13,447	122
Cookstown	34,769	316	9,322	85
Larne	31,256	284	7,216	66
Magherafelt	42,419	386	11,433	104
Moyle	16,541	150	4,000	36
Newtownabbey	81,204	739	19,041	173
Total	444,709	4,045	109,063	992

Source: NISRA Mid Year Population Estimates 2006  
Wing and Gould; Ehlers and Gillberg Aggregated Prevalence Rate





of children and some adults with learning disabilities have had access to more specialist provision but, even then, the lack of diagnosis and displacement to other services are unquantified factors. The following information must therefore be viewed with these caveats and no attempt is made to present it as a definitive picture of need.

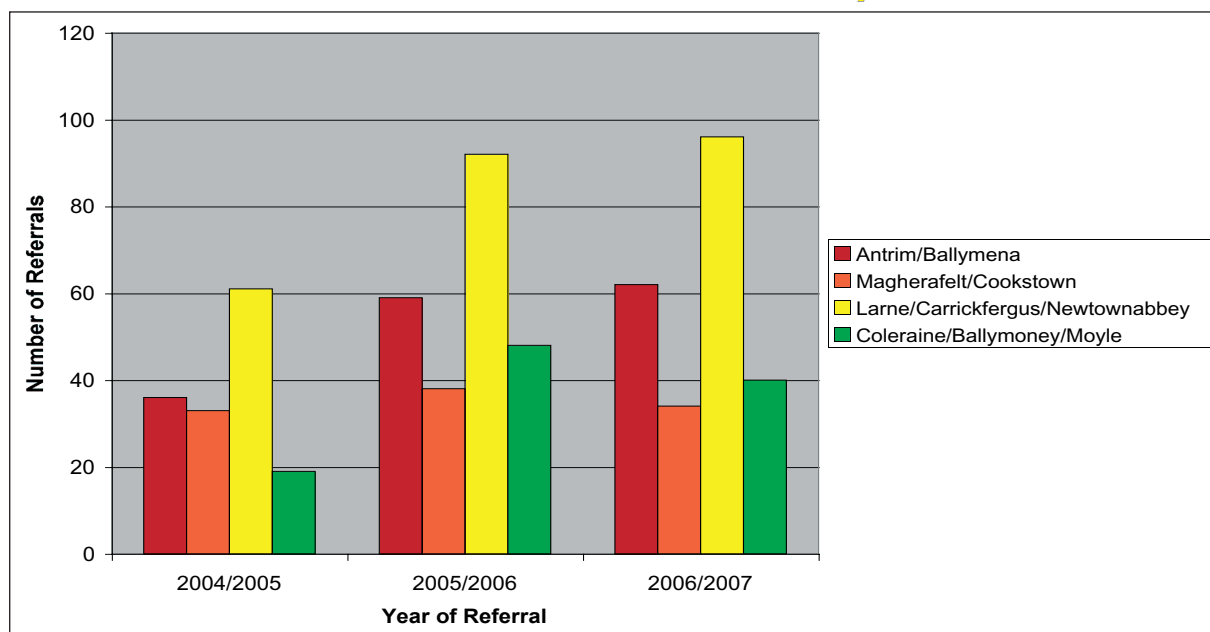
#### Specialist Diagnostic Services - Children

Referral information is only available for the years 2004/05 - 2006/07 from the **Autism Assessment and Diagnostic Service (AADS) Teams** for children in the former Causeway and Homefirst areas. However, some information was collected in Larne, Carrickfergus and Newtownabbey in 2003/04 where there was a total of 51 referrals.

**Figure 1** shows the numbers of referrals across the NHSSB and highlights the increasing numbers of clients with suspected Autism or Asperger Syndrome being referred to specialist services. There is clearly a significant increase in referral rates since 2004/05.

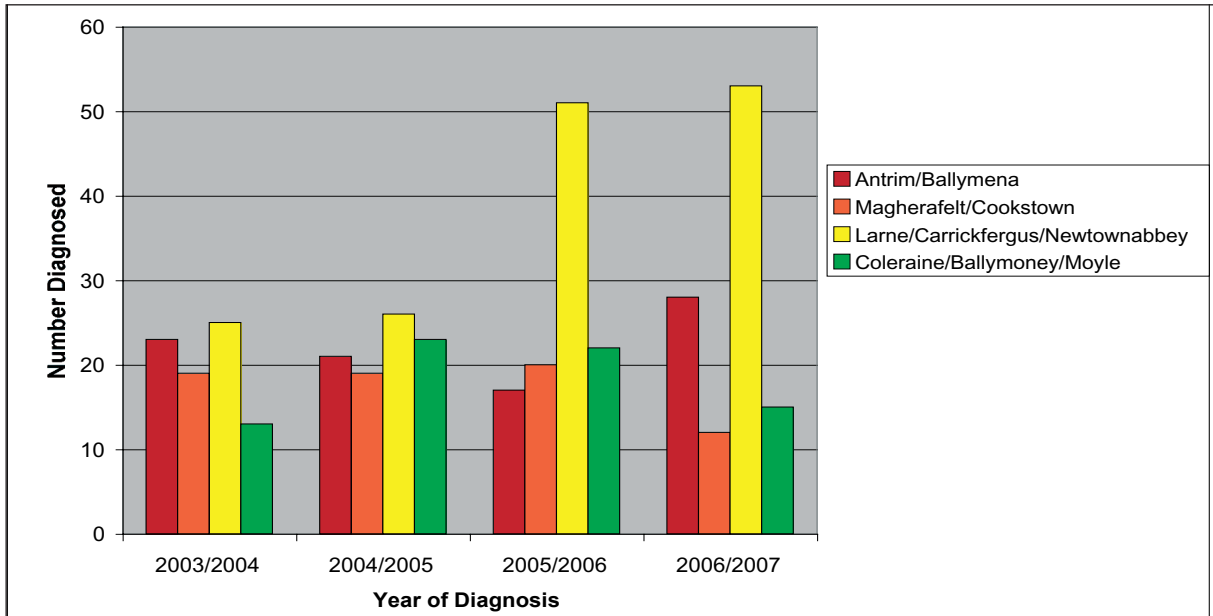
**Figure 2** shows the outcome of these referrals in terms of diagnosis. Of the total number of recorded referrals (669) across all District Council areas since 2003/04, 58% received an actual diagnosis of either Autism or Asperger Syndrome, 34% were not diagnosed and 8% required further assessment and investigation. Of the 387 (58%) who received a diagnosis, 126 (33%) were diagnosed with Asperger Syndrome.

**Figure 1: Number of Referrals to Specialist Diagnostic Services for Children in the NHSSB from 2004/05 - 2006/07 by Sector**



Source: AADS Teams, NHSSB

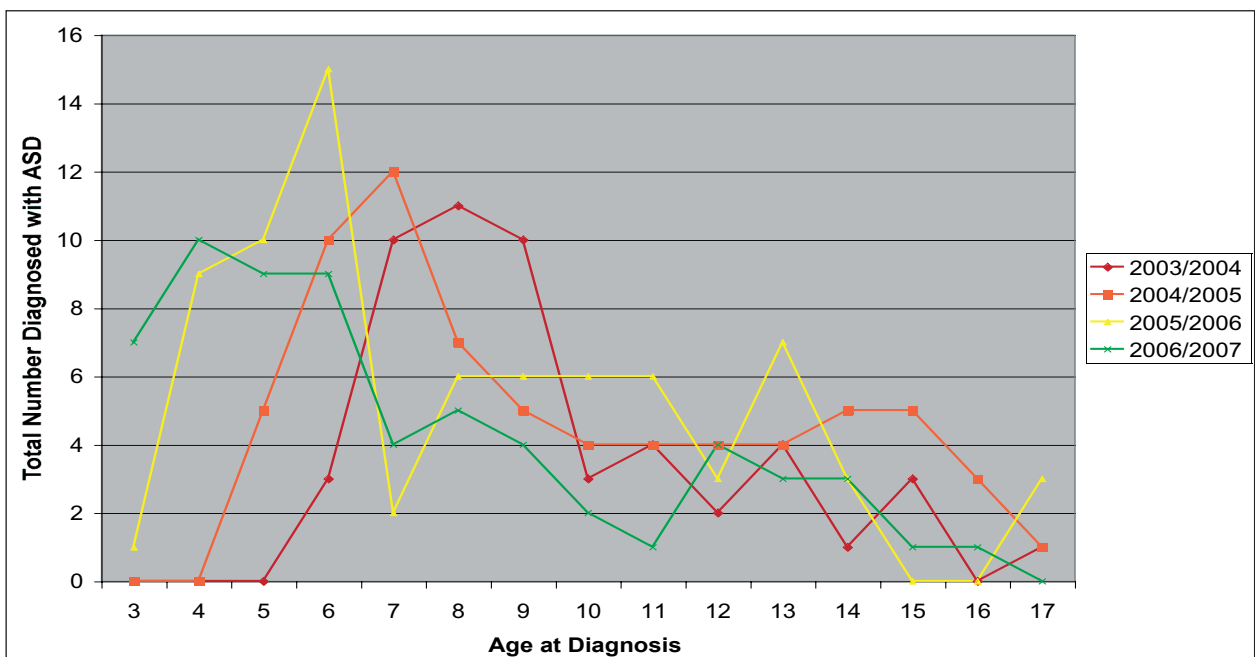
**Figure 2: Number of Children Diagnosed with ASD in the NHSSB from 2003/04 - 2006/07 by Sector**



Source: Child Health System, NHSSB

There has been a 26% rise in diagnosis since 2003/04 to date. This is most evident within the Larne, Carrickfergus and Newtownabbey sector.

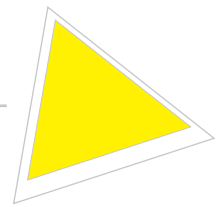
**Figure 3: Number of Children Diagnosed with Autism in the NHSSB from 2003/04 - 2006/07 by Age at Time of Diagnosis**



Source: Child Health System, NHSSB



### 3. PREVALENCE AND NEEDS



**Figure 3** shows the age of the 261 children and young people (67%) who received a diagnosis of Autism during the period, the modal age at the time has fallen from age 8 in 2003/04 to age 4 in 2006/07, which could be attributed to the increased awareness of ASD and the development of the specialist diagnostic teams.

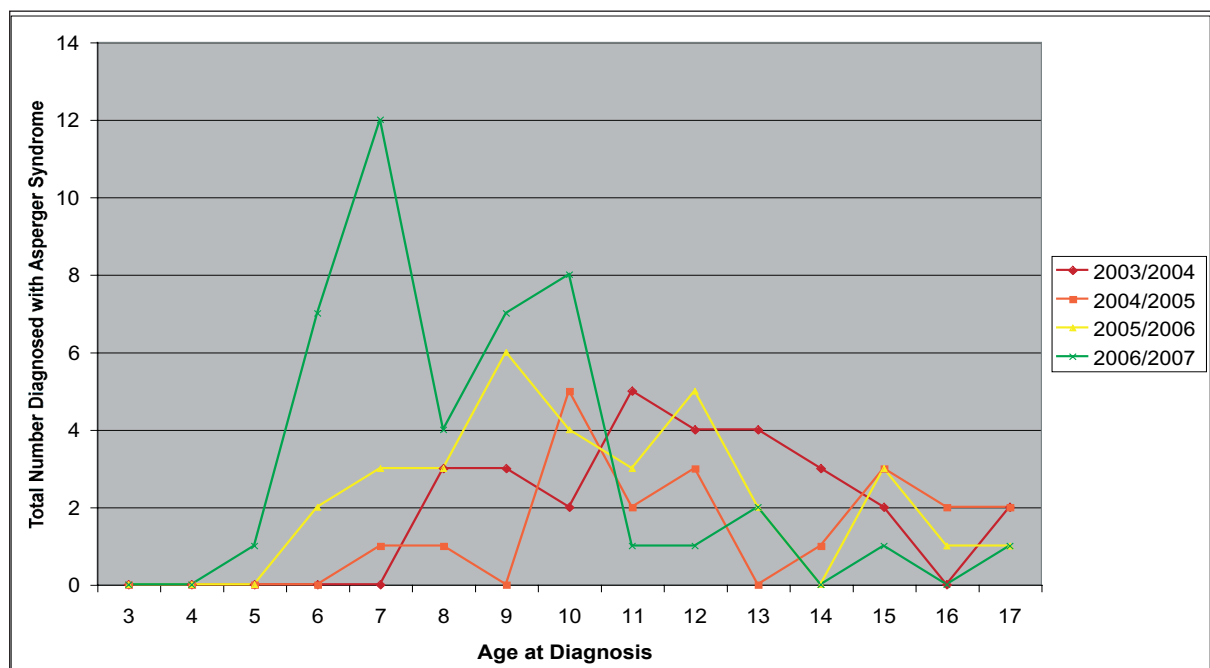
The modal age at time of diagnosis for the 126 children and young people (33%) who received a diagnosis of Asperger Syndrome during the same period, (see **Figure 4**), has also fallen from age 11 in 2003/04 to age 7 in 2006/07, probably for similar reasons to those referenced previously.

The average age at time of diagnosis for Asperger Syndrome, both in the NHSSB and regionally, is higher than Autism in line with findings by Teitelbaum et al (2004).<sup>12</sup> During the period 2003/04 - 2006/07, 88% of the total number of 387 children diagnosed with ASD, were male. A similar percentage diagnosed with Asperger Syndrome was also male. This gender ratio is reflective of the national/international trend.

#### Child and Adolescent Mental Health Services (CAMHS)

Prior to 2004, CAMHS accepted referrals for children and young people for assessment and interventions when ASD was

**Figure 4: Number of Children Diagnosed with Asperger Syndrome in the NHSSB from 2003/04 - 2006/07 by Age at Time of Diagnosis**



Source: Child Health System, NHSSB

suspected and for intervention when a diagnosis had been provided by another service.

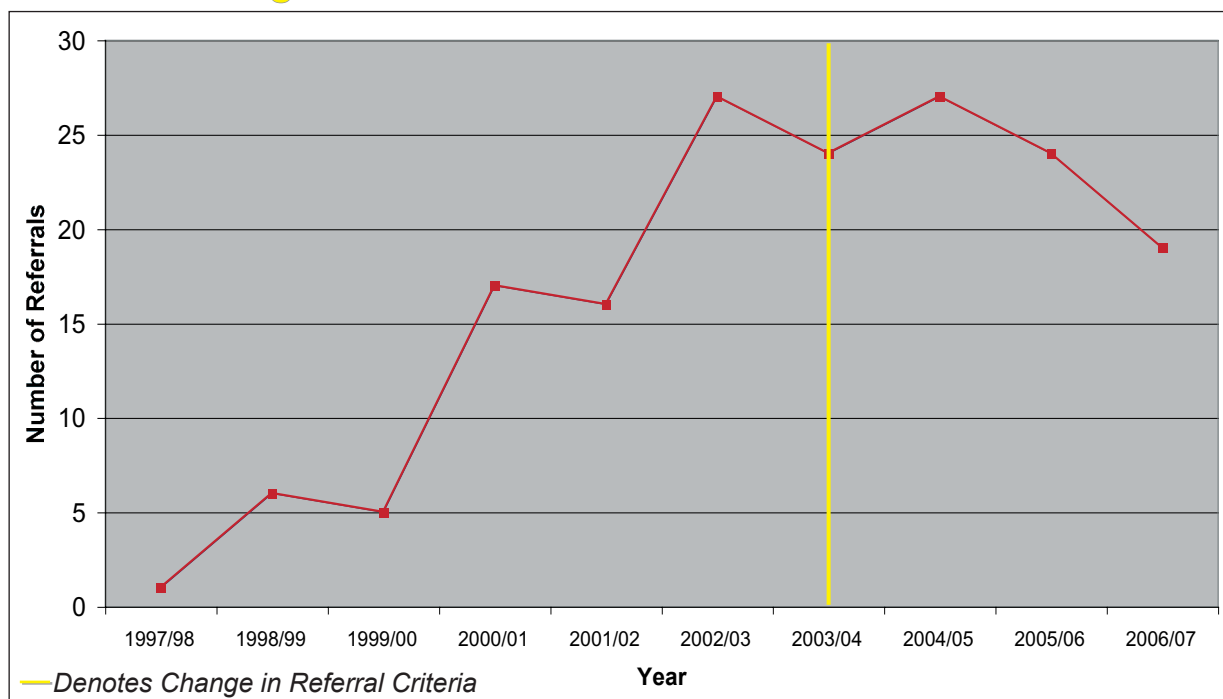
Interventions at this time included post diagnostic support and education in relation to the diagnosis of ASD, assessment, diagnosis and treatment of mental health difficulties. Advice/support was given about the management of issues associated with ASD to the young person and the family as they moved through developmental milestones in childhood and adolescence, eg transition from primary to secondary school.

Since 2004, CAMHS no longer accept referrals for the assessment

of ASD given the development of specialist diagnostic teams and now only accept referrals for a child/young person who has ASD if there are mental health concerns and/or if a second opinion is requested regarding diagnosis.

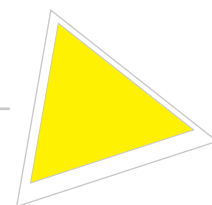
The number of referrals to CAMHS for children and young people with a suspected or actual diagnosis since 2004 have totalled 70 (see **Figure 5**). The annual rate has only decreased marginally even with the change in referral criteria. The children and young people who are referred do, however, meet the criteria for CAMHS as there are mental health concerns.

**Figure 5: Referrals to CAMHS of Children with a Suspected or Confirmed Diagnosis of ASD in the NHSSB from 1997 - 2007**



Source: Child and Adolescent Mental Health Services (CAMHS), NHSSB

### 3. PREVALENCE AND NEEDS



#### Adult Mental Health Services

In Adult Mental Health Services, there is no authoritative data available in relation to diagnosis for ASD/Asperger Syndrome. A number of people who have accessed services have had a diagnosis from childhood.

Expertise in relation to diagnosis or treatment is not as well developed within Mental Health services as in some other programmes of care. Services for people with ASD are provided through general Mental Health teams with support from Autism Initiatives and Autism NI (PAPA). The latter has been involved in some training for Social Work staff and staff in supported living accommodation.

A very small number of NHSSB residents access specialist assessment and treatment in Great Britain and a few are living in specialist supported housing. Finding appropriate accommodation for people who have a diagnosis of Asperger Syndrome is particularly difficult. On a case-by-case basis, Mental Health services have tried to find ways around this by providing training for staff in supported accommodation. Recently there has been agreement to fund a Peripatetic Floating Support service to people in the former Homefirst provided by Autism Initiatives.

Within Mental Health services, it is recognised that there is a potential population of undiagnosed

**Table 2: Clients Referred to the Adult Mental Health Teams 2003/04 - 2006/07 by District Council and Category of Diagnosis**

District Council	Total Diagnosed	
	Total ASD	Asperger Syndrome
Antrim/Ballymena	5	4
Magherafelt/Cookstown	1	1
Larne/Carrickfergus/Newtownabbey	4	3
Coleraine/Ballymoney/Moyle	4	4
Total	14	12

Source: Adult Mental Health Teams, NHSSB

people who receive services, including daytime activities and accommodation. These only present when situational crises occur or when behaviours become too difficult for families.

In the last three years, a total of 14 people have received a diagnosis; 85% of whom were identified as having Asperger Syndrome (see **Table 2**).

### Adult Learning Disability Services

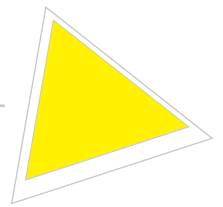
If the estimates by Wing and Gould, referenced earlier, are extrapolated to the NHSSB/ NHSCT population, one would anticipate a total of 660 adults with both a learning disability and an ASD locally.<sup>8</sup> However, identifying Autism in adults with a learning disability can be challenging. Indeed, recent research in one NHS Trust in England identified only 171 adults (out of a total of 571 in receipt of *any* form of adult learning disability services) from a general population of 230,000 adults.<sup>13</sup>

Between 1997 and 2001, an informal ASD advisory service operated within the former Homefirst adult learning disability services, initially focusing on training and then on an assessment and diagnosis service akin to that developing at that time within children's services. A total of 28 referrals were made to the

service, 10 specifically for ASD assessment and, of those, 4 were provided with a formal diagnosis of Autism.

A survey in October 2004 of the 8 adult centres for individuals with a learning disability within the former Homefirst - which comprises approximately 75% of the population of the NHSCT - indicated that, of the 648 attendees at that time, 27 had a diagnosis of Autism and a further 15 were believed by staff to require a formal assessment. An identical survey carried out in October 2006 showed that the adult centre population had by then increased to 660, of whom 32 had a formal diagnosis of Autism and only 9 still required assessment.

At first glance, these figures suggest a significantly lower number of diagnosed cases of ASD among the local population of adults with a learning disability than might have been anticipated from even the NHS research cited above.<sup>13</sup> However, the English survey sampled all services for adults with a learning disability, whereas the Homefirst study was restricted to the adult centre population and specifically omitted the Trust's specialist hospital population (amongst whom the proportion of adults with an ASD could be expected to be especially high).



Adult centre members are also more likely to have a *severe* learning disability and, in light of the Wing and Gould research, a higher proportion of adults with more severe and more readily detectable (and a lower proportion of those with less severe and less readily detectable) forms of ASD.<sup>8</sup> The numbers identified in the Homefirst survey may be considered a reasonable estimate of the number of adults with both a learning disability and Autism who attend local adult centres. Extrapolated figures for the NHSCT suggest that there are currently 43 adult centre attendees already diagnosed with Autism and a further 12 requiring assessment.

There is probably an additional number of adults with learning disability who have less severe (and less readily detectable) forms of ASD in the NHSCT area who require an initial assessment.

#### **Conclusion**

The preceding figures show the steady increase in the incidence of those diagnosed or identified as having Autism, by a variety of services, in the Northern Board area in recent years. This is consistent with the much longer and consistent trend elsewhere in the UK since the early 1990's as outlined by the National Institute of Health in 2005 which has identified improved diagnosis and wider

public awareness of the condition as important contributory factors.<sup>14</sup>

The very striking differences in the availability of information across the various services illustrate markedly the difficulty in developing an equitable response to need. It is clear that a major objective for the future is to produce much improved information in order to address it in a targeted and balanced way. There is a very large gap between research estimates, presenting needs and validated diagnoses. There are also very obvious differences between POCs, localities and between children and adult services. These observations are further compounded in the next part of the report which deals with the actual service response.

## 4. THE SERVICE RESPONSE

Despite the dilemmas and contradictions outlined in the previous section arising from the absence of validated, local prevalence data, a range of specialist/non-specialist services have developed largely due to individual professional and parental commitment and lobbying. This section gives an overview of the services currently available within NHSSB/NHSCT.

### **Children's Services - Northern Health and Social Care Trust (NHSCT) Autism Assessment and Diagnostic Service (AADS)**

In the former Homefirst, prior to 2000, children suspected of having an Autistic Spectrum Disorder were assessed by the local Paediatricians and occasionally jointly assessed with a specialist Speech and Language Therapist (SLT). A pilot multi-disciplinary assessment clinic was undertaken in 1997 which indicated the need for a multi-disciplinary assessment team.

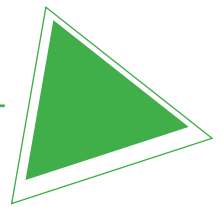
In 2001, funding specifically for ASD following the pilot diagnostic service in East Antrim sector, allowed for the appointment of 0.5 WTE (Whole Time Equivalent) specialist SLT and 1.5 days per month Clinical Psychology time. Medical services were to be provided by the existing trained community Paediatric medical staff (Associate Specialist and 2 Senior Clinical Medical Officers). It was agreed that 8 children could be assessed per month based on each child needing at least two appointments.

The specialist Clinical Psychologist left the team circa 2001 and was not replaced. Since 2003 a senior specialist Educational Psychologist employed by NEELB has supported the team in the assessment of children and acted as a point of contact with colleagues in Education. The establishment of the service was followed by a Trust-wide awareness raising training programme for all Health Visiting (and a few other) staff, resulting in a rate of referral that increased waiting times for assessment to more than 2 years in parts of the Trust.

In 2004/05 recurrent funding was secured which allowed for the appointment of another SLT, 0.6 WTE specialist Occupational Therapist (OT), 0.4 WTE lead Occupational Therapist; and a Clerical Officer. In December 2006, an unfunded service Co-ordinator post was appointed on a temporary (6 month) basis.

In 2007/08, the Board funded an additional 0.9 WTE OT and 2 Therapy Assistants. There has been no dedicated funding for the medical input into the service but the input has greatly exceeded the time initially allocated (ie 8 sessions per month in Newtownabbey sector and 8 sessions in the remainder of Homefirst).

Developments within the former Causeway have differed due to the management structures in



place prior to April 2007. In 2001 Clinical Psychology services (area wide) were available on a consultation basis only, for children with a learning disability. The funding in 2004/05, allowed for the appointment of 0.5 WTE SLT; 0.4 WTE staff grade Paediatrician and 0.5 WTE Clerical Officer. Service delivery to this client group in this sector differed from the former Homefirst although the same diagnostic criteria apply. This team currently has funding for 0.5 WTE OT. The service in this area has very good links with the NEELB Educational Psychology Department.

There is some variation within the new NHSCT regarding the process of assessment for ASD but there are also common features:

- assessment is carried out by a multi-disciplinary and multi-agency team across a variety of contexts;
- assessment is viewed as a process and not a single event;
- an open referral system is in place.

An initial screening may take place to determine the most appropriate method of assessment and to ensure that there is sufficient evidence to warrant further consideration. There is a high rate of referral to the service, waiting times are closely monitored and attempts are made to begin the assessment process within six months of referral.

The teams are multi-disciplinary, as outlined above, and draw on the expertise of professionals closely involved with the child, eg Teachers, other Consultants, Allied Health Professionals and Health Visitors. The child may be assessed in a variety of settings: clinic based in either a one-to-one situation or group setting; school; nursery/playgroup; or at home.

The outcome of the assessment is determined by the team after either an individual appointment or at a subsequent meeting. Diagnosis is based on the ICD 10 (International Classification of Diseases, 10<sup>th</sup> edition) Criteria (for Autism or Asperger Syndrome).<sup>15</sup> If this is unclear, the decision is likely to be deferred pending further assessment(s).

Parents are informed of the outcome verbally; written reports are sent to parents and relevant professionals; and staff are available by telephone to respond to subsequent queries. Occasionally, the parent may request that the young person is also present at the time the outcome is shared. Written information about the diagnosis, local support groups, etc, is given to families at the time a diagnosis is given. Following the diagnosis, practitioners make their own arrangements for review and follow-up. Referrals to other services may be made with consent from the person with parental responsibility or



from the young person himself/herself. Parental views as to the effectiveness and responsiveness of the service are sought.

Once assessed, if children with a diagnosis of ASD are not in receipt of core services, the demands on Paediatric Medical services are significant on 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.

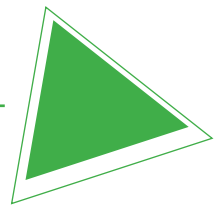
### **Services for Adults - Northern Health and Social Care Trust (NHSCT)**

Investment in the development of specialist services for children with an ASD has not been replicated within adult services. A multi-professional group of three professional staff with a personal interest in ASD (a Clinical Psychologist, a Speech and Language Therapist and a TEACCH Co-ordinator) operated an assessment and diagnostic service for adults with a learning disability in the former Homefirst prior to 2002 within existing resources. Following the discontinuation of the service in 2001, a uni-professional service has been provided by Clinical Psychology, as part of its general assessment and diagnostic work. However, the impact of this service has been limited over the last few years, and there remain a number of adults identified by adult centre staff as requiring a formal ASD assessment who have yet to be seen.

It has been suggested above that whilst the more severe forms of Autism may have already been formally diagnosed, there are likely to be many learning disability clients with less severe Autism. At present there is little prospect of an adequate service response to these needs.

Since the cessation of the team based diagnostic service in 2001, an ASD training and consultancy service has been provided to adults with Autism throughout the former Homefirst. SLT input of one day a month, and two days a month from a TEACCH Co-ordinator, in partnership with Autism NI (PAPA), has been allocated specifically to this population. SLT also allocates one day each week, on a Trust-wide basis, to the assessment of communication difficulties and the implementation of intervention strategies for adults with ASD, including both TEACCH programmes and the use of alternative communication systems such as PECS (Picture Exchange Communication System). Since 2001, there have been 47 referrals to the SLT and TEACCH Co-ordinator in Homefirst.

The situation in the former Causeway has developed somewhat differently. Although Clinical Psychology (as an area-wide service) has always operated similarly across the Board, Autism NI (PAPA) has not been involved directly and the SLT service has



not, to date, dedicated sessions specifically to adults with both a learning disability and Autism, although negotiations are ongoing regarding this service. These individuals are seen as part of a general learning disability service, across a variety of day care and residential settings. TEACCH is endorsed and supported (although the vast majority of programmes are introduced in the school sector) and the Therapist supports day care and other professional staff in the use of symbols and to help structure the environments of adults with an ASD. Priority is afforded to those who have challenging behaviour who are about to be discharged from Muckamore Abbey Hospital, or are making the transition from a school environment.

### Training

Training is a crucial component in ensuring that staff and parents are able to respond appropriately to the needs of people with ASD.

### Staff

There has been considerable investment of staff time and resources in securing training from external providers such as Autism NI (PAPA), the Centre for Professional Development for Allied Health Professionals, the Royal Society of Medicine, the Royal College of Paediatrics and Child Health and other professional groups. The specialist teams also provide in-house training. Health Visitors, Speech and Language

Therapists and Social Workers have been the focus of specialist training inputs.

Within the NHSCT Social Services training provision, training is offered in relation to TEACCH, Awareness and Understanding Autistic Spectrum Disorders as well as a range of relevant generic training such as Understanding Child and Adolescent Mental Health, ABA, Managing Challenging Behaviour and a range of training in relation to the Protection of Children and Vulnerable Adults.

### Parents/Carers

Trusts do not provide specific training in ASD awareness, however, parents/carers receive training on an individual basis from SLTs on an ad hoc basis as described above. Parents can also receive training from voluntary groups such as Autism NI (PAPA) and local groups focused on providing training and advice on ABA, ie PEAT (Parents' Education as Autism Therapists), CEAT (Centre for Early Autism Treatment), and SPEAC (Special Provision for the Education of Autistic Children).

Autism NI (PAPA) provides specific parent, grandparent and sibling training and also general ASD training for the extended family. This has been taken up in the Board with many parents completing the ACCESS training workshops which provide practical advice and support. Autism

NI (PAPA) has also delivered grandparent workshops, special workshops for siblings and a series of Social Skills workshops for children with ASD.

### **TEACCH Training**

TEACCH is a model developed in North Carolina which identifies seven key concepts: improved adaptation; parent collaboration; assessment for individualised treatment; structured teaching; skill enhancement and cognitive and behaviour therapy. Children with ASD require a very structured approach to help them to develop their skills, using a range of visual aids. TEACCH can be used both at home and at school and has been actively promoted since its introduction within the Board in 1997 in partnership with Autism NI (PAPA).

Funding has been provided to promote the co-ordination of TEACCH in adult centres and other facilities and to develop staff skills. In addition to consultancy training, an awareness training programme takes place two days every six months and is co-ordinated by the Training Units. Within children's services, there is a Speech and Language Therapist working within Special Education who is a TEACCH tutor.

### **Other Agencies**

#### **Education - ASD within NEELB**

This report has reiterated the value of multi-agency as well as multi-disciplinary working.

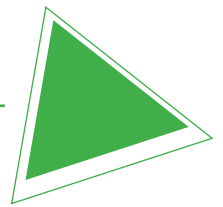
It is important, therefore, to acknowledge the very significant contribution, much of which has been outlined above, in relation to services for children and training initiatives, by Education and Library Board (ELB) colleagues in particular. There has been a considerable degree of collaboration and joint working at a local level since 2000/01 which has primarily consisted of joint planning, synchronization of staffing inputs and work on joint procedures/protocols. There had been hopes of co-ordinating finance inputs which will be outlined in the following section of the report but these have met with limited success.

#### **Autism Support Service (ASS)**

The North Eastern Education and Library Board (NEELB) has provided a dedicated Autism Support Service for children and young people with Autism and Asperger Syndrome for more than a decade to date.

Originally one Assistant Advisory Officer for Autism was deployed to respond to the needs of pupils with ASD. However, a year-on-year increase in referrals to the Autism Support Service has seen the expansion of the service to its current level of staffing of: four Assistant Advisory/Field Officers, two Autism Intervention Officers and one Senior Educational Psychologist.

Adjustments to, and development of, the NEELB's Autism Support



Service Policy have also been necessitated by the growing demand for support and the increasing number of staff.

The aim of the Autism Support Service is to ensure that the needs of each pupil with an ASD are met in the most appropriate way. This involves providing support to pupils with ASD and their schools through training, giving advice to Teachers and offering individual input for pupils.

### Training

ASD training is organised annually, on a rolling programme and covers topics such as communication, behaviour, Asperger Syndrome and sensory problems. A 3-Tier training model has been constructed and particular sessions, at Tiers 2 and 3 are delivered in collaboration with specialist colleagues from NHSCT.

- All schools within the NEELB geographical area have the opportunity to receive **Tier 1** (general) training in a range of basic ASD topics. This is typically provided within the school by the NEELB's Autism Support Service team, on a bespoke basis, in accordance with pupil need and staff awareness. (Advice and training can be accessed, on request by special schools).
- At **Tier 2**, 500 places are made available to schools to gain access to more specialised training in ASD. These

sessions tend to be offered in-house, at the Antrim Board Centre. A training menu is sent to NEELB schools and they select from this, in accordance with their pupils' needs.

- With **Tier 3** training, 250 places are made available for multi-session specialist training in ASD. Venues for these courses are selected according to the locations of the participants. Further longitudinal training programmes for Teachers and Classroom Assistants have been developed and added to the menu, as the Autism Support Service has expanded.
- Although **parent training** is not currently included within the 3-Tier model outlined above, parent training sessions are delivered regularly by the Autism Support Service's Senior Educational Psychologist through the (NHSCT/NEELB) Autism Assessment and Diagnostic Service's diagnostic group assessment sessions.

A discrete training programme - for parents of pre-school children undergoing ASD diagnostic assessment was also planned and presented in collaboration with multi-disciplinary colleagues from the former Homefirst, from May to June 2006.

The role of training has been afforded enhanced status as the NEELB's Autism Support Service has grown. This is chiefly in recognition of its two-dimensional benefit in supporting pupils with ASD. Training not only offers an arena to share information but more importantly, an opportunity to acquire skills.

### **NEELB Schools meeting the Needs of Pupils with ASD**

The drawing-up and implementation of a pupil's Action Plan or Education Plan at Stages 1-3 of the Code of Practice permits the pupil's special educational needs to be addressed and reviewed regularly by the school. The provision of training, detailed above, is intended to enable schools to meet those educational needs, more effectively.

Within mainstream schools individual pupil support is provided at Stages 3-5 of the Codes of Practice by the Autism Support Service.

The majority of the NEELB's Moderate Learning Disability (MLD) schools (Primary and Post-Primary) have recently been re-designated as 'Learning Support Units'. These Units are in the process of being equipped to provide appropriate support for children and young people with ASD and other specific special educational needs. The majority of the Severe Learning Disability

(SLD) schools in the NEELB (four in total) have specialised classes for children with Autism.

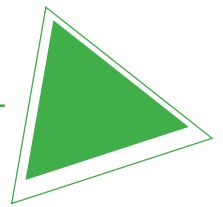
### **Supporting Individual Pupils**

NEELB Educational Psychologists may refer individual pupils on to the Autism Support Service, having carried out an informal assessment of a pupil's special educational needs at Stage 3 of the Code of Practice.

Officers from the NEELB's Special Education Department may also refer individual pupils to the Autism Support Service at Stages 4 and 5 of the Code of Practice, with this support detailed in any Statement of Special Educational Need which may be drawn-up for the pupil.

The number of individual pupils referred to the NEELB's Autism Support Service, for individual support, currently stands at more than 400.

When planning individual support for a pupil, an initial school visit will typically be carried out by an Assistant Advisory Officer or Field Officer (ASD). A support programme may then be devised and this will be likely to include some, or all, of the following:



- further observation;
- educational assessment;
- advice on Education Plans;
- sharing/modelling of strategies;
- access to training;
- access to cluster groups;
- meeting the pupil's parents;
- liaison with other agencies;
- identification of useful resources;
- use of Autism Intervention Officers.

Autism Intervention Officers may be deployed by the Autism Support Service to work with individual pupils, for an agreed period (of up to one term) prior to a review of the pupil's case.

### Multi-Disciplinary Work NEELB/ NHSCT

The Senior Educational Psychologist within the Autism Support Service is a member of the core multi-disciplinary Autism Assessment and Diagnostic Service (within the former Homefirst area). This work involves the diagnostic assessment of young people through a range of options (such as school, clinic and group assessment).

Individual Educational Psychologists provide psychological input within the former Causeway area.

Details of the outcomes of diagnostic assessments are typically forwarded to the Autism Support Service by the Autism Assessment and Diagnostic

Service, to facilitate the informed management of each pupil's case.

Over the years, co-working on diagnostic assessment and training, across the NHSCT and NEELB, has led to these agencies becoming inextricably linked. This has, in practice, permitted the development of pioneering approaches to ASD assessment and has acted to enhance the service delivery capacity of both agencies.

### Voluntary Agencies

Close links have been established with Autism NI (PAPA) over many years and more recently with the National Autistic Society (NAS).

Joint training is regularly delivered by the Assistant Advisory Officer for ASD in TEACCH. Members of the Autism Support Service also provide training sessions and attend Branch meetings of local parent support groups.

### The Inter-Board ASD Group

The impetus for many of the developments within the NEELB's Autism Support Service was gained for the Task Group Report on Autism (2002).<sup>3</sup> The influence of the report extended well beyond NEELB, with the establishment of a Province wide, five Board ASD specialists' group in 2003. This group is composed of an Assistant Senior Education Officer, a Principal Educational Psychologist, five Senior Educational Psychologists (specialising in ASD) and five



Autism 'Board Officers' (highly qualified ASD specialists from a teaching background). The group continues to meet monthly and has a brief from the Department of Education to promote and develop consistency and commonality within ASD practice and services, across all five ELBs.

- Work to date, by the group has included the drafting of an early years ASD specific programme and guidance document for the psychological assessment of pupils with ASD.
- Present work includes the completing of a core training menu of ASD courses which can be available to schools' staff.

While working relations are good at a number of levels within Education and HPSS, it could be suggested that more formal linkages should be established between respective planning groups to improve co-ordination and make optimum use of resources.

### **Housing**

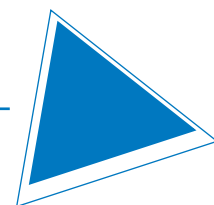
Brief reference can be made to tentative proposals from NHST staff to develop specialist supported housing provision for individuals with Asperger Syndrome through the Supporting People programme in conjunction with the Northern Ireland Housing Executive (NIHE). The specification for this type of provision still needs to be

developed and will be considered when completed.

### **Conclusion**

The development of the range of services outlined in this section has relied heavily on the commitment of a relatively small number of individuals in the absence of a well co-ordinated or strategic approach to responding to the needs of people with ASD. These services also need to be considered in conjunction with more mainstream provision for children and adults although it is not always evident that the contribution made by the latter has been fully acknowledged and that appropriate service linkages have been made. It would seem obvious that piecemeal and relatively unco-ordinated development is not the way to plan services for the future and that a more systematic approach needs to be adopted.

It is also important to acknowledge the increasing numbers of both children and adults from ethnic minority groups living in Northern Ireland and the requirement of services to be able to identify and respond appropriately to their needs in this field.



## 5. INVESTING IN ASD SERVICES

As a result of the anomalies previously identified, a lack of precision and absence of a broad strategic approach to responding to ASD, the levels of targeted investment have been comparatively low to date. There have been two main drivers in ensuring that some funding has been made available - namely the consistent lobbying of parents, professionals and special interest groups alongside the fluctuating interest at a policy level. The former has been instrumental in modest but incremental growth in funding, whilst the latter has resulted in relatively higher allocations of funding with little evidence of a longer term vision.

Since 2000, a mix of recurrent and non-recurrent funding has been provided, on virtually a yearly

basis, to advance this agenda. **Table 3** outlines the varying amounts made available during this time.

This represents a cumulative total of £271,000 invested recurrently in specialist inputs and a total non-recurrent commitment during the period of £10,500 in training and grants to support community/voluntary organisations. The unsatisfactory nature of this method of investing in services needs to be acknowledged but the combination of opportunism and lack of synchronization is symptomatic of the absence of a strategy as to how service development should be taken forward.

The DHSSPS Priorities for Action in 2003/04 identified what was

**Table 3: Investment in ASD Services by the NHSSB since 2000**

Year	Funding	Source/Deployment
2000/01	£5,000	Voluntary Grants & Training (N/R)
2001/02	Nil	
2002/03	£4,500	Voluntary Grants & Training (N/R)
2003/04	£16,500	Voluntary Grants & Training (R)
2004/05	£127,000	Diagnostic Team investment (R )
2005/06	£1,000	Training (N/R)
2006/07	£121,000	Service Development/Floating Support (R) and Voluntary Grants (N/R)

N/R = Non Recurrent Funding R = Recurrent Funding  
Source: NHSSB

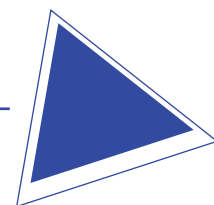
to be the first commitment of a two year investment plan for ASD.<sup>4</sup> This consisted of £127,000 which provided a useful stimulus for incremental planning which unfortunately did not benefit from the subsequent, anticipated allocation. It did, however, provide a focus for more integrated planning and dialogue between the Children's, Learning Disability and Mental Health Programmes of Care and Education colleagues than had been the case before.

Building on this initial investment in diagnostics, a further unanticipated amount of £121,000 was identified in 2006 specifically to promote ASD services. These resources have been used flexibly on a recurrent and non-recurrent basis, to provide funding for additional posts, namely an Autism Service Assistant, an OT and a Psychology Assistant. An outreach service for Children and Young People with ASD was also funded at a cost of £39,000. Staff will be integrated across the NHSCT to ensure equity of access for all individuals. A share of the £121,000 was also used to assist with respite and training (£64,000) for staff and families/carers. Monitoring of this funding in future will focus on outputs of an individual ASD team as the plan to integrate services across the NHSCT progresses.

It is also worth referring to the very substantial investment in multi-disciplinary teams to support children with disabilities in Education. This was announced by the Secretary of State in May 2006 as being one strand of the Children and Young People's Funding Package. This amounts to some £966,000 in the Board and a proportion of the therapy and psychological support which has been proposed is likely to benefit a wide range of children including those with ASD, Attention Deficit Hyperactivity Disorder (ADHD) and challenging behaviours.

Almost £70,000 has been made available to begin to develop a children's challenging behaviour service for the NHSCT in 2007/08. The Board is also working with colleagues in Education to further develop this model which will mean additional funding of £51,000. Finally, a major investment of £232,000 has been agreed, also for 2007/08, to complete the roll-out of the adult challenging behaviour service to the Causeway sector of the NHSCT.

All of this points to the need for an overview of current and future resource decisions in order to begin to get greater clarity about the actual and potential benefits of more strategic co-ordination in the future.



## 6. DEVELOPING THE ANALYSIS

The previous sections have highlighted the difficulty to date in constructing a coherent and sound basis for developing a responsive framework of services for people with ASD and their families. There is a need to rectify this by adopting a broader, more objective approach to the task. The aim should be to obtain ownership by people who use and provide ASD services for a co-ordinated programme of developments.

The closest that relevant agencies have got to achieving this objective locally was previously reflected in the joint submission requested by DHSSPS following the first specific reference to ASD in official planning priorities for 2003-2004.<sup>4</sup> It gave formal recognition that ASD was a service issue that needed to be addressed and underlined the need for a strategic approach. The requirement for each Board to produce costed proposals resulted in a degree of collaboration between HPSS and DE that had not been present hitherto.

The resulting four Board Paper<sup>16</sup> on the Development of Autistic Spectrum Disorder Services established a number of principles that have subsequently stood the test of time, for example:

- the importance of well resourced, accessible and equitable Trust diagnostic services;
- the need for a lead professional to take responsibility for ASD issues;
- the importance of consistent funding over a number of years to allow a multi-dimensional framework of services to be developed;
- the need to strengthen and formalise links with Education;
- the requirement to address the implications of diagnosis in the form of adequate family support;
- adopting a broader view of the various life stages and transitions which will impact on the nature of services required;
- acknowledging that more obvious links needed to exist between programmes of care, specialist and non-specialist services; and
- promoting a mixed economy of provision which would include voluntary sector inputs.

In anticipation of further funding, a tentative three year investment plan was produced which still retains a good deal of its initial validity. A subsequent workshop was held in October 2004 involving NHSSB, NEELB, local Trusts and voluntary sector participants to further develop planning aspirations and priorities. The event resulted in a summary Report “The Way Forward for People with Autistic Spectrum Disorders in the NHSSB”.<sup>5</sup> The recommendations focused on Diagnosis, Post Diagnosis, Transitions and Employment, Training, Adult Intervention and Support.

The proposals have retained validity but, apart from training initiatives,

have proved difficult to action. They may have suffered from naive expectations regarding resources, not being sufficiently clear about the difficult choices which might have to be made and lack of specific initiatives. This section attempts to rectify these deficits.

In the interim, two important reports have emerged to inform thinking and prepare the ground for change. The first is “Blueprint for Change”,<sup>17</sup> produced by Autism NI (PAPA) and the previously referenced Review of Mental Health and Learning Disability (NI) in its paper ‘Autistic Spectrum Disorders’.<sup>6</sup> Whilst there was a high degree of convergence in terms of desired developments, there were differences about the degree of special status that ASD services should be given. This can perhaps best be described as the tension between specialisation and integration. They have not addressed the issues of prioritisation and sequencing of investment.

In order to move this debate forward, a second NHSSB workshop was held in November 2006 to try to deal with these pivotal issues. The consultation carried out was a multi-agency and multi-disciplinary event involving statutory and voluntary organisations and carers. Participants identified the core elements of a service for clients with ASD as follows:

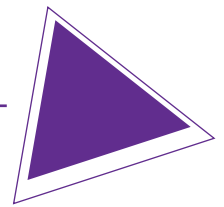
- clear diagnostic services for adults and children;

- role of key worker/dedicated link person;
- information systems/improved communication strategies;
- continuity of service - ‘cradle to grave’ pathway;
- training/awareness of ASD - multi-agency approach;
- carers/family support;
- respite;
- challenging behaviour services; and
- intervention for people with ASD without learning disability or mental ill health.

The discussion did not totally resolve the issue of making choices about where limited new resources could be best applied. It did help, however, in acknowledging the breadth of the challenge, in recognising how unevenly services were provided, in underlining the need for practical support and identifying that co-ordination was a crucial factor in advancing the agenda.

### **Conclusion**

The next section tries to move this debate forward by highlighting the main areas for development and it goes on to identify a small number of quite specific initiatives which may improve the situation for people with ASD and their families in the NHSSB/NHSCT. Experience to date which has shown that ad hoc responses to unexpected or short term funding are not the best way to shape the service system and that it is preferable to have realistic, agreed, priorities identified in advance.



## 7. SERVICE PRIORITIES

On the basis of the information gleaned from the overview of activity across the NHSSB/NHSCT area, direct consultation with service users and professionals and the work undertaken regionally, it is possible to identify the following areas of work for special consideration to move this agenda forward. They summarise this complex analysis in order to produce a realistic, constructive and potentially affordable blueprint for change.

### **Management and Co-ordination of ASD Services**

It is clear that the development of services for people with ASD and their carers has not been helped by the fragmented and piecemeal nature of what has been done to date. The investments which have been made, whilst valuable, have not been sufficiently well co-ordinated and have resulted in an unbalanced service system where some areas are relatively well resourced and others are virtually undeveloped. If this continues it will, in time, create difficulties for individuals and families in terms of unrealistic and frustrated service expectations. The debate regarding a legislative mandate for ASD services and the most appropriate structures for delivering them continues. It is possible to consider shorter term, practical and achievable actions to deal with the problems identified above.

There is a need to consider creating a specific post/portfolio for an ASD Co-ordinator within the new commissioning and NHSCT structures. The post could be at senior manager level with a specific responsibility for the development and co-ordination of services for children and adults with ASD on a multi-agency, cross sectoral basis. This could capitalise on the joint working that has contributed to this document and the increased recognition of the wider ASD service agenda. An ASD Steering Group could be established, comprising representatives from relevant interests meeting on a quarterly basis to oversee and review developments.

This role could help unify and standardise ASD practice within the new NHSCT structure. An important aspect of this would be the development of a Care Pathway for ASD, within and between agencies, which would provide better information to parents and professionals about accessing and moving between services. This would help reduce confusion and highlight areas for development. It would allow for consideration to be given to the concept of 'key workers' for ASD who could help individuals and their families negotiate the current, often confusing, arrangements.

Finally, the postholder could examine how the information differences between estimated and identified need might be dealt with for planning purposes.

### **An Equitable Service Response**

A major theme of this report has been the patchy nature of services and it is important to ensure that any future investments resolve, rather than compound, the problem. There are glaring deficits in adult services, particularly in relation to mental health and, more specifically, Asperger Syndrome, the diagnosis of people with Autism in learning disability services and the population which does not fit into any current provision.

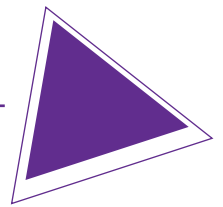
There is an urgent requirement to take stock of what is currently provided and what is required in the short, medium and long term to develop a meaningful response to need. This should be done at an inter-agency level to avoid duplication and make best use of resources on a joint basis. A very pragmatic approach is required if the present imbalances are not to overturn the good work that has been done to date. A useful starting point would be to distinguish between areas of activity where existing services could be reshaped or augmented and those areas where much more basic needs assessment is required before investment can

be made. A small number of such projects could usefully be taken forward, in the form of an action plan, by the ASD Steering Group.

### **Individual and Family Support**

Whilst assessment and diagnosis is vitally important for people with ASD and their carers and there has been progress in addressing this issue, it is clear, however, that post diagnostic support and the development of practical service responses has proved more difficult. There has been a number of promising developments particularly within the voluntary sector but these have not been adopted and mainstreamed to the degree that one might have expected. There would appear to be scope to invest in such initiatives in order to begin to develop a more balanced continuum of provision. Carers refer to deficits in the provision and timeliness of appropriate support. While emotional, practical support and intervention after diagnosis may be available, from core rather than specialist services, subsequent assistance at transition, particularly from the education system, and into adulthood is often absent.

Carers also emphasise the need for flexible and responsive respite services. The development of respite care has highlighted the debate about specialist versus



mainstream provision and in fact has been difficult to put into practice. It is clear that many individuals with ASD access a range of non-specialist services which appear to meet their needs reasonably well. This is often due to the training inputs provided to increase staff awareness and responsiveness. There is scope, however, for more finely tailored responses although this should be done via a process of planning and evaluation. Pilot initiatives should be promoted in respite care, family support and befriending in particular. These do not have to be high cost and can be grown incrementally as additional resources become available.

### **Training**

In the absence of a range of specialist ASD services, training has had an important role in ensuring that staff are attuned, to varying degrees, to the needs of this population. The commitment to promoting a variety of training initiatives ranging from basic awareness to specialist interventions is impressive. It should not be a proxy for the type of service requirements mentioned above. It has to be recognised that parents are equal partners in these endeavours and that training is not about improving professional expertise alone. A potential downside has been the number of available interventions and the way

in which they may be subject to individual parental or professional interest. There is a need for an audit across, the NHSCT to examine the capacity for a 'best practice' approach in relation to training in order to optimise effort and promote greater consistency for professionals and carers.

## 8. RECOMMENDATIONS

A stated intention in undertaking this examination of ASD provision across the NHSSB/NHSCT was to produce a small number of prioritised actions which could make a meaningful contribution to improving services for people with ASD and their carers. In order to identify a direction of travel for services in the short term, ie 2007-2010, the following actions have been identified and sequenced as the stated priorities for the HPSS locally. They would also take priority in the event of any new funding.

### **8.1 A Trust multi-agency/ multi-professional steering group should be established to co-ordinate and oversee developments in relation to ASD**

Developing a local strategy for ASD requires the establishment of a multi-agency/multi-professional steering group. This group should be chaired at a senior level within the HPSS and comprise professional, carer and service user representatives committed to developing services for ASD.

### **8.2 A specialist post should be established with responsibility for ASD across the NHSSB/NHSCT area**

The specialist post would be identified in the new NHSCT without being prescriptive about its location within any specific programme of care. This individual

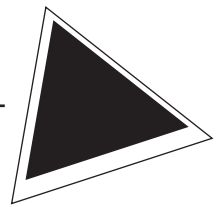
would have lead responsibility for co-ordinating the implementation of regional and local strategic developments within the NHSCT.

### **8.3 A care pathway for people needing access to ASD services should be developed on a multi-agency basis supported by a key worker system**

Professionals, people with ASD and their carers must be clear about the range of services/options available and arrangements for accessing/making transitions from them. This should be addressed via the previous recommendations and endorsed by relevant interests. This would require investment in a number of key worker posts to assist, and advocate for families negotiating the service system. The funding of up to three posts would be a funding priority to progress this across the NHSSB/ NHSCT.

### **8.4 A diagnostic team for adults should be established similar to the children's services model**

In order to deal with the service deficits within adult services, priority should be given to reactivating the previous model in learning disability services, and applying it more widely to Learning Disability and Mental Health Programmes of Care.



### **8.5 Post diagnostic support and intervention services should be further developed**

The capacity for providing effective, structured support programmes to families post diagnosis needs to be actively progressed. This could be delivered via an extended Autism Assessment and Diagnostic Team, with Education colleagues and through voluntary sector initiatives.

### **8.6 Alternatives to existing respite services should be considered**

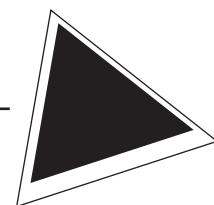
There is scope for a wider range of imaginative respite/adult placement services and this is viewed by carers as a high priority. There should be continued development of alternatives, eg family based residential, domiciliary or home based respite.

### **Some closing thoughts**

This document has been the product of a combination of frustration and commitment on the part of those affected by, working with and planning for ASD. The latter emotion needs no explanation as is obvious when one engages with the people who have lobbied, argued and agitated for greater recognition that this is an area of work which requires special attention. Whilst the same could be said of many other conditions, disabilities and interests there has been an increasing contrast in recent years between the enormous growth in the awareness and profile of ASD and the service response. Whilst this report commends the efforts which have been made in many quarters, there is now a need to move away from ad hoc and piecemeal developments to ones based on a sense of vision and direction, supported by resources, which are realistic and achievable. It is only by beginning to acknowledge that this is an issue which deserves specific attention and which will be addressed in a focused way that people with ASD and their families will be able to gain optimum benefit from the services which are available.

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## GLOSSARY OF TERMS

ABA	Applied Behaviour Analysis
ASD	Autistic Spectrum Disorder
AADS	Autism Assessment and Diagnostic Service
ADHD	Attention Deficit Hyperactivity Disorder
ASS	Autism Support Service
CAMHS	Child and Adolescent Mental Health Services
Causeway	Causeway Health and Social Services Trust
CEAT	Centre for Early Autism Treatment
CDCs	Child Development Clinics
DE	Department of Education
DHSSPS	Department of Health, Social Services and Public Safety
ELB	Education and Library Board(s)
Homefirst	Homefirst Community Trust
HPSS	Health and Personal Social Services
HSSB	Health and Social Services Board(s)
ICD	International Classification of Diseases
MLD	Moderate Learning Disability
NAS	National Autistic Society
NEELB	North Eastern Education and Library Board
NHS	National Health Service
NHSSB	Northern Health and Social Services Board
NHSCT	Northern Health and Social Care Trust In April 2007, Homefirst Community Trust, Causeway Health and Social Services Trust and United Hospitals Trust combined to form the NHSCT
NIHE	Northern Ireland Housing Executive
PAPA	Parents and Professionals and Autism
PEAT	Parents' Education as Autism Therapists
PECS	Picture Exchange Communication System
POC	Programme of Care
RPA	Review of Public Administration
SLD	Severe Learning Disability
SLT	Speech and Language Therapy
SPEAC	Special Provision for the Education of Autistic Children
TEACCH	Treatment and Education of Autistic and related Communications-handicapped Children
UK	United Kingdom
WTE	Whole Time Equivalent

## Appendix 1

### **ASD Working Group Members**

#### **Northern Health & Social Services Board**

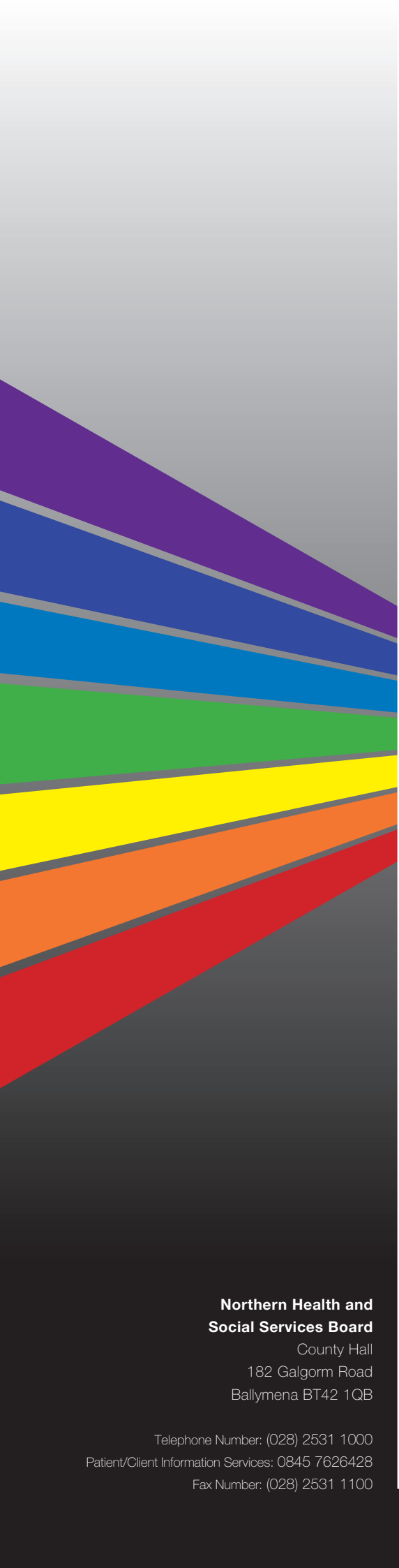
Dr Pamela Hannigan (deceased)  
Mrs Eimear Kearns  
Mr Kevin Keenan  
Miss Stephanie Mullan  
Mr Brian Mullin  
Mrs Amanda Weightman

#### **Northern Health and Social Care Trust**

Dr Clare Bailey  
Dr Ivan Bankhead  
Mrs Mildred Bell  
Mrs Dawn Braden  
Mrs Judith Brunt  
Mrs Louie Fillis  
Dr Karen Kearney  
Dr Linda Nevin  
Mrs Mary O'Boyle  
Miss Rosalind Patterson

#### **Autism NI (PAPA)**

Ms Fiona McCaffrey



**Northern Health and  
Social Services Board**

County Hall  
182 Galgorm Road  
Ballymena BT42 1QB

Telephone Number: (028) 2531 1000

Patient/Client Information Services: 0845 7626428

Fax Number: (028) 2531 1100