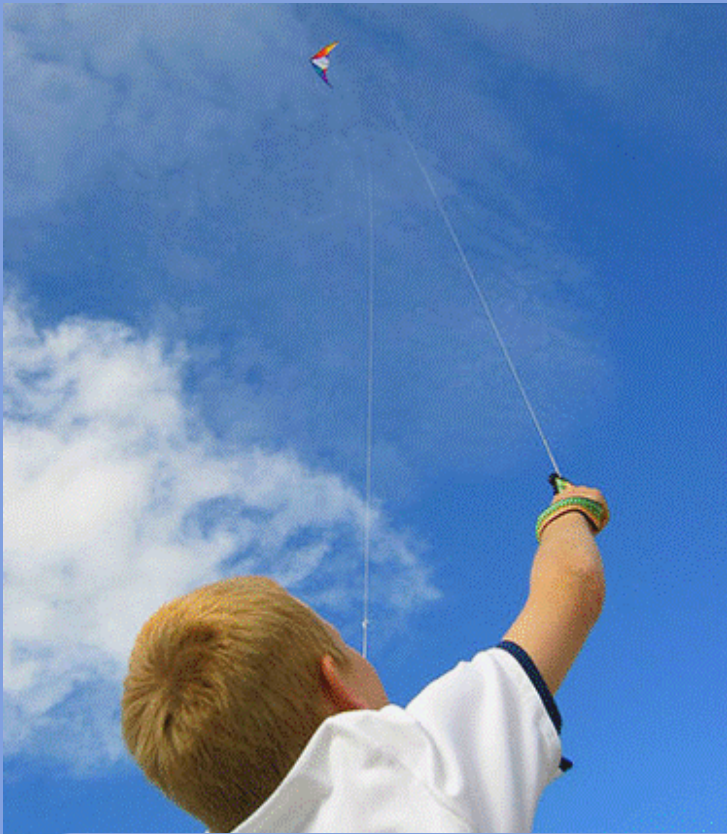




aspire  
Asperger Syndrome Association of Ireland



Aspire - The Asperger Syndrome Association of Ireland

# Development Plan

2007 - 2010



**Aspire - The Asperger  
Syndrome Association  
of Ireland**

**DEVELOPMENT PLAN  
2007 - 2010**

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# Foreword

by Des McKernan, Honorary Secretary

As a founder member of Aspire in 1995, it is a great honour to write this foreword to our latest and most ambitious Development Plan which will take us to the year 2010. At present we provide a limited number of services and our vision is to expand these and also to develop a whole range of new services. The vision is to provide comprehensive quality services and supports to those with Asperger Syndrome at all stages of their lives together with supports for their carers.

Aspire - The Asperger Syndrome Association of Ireland, was set up by a group of parents in March 1995 to provide support for people with Asperger Syndrome (AS) and their carers, and to encourage research into the condition. We organised the first seminar on Asperger Syndrome in June 1995 and since then we have worked tirelessly to raise awareness of the syndrome and to develop services for those affected by the condition and also to assist their carers. The Association was set up as a company limited by guarantee with a registered number 231996. Aspire has also been granted charitable status (CHY 11438) by the Revenue Commissioners. We have submitted audited accounts to the Companies Registration Office every year since establishment.

Various reports on autism and Asperger Syndrome have been produced by former Eastern Health Boards/Authority and a major report was produced by the Departments of Education and Science five years ago. All contained large numbers of recommendations. These Reports were -

- Report on Asperger Syndrome - South Western Area Health Board, 2000
- Eastern Region Health Authority Report, 2001
- Task Force Report on Autism - Dept. of Education and Science, 2001

The Development Plan put forward in this document has drawn on the various recommendations made in these reports and also our extensive consultation over the past eleven years with parents and all other stakeholders involved.

We look forward to the implementation of this Development Plan over the next three years and have set out an ambitious programme of work to be achieved. Ireland has improved so much economically over the past number of years that it should no longer be a question of lack of resources to develop the services required. Aspire will also endeavour to fundraise as much as possible to reduce the input required from the Exchequer. In many ways the resources required from the Health Service Executive (HSE) will be recovered by the State with the prospect for those, with this particular disability, of a full life of employment and participation in the social and cultural life of the country instead of the prospect of unemployment and depression leading to long stays in psychiatric hospitals. With the implementation of the proposed Development Plan, the potential savings in pure financial terms are considerable.

Research internationally has shown that the outcome for people with Asperger syndrome/high functioning autism can be very positive once the supports are in place.

# Foreword

The aim of this Plan is about ensuring that the various services and supports which are needed by people with this syndrome, will be available within a reasonable time-frame and also within a reasonable distance wherever a person lives in this country. Apart from supported employment, now entirely funded by FAS, most services for people with Asperger Syndrome are presently only available in Dublin with parents travelling long distances in order to gain access to the training and other services their children require. As can be seen from our membership survey in December 2005, there are a large number of children and teenagers (60 in Dublin alone) aged between 6-15 who require the services presented within this development plan or who will require these services in the near future.

Aspire has demonstrated that it is capable of organising and running services efficiently as in the case of our special Drama classes, supported employment, residential service and Helpline. We have been involved with supported employment since 1998 and have successfully placed large numbers of adults with Asperger Syndrome in commercial employment. Aspire has also been successful in assisting children and teenagers with the syndrome in improving their social, emotional and life skills using special drama which specifically targets those areas of social deficit experienced by those with the disability. We have also set up and maintained a residential service in south Dublin for the past three years. All of the objectives in this development plan are supported by the National Disability Strategy and the latest Social Partnership Agreement 'Towards 2016'.

# Members

of the Aspire Council

## **Chairman**

Brian Wray

## **Honorary Secretary**

Des McKernan

## **Honorary Treasurer**

Treasa McKernan

## **Council Members**

Geraldine Troy  
Eunice Nicholls  
Larry Fingleton  
Ashley Lewis  
Veronica Leaney  
Brendan O'Leary

# Mission Statement

The mission of Aspire – The Asperger Syndrome Association of Ireland is:

To provide material support and assistance for those with Asperger Syndrome/high functioning autism (AS/HFA) in Ireland together with a support network for families, friends and carers of those affected and to promote and encourage research into the condition.

# Introduction

Aspire - The Asperger Syndrome Association of Ireland was set up by a group of parents in 1995 to provide support for people with Asperger Syndrome and their carers, and also to encourage research into the condition. AS is a complex brain disorder and is seen as part of the Autistic Spectrum. Generally those affected by the condition have an IQ within the normal range but have extremely poor social and communication skills.

In Ireland, it is estimated that several thousand people have the syndrome, with about nine times as many men affected as women. The lack of services in this country places an enormous burden on parents. For many, obtaining a diagnosis is often a major undertaking and can take up to several years. Even with a diagnosis parents soon realise that few primary and secondary schools have the staff or resources to deal with the special needs of children with AS. Without proper awareness, training and care, many children with AS in mainstream school are excluded and often bullied leading to school dropout. In later life their difficulties in coming to terms with the world can result in depression, high levels of anxiety and eventually social exclusion. This greatly affects their chances of participating in higher education, employment and living independently.

Common characteristics include a lack of empathy, little ability to form relationships, one-sided conversations and an intense absorption with a special interest. Often their movements are clumsy. However, with the proper support people with AS can lead full and productive lives. Many famous people such as Albert Einstein, Isaac Newton and W.B. Yeats are said to have been affected by Asperger Syndrome.

Aspire has been working over the past eleven years to develop services for people with the condition at all stages of their lives and has lobbied and assisted in the setting up of educational, training, employment and residential services for people with the condition. The Association is in contact with those affected by the disorder at all ages from young children to those in middle age with a membership at present of around 260. Aspire also supports, in any way possible, the families of those with the condition. Whenever possible, research into the condition has been supported and encouraged by the Association.

The Association organises conferences, seminars and courses throughout the year, with the aim of raising the awareness of Asperger Syndrome nationwide. In addition, we have assisted in the set-up of seventeen support groups throughout the country.

# Current Activities

## **AWARENESS**

Aspire has been operating a Helpline since the organisation was established to assist those with the condition, their families and to raise awareness of Asperger Syndrome. For the first six years this was on a voluntary basis from the home of one of our members. In 2001 funding was provided by the Eastern Health Board to set up an office and a Helpline in the Carmichael Centre for Voluntary Groups, North Brunswick Street, Dublin 7. The Helpline, when it was established, dealt with about 50 to 100 calls per month. In 2005, the number of enquiries reached between 200 to 300 per month. Internet presence for the Association was set up in 2002. This involved the development of a dedicated website which provides members with critical data and support information on the syndrome, together with an online forum for discussion.

Aspire has assisted in the setting up and development of seventeen support groups across Ireland to better serve the families of those with this condition. Aspire also organises conferences and seminars on a regular basis and produces pamphlets, leaflets, booklets and a quarterly newsletter.

## **EDUCATION**

Whilst most children with AS attend mainstream school, a large number find it very difficult to cope within a normal school setting and bullying is a serious problem for these children. The first class at primary level was set up in 1998 in St. Peter's BNS in Walkinstown in Dublin. A further class at primary level was set up in 2000 in St. Joseph's Christian Brothers School in Fairview, Dublin. Aspire has also assisted in the successful establishment of support at secondary level in partnership with Southside Partnership. Support services are now available in St. Tiernan's Community School, Cabinteely Community School, Gorey Community School and there is a proposed unit in Kilcoole VEC.

In September 2005, a special unit was set up in St. Joseph's secondary school in Fairview, Dublin for a small number of students. This unit provides a seamless transition for students with AS coming from the primary level special class(es) at St. Josephs. This model needs to be repeated throughout the country.

# Current Activities

## TRAINING

Aspire helped in establishing the Tuiscint Training Centre, a Dublin based vocational rehabilitation centre for adults with AS. Tuiscint offers a three-year training programme which facilitates students to make the transition from dependency to managing their own lives. The centre has national accreditation and offers ECDL and FETAC certification. At the centre there is a high staff student ratio in order to facilitate the individual needs of students. The training programme is very much student-centred and endeavours to provide a supportive learning environment that is conducive to development. Courses are designed to be flexible, providing opportunities for the students to practice and apply the skills being learned.

The course consists of the following modules:

- Social Skills
- Personal Development
- Independent Living Skills
- Workplace Skills
- Job Search Skills
- Catering Skills
- IT Skills
- Work Experience

Anyone over the age of sixteen who has been diagnosed as having AS, HFA or a related social disability may participate in the course. Places, however, are extremely limited and there is a waiting list at present.

Aspire has also assisted in sponsoring many projects to teach social skills to those affected by the syndrome such as The Social Skills Training Course (2004) which was run in Maynooth College by John Harpur in partnership with ASPIRE. A further major development in this area was the establishment of Educational Drama classes for children and adolescents (6 to 18 years) with AS. These are run in conjunction with Dr. Carmel O'Sullivan from the School of Education, Trinity College Dublin. These special classes started in September 2004 and interest in this service has grown since. In 2006 there were forty-seven children and teenagers participating in these special drama classes and a waiting list has developed.

# Current Activities

## **SUPPORTED EMPLOYMENT**

Aspire has been involved with supported employment services since 1998 when a two year (approx.) pilot project was initiated with financial assistance from the European Union Horizon funds. The project lasted 27 months and demonstrated that a supported employment service was urgently required for adults with AS. The service assisted many adults in finding employment who otherwise would never have become employed. The common characteristic amongst the clients was that a small number had held down jobs for short periods prior to availing of our service. At the end of the project eleven people were in employment, of these five were in full-time employment, four in part-time employment and two had taken up Community Employment. Another four clients were in training or further education, one had just finished a training course, four were not available for work due to illness or other reason and one transferred to another service. (See Task Force Report on Autism – Dept. of Education and Science October 2001, Section 10.7.17)

Further financial support for this service was received from the Eastern Health Board and eventually in 2001, FAS took over responsibility for funding all supported employment services. Aspire still assists in the management of both Dublin South Supported employment and also Work4U, which provides employment assistance in North Dublin.

## **RESIDENTIAL**

Aspire set up a residential house for adults with Asperger Syndrome in Ballinteer, Dublin in January 2004. The model of care was based on the Gloucestershire Group Home (GCH) service in the U.K. and the Manager of GCH visited and assisted in recruiting staff for the service. At present, there are a small number of residents and an extension was built to the house, which provided a further two bedrooms. A Business Plan for the development of the residential service was submitted to the HSE in August 2005.

# Development Objectives

## **DEVELOPMENT PLAN 2007 - 2010**

This Development Plan follows from Aspire's previous Development Plan 2003 - 2006. The goals of this new strategy relate to the creation and provision of new services to be offered by Aspire, the further development and improvement of existing services and the continuing task of raising awareness of Asperger Syndrome in Ireland.

- ⇒ **FAMILY SUPPORT OFFICER (2007)**
- ⇒ **DIAGNOSIS AND ASSESSMENT CENTRE (2008)**
- ⇒ **AWARENESS (ongoing)**
- ⇒ **EDUCATION OFFICER (2007)**
- ⇒ **TRAINING (2008)**
- ⇒ **EXPANSION OF RESIDENTIAL SERVICE (2007/2010)**
- ⇒ **DRAMA GROUP DEVELOPMENT (2007/2010)**

# Development Objective One

## **FAMILY SUPPORT OFFICER (2007)**

A Family Support Officer, in their capacity to provide counselling, advice and support to families affected with Asperger Syndrome, is an urgent requirement and should be immediately implemented. The Family Support worker would also assist in the establishment of social groups for people with Asperger Syndrome which would ease the considerable burden on families who suffer enormous stress in living with a person affected by Asperger Syndrome.

Support for the Family Support service may be found in the following sections of the 2001 Task Force Report on Autism:

“Many of those diagnosed during late adolescence have already outgrown designated health and education provision and are forced to rely entirely on their families for support. Lack of clear ‘ownership’ and a designated service provider to meet the needs of those with AS / HFA (Asperger Syndrome / High Functioning Autism) adds to the confusion. (SWAHB, 2001). Families are isolated, carrying an enormous burden of care and under immense stress...” (Task Force Report on Autism – Dept. of Education and Science October 2001, Section 4.2.1)

„However, to date, there has been little recognition of such needs among those persons with AS/HFA...This situation has placed an intolerable burden on parents who are the primary service providers (by default) for this group. The absence of dedicated late adolescent/adult AS/HFA specific support services and interagency support structures is a source of continuing concern in this regard. The consequences of long-term social isolation, marginalisation, peer rejection and stress related anxiety, on the self esteem of many self-aware individuals with AS/HFA who may be at home without any service provision...have been overlooked entirely...it is the view of the Task Force that...intervention programmes i.e. peer support groups/ social understanding initiatives should be implemented immediately.” (Task Force Report on Autism – Dept. of Education and Science October 2001, Section 5.6.3.5)

Aspire would also wish to develop a support service for siblings which would involve the siblings meetings for a period of about five weeks to have fun, talk to other children, make friends and to learn more of their siblings’ disability.

“As outlined elsewhere in this Report, the Task Force considers that all people with ASDs and their families should have access to a range of family support services...These services should include...sibling support services and information regarding entitlements, dietary interventions and current research findings on educational approaches.” (Task Force Report on Autism – Dept. of Education and Science October 2001, Section 9.8.7)

## Development Objective Two

### **DIAGNOSIS AND ASSESSMENT CENTRE (2008)**

Aspire is proposing the development of a one-stop diagnostic and assessment centre by 2008. This would be of an enormous benefit to those with AS and their families as the centre would be in a position to provide a detailed diagnosis and assessment for clients and to give advice on services required. The necessity of such a centre is obvious as most of our members have to go to consultants privately. Further evidence can be found in the replies made by participants in the following two surveys:

"Lack of a co-ordinated diagnostic and treatment approach is very frustrating as is the different classification systems." (Report on Asperger Syndrome - South Western Area Health Board 2000, Pg 30)

"That a comprehensive diagnostic and assessment service be set up and work in partnership with parents." (Aspire survey - Regarding Services for People with Asperger Syndrome, August 2000)

The following is a list of the services that it is anticipated the centre would provide with accompanying notes and recommendations in relation to the current situation regarding the provision of these services.

#### ***Diagnosis:***

It is vital that when dealing with Asperger Syndrome that a diagnosis is performed at an early age.

"Securing a diagnosis is in itself something of an endurance test for parents in view of the current difficulties within the system. Many parents spend years going from one service to another searching for an answer to their dilemma. The lack of co-ordination was referred to by a number of the professionals themselves and it would seem that this is one issue which needs to be addressed." (Report on Asperger Syndrome - South Western Area Health Board 2000, Pg 38)

"The difficulty appears to arise from the complex nature of the AS/HFA diagnosis and the fact that professionals working at primary level are not familiar with the syndrome, hence the delay in identifying the problem...This delay represents, in most cases, the missed opportunity of early intervention and proper assessment for these children. It highlights the urgent need for a Diagnostic AS/HFA Service in the Eastern Region." (Report on Asperger Syndrome - South Western Area Health Board 2000, Pg 29)

## Development Objective Two

### ***Information on AS educational assessment – Individual Educational Plan (IEP):***

“The review, by the Task Force on Autism, of primary education provision for children with ASDs shows that there are many problems and deficiencies. The Task Force recommends that a range of differentiated provision, suitable to the varying needs of pupils across the spectrum, be made available. This must be sufficient to meet the demands, across the geographical regions, and should be based on age, ability, disorder-appropriateness and parental choice. It must be accompanied by appropriate and sufficient services and must be made in the context of effective school planning...ability appropriate and Individual Educational Plans must be available for all children with ASDs.” (Task Force Report on Autism – Dept. of Education and Science October 2001, Section 8.7)

### ***Speech and language Therapy:***

“The development of social, communication and pragmatic language skills of those with AS/HFA may be addressed by a variety of strategies which include:  
a) Speech and language therapy: as persons with AS/HFA have literal interpretation because of difficulties with pragmatic and conceptual language and difficulty with metaphors, sarcasm and humour, they experience serious difficulties understanding the intentions and views of others and it is important that school staff be aware of these characteristics. The vital input of speech and language therapists in the development of ASD children is fully recognised by the Task Force. Many of those with AS/HFA will need some individual speech and language therapy in addition to communication training.” (Task Force Report on Autism – Dept. of Education and Science October 2001, Section 6.6.3)

“The clinical services that do exist are unevenly distributed throughout the country and are non-existent in some areas outside of the greater Dublin area. In relation to speech and language therapy, in particular, the fact that the Department of Education and Science has not been involved...in the provision of such services is seen as a major obstacle to adequate provision in this area.” (Task Force Report on Autism – Dept. of Education and Science October 2001, Section 8.3.8)

## Development Objective Two

### **Occupational Therapy:**

“It is the considered view of the Task Force that the provision of education and support for persons with ASDs and their families must be considered as a whole of life process because of the uniqueness of their situation...Non-disabled adults in Ireland can avail of lifelong education through formal institutions of higher learning, vocational training, community school education, sports and leisure projects etc. This wide array of options also needs to be made available through the provision of appropriate supports and accommodations to those on the autistic spectrum, and indeed all citizens with a disability...Active citizenship, academic success and social inclusion for those with ASDs are largely dependent on access to continuing education and training opportunities throughout life. The employability, independence, and the quality of life of this group are likely to be greatly enhanced by improved access to formal and informal learning opportunities. In sum, the late adolescent/adult with an ASD needs:  
- Therapeutic supports. e.g. occupational therapy.” (Task Force Report on Autism – Dept. of Education and Science October 2001, Section 10.6.3)

### **Social Skills:**

“The Report of the Working Group on Asperger’s Syndrome (SWAHB, 2001) emphasises the critical need for understanding of the social skills deficit and communication problems which are core impairments of AS/HFA. The report stresses the need for clarity regarding the interventions required to redress the balance and states that:

*The social impact of these difficulties (social, pragmatic language & communication skills) is significant and results in an inability to relate to others in a conversational manner. Language delays may be identified as one of the causes for poor relationships, bullying, victimisation and loneliness and may result in referral to the Speech and Language Therapist. What needs to be established is the underlying mechanism causing these ongoing difficulties. Any degree of impairment in socialisation however subtle has a devastating effect on the life of an individual and the need for specific and sustained support is imperative.”* (Task Force Report on Autism – Dept. of Education and Science October 2001, Section 6.6.1)

### **Training Family support:**

The Task Force Report on Autism outlines a wide range of important and necessary support services that should be made available to people with ASDs. Specific reference in this regard is given to family support/counselling. (See Section 9.8.1 for further details)

## Development Objective Three

### **AWARENESS (ongoing)**

There are two key areas in which Aspire could help further disseminate awareness of the condition.

#### ***Helpline extension***

The Helpline has proven itself to be of vital importance for people with AS, their carers, newly diagnosed families, teachers and other relevant professionals. At present, the Aspire Helpline is managed from 8 am to 3 pm. We are looking to extend the hours of this service so that it will run from 8 am to 6 pm.

#### ***Creation of a CD Rom/DVD***

Aspire would like to produce a CD or DVD on the topic of social skills and Asperger Syndrome to assist families in their everyday lives. This production would include Irish actors and if possible families who have a member with Asperger syndrome. The CD/DVD would be distributed to schools and families upon request.

"Awareness of AS/HFA should be raised among parents and professionals in contact with young people. In particular teachers should be alerted to the possibility that students, who are socially isolated and who are experiencing communication difficulties, may fall within the AS/HFA category. The circulation of an AS/HFA information pack, which includes video and written material, to all mainstream schools would facilitate awareness raising of AS/HFA..." (Task Force Report on Autism – Dept. of Education and Science October 2001, Section 9.11.1)

## Development Objective Four

### EDUCATION OFFICER (2007)

The Education Officer will provide educational information and support to those affected by Asperger Syndrome. The position would also involve assisting families experiencing difficulties in the education of their children with the condition. It would also involve visiting schools to give talks on Asperger Syndrome. The officer would also assist in the development of educational services for people with Asperger Syndrome around the country. The necessity of having an Educational Officer can be seen in the following observations:

"Although the majority of students with AS/HFA are in mainstream classes and some possess the undoubted potential to excel academically, (particularly in their areas of special interest) if appropriate levels of support are provided, evidence to the Task Force suggests that marginalisation, isolation peer rejection and social exclusion are difficulties which pose a continuing problem for those students with AS/HFA attending mainstream schools. Yet, this aspect of mainstreaming has received little attention to date. Bullying is a serious problem that can dramatically affect the ability of students to progress academically and socially.

Although there are no statistics available relating to the extent of bullying which occurs in the ASD population in mainstream schools in Ireland, a nationwide study in Irish schools (O'Moore et al, 1997) reveals that bullying is widespread throughout primary and post primary schools in Ireland.

Similarly, a psychiatrist states that:

*There is a huge gap between the primary and secondary provision and particularly those young people with Asperger's, who have the intellectual ability to cope with the secondary school curriculum but do very badly there because the system there does not suit them and they must run at very high stress levels. Individual schools try to do their best but they do not understand what is involved."* (Task Force Report on Autism – Dept. of Education and Science October 2001, Section 6.10.3.2)

"There is a need for wide dissemination of accurate and detailed information on AS/HFA among education (and health) professionals." (Task Force Report on Autism – Dept. of Education and Science October 2001, Section 6.10.3.3)

"Because children with AS/HFA may be good academically and indeed excel in some subjects, education is a critical factor in their development and it is essential that such children are helped and encouraged to stay in school as long as possible. Teachers need to be aware of the condition and be trained in the appropriate ways of managing the children in class." (Report on Asperger Syndrome - South Western Area Health Board 2000, Pg.3)

## Development Objective Five

### **TRAINING (2008)**

The Tuiscent Training Centre provides pre-employment training for people affected by Asperger Syndrome or a related social disability. Tuiscent trains students to successfully make the transition from dependency to managing their own lives more effectively. More training centres urgently need to be established in Dublin and the service needs to be established in different regional locations so as to avoid exclusion of those with the condition not living in Dublin. Currently, the Tuiscent Training Centre in Dublin is operating at full capacity at twenty students (October 2006) with a further twenty students on a waiting list.

“The training needs of persons with AS/HFA have been outlined...and merit serious attention. Clearly, there is a need for dedicated provision to meet the needs of late adolescents/adults with AS/HFA who may not be ready for mainstream options. There is a need to develop AS/HFA specific initiatives, which would ideally incorporate links with local colleges, and the work place, whilst addressing core social understanding /communication skills in conjunction with career guidance and vocational skills.” (Task Force Report on Autism – Dept. of Education and Science October 2001, Section 10.7.19)

## Development Objective Six

### **EXPANSION OF RESIDENTIAL SERVICE (2007/2010)**

There is a serious need for an expansion of the residential service that was initiated and established by Aspire for Asperger Syndrome adults in Ballinteer, Dublin. This is an extremely important service as it offers the possibility of a full, enjoyable and meaningful life for individuals with this syndrome. Due to the dire need for this service and the ultimate limitation of space within a single house, a second residential home will need to be established. This should be made available by 2010. A Respite House to provide temporary relief for families or caregivers will also need to be established. A manager to oversee the day to day running and development of these services will need to be employed by 2008. The need for such services can be highlighted in the following sections of the 2001 Task Force Report on Autism:

"Reports of High Court cases, have highlighted the plight of adolescents and adults with ASDs who do not have access to...social and accommodation supports that they require to live with dignity and equal status within society. The inadequacy of the response of the State has been clear in such instances. Newspaper reports and Task Force submissions also note that parents of adolescents and adults with ASDs have had no option but to agree to referrals for residential accommodation and support services in England, Wales and Northern Ireland, as the continuum of supports and services required to meet the needs of this population do not yet exist in Ireland. Submissions to the Task Force have highlighted cases where...extended residential respite accommodation has been used as an alternative to providing the education, training, employment, community and residential support structures necessary to meet the needs of some individuals with ASDs." (Task Force Report on Autism – Dept. of Education and Science October 2001, Section 10.5.4)

"The negative impact on family functioning, on parents and siblings, is well documented both in the literature and in the Task Force submissions received. The stress experienced by families with a member with a disorder on the autistic spectrum permeated virtually all of the submissions, especially those from parents and parent's groups. One parent argued that a whole package of supports is essential to enable parents to cope:

*Nothing prepares a parent for the diagnosis of Autism and from that moment onwards every aspect of family life is affected by a multitude of problems. From the outset, parents need counselling, guidance, support and home help and most of all RESPITE to enable them to cope and survive. The present system does not support parents in their many crises and survival by 'trial and error' results in parents despairing and in even more isolation for their child.*

Practical support is very thin on the ground, and in great demand...

## Development Objective Six

...even something that is typically quite simple, such as a haircut, or visit to MacDonald's, can cause a very high level of stress in these families. Normal outings can be a nightmare and result in progressively increasing social isolation for the family. Society must find a way to share such responsibilities with these families. It must be acknowledged that, as difficult as it is for any family to cope with a child with special needs, most of those dealing with a child/young person with an ASD have an even greater level of stress and challenge.

Many parents expressed significant concern for the brothers and sisters of the child with an ASD. These children have to cope with their unique home life, exhausted parents, and the very different behaviours of their brother or sister, which in some cases, can be very upsetting, restricting, and/or intrusive. The urgent need for respite services was mentioned in approximately twenty-five per cent of Task Force submissions. There was absolute consensus among all those who mentioned respite care that there is a need to develop such services around the country, as living with a person with a disorder on the autistic spectrum can be very demanding and exhausting. This point was well made by one mother who wrote as follows:

*Respite should be available, in all its forms, as a right. Rearing an autistic child is very demanding and extremely stressful for the whole family. Erratic sleep patterns and the behavioural problems of the autistic child can cause great distress.*

The submission from an organisation stressed:

*The highest priority should be given to home support and respite care with need as the only criterion for its provision.*

Home supports, out of home respite and...residential care must be offered from a very early age and continue through adulthood. This is not because parents do not want to have their child in their home, but for many families they find that they just cannot cope 365 days and nights a year. Their children do not visit their aunts and grannies for overnights, or spend nights at friends' houses as typically developing children do. It is even difficult and in some cases impossible to find a childminder for the parents to go out on their own now and then.

Residential support and options for these older teens, young adults and adults must also be developed. For ageing parents there is the stress of worrying what adulthood has in store for their sons/daughters when they themselves are no longer able to care for them. They spend their lifetime as carers, advocates, lobbyists, and activists with little time for lives of their own. They are not able, as most other parents can, to look forward to some independence and peace of mind in retirement and old age. A full range of age, adaptive functioning and ability appropriate residential options, as well as respite, is necessary, ranging from fully supported part time, to partially independent full time out-of-the-family home residences." (Task Force Report on Autism – Dept. of Education and Science October 2001, Section 11.3.3)

## Development Objective Seven

### **DRAMA GROUP DEVELOPMENT (2007/2010)**

Due to the outstanding success and increase in demand for the educational Drama classes run by Aspire in partnership with Dr. Carmel O'Sullivan of Trinity College Dublin, we want to expand this service on a regional basis for the benefit of parents nationwide.

Parents of children with Asperger Syndrome and other disorders not living in the Dublin area, often find that they are excluded from many of the opportunities and services available to those living in or near the capital. This is also unfortunately the case with the drama classes as they are based in Dublin. Given the marked improvement in social skill development of those children that have taken part in the drama classes to date, it is our intention to regionalise this service so that other children across Ireland will not be unfairly excluded, and also to offer the approach to children on the wider autistic spectrum together with those affected by ADHD. Triangulated evidence from non-participant observation, video recording, parent interviews, participant focus group interviews, school observation and interviews with classroom teachers and resource teachers testifies to the success of this innovative methodology as an extremely positive contribution in the development of social and communication skills in young people with disabilities.

An important distinction is drawn in this project between simulation, a commonly used method for the teaching of social skills, and Drama in Education, as used in this approach. Simulation is about *imitating* other people's code of conduct without necessarily understanding the logic behind their behaviour, a practice which can be particularly frustrating and mentally exhausting as far as the individual with an ASD or social/communication disability is concerned. Drama in Education however, offers an existential experience enabling personal, social and emotional growth, whilst providing the opportunity of enhanced understanding and decision making.

The aim of this project is to develop participants' confidence and social skills so that they will have the same rights and opportunities as others within mainstream society. The Drama project was a feature on the RTE Radio programme 'Morning Ireland' in November 2005 and there was a huge response to this piece on our helpline.

## Development Objective Seven

Specifically, the project aims to:

- ⇒ improve participants' communication skills;
- ⇒ increase participants' understanding of the world in which we live and the social rules that govern it;
- ⇒ provide participants with concrete tools and skills to help them successfully mediate the social world and improve their ability to interact with peers and others;
- ⇒ create autonomous and empowering learning situations through the medium of drama in education in which participants can safely explore and test out their newly acquired skills;
- ⇒ provide structured opportunities that facilitate the education of participants' emotions.

*Project objectives:*

At the end of the programme, participants will have: -

- ⇒ enhanced their self confidence and self esteem;
- ⇒ improved their listening skills;
- ⇒ learned how to respond appropriately to others in various situations;
- ⇒ gained experience of seeking information through interaction with peers and others in group and one to one situations;
- ⇒ worked collaboratively in pairs, small group and whole group scenarios;
- ⇒ negotiated with others in demanding fictional situations;
- ⇒ developed their imagination;
- ⇒ improved their level of concentration
- ⇒ developed skills in turn taking, problem solving and the ability to express their emotions;
- ⇒ gained experience of making oral presentations to group members;
- ⇒ improved their ability to maintain eye contact during social interactions;
- ⇒ improved their ability to read and interpret non-verbal body language and tone of voice;
- ⇒ expanded their visual literacy and improved ability to use vocal and facial expression;
- ⇒ experienced friendships bonds within the group;
- ⇒ developed skills to cope with changing routines and sharing space with others; experienced a range of social and cultural activities both within the workshops and beyond.

From data gathered to date there is conclusive evidence that this type of educational drama not only provides a safe environment for young people with Asperger Syndrome, but positively encourages and assists them in the development of their social and communication skills.

# Glossary

**HSE**

Health Service Executive

**GCH**

Gloucestershire Group Home

**IEP**

Individual Education Plan

**ASDs**

Autism Spectrum Disorders

**AS/HFA**

Asperger Syndrome/High Functioning Autism

# Appendix 1

## FINANCIAL FORECASTS

## FINANCIAL ESTIMATES OF ASPIRE DEVELOPMENT PLAN 2007 - 2010

### FAMILY SUPPORT OFFICER (2007)

	€
Salary incl. PRSI	50,000
Rent of premises	2,000
Computer etc.	5,000
Travel and subsistence	5,000
Insurance	1,000
-----	
-----	
Sub-total	€ 63,000

### DIAGNOSIS AND ASSESSMENT CENTRE (2008)

	€
Salaries (Psychiatrist/Clinical Psychologist)	300,000
Other Professionals	100,000
Receptionist/Administrator	40,000
Rent of premises	20,000
Heating/lighting	5,000
Insurance	10,000
Miscellaneous	5,000
-----	
-----	
Sub-total	€ 480,000

### AWARENESS (ongoing)

- (A) Additional Helpline Assistant sanctioned by the HSE - to extend the hours of the Aspire Helpline to from 8am to 6pm.
- (B) CD Rom/DVD - Professional costs estimated at € 3,500 per minute of final recording

## FINANCIAL ESTIMATES OF ASPIRE DEVELOPMENT PLAN 2007 - 2010

### EDUCATION OFFICER (2007)

	€
Salary incl. PRSI	40,000
Travel and subsistence	5,000
Rented space	2,000
Computer etc.	2,000
Miscellaneous	1,000
-----	
-----	
Sub-total	€ 50,000

### TRAINING (2008)

	€
Salaries plus PRSI - 5 staff	200,000
Rent of premises	40,000
Training of staff	20,000
Heating, lighting etc.	10,000
Insurance	10,000
Miscellaneous	20,000
-----	
-----	
Sub-total	€ 300,000

### DRAMA GROUP DEVELOPMENT (2007/2010)

We estimate that the total overall cost of providing this service will be in the region of about € 200,000

# FINANCIAL ESTIMATES OF ASPIRE DEVELOPMENT PLAN 2007 - 2010

## EXPANSION OF RESIDENTIAL SERVICE (2007/2010)

Estimated Cost 2007	<u>€</u> 150,000
Estimated Cost 2008	350,000
Estimated Cost 2009	600,000
-----	
-----	
Sub-total	€1,100,000

## Total Estimate

Overall estimate to implement the entire proposed Aspire Development Plan for 2007-2010 would be approx. € 2 million over the period.

## Appendix 2

### ASPIRE MEMBERSHIP OVERVIEW - 2005

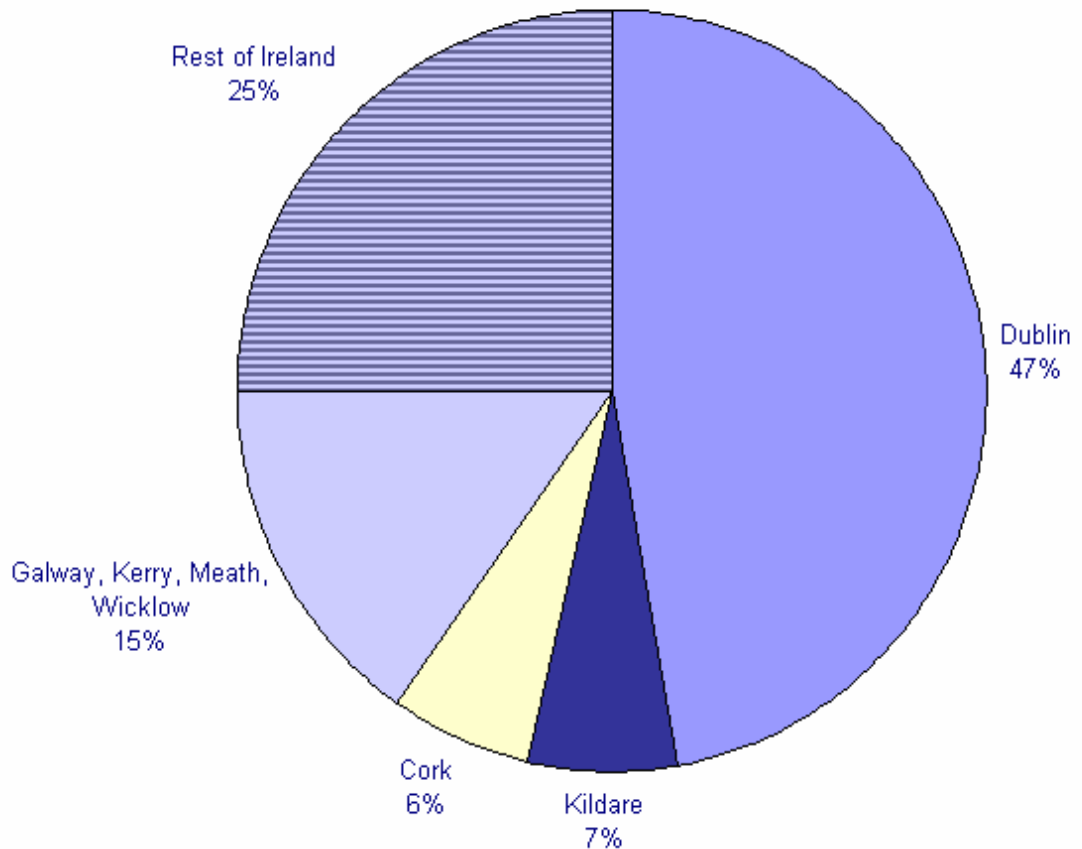
# Membership Table 1.A

County	Total No.	Age Range (Dec 2005)					
		< 6	6 - 15	16 - 24	26 - 35	36 - 45	46 - 55
Dublin	100	5	60	21	12	2	0
Carlow	5		3	2			
Clare	6		5		1		
Cork	13	1	9	1	1	1	
Cavan	1		1				
Donegal	3		2	1			
Galway	8		2	6			
Kerry	8		6	2			
Kildare	14		9	5			
Kilkenny	3		1	2			
Louth	4		3	1			
Laois	4		3	1			
Limerick	3		3				
Longford	1		1				
Mayo	2			1			1
Meath	8		6	2			
Offaly	2		1		1		
Roscommon	2		2				
Sligo	1		1				
Tipperary	7		4	2			1
Waterford	1			1			
Wexford	5		5				
Wicklow	8		5	2	1		
Westmeath	3		2		1		
<b>Total</b>	<b>212</b>	<b>6</b>	<b>134</b>	<b>50</b>	<b>17</b>	<b>3</b>	<b>2</b>

## Notes:

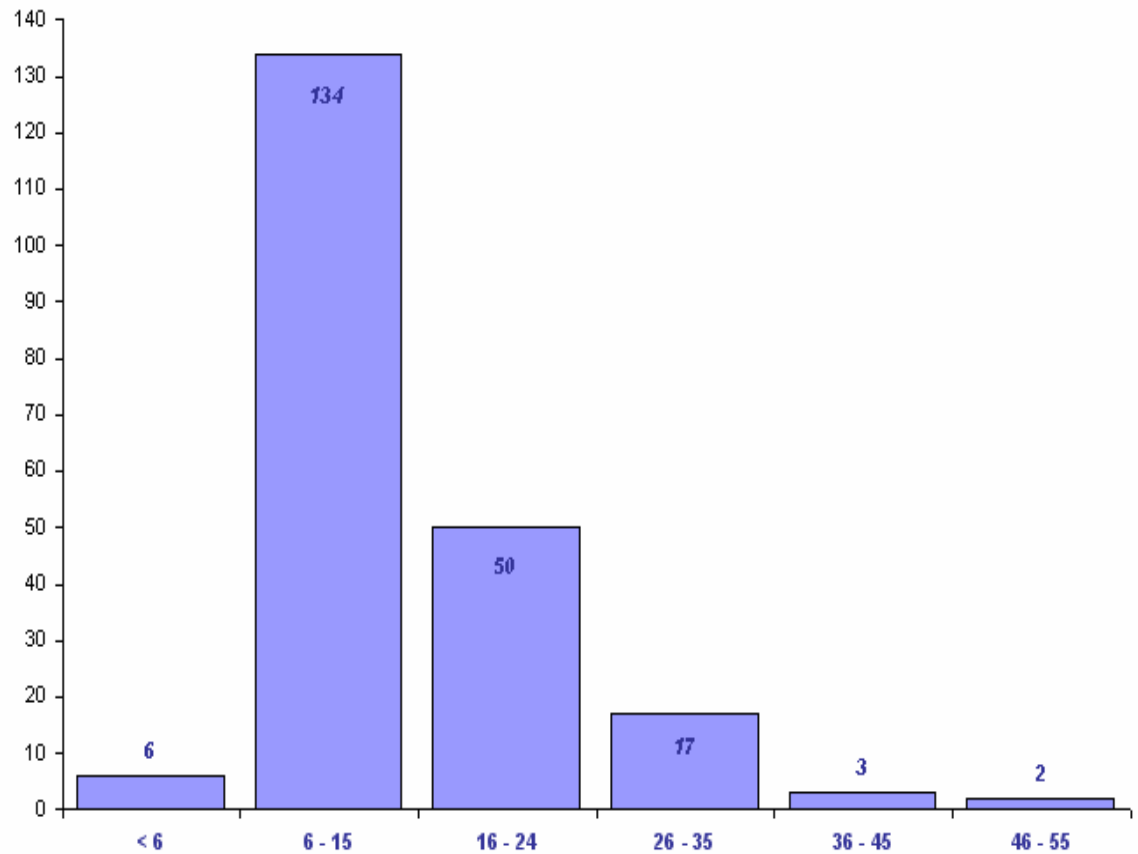
- Not all who have been diagnosed with Asperger Syndrome are members of the Association
- There are likely to be large numbers who have the syndrome but the condition is undiagnosed
- In Dublin there is a large group (65) who are under 15 years. A further breakdown of these figures showed that there are 27 in the 11 – 15 age group.
- A breakdown according to gender shows a ratio of 13 males to every female
- There are no members in counties Leitrim and Monaghan

## Membership Chart A.



Membership Chart A. represents a graphical overview of 2005 membership to Aspire based on figures taken from the Membership Table 1.A. As can be seen from the above chart, the highest percentage number of members can be found in the greater Dublin area.

## Age Range Chart B.



Data for the Age Range Chart is taken from the Membership Table 1.A. Chart B represents the varying age differentials between our members. From this chart we can see that the largest amount of our members are families with children within the 6-15 age group category. Adolescents and young adults form the second highest age category.

# Appendix 3

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