



Registered Charity No 1111713

### **What is HAFS and What Does it Do?**

HAFS Ltd (Halton Autistic Family Support Group Limited) is a community based voluntary support group that operates in the borough of Halton. It was officially constituted in November 2001 and was initially granted Charitable status in June 2003. That status was changed to that of an incorporated body, company limited by guarantee, but still retaining its charitable status, in June 2005.

As there are currently no out of school services provided specifically for Autistic children or families in Halton, HAFS fills this gap in provision and provides a unique service. The Group meets as a whole family unit, as all members of the family are affected by living with Autism.

HAFS provides services to all members of the family unit in Halton who have a child or young adult with a condition within the broad range of ASC (Autistic Spectrum Conditions). HAFS is unique in this respect as most support groups either cater for the affected person or parents. HAFS brings together all members of the family including siblings and sometimes Grandparents and encourages each group to interact independently (as much as is possible) i.e. the siblings are encouraged to congregate separately in an area of the building so as to discuss the issues of living with an Autistic brother/sister and to offer each other support. As young carers, they have issues that are unique to their peer group and different to those of the adult family carers.

The parents operate in the same manner (where the affected children will allow) to offer each other advice and guidance on common problem areas, pass on experience and encourage and informally counsel each other. The Autistic children/young adults themselves are supervised and led in play/learning by paid staff, parents, older siblings and non family volunteers who are all enhanced CRB checked and experienced in caring for Autistic people. The children/young adults are encouraged to develop social and communication skills and imagination through play/learning, addressing some of the primary issues around Autism. Pampering, Podiatry and Massage/Relaxation Therapy sessions are now a regular part of meetings provided by fully qualified Therapists, primarily aimed at the parents/carers.

A reference library is utilised to allow families to keep up to date with Autism issues, research information and personal accounts of living with Autism and general guidance information for parents and young people with ASC conditions.

In addition, advocacy is provided to help families in dealings with local and national statutory bodies, particularly vulnerable families who may feel intimidated by the process. HAFS will represent them at all levels, typically in meetings with Education, Social Services, Health Services or benefits departments. This advocacy service will assist families by acting on their behalf with official complaint procedures and in Tribunal situations. They will also be assisted to access legal support and representation where necessary.

Social and educational outings and trips are arranged throughout the year for the whole family unit and whole HAFS group, at no cost to the families. This usually involves activities arranged throughout the year such as hire of indoor and outdoor playcentres, bowling, trampolining, zoo visits, seaside trips, children's disco/karaoke, theme parks and other educational and leisure activities and weekly football sessions plus regular swimming sessions. The main event is the very popular annual to Prestatyn, where a full itinerary of activities is organised at a Family Funday by the beach. At Christmas time, several children's parties plus a trip to Gullivers World (Warrington) is arranged to try and make a special time for the children. An alternative is provided for those who feel too old for Gullivers World, such as ten pin bowling and a meal.

### **Background to HAFS Formation – The Need**

To fully plan and understand where The Group is heading in the future and why it needs to exist at all, it is important to understand the background to its inception, the relevant history behind it, how and why it was formed and where it is today in terms of development against the original expectations.

Autism is one of the lesser known and understood conditions and is often mis-diagnosed or not diagnosed at all. It is widely accepted as "Severe Mental Impairment" and is a neuro-biological condition that is often accompanied by a cocktail of other disabilities such as Epilepsy, Dyspraxia and in some cases Cerebral Palsy. There is a great deal of ignorance of the subject amongst the educational and medical professionals except for a few islands of knowledge that have had exposure to Autism. This is a national problem and Halton is no different in this respect except that it appears to be worse than the average in terms of service provision and seems to have a high Autistic population in comparison with other geographic areas.

Although there are no accurate figures available, HAFS believes that there are approximately 300 children and young people at any one time in Halton alone, on the Spectrum. HAFS currently addresses approximately 100 of these families. Some of the key issues of support are:-

- due to a lack of resources and expertise, many children are completely undiagnosed, mis-diagnosed or just given a catch all category of “learning difficulties”
- these figures will not include adults (over 18) with late diagnosis
- many higher functioning Autistics (generally known as Aspergers Syndrome) slip through the net completely
- there is a reluctance for statutory services to diagnose Autism due to the demand on support services as a result
- inadequate statutory services for ASC, particularly in the area of education
- Mainstream education placements break down on a regular basis due to lack of expertise and resources but special school placements are extremely difficult to achieve as parents are refused and fobbed off by professionals in the statutory services who view meeting their budgets as more important than meeting the needs of the child.
- some parents are in denial, will not get a diagnosis and believe that their child “will grow out of it”. This of course is tragic ignorance as there is no cure or sudden shedding of Autism. If anything it gets worse if not addressed and appropriate support provided.

As a result, many families in the Halton area have struggled, under very stressful conditions, to try and get access to appropriate help and services. They often felt that they were on their own and in fact barriers are often put in their path due to a combination of ignorance, lack of human and financial resources and a lack of political will to address the problems and issues associated with Autism. Each set of parents/carers felt that they were on their own and just had to get on with it, without support and being kept in ignorance about their rights and what little assistance might be available to them.

The need for such a support group to address current priorities and plan for the future became very apparent. After several abortive attempts to form a group over a two year period, a few like minded parents got together, with the assistance of Halton Social Services - Children’s Services Department, in June 2001 to try and form a self help support group and initially met at Glendale Family Centre. More parents/carers were encouraged to join through word of mouth and advertising and eventually a Management Committee and a Constitution, including a set of aims and objectives, were officially approved on 29<sup>th</sup> November 2001. Immediate priorities were agreed as being raising awareness of Autism and of The Group in the Halton area and fund raising and grant application activities.

In the subsequent sixteen years since formation, the Group has been very successful beyond its original expectations in terms of numbers, publicity and funding. The Group has 100 families on its active member register (there are also an additional 20 families who have made enquiries with HAFS but are on a waiting list due to lack of funding and support from Halton Borough Council and Halton CCG. Approximately 50 families are represented at each of the two monthly meetings, now held in The HAFS Family Centre, High St, Runcorn (Seniors 13 - 18 and older Seniors) and Jelly Beans Playcentre (Juniors 0 - 13) on Thursday evenings from 7pm.

HAFS also operates a respite caravan based in Prestatyn, North Wales, that families can hire for a small donation throughout the year. For some families, this will be the only break/holiday they will be able to achieve and is a vital facility. This is available from March through to November each year.

Parents/carers, siblings and most importantly the affected children themselves are receiving great benefit from being part of The Group. Guest speakers have provided a valuable insight into specific issues and problems surrounding Autism. Many day trips, outings, e.g. football, swimming sessions, soft play play centres, have been organised to assist in helping social inclusion and independence training. For some of the children, this is the only service they can access, due to their disabilities and is the only time the family carers can get a couple of hours respite.

It should be stated here that HAFS currently receives no committed long term funding streams from any source. Running and core costs are covered from general fundraising activities, donations and one off grant applications.

There is no current provision for Autism specific services in Halton from either Health, Education or Social Services. This has been the main driving force behind the formation of HAFS. HAFS will be the main agent for change in addressing this vacuum in the Halton area as it is currently the only dedicated Autism specific service in the area. A Halton Strategy for Autism has often been mentioned but not realized as HAFS currently feels that it is not taken seriously and that the families of HAFS and its representatives should be the lead body to ensure it becomes a reality.

## **HAFS Family Centre and Charity Shop**

In recent times, HAFS has developed its own base i.e. The HAFS Family Centre and a separate Charity Shop. The costs of running this family centre are partially met by the HAFS Charity Shop which not only brings in badly needed revenues but also acts as a volunteer hub for parents and family members plus work experience for some of our young adults on the spectrum. The Family Centre is a meeting place and work place in one and benefits the community for the large amount of recycling that goes on there.

## **HAFS Mission, Objects, Aims & Tasks**

### **Mission**

HAFS mission is to provide support and life enhancing services to help the children and young adults of Halton (and their families), affected by Autism. This involves assisting them to achieve their maximum potential for community involvement, social inclusion and the opportunity to access employment and other facilities enjoyed by other non Autistic members of Halton's community.

### **Constitutional Objects and Aims**

The stated Objects and Aims of HAFS (as per our Constitution) are :-

- (i) To promote the relief of persons suffering with Autistic Spectrum Conditions by providing them and their families and carers with information, support and education
- (ii) To provide or assist in the provision of facilities for recreation or other leisure time activities for Autistic children and their families with the object of improving their conditions of life.

### **Tasks**

To achieve these strategic aims, a number of tasks to be achieved and initial service to be delivered have been defined to allow the philosophy of Supporting and Empowering families by providing :-

- an opportunity for parents/carers and siblings as well as the affected children/young adults to meet up on a regular basis as self help and support group to each other, as a family unit and reduce isolation, stress, depression, self harming and obesity

- badly needed social interaction/play opportunity for the able bodied brothers and sisters as well as the disabled to discuss how ASC affects them and to offer

each other support, which increases confidence , self esteem and better overall mental and physical health

- parents/carers can discuss the experiences and problem areas encountered and support each other through the various hurdles that have to be overcome such as diagnosis, appropriate special school placement/Tribunal, respite, benefits, independence issues, further education, supported independent living, planning for the future etc

- bring in outside help and advice from experts in the field, such as external organisations, service providers and professionals who have expertise in Autism

- generally strive to raise awareness and support of ASC families in the Halton Borough area

- become an organised group and apply pressure on the officials of local and national service providers and statutory bodies to provide adequate support and services to ASC families in Halton by meeting their needs effectively and appropriately, meet unmet need and address gaps in provision.

## **Outcomes**

The overall impact of HAFS services is that the quality of the lives of all members of the family is significantly increased. Member families will benefit from the following specific outcomes:-

- More families of Autistic children will be empowered through having a voice and informed choice with increased confidence and self esteem

- Their isolation will be reduced and access to community involvement and social interaction opportunities improved

- Families will lead less stressful lives with better emotional health and well being

- Their children and young people will be allowed to reach their full potential through accessing appropriate support that meets their individual needs

- Young adults and parents will benefit from work experience in the HAFS Charity Shop which will also lead to greater confidence and self esteem as well as help towards getting into the employment arena

- Less families will break up under the pressure of unsupported crisis situations.

## Recognition

HAFS work has been seen to address an obvious unmet need and has been recognized by major accolades:-

- being chosen as The Mayor of Halton's Chosen Charity in both 2005 and 2007
- An Award from the Halton Voluntary and Community Sector as "Best Lesson Learnt"
- An award for "The Most Innovative Project on Merseyside" from The Community Foundation For Merseyside (from amongst 1300 projects). June 2008
- Winner of one of The Positive Action North West Awards for 2011. Being the only Halton based organization chosen from throughout the North West, on the positive impact HAFS has on the lives of Autistic people in Halton
- Finalist Certificate for "Exemplary Services" in the Children, Young People and Families category by The Spirit of Merseyside Awards June 2012.
- Runners Up in The North West Regional Finals of the Great British Care Awards – Carers Category, October 2012. "The Award seeks to acknowledge and celebrate the dedication that Carers give to those they care for and the incredible contribution they make and demonstrate commitment and perseverance."
- Runners Up in the North West Regional Finals of the Your Champions Awards (Scottish Power/Trinity Mirror sponsors) as Halton Team Champions. Although not winning the regional title, the Halton Team Champions title was confirmed on the night (09/11/12), "Awarded for their commitment to the Community".
- In 2013 both Lloyds Banking Group and Santander Bank have recognized HAFS outstanding Community work and have awarded both Certificates and cash amounts to reflect this view. Indeed the Lloyds award was based upon a public vote which put HAFS into the top category and top prize section.
- In 2016 two large local companies, The CO-OP and Sellafield have chosen HAFS as their Charity of The Year, due to the quality and uniqueness of its services to local people. Both companies staff worked hard with HAFS in internal fund raising activities to raise as much funding and awareness on behalf of HAFS.

- In 2017 a further two large local companies, AAK and Halton Housing Trust employees have chosen HAFS as their Charity of The Year and plans are now underway to agree the activities to fundraise and raise awareness of HAFS and Autsim in general.

## **Future Developments**

The views of the children and their families drive forward the development of HAFS and new services to reflect that declared need. The key developments for the future have been identified as:-

- Increase the quality and quantity of current service delivery to more families
- Increase self sustainability and independence through increasing revenues through the HAFS Charity Shop and investigate other areas of generating revenue income
- Encourage more volunteering particularly from local community members
- Campaign for and encourage the development of Dedicated Autism Specific skills and services
- HAFS own new purpose built building to become “A Centre of Excellence For Autism” delivering many services including, Respite, Outreach, Training, Soft Play etc. The land required has been donated by Homes and Communities Agency (formerly English Partnerships) and the development fund (approx £3.1m cost) has recently been kicked off with a donation of £35,000 plus £60,000 coming from HAFS fundraising activities.
- Investigate the option of developing HAFS own Dedicated Autism Specific Education Provision (Free School)
- Look into the possibility of setting up a badly needed stand alone Adults Group to engage in more age appropriate activities.