



DÓCHAS

**AUTISTIC SPECTRUM DISORDER
EMERICK SUPPORT GROUP**

Mt. West District 66 O'Connell School, Limerick

Tel: 001 313366 Fax: 001 313360

Email: asddochas@eircom.net

A Presentation to

the MWHB

For

Respite Services

For Adults with ASD

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DÓCHAS (HOPE FOR PEOPLE WITH AUTISM)

In June 1997 Dóchas was established in response to a desperate need for an organisation to represent the needs of people diagnosed with Autistic Spectrum Disorder. Dóchas works in collaboration with the Departments of Health and Education to highlight the individual needs of A.S.D people and also to secure appropriate services for our people.

To date Dóchas in its short life span has,

- Acquired an office at 66 O Connell Street Limerick, which operates daily from 9 a.m. to 5 p.m. as an advice and information centre.
- Operates a summer-camp for children with Autism for three weeks during the month of July.
- Holds monthly support group meetings for families with an Autistic member.
- Has been successful in highlighting the need for a respite centre for Autism. Dóchas is pleased to announce that the Red Hill Respite Unit opened in July of 2000 and appears to be a success. This facility is run by Rehab Care in association with the Mid-Western Health Board.

Dóchas Mission Statement

Dóchas is dedicated to creating hope and a practical future for people with Autistic Spectrum Disorders within the embrace of family supervision.

Objectives

- To educate and inform the public about Autism.
- To promote full participation by Autistic people in all areas of Irish society.
- To create an access for Autistic children to the mainstream education system, with the provision of support, including suitably trained classroom assistants, where required.
- To secure for Autistic people comprehensive and appropriate healthcare based upon an inclusive "Cradle to Grave" philosophy.

The Needs of Adults with Autism: from Residential to Employment Opportunities.

Only recently have children or adolescents with autism grown up to be called adults with autism. Prior to 1943, the year Leo Kanner identified the syndrome, people with autism tended to be labelled schizophrenic or mentally retarded. There were services available for children and adults who were either schizophrenic or mentally retarded, but none specifically for those with autism. People with autism were placed in whatever services were available, even though those services were not designed to meet their needs and generally proved ineffective. This trend is gradually changing for children as advocates procure more services designed specifically for people with autism

As the services available to adults with autism expand; the needs of adults are being discovered in more detail. Adults with autism are emerging as people who very often require a continuation of the intensive training they received in childhood and adolescence in their educational years. Adults are able to retain skills they have acquired over their educational years, and are able to learn new skills when specialized services follow them into adulthood. Without such a continuation of intensive services, however, many adults with autism will regress terribly. As children and adolescents with autism become adults, many of their needs remain the same, but many change. Adults require some skills that children and most adolescents do not yet need. Adults need to be able to generalize their skills across a wider variety of environments, because they often both live and work in the community. Adults also need to be prepared for the changes their body goes through as they mature. For example, they need to be taught how to control their diet, or how to take care of menstruation. Adults also need to be taught to engage in differing age-appropriate activities, such as taking a walk or jogging instead of playing on a slide or swing.

Residential / Respite Services

The most important functional needs adult with autism have, however, focus on respite and/or residential services in the community and support in finding and carrying out employment. Residential and employment services are necessary for adults with autism because these services enable adults to have the same experiences as their non-disabled peers: living apart from one's family and supporting and taking care of one's self; having social contacts; and working for monetary rewards, as well as gaining a sense of accomplishment, pride, and self-esteem.

The main types of appropriate residential programs for adults with autism are

- Community Group Homes
- Supervised Apartments
- Skill development homes
- Natural or surrogate family homes

Group homes usually house up to six to eight residents and several staff members. They are located in typical neighbourhoods in the community.

Supervised apartments house fewer people in general, and people who are more able to take care of themselves. In supervised apartments, a supervisor or staff member regularly checks up on the residents, but may not live in the apartment.

Skill development homes are typical family homes in which a person with autism can live. The families have been trained in teaching people with autism, and take the person into their home as another member of the family.

An adult's natural family, of course, is also an appropriate option, but is not as secure an option as the programmes mentioned above. It is very important for parents to secure quality community based services while they are able. To wait until they can no longer serve their adult child will result in less than appropriate services for him.

Residential / respite placements for adults with autism should be no different than any other residence, except that they are more highly structured. The residence should become the new base for learning in the adult's life, and so must serve functions formerly addressed by the family and school or currently addressed by his employment services. Life skills, recreation, community experiences, and communication and socialization skills must all be taught in the residence. The only skills the residence does not focus on are work skills. These should be taught in the work place or at an employment-training centre.

Employment Services

Work placements must have similar attributes to residential placements. The jobs generally held by people with autism require consistency and to follow a set schedule, as most autistic people live for structure, many of them seem to find work highly satisfying and very therapeutic.

The main types of appropriate work placements for adults with autism are

- Supported Employment
- High Supported Employment
- Supported Work Placement
- Independent Work

1. Some people with autism are able to work independently, but others require more support. Employment programs must provide varied levels of independence in the work place to suit each person.

2. For adults who require a great deal of support, employment should be provided in secure work settings. In secure work programs, individuals are taught adaptive work and life skills, and contracted work is brought in for completion.

Adults work in a highly specialized environment and are carefully supervised by trained staff members.

3. For those who can sustain more independent employment, a supported work placement should be provided. In supported employment, adults usually work with a job coach in the community.

4. For people who can work virtually independently without specialized supervision, competitive employment placements should be obtained. Working as a groundskeeper, data entry clerk, and packing goods for shipment all without specialized supervision are examples of other competitive employment placements.

RED HOUSE RESPITE UNIT

RehabCare in partnership with the Mid Western Health Board and with the active support of Dóchas have a respite centre currently in operation at Red House, Patrickswell, for children and young adults with autism and their families.

There are currently 32 families availing of respite on a regular basis as well as providing crisis respite in emergency situations. Red House has four beds available for planned respite breaks plus a fifth bed, which is kept for admissions for families in crisis. The target age group for this service was originally from 8 years up to 21 years but clients range in age from 5 years to 24 years. Clients who are reaching the upper age limit need to be discharged. However, there is no respite service for adults with autism in the region. The Draft National Standards for Disability Services emphasis that respite services for children should be provided at separate times to respite services for adults.

The crisis bed is being used on a continual basis as there is a lot of pressure on Red House to accommodate newer referrals.

Seven clients who avail of this service are aged 18 years and over. An additional two adult clients were discharged in November 2003. As you can imagine this has caused a lot of hardship not only for the clients who were used to the service but for their families as well.

Seven clients are aged between 15 and 18 years and there are currently 3 new referrals on the waiting list who cannot be offered any place until some of the existing client group exit the service. These clients will be due to leave the service within the coming years and we believe that preparation for an adult service should begin at 16 years.

The service offered at Red House is completely booked up for the coming year. The service is so backlogged that Red House has had to stop taking referrals.

It is evident that there are a number of groups of clients accessing the service, which for reasons of age and functioning ability are incompatible with each other. It is therefore becoming increasingly difficult to adequately meet the needs of such a diverse client group. The smaller children are at risk from injury from the older adolescents as many of them present with challenging behaviour and do not have the coping and tolerance skills to deal with smaller children.

Services offered by Red House

1. As well as providing a break for the client and family, the service also provides opportunities for personal development, social interaction and community integration for the client. Where appropriate, independent living skills are encouraged, i.e. participating in their own personal care routines, participating in planning/cooking meals etc.
2. Red House also operates an after school service, whereby they collect children from schools, allow the children to participate in various activities in Red House or community, have their evening meal and then they are brought home.
3. A group of four teenagers with Asperger's Syndrome have a social club every Thursday night at Red House. However these Thursday nights have frequently had to be cancelled due to pressure to accommodate younger clients during the school break.

Currently Dóchas has 97 families with an autistic member on their books and this will grow as newer referrals are being made. **There are thirteen teenagers between the ages of 15 and 18. There are fifteen adults aged 18 years and over.** There are obviously other young adults with autism out there of whom we are not aware. From the above numbers as well as the figures obtained from Red House, one can see that there is a growing need for an adult respite centre to be set up as a matter of urgency.

15 Merval Drive
Clareview
Limerick
7th March 2004

To the Mid Western Health Board

My wife Sheila and I have a daughter Óma who is autistic. This was discovered after a long and torturous route, starting at about 2 years of age.

A lot of improvements have been achieved since then as she is now 16 years of age. By far and away the most significant of the developments was the establishment of the respite unit at Red House, Patrickswell for autistic children. This service caters for children up to the age of 18 years. Great credit goes to Dóchas, the Health Board and RehabCare for achieving this.

Anybody that knows about parents catering for an autistic child knows that frequent breaks are necessary as it is very exhausting. Without the respite facility it would not be possible for the parents to have these breaks. I can safely and surely say that without that without that respite unit many parents, ourselves included would have had to permanently institutionalise our child long ago. This would be extremely stressful and heartbreaking to us and to the child as well as being enormously expensive to the state.

As can be seen from the above, respite is essential for children, it is even truer when they are becoming or are adults. It must be understood that the autistic child will throw a tantrum for any or a multitude of reasons. Some you discover and eliminate as you go along, wrong diet etc.

Óma now for instance suffers a lot from PMT and is very hard to manage at certain times. When she throws a tantrum it borders on the violent and it takes both Sheila and I to calm her. She is very strong and getting stronger as we are getting older and weaker.

A peculiar thing is that this side of her is not seen at school or at respite. All the frustrations and tensions are released at home. We are mustering all the medical expertise we can at the moment to improve the situation.

It would be a pity if because of not having an adult respite unit and appropriate back up facilities, we could not cater for our own child at home or more to the point our adult at home. Without this adult respite unit I regret to say, with a broken heart, she will be institutionalised permanently. However, I'm very hopeful this will not happen to her as she is a lovely gifted little person in her better moments.

Yours sincerely

Sheila & PJ Lowney

11 Rossa Avenue
Mulgrave Street
Limerick

Dear Board members

Our names are Mary and John Ryan and we are the parents of two boys with Autism. David is 27 years old and is a resident of Bawnmore, Brothers of Charity, Limerick. Owen is 19 year old and attends the Vocational Training Centre at Lisnagry, Limerick.

In July 2000 the doors of Red House Respite Unit opened for the first time, but it was not until March 2001 that we decided to avail of respite for our son Owen. He initially started out by having the half day here and there and then we took the big step of allowing Owen to stay at Red House for a full weekend. We were on tenterhooks but Owen enjoyed his stay so much and we were so rested from the break that we made the decision to make respite a part of Owens' life.

Red House Respite Unit has given both of us a new lease of life. We took our first holiday in over 11 years together as a couple last year. We now enjoy weekend breaks away, a thing that was incomprehensible a couple of years ago. Owen loves going to the respite unit as there is an individual care plan in place for him which deals with his interests and likes. The staff there has been highly trained in current thinking in autism and avail of the many training opportunities that are afforded to them. Owen comes home from a break happy and contented and we are refreshed and rested, ready to face the week ahead.

Owen is now approaching the upper age limit for the respite centre and will have to vacate the service in a few short years. As parents we fully believe that given the success of the children's respite facility that the natural progression is an adult respite facility. It would be cruel and detrimental to the wellbeing of our autistic child if this service was taken away from him. Owen has other older siblings and we do not want to place the burden of taking care of him on their shoulders as they have their own lives to contend with.

Owen will never live an independent life, but does not need to be in residential care as his brother is. We would hope that Owen would eventually live in sheltered accommodation with the adequate supports. For now we would like him to stay at home with us and to progress onto adult respite.

We implore on you not to look alone at the cost of such a service, but see how such a service can dramatically improve the quality of life of the person with autism and his family.

Yours sincerely

Mary & John Ryan

25 The Moorings
Westbury,
Corbally,
Limerick.
7th March 04

Dear Board members

The type of service we would like to see in place for our son Conor would need to be a secure spacious rural type setting. He would need his own room, organized structured activities suited to his particular needs.

Conor is a very healthy active 16-year-old autistic boy. He must have constant supervision, i.e. 24/7. The main means of stimulation for Conor are little jobs around the house, long walks & drives in the car. He is unable to read or write, watch t.v. or engage in any type of social activity. Everything he does involves input from one or both parents.

From a parent point of view Conor is not always easy to take care of, there are times when he is hyper active & does not sit still for more than five seconds at a time. During these times taking him anywhere is a night mare. We cannot take him to Mass, into a shop, for a hair cut or indeed in to any enclosed public area. We have had to give up so much of our lives in the last 10 years, e.g. weddings, family events sporting occasions, and career opportunities.

Conor goes to Red House respite centre about one weekend a month & for a week during the summer. While this is a very well run & a very welcome service for which we are extremely grateful, we are getting to the stage in our lives when the demands of looking after Conor on a full time basis are beginning to leave us worn out most of the time. Conor will be 18 years old in just over two years time; we expect the type adult of service outlined above will be in place by then.

Yours sincerely

Eddie & Nora O Dwyer.

Adult Respite Unit

My son Stephen is presently fourteen years old. He received a diagnosis of autism when he was aged five years and three months. It was a devastating time for us as a family but we finally came to terms with it. Throughout the years we have been faced with various issues relating to accessing services that take the autistic condition into consideration. Among these were and still remain,

- Access to autism specific education
- Access to autism specific therapies
- Access to autism specific respite

We identified the need for autism specific respite as a priority and met with the MWHB to discuss this issue. As founder members of the information and support group Dochas, we were delighted to, in association with the MWHB and the Rehab service providers, to secure a respite facility specifically for autism. To date this facility has been a welcome break to us as a family, but once again its time to look ahead to our son's changing needs.

The respite center presently based in Patrick's Well was initially developed to cater for children from the Limerick area, the intention being to extend this type of facility to the rest of the Mid-West. Sadly this has not happened, with the result being that the respite facility is curtailed in its service delivery. The clientele that is accessing it varies in age from 5 to 24. This in itself advocates the immediate need for an adult respite facility/facilities.

Our situation at present is as follows

Stephen is a six-foot, fourteen stone autistic teenager, who presents with challenging behaviour. He requires a two to one staff ratio to participate in attending at respite. As a family we identified that Stephen's needs would be best met by availing of after school respite. With the established cooperation from the service providers and the excellent trained staff at Redhouse this works very well at present, but we now need to look forward.

In order to provide a structure for future respite for Stephen we need to establish an adult respite facility now. In our particular circumstances we believe that Stephen will never be able to live independently, but neither do we want him in a residential facility. It is our fervent wish for Stephen to remain at home with the ongoing support of an adult respite/residential facility. We would envisage this facility to be a replica in model of the existing children's respite facility with the necessary requirements to address the autistic adults needs. Stephen was one of the first clients to access the present Redhouse respite facility and I dread to think about the damage that could occur to him, if an autism specific adult facility isn't on the Midwestern Health Board's priority list. As a parent I firmly believe that given the success of the children's respite facility that the natural progression is to establish an adult respite facility. Our son's quality of life has been improved dramatically since accessing Redhouse. By extension our quality of life as a family has entered the "we can do that zone". For those of you reading this submission what this means to us to have access

to respite is immeasurable. For the first time since my son James's was born we could go on holiday. It entailed our giving notice to Redhouse seeking a weeks respite for Stephen during last summer's holidays, which they sanctioned. The joy on my nine year olds face was indescribable. He is already querying another break this year. For one full week in summer we enjoyed the luxury of being " a normal family".

For those of you involved in the decision making process in prioritizing services I would implore you to look not alone to the cost of such needed services, but to the implications on the service users and their extended families.

Conclusion

It would be a great pity for to allow the numerous benefits of the present respite system provided by Red House to be lost when the child with autism becomes an adult. As you have seen this respite means a great deal not just to the families involved but also to the individuals themselves. It would seem that the natural progression from the present situation would be the provision of adult respite. As the number of individuals involved is substantial and will continue to grow the provision of adult respite has become a matter of urgency.

Given that all people with Autistic Spectrum Disorder are individuals they all present with differing needs. To accommodate these needs there are a variety of options available which include as we have mentioned;

- A service similar in nature to that provided by Red House at present but tailored to suit the needs of the adults attending.
- Community group homes may be more suitable for some.
- Supervised apartments could be an option for the more able individuals
- Skill development homes are also a possibility

We can only ask that you find some way to accommodate the needs of our adult daughters and sons and those on the brink of adulthood as a matter of priority. The decision that you make will profoundly affect not just the lives of the individuals involved but also that of their family. We at Dóchas would like to extend our thanks to the Board for making the time to listen to our presentation.