

**A Three Year Strategy for  
Services for Able Adults with  
Autism aged 16 and over in  
Dudley.**

**2007 - 2010**



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## **Introduction :**

1. Autistic Spectrum Condition (also known as Autistic Spectrum Disorder or ASC) is a life long, developmental disability, affecting social interaction, communication, social relationships and making sense of the world.
2. People who have ASC can also have accompanying learning disabilities and/or physical impairments. This strategy focuses on the more able end of the autistic continuum.
3. Across the autistic spectrum there are an estimated 535,000 children and adults living in the UK. There may be up to 2000 adults across the autistic spectrum in Dudley Borough. There is no means of accurately estimating how many of those are at the higher functioning end of the spectrum – those who are known in this Strategy as HFASC.
4. In Wales The Welsh Assembly has begun developing an All Wales Strategy for Autism with a comprehensive multi agency approach for children, adolescents and adults. They aim to provide services from 'cradle to grave'.
5. The All Party Parliamentary Group on Autism (APPGA) was set up in February 2000 as a cross-party backbench group of M.P's and Peers with an interest in Autism and Asperger's Syndrome. Their aim is to highlight the need for improved services for this group of people.
6. The latest Department of Health document, 'Better services for people with an Autistic Spectrum Disorder', (Nov.2006) clarifies the nature and intent of existing government policy as it relates to adults with an Autistic Spectrum Condition. It is intended to encourage people in the social care and health field to develop local agendas for action.
7. The DH document states:
  - a. The current position whereby some people with an ASC 'fall through' local services – in particular between mental health and learning disability services, is unacceptable and contrary to the intention of government policy
  - b. Proper individual assessments, based on eligibility criteria as set down in 'Fair Access to Care' are the starting point for people getting the services they need. This should be supported by the use of person centred approaches
  - c. The services required to meet identified needs are best provided by local services that have the right skills and trained staff to

provide what an individual requires. This is better than deciding that either mental health, learning disability or physical disability services should provide all ASC related services as a matter of principle.

- d. Services and supports should focus on supporting each person's inclusion in society. New approaches to funding and support such as direct payments and individual budgets should be made available to people with ASC in the same way as everyone else
  - e. This whole approach should be underpinned by effective partnerships, including not only the relevant service sectors but also local representatives of people with an ASC and their families.
8. In June 2002 DMBC Social Services set up the DART (Dudley Autistic Resource Team) Project. The aims of the DART Project are to raise public and professional awareness of autism, promote independence, assist people in achieving life choices and gaining social inclusion.
9. The DART Project runs a once a week Drop In Service on Tuesday mornings at The Bonded Warehouse, Stourbridge. The parent support group TOADS, (Triumph Over Autism Dudley Support) meet at the same place.
10. The DART Social Club was taken over by a parent committee in January 2006 and have renamed themselves The ABC (Autism Black Country) Social Club. They are self funding and are applying for charitable status. The project also runs a Social Group of 16 young men.

### **About this Strategy**

11. This draft Strategy document identifies existing services in Dudley and the gaps in those Services
12. It is about people aged 16+ who fit the definitions of 'Autism', 'High Functioning Autism' (HFA) and 'Asperger Syndrome' (AS) 1. It does not cover children.
13. The document does not try to make a special case for people with an ASC but aims to clarify how national policy applies and to make clear what services people with an ASC can reasonably expect to have access to in Dudley.
14. Finally, the Strategy sets out specific action points to improve these Services, and to promote the independence and inclusion of people with ASC.

**The Key Principles are as follows:**

15. Government policy requires public bodies to identify, assess and meet the needs of adults with an ASC in their area. This overall responsibility falls to the Director of Adult Social Services (DASS) and/or the Director of Public Health.
16. Some people with an ASC who need services fall through the gaps created by traditional service boundaries. Strong protocols which cover assessment, diagnosis, joint working arrangements, care pathways and decision making can give more clarity about how people get access to a service.
17. People with an ASC should be able to access the same services as anyone else. The Disability Discrimination Act and the new Disability Equality Duty underline the need for all services to understand, and respond to, the needs of disabled people. This means that day, employment, leisure and education services (as well as all other public services) must make reasonable adjustments to facilitate the inclusion of people with an ASC.
18. People with ASC are entitled to receive direct payments and individual budgets in the same way as everyone else. It is thus expected that there will be a growing number of people with ASC who will take up this option and purchase their own services provision.
19. Good local services only exist where agencies work well together. This includes those with a role in: learning disability, mental health, primary care, adult services, services for young people, housing, support providers, treatment services, along with people with an ASC and families.
20. An effective commissioning strategy will build the local infrastructure and capacity of local providers. This will help to stop over-reliance on single, specialist providers and/or sending people to services a long way away from their homes.
21. Local supported employment and other specialist employment services should have the competence to support people with ASC into paid work.
22. The following services should be in place for family carers;
  - The right to an assessment
  - Expert carers programmes
  - Respite

**In reality, many of the services, systems and partnerships described in paragraphs 15 to 22 above are not yet in place in Dudley.**

## **CHAPTER 1 - CHILDREN & YOUNG PEOPLE.**

### **Children & Adolescents Mental Health Intensive Support Service – CAMHISS**

23. CAMHS is a multi disciplinary team comprising of Child & Adolescent Psychiatrists, a Staff Grade Doctor, Specialist Nurses in Learning Disability and Mental Health, a Clinical Nurse Specialist linked with youth offending services, Specialist Social Workers, Occupational Therapists, Child & Clinical Psychologists and a Family Therapist.
24. CAMHS has a multi disciplinary specialist ASC Tier 3 working group which includes Speech & Language Therapists and representatives from the Autism Outreach Team.
25. The team are involved in assessment and diagnosis of ASC and offer post diagnosis support to the young person and their family linking them to other ASC professionals to develop a consistent support network.
26. Where the young person is in mainstream education and parents consent, they are referred to the Autism Outreach Team in the Directorate of Children's Services.
27. Once the young person reaches 16 it is difficult to find appropriate services and resources, particularly where there are no additional mental health problems. Currently, CAMHS refers young people over the age of 16 to the DART Project which lacks sufficient resources to meet the increasing need.
28. Dudley facilitates early identification and early intervention to a child likely to have an ASC by referral to the Pre-School Special Needs Service – PSSNS, the Autism Outreach Team – AOT and Speech and Language Therapy Service – SALT.

### **Specialist Early Years Service**

29. A specialist team of nursery nurses managed by a specialist teacher supports children with autism.
30. PSSNS provides a 3 months practical and strategic training course for parents to meet the needs of their children.

### **Autism Outreach Team (AOT)**

31. AOT has 5 specialist teachers, 7 teaching assistants who work on a peripatetic basis across the borough's primary and secondary schools. Support is also given to pupils in Special Schools. Since the development of the AOT two years ago there has been an increase in the number of children being diagnosed with ASC .

32. The majority of children with ASC will be included in mainstream school and some will have a Statement of Educational need. Those pupils with more complex difficulties may require Special School Education.

### **Special Educational Needs Strategy**

33. Corporate Board recently approved 'Giving Every Child the Opportunity to Succeed : The Dudley Strategy for Children With Special Educational Needs' . This document recommends that 5 specialist ASC units are developed in one secondary school in each township. A multi agency ASC SEN Implementation Group is leading on the development of a Joint Policy and the educational provision.

### **ACTION POINTS**

- **Services and resources have to be developed to support and sustain ASC children upon leaving school e.g. independent living skills; travel training; preparation for employment. As part of transition school leavers will be referred to the DART Project where parents are agreeable, but this does not constitute an appropriate transition for these young people to adult services. In short, services for children and young people in the Borough are relatively well-developed but there is a relative paucity of good services for young adults.**

## **CHAPTER 2 - RAISING AWARENESS & ADVOCACY.**

### **Background**

34. Lord Ashley presented his Disabled Persons (Independent living) Bill to the House of Lords on 8<sup>th</sup> June 2006. The Bill, if passed, will introduce new rights for people with disabilities including those with autism. It will also impose additional duties upon local and central government to work towards changing public opinions and raising awareness about autism.
35. National and Regional autistic societies plus increased media coverage have promoted the profile of Autism and Asperger's's Syndrome over recent years.
36. The DART Project has held 5 Autism Awareness days, the last one being in May 2006 at Merry Hill Centre.
37. Advocacy has been an important aspect of The DART Project assisting clients and families/carers to find a voice to express what they need.
38. The Council already funds TOADS, the parents support group through the Carers' Grant.

## **ACTION POINTS**

- The development of an advocacy service for people with autism preferably by the appointment of a specialist worker to an existing advocacy organisations to take on referrals of ASC people.
- New DART Information packs are being developed to include more link details including web sites and an on line referral system.
- A DART Newsletter is also planned and will be available in hard copy or on the web
- Current Autism Awareness Training is being planned for workers in local agencies and information days with presentations from independent researchers are being set up.
- Closer links to deliver awareness sessions to staff and professionals involved with higher functioning individuals particularly the emergency services, police, judiciary, and probation where many staff may currently have limited understanding of able autism or how to recognise the condition. This will enable more appropriate responses and support in dealing with the individual.

## **CHAPTER 3 - HEALTH AND DIAGNOSIS**

### **Background**

39. The Royal College of Psychiatrists Report (April 2006) 'Psychiatric Services for Adolescents & Adults with Asperger's Syndrome and Other Autistic Spectrum Disorders' recommends to health commissioners that they should ensure that there is access to local, basic diagnostic expertise that allows a firm diagnosis to be made in clear cut cases. Where the diagnosis is uncertain there should be access to secondary diagnostic expertise to enable further assessment to take place.
40. Currently there is no defined diagnostic pathway in the Borough once an individual reaches 16 and leaves school. A referral for a diagnosis, usually at the request of the individual or their parents, can depend on where you live, how knowledgeable the GP is about autism, the determination of parents/carers to pursue a diagnosis or their means to pay for private consultations, which usually means travelling out of the Borough.
41. For some people with an undiagnosed ASC their desire to have a formal diagnosis is very important to them and their parents/carers. It can answer many questions and assist them in beginning to

understand why they behave, react and respond to situations in the way that they do and to develop coping strategies.

42. Without a formal diagnosis, individuals have no 'proof' of having a disability and so have no access to claiming welfare benefits or accessing support.

## **ACTION POINTS**

- **To formulate a clear diagnostic pathway that is accessible and available to all those who need it and request it.**
- **To seek funding for a sessional neuro-psychiatrist for one or two sessions a month, for assessment and diagnosis of new cases.**
- **Such funding application should also include a sessional health facilitation specialist nurse to advise on diet, food intolerances, gastrointestinal and bowel/gut problems, medication advice in relation to epilepsy and diabetes which may react to drugs for behaviour management, assistance & advice on sexual health and irregular sleep patterns.**
- **To consider the viability of a separate specialist service as recommended in the Royal College of Psychiatrists report, National Autistic Society reports, and the Department of Health document, 'Better services for people with an Autistic Spectrum Disorder',**

## **CHAPTER 4 REFERRAL AND ASSESSMENT**

43. In Dudley, once they leave education, people with able autism and Asperger's Syndrome may not meet Fair Access to Care criteria for eligibility to social care services. Many do not have a Learning Disability or a diagnosable mental illness, and most do not fall within the remit of Older People and Physical Disability Teams.
44. Hence, there is no clearly defined referral pathway into Adult Social Care for people with ASC. Many do receive a service from DACHS, but the process for allocation does not follow a logical route.
45. Social Care assessments may not recognise that high academic achievement can mask an unseen inability to cope with such things as being an independent traveller or being included in the community.
46. This is also a major issue for carers - if the person they care for does not meet our criteria they themselves have great difficulty getting a carer's assessment. as well as concrete support like Carers Direct which is only available following assessment.



47. Early intervention can enable ASC adolescents and adults to gain more independent living skills and by helping to maximise the individual's potential they are more likely to lead a more fulfilled life, achieve their life choices and become integrated into the community. Early acknowledgement of the parent/carer's and siblings' needs can enhance the carer(s) capacity for offering continued support to the client and help the whole family to lead a more 'normal' life. These needs often centre around the need for information and support from other families rather than what we might consider to be formal 'services'

### **ACTION POINTS**

- **To establish proper protocols, that identify a clear referral pathway.**
- **To ask the Member champion for Learning Disability or Mental Health to champion services for people with autism and Asperger's as well.**
- **To explore innovative ways of meeting needs and identifying appropriate funding**
- **To commission specific services and resources from independent sector providers to create services to meet individual needs.**

## **CHAPTER 5 – ACCESS TO LEISURE AND RECREATION**

### **Background**

48. Autistic people can experience considerable difficulty in accessing appropriate leisure and recreational facilities. Girls/young women with ASC experience particular difficulties given their smaller numbers and some of the behaviour traits of clients within this group

49. The DART Project Social Group and The Autism Black Country Social Club run activities that offer social inclusion. The project has begun a partnership with Adult learning4life and this has provided some summer activities, producing a magazine and a programme of swimming activities at Pedmore School. Programmes are now being developed for a weekly gym club, indoor sports of five a side football, baseball, cricket, volleyball, badminton and table tennis.

### **ACTION POINTS**

- **The DART Project cannot continue to meet at the Bonded Warehouse and seeks to acquire alternative premises that will provide a venue for clients to meet and engage in a variety of activities.**

- **DART will continue to arrange activities, trips and events of their own choosing and an autism friendship/chat internet site which will link us to HFASC people globally..**
- **The project will also explore ways in which the local community can become involved to highlight the need for specific support to enable the client group to enjoy a wider access and choice to leisure and recreation including local theatres and concert halls, which will promote social inclusion.**

## **CHAPTER 6 : EMPLOYMENT & TRAINING**

### **Background**

50. The National Autistic Society's report 'Working For Autism?' found that

- Only 33% had sufficient autism awareness and knowledge to support a client with ASC to find suitable employment.
- 42% said they had been unable to place any ASC client in employment or training.
- 46% attributed their failure to assist ASC clients into employment on employers negative attitudes and ignorance towards autism.

51. Nationally it is calculated that 94% of the working age ASC population are unemployed and are on long term welfare benefits, such as Income Support and Incapacity Benefit.

52. Autism West Midlands has appointed an Aspire Employment Support Worker to work in the Black Country and we can access this service free of charge.

### **ACTION POINTS**

- **The DART Project is working with New Deal, Job Centre Plus disability employment agencies and private ASC providers to promote the positive advantages of employing someone with HFASC.**
- **The DART Project is applying for joint funding to work in partnership with Beacon Employment, a disability employment agency which is willing to develop a work preparation and work step programme for HFASC individuals. This will involve preparing a CV, learning how to 'market' themselves, identifying strengths and building strategies to cope with difficult areas, how to work search and apply for a job, preparation for an interview and offering support at an interview, working with and alongside the employer and supporting them in understanding how to get the best from their HFASC employee.**

- **The DART Project is looking to develop business initiatives with private providers. One such initiative is currently being explored by DART and Inshore Midlands together with New Deal and the Police. This is a gardening project that will enable higher functioning autistic individuals to learn how to grow organic vegetables and herbs.**
- **The DART Project will continue autism awareness training sessions with local Job Centre Staff.**

## **CHAPTER 7 : SUPPORTED LIVING ACCOMMODATION**

### **Background**

53. Adults with autism tend to have difficulty accessing assistance with housing and appropriate support. Nationally more than half of the people with ASC are still living with parents.
54. DART Project members who are living alone in the community are not coping very well and require a lot of support. The Project has emphasised the importance of ensuring continuity of support to sustain the tenancy. In some instances two people sharing with appropriate support may be more likely to succeed.
55. There is a need to develop programmes to support young people with autism moving into independent supported living accommodation who have probably lived with parents for some considerable time.

### **ACTION POINTS**

- **Supporting People funding has recently been agreed for a housing support service for people with HFASC in or around the Stourbridge area. This will involve identifying tenancies either through Council Lettings or Housing Associations.**
- **Two types of supported living accommodation are being pursued.**
  - A Community based supported network housing scheme for 9 people where properties/flats are in close proximity to one another and where a block purchase of autism trained support can be provided to support individuals to be used on a flexible basis depending upon individual need. Possible sharing of tenancies where appropriate.
  - A large community house converted into flatlets with a support worker either on site or living nearby.
- **The DART Project in conjunction with Adult Learning4life will set up a year- long independent living skills programme in 2007. A tutor will work with 3 ably autistic people in a community house in**

**Lye. DART Project members will also be able to access a training flat to consolidate independent living skills in preparation for moving into supported living accommodation.**

- **There is also the opportunity to use the new Learning Disability Centre at Ridge Hill Hospital site to further support DART Project members in gaining confidence and expertise in skills for independent living.**

## **CHAPTER 8 : RESPITE AND HOLIDAYS**

### **Background**

56. Respite and short breaks play an important and vital role in carer support and can be a cost effective form of support that can divert a family crisis.
57. The All Party Parliamentary Group on autism has recommended that there should be statutory guidance on access and entitlement to short breaks.
58. The majority of such respite/short breaks are, however, only available to children. For the clients on the DART Project there are few opportunities for any respite or holidays as many potential providers lack the knowledge and understanding of autism necessary to meet their needs.
59. Supporting the client to be more independent outside -or within - the family home also allows the carer to go about their own affairs - without the need for any formal services. Carers of adults with ASC can access Carers Direct payments if the barrier to their break is financial. Many carers have used this most creatively but the difficulty is in getting the carer's assessment as highlighted above.

### **ACTION POINTS**

- **To examine more inventive ways of providing respite and carer breaks, using the Carers' Grant where possible. This may include placement with families, local weekend stays or, as independent living skills increase, pairs of clients may be able to support one another with minimum support.**
- **As confidence increases it may become more feasible for 2 or 3 HFASC friends to access a holiday with minimum support.**
- **Use of a training flat for short respite stays would also consolidate learned independent living skills and highlight any likely difficulties in preparation for moving to independent living.**

## **CHAPTER 9 – A SPECIALIST SERVICE FOR AUTISM AND ASPERGERS**

60. Specialist skills and knowledge about ASC can be developed in primary health care, health facilitation teams, Community Mental Health teams, and Adult Social Care teams.
61. Where they exist, specialist workers would need to be clearly identified in the local system and their role described in joint working protocols. Their role would be to help generic workers by providing diagnostic services, advice, support and training
62. There is evidence to support the development of a specialist team with wide range of professional input and the expertise to identify the complex and diverse needs of people with HFASC and to create services tailored to meet individual needs.
63. A specialist autism and Aspergers team in the Borough could comprise:
  - The existing Senior Social Worker from the DART Project
  - A second Social Worker
  - A Support Worker
  - A sessional neuro-psychiatrist for a clear diagnostic pathway
  - A specialist, sessional, health facilitation nurse
  - Admin support
  - Other professional/clinical support can be drawn from staff with special interest and knowledge in ASC
64. This would require commitment from local NHS organisations to resource Health inputs to the team e.g. with reference to the diagnostic pathway.
65. A specialist team could take the lead responsibility for implementing this Strategy in partnership with appropriate agencies. The team would also collect data and to create a centralised database using the Special Needs Register, on which to base projections of future needs, the development of services and resources and evidence for use in funding applications.
66. The DART Project itself could then become a community project/provider of services run by people with autism and parents/carers for the whole Borough not just the South. The project would need a base / centre to provide office space, admin, activity room/s, training/resources clinical/consulting rooms, kitchen, hall. A management committee would be set up to apply for charitable status to become a Community project in 2007.

**67. The specialist team, working with the DART Project, would deliver:**

- An on line referral service and a helpline.
- Person centred holistic assessments
- Individual programmes of support including a counselling service and therapy treatments/ relaxation/sensory room.
- Signposting individuals to other services which could meet their needs.
- Independent living skills training in preparation for moving into supported living accommodation
- Work preparation and partnership with local employers to provide work opportunities utilising ASC people's talents.
- Parent/carer support, information, resource material.
- Daily Drop In service with activities and a place for people to meet.
- Sessional input from private providers to develop schemes or programmes to meet specific needs.

**Funding**

68. The consultation on the Strategy is designed to stimulate a debate on how services for people with autism should be organised in future. It is recognised that if the specialist team was agreed as the best model, funding would have to be identified via the PCT and the Council, and perhaps income streams such as Learning Skills Council, Awards For All, The Big Lottery, Community grants, Charities & Trusts etc.

## APPENDIX 1



### Task group Membership

<b>Richard Carter</b>	Assistant Director for learning Disability and Mental Health/ Chair
<b>Carol Richardson</b>	Manager for LD Specialist Health Services
<b>Chris Morgan</b>	DART Project (Dudley Autistic Resource Team)
<b>Pete Scott / Phil Clinton</b>	Private Provider / Inshore Midlands
<b>Amanda Irwin</b>	L.D Specialist Speech Therapist
<b>Sarah Sivell</b>	Specialist Behavioural Nurse / Intensive Support Team
<b>Neale Pilkington</b>	Parent / Chair of Dudley Autism Parent Support Group
<b>Kath Watton</b>	Parent representative from TOADS
<b>Daniel Croot</b>	Service User
<b>Geoff Copeland</b>	Private provider / Safeharbour Stourbridge
<b>Maggie Macdonald</b>	Consultant Nurse Children & Adolescent Mental Health Intensive Support Service
<b>Justin Fellows</b>	Manager of Beacon Employment
<b>Diane Hanke</b>	Team Manager Education Outreach Team
<b>Brian Chamberlain</b>	Service Manager – Mental Health

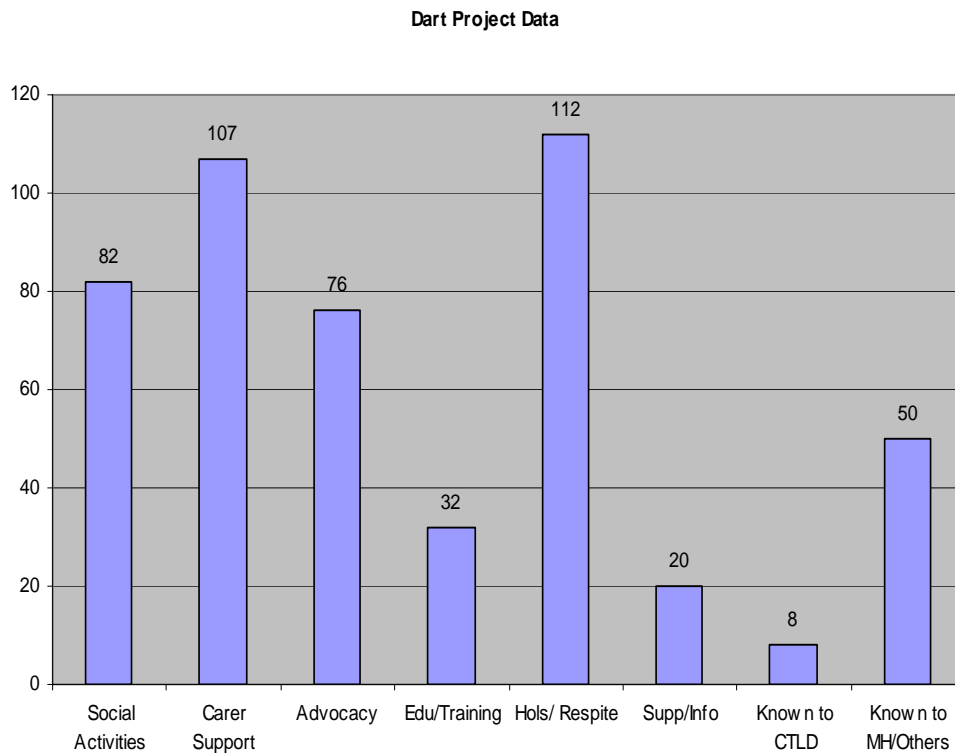
## APPENDIX 2– MANAGEMENT INFORMATION

### Background

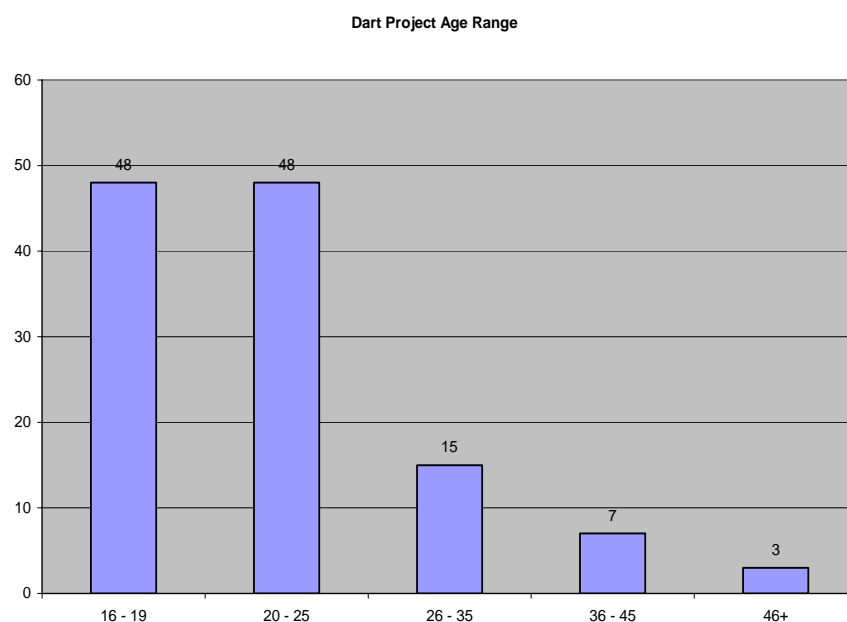
69. Since the DART Project began there have been 121 requests for registration with the project that has involved a response, action and follow up. This is without widespread publicity and only recent inclusion on the council website.

<b>Dart Project = 121 Referrals</b>	
 <b>Males = 105</b>	 <b>Female = 16</b>

70. The graph below is based on information from the 121 referrals. The highest need is for holidays and respite provision, carer support, social activities followed by advocacy.

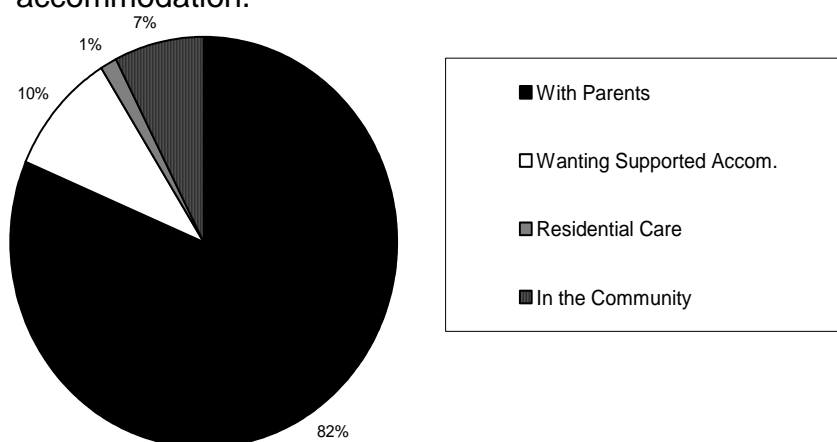


71. The graph below indicates the age ranges. The greatest proportion of referrals are aged 16 to 25. Asperger's Syndrome was not really accepted in the UK until the mid 1980's, which explains why some older people with ASC had a late diagnosis or may still not have a diagnosis.





72. The pie chart below indicates how many DART Project members still live with parents, and how many of those are actively seeking supported accommodation.



73. Of the 121 DART members only 11 are in some form of paid employment, 7 being full time, 3 part time, 1 in seasonal work. Two are in regular voluntary work and a few gained a brief work experience placement. 23 other DART members are actively and persistently seeking employment.