

Case Study: Dorset Adult Aspergers Support



Dorset Adult Aspergers Support Group (DAAS) was first established in 2007 in Bournemouth and Poole as an informal group of carers of adult children with Aspergers, who came together, in the absence of any other local support group, to discuss experiences and frustrations with their caring role. For many of the parents, their main concern was to share their anxieties about who was going to look after their 'children' when they were no longer able to do so. A few adults with Aspergers also attended for the support and comfort they received in a non judgmental environment.

It became clear during their initial meetings that harnessing these experiences into a more constructive dialogue with local agencies might be able to bring about improvements in overall services for both carers and adults with Aspergers. Many of those with Aspergers had had numerous contacts with different services throughout their childhood/teenage years, such as one young man who had seen over 100 different professionals from various support services (social services, health services, educational services etc). Despite all these contacts no worthwhile improvements were made to the young man's condition and situation and so he now chose to live as a recluse avoiding contact with any agency. Everyone in the group agreed that the service provision agencies would be more effective if they had a greater understanding of Aspergers and the problems the carers faced.

Inspired by the momentum of a high profile day in February 2008 at Poole Lighthouse theatre entitled 'Aspergers Syndrome in Dorset—the Way Forward' with over 150 attendees (predominantly professionals) in February 2008, the group decided, with considerable help from BCVS, to formalise their structure by:

- establishing a Steering group;
- deciding whether the group should include adults with Aspergers as well as their carers
- agreeing their aims and writing a mission statement; and
- finalising their name.

The following aims were agreed:

- To provide information and advice;

- To identify training opportunities;
- To identify gaps in service provision;
- To work with other agencies to promote understanding and support;
- Ultimately to have a voice wherever decisions are being made for the care and service provision for adults with Aspergers and their carers, in Bournemouth and Poole initially, and then latterly in Dorset

At this stage it was agreed that in order to be effective, the group needed to attract more members, raise their profile and secure funding to hopefully pay for a development officer. Unfortunately DAAS have never had sufficient money or the means to employ a development worker. In the absence of such a person most of the DAAS development work was taken on by the DAAS chair and a few others within the organisation. With the ongoing support and guidance of the Chief Executive of Dorset Healthcare Foundation Trust (DHCT) and continuous advice from BCVS, the group planned launch meetings in both Dorchester and Bournemouth for Autumn 2008, both of which attracted over 70 people. The lead officer of BCVS was one of the five speakers at those meetings and his contribution was seen by the chair as *'very helpful.'*

In October 2008 DAAS registered as a Company Limited by Guarantee and set up the existing organisational structure. There is currently a Board of five Directors with a Chair (the original founder of the group), a Secretary and Treasurer and two other members who meet regularly, and are responsible for the governance of DAAS. In addition monthly meetings are held in both Dorchester and Bournemouth which are attended by approximately 20 - 30 people (often depending on who the guest speaker is) and aim to provide information, education, support and guidance for both adults with Aspergers and their carers. The Dorchester meeting is currently chaired by the Treasurer and the Bournemouth meeting by the current Chair, although both operate quite independently of one another, according to the needs and wishes of their local group members.

DAAS maintains a database of all attendees, compiled from a form which most of those attending the monthly meetings are happy to complete, and to date there are approximately 150 names registered. This form also captures individual views about service gaps and what they feel are the priority areas for development. Although all of this information is filed, time constraints have prevented the full analysis of the results, however the following are examples of a few of the comments made from adults with Aspergers and carers;

'It would be really useful for carers to have a 'definitive' list of contact places that they could turn to for help'

'Isolation is a major problem –as a person suffering from Aspergers can become very isolated due to communication difficulties'

'A simple point of contact for services would be helpful rather than multiple organisations doing their own thing.'

'Lack of and varying support in mainstream education ... automatic continuing support when a child becomes an adult.'

'I currently do voluntary work in the autism base at a school but I am not supported. I would like to have some support. My dad died in April. I am worried about what will happen when my mum dies as I have no other family members in Dorset county. I know I will always need some support, what will happen?'

For the first 18 months of the group's existence the only income they received was a £50 private donation and £80 from a charitable event. DHCT and a community church provided free accommodation for the monthly meetings in Bournemouth and Dorchester respectively, whilst all other expenses (registering as a Company and setting up the web site) were paid by the Chair and other Directors in the hope of being able to claim back the costs at a future date. Then with the help of BCVS the group was successful in securing a Grassroots grantⁱ of £4985 in Spring 2010 and also benefitted from 3 further contributions from the NHS- £1000 from both DHCT Start up funding and Bournemouth & Poole PCT and £1500 from CAAS (Community Adult Aspergers Service):

To date very little of the income has been spent and that which has, has all been used on consolidating the infrastructure of the organisation. The Grassroots grant enabled officers to recoup their earlier expenses. The money will also be used to continue to run two monthly meetings, pay transport expenses, purchase public liability insurance for the meetings and raise the profile of DAAS. DAAS leaflets were produced using money provided by CAAS, who were also involved in developing the leaflet contents and also organised the actual printing.

Given their relatively short existence and virtually non existent income for the first 18 months DAAS has been remarkably successful in meeting its identified aims, for example:

- 150 adults with Aspergers and carers now receive information about DAAS and the monthly meetings in the East and West of Dorset, where they are able to meet with accepting people who *'speak their language'* and where they can share experiences, learn about different services, and raise concerns about gaps in services.

'They know they are not alone and groping in the dark and trying to find a way through the system' Chair

'Thanks for being able to help and advise' Carer

'My original reason for attending the group was to offer an account of how I have been able to hold down a responsible job, before and after diagnosis. In particular, the coping strategies I have developed for the work place and the accommodations made by both my client and my employer who wish to

continue making use of my skills. I am happy to share this with the group if it would be helpful and relevant to their own situation.’ Adult with Aspergers

- The website, although still under construction already gives details of when and where the two regular monthly meetings are held. The Chair also recently published a Frequently Asked Questions section which provides answers/signposting to relevant services etc;
- There is a newly established specialist CAAS (Community Adult Aspergers Service) which serves East Dorset, Bournemouth and Poole. DAAS like to think that their efforts in raising awareness of the needs of those with Aspergers and their carers was a big influence in the decision made to create the CAAS team.
- Feedback from those with Aspergers and often their carers is hard to obtain as they are usually not very demonstrative at showing their appreciation however one individual did write and say

‘You tell Dr S that I mentioned the amount of tremendous respect I have for her and her team. ... PLEASE let her (know) through CAAS and DAAS what has happened. ...I can NEVER forget what DAAS did for me’

DAAS now faces a positive but challenging future as the long standing chair resigns and new individuals will need to take on the further consolidation and development of the organisation. As with many small voluntary organisations, the potential is very exciting, but finding enough people to help realize that potential is a major task.

Throughout its entire existence DAAS has been fully supported by BCVS and is absolutely clear that their support, direction, expertise and guidance have been essential to the success of the organisation. The Chair noted:

‘It is true to say that our group would not exist if it were not for the help that BCVS has given us.’

In particular the organisation has valued:

- The expertise about how to set up an organisation from scratch, the legal processes, the financial and governance arrangements etc;

‘We didn’t know anything, we needed someone to guide us through every single step, I knew more than most but even I knew very little. He was absolutely invaluable, held our hand right the way through the whole process. From helping us decide what kind of company we should form, what our commitments and obligations would be and the costs involved. He then helped us with all the form filling and formalities and even accompanied the DAAS chairman to the solicitors for the company to be formally registered. He helped with every formality we had to comply with.’(Chair)

The sense of confidence from knowing they were following the correct legal procedures;

'He always stuck to every letter of the law, has stopped us doing anything dodgy; (it) gave me enormous confidence'

- The ongoing advice, signposting and guidance, practical support and willingness to attend meetings and speak at events;

'The lead officer makes himself available to attend meetings or give advice whenever you ask for it. He has attended several meetings outside of office hours as well as within. He has given us use of the CVS meeting room several times for Directors meetings etc...'

- Fundraising advice, identifying appropriate sources and assisting with the completion of application forms;

'The CVS were absolutely indispensable regarding us getting some money. BCVS told me what funding opportunities were possible and appropriate. Once identified I was able to make a successful application for Grassroots funding and BCVS helped explain any ambiguity or technical aspects of the application form.'

- The quality of support provided by the lead officer

'He has kept me going...of all the people I have ever dealt with he is the top, no-one else can come close.'

'The speed and quality of the advice I got gave me the confidence to take on the role of chairman. Without this support I would not have contemplated taking on such a role'

DAAS are fulsome in their praise for such a service.

'It was exactly what was needed...the crazy thing was before I met him (the lead officer) I had no idea such an organisation existed. If I had imagined the help we needed it would have been that organisation'

DAAS feels strongly that the contribution the CVS can make in terms of cost effectiveness needs to be more widely recognised within the voluntary sector:

'the fact that this fantastic facility is not being used and we are spending time and money on professionals when this expertise is available for free...you don't need to ask anyone else for help with anything if you know where the bible is.'

To test this DAAS were asked whether they would have preferred to have had the approximate amount of money the service had cost and they commented,

'The expertise 100%, far more valuable than the money; that wouldn't have bought us even a quarter of that expertise in the outside world. We found practically all the technical and financial advice we needed under one roof. If we had sought that advice elsewhere it would have involved solicitors, accountants and other professionals, all at great expense. We were even advised where to buy our computer software at a fraction of the normal retail price because we were a charity, thus saving our group even more money.'



This case study is being written as part of the evaluation of the Bournemouth Integrated Advice Service (IAS). The Evaluation Trust have visited four voluntary sector organisations who have received both organisational development and funding advice from the IAS officers, to understand and evidence their contribution to the overall success of each of the organisations.

ⁱ Grassroots Grants offers small grants of up to £5,000 to community groups with an income of less than £30,000 a year. This is a three-year programme running from 2008 -2011. The funding is from the government.