

vDoH: Autism Strategy for Adults- external consultation Sept 09: Response from DASH

1. DASH is happy with themes.

2. DASH is involved in service delivery to adults of working age living in Swindon diagnosed, or waiting for assessment and diagnosis, of Aspergers syndrome and/or high functioning autistic spectrum disorders.

We are not commissioned and indeed are largely unacknowledged by Swindon PCT. DASH arose from a shared concern of individual workers/practitioners from both statutory and voluntary sector mental health services of the unmet needs of people with an autistic spectrum disorder embedded in mental health services.

We conducted our own local research and published a report in 2007 called 'Seeing the Gap' which clearly identified what carers and adults with Aspergers syndrome/HFA felt was needed to improve the quality of their lives; which has in turn led to the development of a 'menu' of direct Asperger specific services. (There is also a parents self help group- SCAAS)

All of our costs have been met through funding applications, including our first, albeit small, grant from the local authority in recognition of the needs of this particular group of adults.

The benefits of our services accrue to individuals in terms of post-diagnostic support and/or advocacy to access an assessment and diagnostic service – currently unavailable in primary care but available in secondary mh services (and only because of the special interest of one individual clinician rather than widespread understanding and/or awareness of the condition).

DASH services include: a weekly support and discussion group, a weekly non-buildings based social group, monthly psycho-educational workshops, one to one personal action planning and support, volunteering opportunities, supported employment opportunities, access to employment support through a partnership arrangement with the Richmond Fellowship for whom we invested in training via Progress to Work, and individual advocacy provided by volunteer advocates. We employ 5 part-time staff whose combined hours are less than 1 full-time post.

We measure and report hard and soft outcomes in relation to individual members goals and aspirations – through self-assessment and staff observation. Soft outcomes relate to confidence, engagement, social skills, work skills, motivation etc; hard outcomes relate to attendance, courses and training, work etc.

The strength of our service lie with our committee of workers from housing, mental health services, learning disabilities, PALS, SUNS (service users network Swindon) and adults with AS themselves; and staff who understand the condition and work positively with it. There are many opportunities for development of the service to meet needs in terms of employment skills and support, partnerships within the community for new vocational projects, befriending, outreach, development of advocacy especially in the criminal justice system and transitions for young adults. Our main weakness relates to the invisibility of our work to commissioners and the absence of a primary care assessment and diagnostic service that GPs can refer to in order to deliver equality of health care for adults with AS/HFA. Currently our referrals are restricted largely to one practitioner from mental health services with a recent growth in referrals from Learning disabilities services following a professionals workshop we staged earlier in the year.

The major threat/ risk to the on-going delivery of these services is that we have to rely on fund-raising from grant making trusts and foundations in what is now a very competitive climate, with no resources apart from the goodwill of volunteers to undertake this.

3.

Disability:

If you consider mental health we have a considerable body of local evidence to show that people who have not received a diagnosis as a child and who have reached 30 – 50 years prior to diagnosis, are often embedded in mental health services because of long-term depression and anxiety associated with trying to fit into a confusing social world with Aspergers. They can remain mis-diagnosed and poly-medicated for decades and even when referred for assessment and are diagnosed with Aspergers, they run the risk of either being discharged – having been told mental health services have nothing to offer them – or their care plan and medication remains unchanged and they continue to receive inappropriate treatment and support - both of which outcomes are very distressing.

To reduce the adverse impact: there needs to be

1. much more awareness of the condition in mental health services and across all social care and health service staff,
2. access to assessment and diagnosis in primary care, and
3. post diagnostic interventions and support.

Age:

⌘ There is undoubtedly a 'lost generation' for whom diagnosis, if it comes at all, is too late in terms of a working lifestyle and a career commensurate with their intellect and aspirations.

⌘ Young adults in transition leaving college / FE who then fall into a 'big hole' – probably returning to or remaining living at home with parents with no occupational or social activity, increasingly isolated and depressed.

To reduce the adverse impact: there should be

1. a tapering investment in vocational services for the middle - older generation (as they progress towards retirement age);
2. early intervention of assessment and diagnosis for children and young adults; **plus**
3. investment in ASD specific vocational services for young adults, immediately post college and as a transition into employment.

4. social inclusion

We agree that these are key areas where action is needed to improve social inclusion for people with an ASC

Here in Swindon over a year ago, DASH presented a model of services to the joint commissioner of health and social care to overcome the present situation of adults with Aspergers/ HFA either ending up in mental health services or learning disability services - neither of which are meeting their needs appropriately. The model comprised a PCT commissioned 'intermediate' care' team that pulled in clinicians on an as needed basis to assess and diagnose and offer short-term interventions with a supporting partnership of services offered by the voluntary sector, including housing support, vocational support, social networks and advocacy.

We have no local champion or lead in the PCT/SBC so there has been no interest in following this up to address or resolve this situation, so far as we have been made aware of. There is no local register / database of numbers of people with ASD living in Swindon or accessing services.

It has become increasingly clear to DASH that the local 'one stop shop' – Careline, for accessing health and social care services - when contacted by an adult with AS has been known to give the person the telephone number of the community mental health team (which is not an appropriate referral pathway) and alternatively offer to make a referral to learning disabilities services (which is where we now realise that people are being sign-posted to however inappropriately).

Evidence of our members also demonstrate that community care assessments are not offered in any way that is appropriate for adults with AS despite them flagging up their condition; and no suggestion to involve their parents carers in the assessment.

5.

Challenges facing adults with AS is that because they are high-functioning and can learn what is needed to fit in, the more they try to fit in, the less understanding they receive and the higher the expectations of others become, sometimes with unexpected consequences.

Facilitated self-help groups and one to one and/or group training with role play can really help people to understand their condition and how to learn to cope and improve their social skills and confidence whilst reducing stress and anxiety in for example the workplace.

Advocacy is much needed by adults with AS however high functioning they are and in our experience this has been needed in the following areas:

- ✘ negotiating with suppliers and entering contracts eg for purchasing IT equipment or arranging telephone contracts
- ✘ landlords and tenancies
- ✘ benefits advice and access to benefits advisory services
- ✘ entering, sustaining and retaining employment through changes
- ✘ treatment in mental health services
- ✘ criminal justice systems – as victim and as perpetrator
- ✘ access to community care services
- ✘ access to advocacy itself

On-going support / mentoring is needed to help people to manage in

- housing;
- the workplace;
- interpersonal relationships

6.

To facilitate social inclusion there needs to be developed a local model of vocational services that support people across the spectrum. If an adult with a ASC also has a learning disability they should be able to access these services. For people with HFA and AS it may be appropriate to create partnerships with services in existence in the community to support people with disabilities & / or mental health needs towards work and employment. There is then a gap for those people who would not fit into either / are not ready for work / need to make the transition from FE into the world of work. Therapeutic work and supported employment opportunities need to be created to act as 'stepping stones' or as an end in themselves for people unable to make the transition to mainstream employment. This is a familiar model of services for people with mental health needs in Swindon and some of these services work in partnership with DASH to provide a range of opportunities.

Community care assessors need to be trained to respond appropriately to people identifying themselves / a family member with an ASC not just in making the assessment but also in sign-posting with knowledge of what is available in the community.

People at with HFA/AS in Swindon who want to work, need to retain work or change their employment do have access to a specialist mental health employment support service through DASH's partnership with the Richmond Fellowship with access to a range of services from therapeutic work to supported employment if they are not able to progress immediately to mainstream labour market. Also both local colleges of FE have specialist student support for young people and adults with an ASC. In New College, there are several age related support groups specifically for students with AS.

DASH offers social and communication skills workshops.

DASH has a small menu of volunteering opportunities – in woodwork, tools restoration, horticulture, administration, a library and with a small investment could widen these AS specific opportunities as proven springboards to progression towards engaging with work and developing self confidence.

Health

Completely agree that these are key action areas.

The following scenarios regularly occur in DASH:

- ⌘ we identify mental health services users with strong autistic traits and have to persuade their workers that it is worth investigating if the person themselves is agreeable. Workers frequently don't understand / believe that assessment and diagnosis is more often than not a positive intervention in itself;
- ⌘ Ex mental health service users come to DASH or are referred by voluntary sector mh providers because strong autistic traits are revealed or exposed when other mh issues have been resolved – and there is nowhere to go. Some GPs literally tell their patients to 'forget it' and some try and refer back into mh services where there is an assessment service – turns it all into a postcode lottery;
- ⌘ We are increasingly made aware by families that there are a number of people sitting in GP waiting rooms who suspect – or along with their partners / parents – that they may be on the spectrum – but their only choice at the moment is to pay for a private assessment. There is no service in primary care in Swindon, which DASH considers to be a health inequality issue.
- ⌘ Post -diagnostic support previously existed in mh services through the intervention of a single clinician who offered small group work - this has now been expanded in partnership with DASH as DASH commissioned workshops; support groups exist in one FE college; DASH supports a social group. A carers support groups also exist for families to come to terms with the diagnosis.

Training for mental health workers, workers in learning disabilities services and GPs needs to be prioritised.

DASH held an Understanding Aspergers workshop for professionals and was overwhelmed by interest – the majority of whom came from frontline worker in LDS and social work teams as they identify people whose needs are not being met appropriately. No statutory mental health personnel attended even though many are not sufficiently familiar with the condition or close enough to their clients to recognise AS/HFA rather than or in conjunction with a mental health problem.

A major concern of DASH is that if mental health service users are diagnosed, often they continue to be supported and medicated in exactly the same way as if the diagnosis doesn't make any difference. These are often people who have been in the mh system for years and are poly-mediated for psychosis, bi polar, schizo-affective or personality disorders. In several cases DASH members have successfully come off all their medication and have benefited from the very practical approach of OTs and the holistic approach of social workers if they are fortunate enough to be offered this support. For some service users they either have to continue as they were or fight for a change in regime - both options being unacceptable.

Some of our members have health issues related to the long-term use of medication.

Choice and Control.

To access choice and control people need to have their needs assessed in an competent and appropriate way as the starting point. Carers need to be listened to and offered carers assessment as the burden of care still falls largely on parents even if their adult child has engaged in FE – when they come out of FE they return to parental home and isolate themselves because there is

no help and support to take the next steps.

Advocacy is an essential service that is currently unavailable except in a very small way for people in contact with DASH via volunteers.

Adults with an ASC cannot be more involved in service development if there are no services, they remain invisible to the commissioners and there is no local policy or plan of action to meet their needs.

Choices and control are limited by lack of appropriate services and / or a lack of brokerage, advice and advocacy to access services.

It has been noted how helpful it is for mh workers in both voluntary and statutory sector to have someone who knows the person with AS well to act as an intermediary. Lack of understanding and training, misinterpretation of high levels of stress, emotional expression and sensory sensitivity etc can create situations that seem unmanageable and out of control to both the worker and the person with AS.

Locally we have been attempting to have a dialogue with the commissioners about advocacy and have sought financial support of £200 to enable DASH volunteer advocates to access training but our requests have been ignored; even though people with AS have been sign-posted to us by SBC/PCT for advocacy.

Swindon Advocacy movement (a service for people with LD) is willing to act in partnership so there are good opportunities going to waste!

Awareness Raising and Training

Yes – agree these are key areas where action is needed if include GPS in targeted training programmes as a starting point with a referral service to back this up; and GPs who work for the DWP, especially those involved in benefits medicals.

Access to Training and Employment

There is training for Employers and Employer handbooks widely available but the emphasis has to be on helping adults with ASC to understand and prepare for the world of work; have on-going external mentoring schemes available to individuals

Making the benefits and tax credits more accessible to adults with an ASC is probably impossible without making it more accessible to all adults with disabilities. At the moment supported permitted work is accessible whilst on incapacity Benefit but the income disregard is just £20/week and has been for the past decade at the same time as the minimum wage has increased year on year. This reduces the effectiveness of the first – and therefore often the most significant 'stepping step' in going to work for many people.

Challenges:

Benefits medicals have personnel that may not recognise the impact of AS especially if the person does have some learnt social & communication skills but may still not be able to describe their difficulties and the adjustments they make in their lives in order to do things.

GPs may not know their patients, especially if the person with AS rarely make appointments, preferring repeat prescriptions, not wishing to talk to GPs. Sometimes they have no understanding of what information a GP might be seeking and what is a 5 minute appointment can last as little as

2 minutes! This can lead to difficulties with the benefits systems when a GP is asked to report on the support needs of their patient. We have many instances where a GP will fail to make any response or 'support needs unknown' – and 9 months later, throughout which time benefits have been suspended and considerable stress has been felt, it culminates in a requirement to attend a tribunal in a magistrates court where the person is asked to explain themselves!

Employment – the danger is being labelled as different, unfriendly, rude or a misfit which can then lead to bullying and intimidation. The Employer's need to know is not always acceptable to the person with AS but changes in the workplace can provoke reactions that are inexplicable to the employer as a result of stress. Through its partnership with Richmond Fellowship DASH is able to offer support to retain employment.

Advocacy, mentoring, advice and support services needed – not necessarily AS specific but AS trained workers and access to AS specific intervention as needed.

Further comments: DASH fully endorses the findings and recommendations of the External Reference Group's initial report.