

Annex A – Covering Template for Responses

Please complete the attached cover sheet when sending evidence, indicating the set of questions to which a response is being provided and contact details of the person for any follow-up queries.

Contact details for respondent	
Name	
Job title	Staff Grade CAMHS, West Dorset Hospital Trust
Do you represent an organisation? (if so, name of organisation and type: e.g. voluntary, public body, private company).	I chair West Dorset Attention and Concentration Working Party and Adult ADHD group These are both multidisciplinary groups based at Dorset County Hospital
Postal address	Childrens Centre, Dorset County Hospital, Damers Road, Dorchester, DT1 2JY
Telephone number	
Email	

	Which area of the review are you responding to? (please mark X)
Prevention strand	
Review of disabled children	
Strategy for youth services	
Review of high cost, high harm families	x

**Call for Evidence: DfES/HM Treasury Joint Policy Review on
Children and Young People 2006**

Response from West Dorset ADHD Service

Summary

This document details the work of West Dorset Attention and Concentration Working Party and West Dorset Adult ADHD Group.

Although it would be possible to comment on three of the four streams in the call for evidence, this paper primarily focuses on the impact of generational ADHD and its association with high cost high harm families. It considers the initial experiences of the West Dorset Adult ADHD group as it looks to quantify needs and establishes ongoing principles of care

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Response from West Dorset ADHD Service

Attention Deficit Disorder with/without hyperactivity (ADHD) is a spectrum condition that can have a profound impact on a child, and his/her family. Many children will do well with medication, educational support and behavioural advice for the family.

Comorbid disorders

In 60 % of cases, ADHD exists with other disorders. These other disorders can be developmental and include Autistic Spectrum Disorders (ASD), dyspraxias, specific learning difficulties global learning difficulties and Tourettes syndrome. This means that an individual with a diagnosis of ADHD is should be carefully reviewed as to whether he or she has a wider group of cognitive deficits.

Complications of ADHD

As the child grows older, he/she may present with new difficulties for example poor peer relationships, low mood, deliberate self-harm, oppositional defiant disorder, conduct disorder, educational and occupational failure, teenage pregnancy, and criminal behaviours. There is some evidence to suggest that optimum treatment may help to prevent these long-term complications.

However, in discussion with other services it can be helpful to delineate:-

- those children who remain undiagnosed and present to services other than health (youth offending teams, housing connexions),
- those children who are treated and respond well to treatment and,
- those children who develop complications despite treatment.

Genetics of ADHD

60 – 80% of ADHD symptoms are inherited. Therefore one has to assume that one or both parents have a degree of adhd themselves. This means that the parent(s) may:-

- be impulsive and reactive
- have had poor experiences of school,
- cognitively find it hard to provide the structure that suits adhd children,
- cognitively find it hard to prepare and plan healthy eating
- have had a teenage pregnancy,
- attend appointments
- find it hard to communicate, in a succinct way, their family's needs when discussing their child with health or education professionals,
- need help in instituting behavioural advice
- have often experienced relationship failure so may live in extended complicated families

Many families with adhd cope well, despite their child's difficulties. However the increasing severity of the ADHD in the child, together with increasing likelihood of ADHD in a family member can mean that some of these families have multiple problems including poverty (Biederman 2006 – this is an American study showing average household incomes, and academic achievement were significantly lower among individuals with adhd. Difficult to compare with UK but clinically , for my CAMHS workload, feels similar), housing issues, and criminal behaviour, and fit within High Cost High Harm families.

There is a great need for more long-term research into how these factors interact.

Fitting ADHD into service reviews

Because a child with ADHD may have a variety of developmental difficulties, achieving his/her optimum management can be challenging. It is easy to segregate service development resulting in a family having input from a number of specialists. Providing joined up therapy can be time consuming or worse contradictory.

On the flip side of the coin ADHD can fall between services.

- Who provides and funds the assessment and treatment service, CAMHS, acute paediatrics, community paediatrics
- Are these children disabled? Some children are certainly incapacitated by their ADHD symptoms, whereas others perform well with medication
- ADHD is treated often differently to ASD at service development level within education and health despite both being considered developmental disorders. This could be partly because children with ADHD can receive symptomatic treatment with medication. The increasing use of atypical antipsychotics for children with an ASD might have an impact on future development.

The Service in West Dorset

Our Service for children with attention problems

Children with a diagnosis are seen by patch based acute paediatricians, community paediatricians and CAMHS. We have a database of all children with a diagnosis of ADHD who are being seen regularly, and therefore are on medication. There have been consistently 500 (+/- 20) children on the database for the last 4 years. This represents 1.6% of the school age population in West Dorset. Each teenage year has a cohort of about 50 young people. Over 16 years this number tails off. This reflects mixed practice for arrangements of care for 16 year olds and above.

There is a range of prevalence across the region with the highest prevalence of ADHD being 3.9% of school age children and the lowest being 0.3% . (see appendix 1). Although it is not a simple relationship the highest prevalence falls in one of the areas of West Dorset that has 54.7 % of 0 – 16 year olds living in families claiming means tested benefits (South West Dorset Primary Care Trust 2003). Given the complications of untreated ADHD such as relationship failure, occupational failure, and mental health difficulties it could be surmised that this high prevalence of ADHD in the children reflects on a group of families who have generational ADHD and are therefore at risk of the complications of ADHD including poverty. This would place a proportion of our families who have a child with ADHD in the category of High Cost High Harm families. I am not aware of formal studies looking at this and further work would be needed to confirm this relationship.

Of the 500 children being seen with ADHD, one third are seen by CAMHS and two thirds by paediatricians. Either service can refer to CAMHS for psycho behavioural work.

If young adults require an on going service they are referred onto patch based adult mental health teams.

Our work with the West Dorset Concentration Working Party has principally looked at:-

- improving communication between services
- collection of relevant data
- drawing up a pathway of care for those with concentration problems, especially looking at the services available to families pre diagnosis. (see attached power point file as appendix 2)
- standardising assessment and treatment
- encouraging named professionals in associated services to provide a link for those children with concentration problems
- education at four different levels:-
 - non medical staff to increase understanding and reduce stigma eg Assist workers
 - medical staff providing basic behavioural support and advice eg health visitors, primary mental health staff, and general practitioners. We have a pack for GPs which is going through the approval process (see appendix 3)
 - education staff, not only teachers but also learning centre staff, and education social workers. We have a schools pack which has gone to all schools in west dorset. This is very similar to the GP pack but has more tabulated advice for specific symptoms
 - specialist medical staff involved with assessment and diagnosis

Adult ADHD working party

Our adult ADHD group consists of acute paediatrics, CAMHS, adult mental health, parent representative, YOTs, and , Connexions. We have also made contact with one of the local housing organisations. It was set up because of interest expressed within adult mental health teams, concern raised by

professionals involved in the care of children and young people with ADHD, ,and, in response to comments from our ADHD parent support group.

It has two main target groups:-

- those young people who have a diagnosis of ADHD and need ongoing care above the age of 16/18. Part of this group are made up of young people with multiple difficulties who are finding it hard to make the transition to independent living. There are also a number of young people who have achieved well and want to access medication for particular life stages such as learning to drive, or, writing dissertations for university courses. This latter group of young people do not require large amounts of clinic time but a contact point with a professional with whom they have an ongoing relationship.
- Access to treatment for parents of children who are being seen by the services for ADHD. Adults do not often present to services saying that they think that they have ADHD. Therefore concern is often raised when these families present with a child with ADHD. Assessment and treatment of the parent who is confirmed as having ADHD could have positive benefits for both the parent and the child with ADHD

The aims of the adult group are very similar to those of concentration working party.

We initially tried to identify the unmet need. Response back from patch based primary mental health workers was that they felt there were more adults known to services with developmental problems (ASD and ADHD) than previously but they often presented with additional mental health issues. We were unable to gain numbers.

We have also explored the possibility of following up a cohort of children with adhd through the Connexions service to see how they managed with work placements. However because we are using organisations not in health to gain information it cannot count as audit and we re having to apply under research grounds. This is still in process and has caused some discussion

between our audit department and our local Research and Development committee.

We have made contact with our further education colleges in the area, who have reported back that up to 20 % of their young people might have significant problems with their concentration and organisation. All had personnel who provided support for student. They were uniformly positive about contact from the group and felt that there was very little regular communication about particular young people. Anecdotally there are some courses such as ALFIE and E2E that have a much higher proportion of students with difficulties. These classes can be a challenge to manage. The systems for support for individual lecturers do not seem to be as well developed at the present time as they are within schools and there is often little two way communication with health.

The overwhelming anecdotal impression is that the services can be quite disjointed for young adults. Their principle carers (usually a parent) can feel isolated and uncertain of how best to support their child. These families can have multiple difficulties, inherited ADHD, relationship breakdown, poor educational achievement, and poverty. They can feel overwhelmed and unsure of where to turn, they struggle to feel empowered within the system.

Our adult group is looking at how best to prioritise our work given our limited resources. The principles by which we wish to work are very similar to the attention and concentration working party –

- To keep the needs of the patient and their family paramount in decision making

- To increase communication between services

- To work towards having nominated people within services who can liase on behalf of their organisation

- To empower people by education in a similar way described on page 5 referring to the work of the attention and concentration working party.

- To look at ways to raise awareness and reduce stigma

- To work towards standardising assessment and treatment

Three members of the group have a particular research interest looking at the impact of assessment and treatment for a parent of a child with ADHD. If the parent is diagnosed with ADHD and treated this may impact favourably on family relationships, and the institution of more consistent parenting. This might mean that less medication is necessary for the child. This research project is only at an early stage. A literature search has been done and applications to COREC need to be made. Dr Stanley, Consultant Child Psychiatrist is the lead for this project.

This group is still at an early stage and is a work in progress. It has not been audited as yet.

Key Questions for Annex B4

Key Questions for Annex B4

We could comment under three of the provisions of this review but have chosen to do so under Annex B4, High Cost High Harm families as a number of our ADHD families fall within this description.

Who are the high cost high harm families?

I would not like to suggest that all high cost high harm families have generational ADHD . However there are a number of families within our ADHD service who do fall into this category. I would propose that the often unrecognised cognitive difficulties in the parents mean that they have

- compounding mental health problems,
- may have experienced homelessness,
- relationship breakdown,
- poor work history,
- have complex families with complex needs
- poverty

Out of 500 children on our database 120 approximately are seen by CAMHS. Out of these half could be considered to have generational ADHD and multiple problems. This as an estimate would count for 60 families in West Dorset.

What Progress has been made in addressing needs of these families?

Our initial step is to raise awareness for generational ADHD. Referrals are made on an individual basis to the patch based adult mental health teams for assessment and diagnosis. We are looking to develop increasing systemic links both for these parents and for young people with multiple needs who require ongoing care. Our service is still in an infancy regarding these needs

Can we better align services?

Having a lead person in organisations such as housing, conneXions, drug advisory services (as has worked for schools) to be a point of contact for health would be incredibly useful. Locally where we have this in place, with YOTs and ConneXions, it feels that we are providing a much more joined up service. This has not been audited.

Are current incentive and levers adequate

Our work has happened locally because there is an interest from particular professionals. There are often conflicting demands for time particularly as this work is seen as being outside normal clinical commitments. Frontline personnel have been very helpful but again are limited by their time commitments

What interventions have been shown to work.

More literature is developing to show the effectiveness of treating adults with ADHD. Surman 2006 presents a review of treatment adult ADHD in the States looking at both medication and cognitive therapy. More work is needed on families with generational ADHD to confirm benefits and risks especially on high cost high harm families.

References

Biederman et al (2006) The effects of Attention/Deficit ? Hyperactivity Disorder on Employment and Household Income *Medscape General Medicine* 2006, 8 (3) posted 07/18/2006

South West Dorset Primary Care Trust (August 2003) *Annual Public Health report*

Surman et al (2006) New findings expand understanding of Adult ADHD
Medscape Review 537384

Appendix 1

Statistics from Adhd database for West Dorset

Information from data base 15.12.03

Total 438

Boys 385 88%

Girls 53 12%

Ratio boys/girls 7/1

Areas:-

Weymouth	131 / 8130	1.6%
Portland	70 / 1795	3.9%
Dorchester	67 / 5574	1.2%
Bridport	22 / 2242	1.0%
Sherbourne	33 / 2634	1.3%
Shaftesbury	11/ 1753	0.6%
Sturminster Newton	16 / 1442	1.1%
Blandford	56/ 2831	2.0%
Gillingham	8 / 2737	0.3%
Lyme Regis	5 / 1406	0.4%
Beaminster	7 / 1365	0.5%
Outside	27	

No. with ADHD come from the ADHD database at WDGH

School numbers come from Mr Farmer, Dorset county council and include school aged children in the respective pyramids

Note: some children in the shaftesbury and gillingham pyramids may have been referred to Salisbury