THE AUTISTIC SPECTRUM DISORDER (ASD) STRATEGIC ACTION PLAN FOR WALES

A REPORT PRODUCED BY THE ADULT TASK AND FINISH GROUP

October 2009
## CONTENTS

1. Chapter One : Introduction 1

2. Chapter Two : Executive Summary 3

3. Chapter Three : Recommended Actions & costs 10

### APPENDICES

<table>
<thead>
<tr>
<th>Appendix</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix i</td>
<td>Sub-group report on Diagnosis</td>
<td>12</td>
</tr>
<tr>
<td>Appendix ii</td>
<td>Sub-group report on Access to Services</td>
<td>19</td>
</tr>
<tr>
<td>Appendix iii</td>
<td>Sub-group report on Community and Monitoring Support</td>
<td>23</td>
</tr>
<tr>
<td>Appendix iv</td>
<td>Sub-group report on Employment &amp; Related Issues</td>
<td>33</td>
</tr>
<tr>
<td>Appendix v</td>
<td>Sub-group report on Housing</td>
<td>37</td>
</tr>
<tr>
<td>Appendix vi</td>
<td>Terms of Reference</td>
<td>41</td>
</tr>
<tr>
<td>Appendix vii</td>
<td>Membership of Task &amp; Finish Group</td>
<td>43</td>
</tr>
<tr>
<td>Appendix viii</td>
<td>Membership of Sub-Groups</td>
<td>44</td>
</tr>
<tr>
<td>Appendix ix</td>
<td>Membership of Focus groups</td>
<td>45</td>
</tr>
</tbody>
</table>
CHAPTER ONE

Introduction

1.1 The Welsh Assembly Government commenced implementation of the pioneering Autistic Spectrum Disorder Action Plan (ASD) for Wales in April 2008. This multi-faceted action plan featured four key actions relating to Adults with ASD namely:

- the identification of local ASD leads who must include adults in their mapping, planning, and stakeholder engagement in action planning
- the provision of research into the circumstances of older people with ASD
- the development of a range of awareness-raising materials which will be directed at those agencies and practitioners who work with adults as well as children with autism
- the establishment of a Task & Finish Group to provide a focus upon the needs of adults with ASD and to make specific recommendations to Ministers for future actions

1.2 The evidence and recommendations from the Task and Finish Group are summarised and seek to enhance the impact made by the Assembly Government’s ASD Strategic Action Plan in a coordinated, creative and achievable manner.

1.3 Seven meetings of the Task & Finish Group took place from 1st October 2008 to 13th May 2009.

1.4 The terms of reference for the Task & Finish Group are contained in the Appendix (vi).

1.5 There were 11 members of the Task & Finish Group with representation derived from key agencies within the statutory and voluntary sectors across Wales and details are contained in Appendix (vii).

1.6 It was agreed at the first meeting to prioritise the work of the Group within five key areas pivotal within adults with ASD service planning namely:

- Diagnosis
- Access to Services
- Community and monitoring support
- Employment and related issues
- Housing.
1.7 Certain of the areas considered such as employment and benefits fall outside WAG jurisdiction as these are not devolved issue. It was also agreed that there was a need for further work to be identified once the initial work of the Task & Finish group had been completed.

1.8 It was considered essential to increase the breadth of the evidence collected and to increase inclusivity by engaging with a wider population of practitioners and users of services from across Wales. Therefore sub-group meetings, chaired by members of the Task & Finish Group were held to collect and consider evidence upon 5 key areas outlined above. Papers from these groups were presented to the Task & Finish Group for consideration. Membership of sub-groups are contained in Appendix (viii).

1.9 Three Service-User Focus Groups, two based in South Wales and one in North Wales were also asked to respond to a paper presented by the sub-group looking at Community and Monitoring Support, and their feedback was formally considered at the Task & Finish Group meeting held on 13th May, 2009. Membership of the three Focus Groups is given in Appendix (ix).

1.10 The recommended actions and indications of costs made by the Task & Finish Group are those which have been prioritised and are believed to give ‘value for money’.

1.11 Subject to the outcome of this report a delivery programme will need to be established which engages with those agencies key to the implementation process.
CHAPTER TWO

Executive Summary

2.1 It is critical that services are not developed in isolation, but are embedded within, and therefore pervade, the existing public delivery of services. Outcomes must lead to a far better informed generic sector, and greater focus, direction and coordination of those services which will be of direct benefit to people with autistic spectrum disorders living in Wales. Therefore, the recommendations made by the Adults Task & Finish Group can be greatly assisted by the national, regional and local ASD posts created as a result of the Welsh Assembly Government’s ASD Strategic Action Plan. These posts, combined with the local ASD leads offer real potential for joined-up thinking, planning and delivery throughout Wales.

2.2 Recommendations and estimated costs have been produced from each of the five key areas namely:

- Diagnosis
- Access to services
- Community and monitoring support
- Employment and related issues
- Housing

2.3 It has been found that there are key action ‘themes’ which run across these five topics specifically:

- awareness-raising
- coordination of service planning and developments,
- infrastructure development on a regional basis,
- sharing existing examples of good practice
- delivery of a consistent All-Wales approach to adults with ASD.

2.4 It has been important to consider the needs of adults with autism across the spectrum of autism disorders which includes those with associated severe/profound learning disabilities as well as those with Asperger syndrome.

Assessment and Diagnosis

2.5 The provision of assessment and diagnostic services to adults with ASD should be the bedrock for the development of an informed and enabling service.
2.6 Wales is currently extremely poorly served by a paucity of diagnostic services to adults with ASD, with a dearth of multi-agency diagnostic services and a very small number of clinicians with an interest and indeed skills in this field.

2.7 The evidence demonstrates a clear need to radically re-shape the delivery of this service through improved infrastructure and coordination. There is an urgent need for the delivery of a consistently applied All-Wales service to be located in the new LHB structure, linked by a managed clinical network, creating an increased number of autism aware diagnostic teams and for the first time in Wales a genuinely multi-agency assessment process for adults with autism. This can itself become a groundbreaking approach within the UK.

2.8 There is also a need to undertake a short period of targeted screening in order to ‘catch-up’ with those adolescents throughout Wales currently within transition processes.

2.9 Post-diagnostic counselling and signposting people with ASD and their families must be provided to ensure that those coming out of the diagnostic process are not left to deal with the consequences of the diagnosis alone. Individuals will require support to initially adjust to the impact of the diagnosis and guidance as to the opportunities available to them and possibly also to the links that can be developed together with them. Two routes are suggested through which this service can be provided, the first provided by a discrete ASD service established within LHBs and supported by the proposed managed clinical network; the second to embed a service within the current operation of the Wales genetic counselling service.

2.10 Continuing Professional Development (CPD) for those involved in the diagnostic process will need to be built-in as an on-going action.

2.11 Children’s diagnostic and post-diagnostic services are not the domain of this report. However, Local ASD Action Planning, carried out as part of implementation of the WAG ASD Strategic Action Plan for Wales, demonstrates that whilst there is some good practice throughout Wales, many ASD diagnostic teams operate on a ‘goodwill’ basis and without funding, nor indeed consistency of methodology. This has the effect of creating a service vulnerable to staff movement, to changes in NHS policy and methodological preference. Therefore, as with the Adult ASD Task and Finish Group, it is recommended that

- a managed clinical network for children’s ASD diagnostic services is established to ensure consistency in methodology, to monitor standards
- continuing professional development opportunities are provided
a short investigation is carried out into the funding arrangements of local ASD Diagnostic teams, leading to the development of a sustainable service

Access to Services

2.12 Whilst the root of service provision should lie in the creation of an effective diagnostic system; a diagnosis of an autistic spectrum disorder does not necessarily lead to any provision of service. Adults with ASD do not fit easily into LD or MH services, and for people with Asperger syndrome and High Functioning Autism especially, this is perhaps their biggest barrier to accessing services.

2.13 It is recognised that there whilst there is a common assessment framework and WAG guidance on the Unified Assessment Process (UAP) and Fair Access to Care Guidance, there remains an element of local determination in respect of eligibility and assessment. Therefore an ASD specific assessment ‘tool’ should be developed in order to trigger the UAP and this should be informed via awareness-raising in order to consistently inform the ‘access to services’ assessment process throughout Wales.

2.14 As part of the development by WAG of awareness-raising materials to be developed and distributed to all local authorities and LHBs within Wales a module will be specially written for those involved in the assessment process within LD and MH Teams. Authorities will need to ensure that those involved in the UAP for people with ASD have the sufficient level of knowledge and skills in ASD to effectively carry out the assessment process.

2.15 There is a need for WAG to clarify the assessment processes to Local Authorities with regard with autistic spectrum disorders. The assessment process will need to take account of the inherent life-long difficulties in inflexibility in thinking and behaviour, social and communicative functioning and the consequential pervasive impact upon an individual’s capacity to cope in everyday life and this will cut across several areas including, employment, education and housing.

Community and Monitoring Support

2.16 Services to adults with ASD in Wales are currently patchy. Most service providers to adults with ASD hail from the voluntary or independent sectors although there are a small number of key examples located in the statutory sector. Measuring autism specific quality within both specialised and generic services is problematic as there is no genuinely independent measure of the quality of autism services in the UK today. Unsurprisingly, in view of population
distribution across Wales, SE Wales hosts the largest numbers of services to adults with autism.

2.17 The Regional ASD Support Officers based with the Social Services Improvement Agency (SSIA), will be the catalyst between local areas by collecting information from the existing local action planning and drawing together regional themes which can be translated into regional service planning and delivery.

2.18 It is proposed that as there are population distribution differences between the three WLGA regions, an annual grant of £80k be made by WAG to each region in order to establish a regional approach to adults with Asperger syndrome, the agreed use of which to be determined by the ASD Regional Support Officers in conjunction with the Local ASD lead Officers and approved by the Welsh Assembly Government via the ASD Implementation Manager.

2.19 There also needs to be a specific focus upon the training and support needs of services and practitioners working in statutory and independent sector services in Wales for adults with ASD especially within generic learning disability services in which many adults with ASD exist. Therefore it is proposed that:

- WAG will coordinate the various strands of the voluntary and statutory sector in Wales to develop an All-Wales Conference on practice for adults with ASD during 2009/10
- WAG will pursue Web-site development via HOWIS as a host location for the sharing of good practice, information and regular updates
- WAG will coordinate and publish three components of the forthcoming WAG ASD Awareness-raising materials which will be focused upon working with adults with severe/profound LD; those with Asperger syndrome; and those with ASD and co-morbid conditions. These will be developed in partnership with statutory and voluntary services
- WAG will encourage local ASD leads and their ASD Regional Support Officers to identify the further training needs of practitioners and this will include professional qualifications in ASD

2.20 WAG will ask local and regional ASD leads to map advocacy services for adults with ASD in Wales, and through them organise training support to generic LD advocacy groups

Employment and Related-Issues

2.21 There are many advantages to be gained for employers who employ an adult with an ASD. Reliability, honesty, and absolute commitment are just three valuable qualities found in many people with
ASD in employment situations. Further, the Welsh economy can be enhanced through the employment of people with ASD and the consequential reduction of those receiving benefits. Yet only a very small proportion of those with an ASD ever achieve and sustain full employment and are therefore restricted by a lack of equality of opportunity. Currently, within Wales there is little awareness of autism by employers and indeed only emerging examples of informed ASD practice with JobCentre Plus, Careers Wales and other related areas.

2.22 Whilst not a devolved matter, the Welsh Assembly Government can play a lead role in boosting significant change both by setting an example itself as an autism-friendly employer but also by spearheading a publicity campaign targeting employers and businesses throughout Wales.

2.23 Alongside the All-Wales ASD Employment publicity campaign there is the need for a Wales ASD Employment Ambassador to create clear links at strategic HR levels within Welsh businesses. In addition to creating opportunities for people with autism this role can also draw upon the expertise of those models which are proven to be effective in sustaining employment and can also promote closer contact with ASD agencies in Wales. In today’s difficult financial climate it should not be too difficult to locate a senior business figure willing to work on a seconded basis in this spearheading role for a 12-month period.

2.24 Awareness-raising and training support for the staff working in the six component companies within Careers Wales and also with JobCentre Plus can be approached in a consistent manner over an initial two-year period, and this also will include guidance for Disability Employment Advisors. Sheltered employment and Social Enterprises providers can also be helped to understand ASD better through a similar approach.

2.25 WAG will publish awareness-raising materials relevant to employers and the related agencies as part of its production of awareness-raising materials during 2009/10.

2.26 The forthcoming DWP welfare reforms will clearly have significant implications for Wales and it is proposed that a small working group be established to monitor, consider and produce recommendations to WAG on behalf of the autism community in Wales.

**Housing**

2.27 The provision of appropriate housing is highly relevant to those with ASD and associated learning disabilities and also those with ASD without an associated intellectual disability. In the former some of the key issues may be around the physical design of the buildings and the
materials that are used. In the latter there are also a significant number
of people who are able to function without any statutory support within
‘ordinary’ housing but as a result of their difficulties with
communication, social interaction and in thinking and behaving flexibly
will find it difficult to navigate the challenges of daily life such as dealing
with relationships with neighbours, landlords or utility companies.

2.28 The forthcoming WAG document Supporting People - Housing
Related Support Five Year Strategy recognises the likely growth in the
numbers of people with a learning disability with a need for housing
and housing related support. In turn a proportion of these people will
have an Autistic Spectrum Disorder. This growth in need will mean that
there will need to be new and creative ways of working with limited
resources. These issues will raise challenges especially for the Local
ASD leads and the Regional ASD Support Officers who will play an
essential role facilitating and supporting planning activity in respect of
these issues.

2.29 The Social Housing Management Grant should be used to fund a
project identifying existing design research literature for people with
ASD and developing an ‘ASD Buildings Design Toolkit’ to assist the
architects, clerks of work and others within Housing Associations and
construction companies operating throughout Wales. It will be the
responsibility of Local Authority and Health Commissioners to ensure
that architects are provided with this ‘Toolkit’.

2.30 WAG will approach the Royal British Institute of Architects to
explore how design issues for people with ASD can be located within
architecture training

2.31 The Regional ASD Support Officers will work with Local ASD
Leads, Commissioners, and Independent sector to identify need,
shared resources, and to plan specialist housing resources to meet
highly complex needs.

2.32 It is recommended that the existing WAG funded research to the
Coastal Housing Group working in partnership with the Housing
Corporation be applied to assess the value of ‘homebuy’ for people
with autism, and for the findings to be disseminated within the housing
and autism communities’ in Wales.

2.33 WAG publication of awareness-raising materials will include
modules relevant to housing personnel and its related components and
this will especially target Supported Housing Support Workers and
Domiciliary Care workers within Social Services Departments.
Future ASD Adult Working Group Priorities

2.34 In undertaking its current work, the Task and Finish Group have identified a number of other issues they believe require further consideration by WAG. The areas identified are:

- Further and Higher Education
- Implications and actions arising from the Older Persons’ Research
- The various aspects of the Criminal Justice System
- The Mental Health needs of adults with ASD
- The implications arising for those with ASD in Wales resulting from the DWP Welfare Reforms

It is therefore proposed that WAG continue to host a Task & Finish Group which oversees the collection of evidence and recommended actions within these areas which will need to be considered within the on-going implementation of the ASD Strategic Action Plan.

2.35 It is recognised that there is already some good work being undertaken within the first three areas in Wales and membership of separate groups will consist of those currently undertaking practice within Wales from across the statutory and voluntary sectors.
### CHAPTER THREE

**Recommended Actions & Costs 2010-13**

**Summary All Costs**

<table>
<thead>
<tr>
<th></th>
<th>Yr 1</th>
<th>Yr 2</th>
<th>Yr 3</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis &amp; Clinical Network, CPD in ASD costs etc</td>
<td>138,659</td>
<td>133,659</td>
<td>128,659</td>
<td>400,977</td>
</tr>
<tr>
<td>Pre/Post Diagnostic Counselling Support</td>
<td>117,026</td>
<td>117,026</td>
<td>117,026</td>
<td>351,078</td>
</tr>
<tr>
<td>Access to Services</td>
<td>20,000</td>
<td>0</td>
<td>0</td>
<td>20,000</td>
</tr>
<tr>
<td>Community &amp; Monitoring Support</td>
<td>260,000</td>
<td>240,000</td>
<td>240,000</td>
<td>740,000</td>
</tr>
<tr>
<td>Employment &amp; Related Issues</td>
<td>100,000</td>
<td>60,000</td>
<td>10,000</td>
<td>170,000</td>
</tr>
<tr>
<td>Housing</td>
<td>10,000</td>
<td>0</td>
<td>0</td>
<td>10,000</td>
</tr>
<tr>
<td>Future Adult Group Data Collection</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>645,685</strong></td>
<td><strong>550,685</strong></td>
<td><strong>495,685</strong></td>
<td><strong>1,692,055</strong></td>
</tr>
</tbody>
</table>
### Break-down related to Diagnosis & Pre-Post Diagnostic Counselling Service for ASD

<table>
<thead>
<tr>
<th></th>
<th>Cost Description</th>
<th>Amounts (£)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Start up training costs¹</td>
<td>15,000 10,000 5,000 30,000</td>
</tr>
<tr>
<td></td>
<td>Costs based on DISCO training Allowance made for accommodation &amp; travel</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Governance arrangements²</td>
<td>9,000 9,000 9,000 27,000</td>
</tr>
<tr>
<td></td>
<td>Specialist training in co-morbidity Clinical governance – audit, clinical/case discussion. Three one day meetings per year to attend (to come out of existing SPA sessions of consultants). Each meeting costing £3,000</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Central costs of network Central administrator @ A&amp;C Level</td>
<td>10,000 10,000 10,000 30,000</td>
</tr>
<tr>
<td>4</td>
<td>Cost for host e.g. Clinical governance, office costs</td>
<td>10,000 10,000 10,000 30,000</td>
</tr>
<tr>
<td>5</td>
<td>Diagnostic sessions³</td>
<td>41,409 41,409 41,409 124,227</td>
</tr>
<tr>
<td></td>
<td>Costed at level of 2 sessions of NHS Consultant Psychiatrist time per assessment</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Multidisciplinary liaison input to enhance current provision</td>
<td>6,687 6,687 6,687 20,061</td>
</tr>
<tr>
<td></td>
<td>Costed at level 7 A&amp;C 100 professional sessions per annum</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Network lead at rate of 2 additional Consultant Psychiatrist sessions per year</td>
<td>16,563 16,563 16,563 49,689</td>
</tr>
<tr>
<td>8</td>
<td>Generic mental health &amp; learning disability training for professionals</td>
<td>30,000 30,000 30,000 90,000</td>
</tr>
<tr>
<td></td>
<td>Sub-totals</td>
<td>138,659 133,659 128,659 400,977</td>
</tr>
<tr>
<td>1</td>
<td>Pre/post counselling service in each LHB area Costed at same level as current genetics pre/post counselling - Level 7 A&amp;C</td>
<td>117,026 117,026 117,026 351,078</td>
</tr>
<tr>
<td></td>
<td>Combined Totals</td>
<td>255,685 250,685 245,685 752,055</td>
</tr>
</tbody>
</table>

¹ The costs here reflect the need for wider multidisciplinary training in assessment methods. This is required so that diagnostic reports can be appropriately interpreted and findings incorporated into care plans. Early pump priming of the network should help to ensure its viability and prevent it being overwhelmed. Training a network together could enhance cohesiveness at an early stage. However it is assumed the network would have a reduction for “block booking”. Reductions could be made if the network were able to contract for accommodation from an academic institution.

² Costs again include accommodation. It will be vital to allow funding of external expertise and linkage with other academic and clinical centres of excellence.

³ The assumptions are for 125 assessments per year across Wales i.e. 17-18 per LHB area. This to be reviewed
The costings are for a Consultant Psychiatrist at the salary mid point. Costings for Psychiatrists are given as they are the most highly remunerated members of the workforce. It is fully recognised that other senior clinicians e.g. Consultant Psychologists can carry out this diagnostic work. Input from a specialist psychiatrist will be probably required in areas of clinical complexity with possible multiple diagnoses.

⁴ This would be to allow the network to have paid dedicated time from representatives of professional groups within LHB areas

⁵ This is based on other central responsibilities attracting similar commitments e.g. Deanery appointments.

⁶ The costs overleaf for generic training for professionals – above basic awareness. Without this there are risks of the network being overwhelmed.
APPENDIX (i) – SUB GROUP REPORT ON DIAGNOSIS

Introduction

1. The establishment of a Task & Finish group to concentrate on issues for adults was established early in the process of strategy implementation; it was recognised that the implementation action plan required focussed work to allow the development of better defined objectives, subsequent priority setting and a coherent action plan.

2. The group was clear its recommendations would apply primarily to Welsh people who lived in Wales but that evidence would be sought from any relevant sources. It was recognised that some adults were placed in services outside Wales – their needs would be acknowledged in the overarching action plan.

3. People with and without learning disabilities were included in the group’s work.

4. This paper concentrates on the diagnosis of autism in adults, however its recommendations are mindful of other key areas within the Task & Finish groups work programme particularly “Access and Assessment” and “Meeting Mental Health Needs.” This synergy was recognised in the planning of a joint workshop with the “Access & Assessment” workstream.

5. The recommendations are made during a phase of major re-organisation of the planning and delivery of Welsh NHS Services.

6. A core value throughout the group’s work was that diagnosis of ASD was neither a prerequisite or trigger for an assessment or a service.

7. Training in the recognition and diagnosis has not been prominent in the training of many professional groups including most notably professionals in mental health services. The situation should improve for psychiatry as all psychiatrists should have some attachment to developmental services. Due to the development of ASD strategies across the UK further need to modify training needs has been highlighted to the Dean & Registrar of the Royal College of Psychiatrists.
Process of Evidence Collection

8. The diagnostic pathways within the published Action Plan formed the basis for this area of work.

9. The joint workshop sought representation from service user groups; professional health groups (psychology, nursing, psychiatry therapies); and the ADSS. Additional workshop participants included a representative from the National Public Health Service (NPHS), the ASD Implementation Manager and other members of the Adult Task & Finish group. The latter included representatives from Chief Medical Officer (CMO), Chief Nursing Officer (CNO), and WAG secretariat. Unfortunately representation from the appointed ASD local & regional implementation managers was not possible.

10. Attempts were made to ensure that workshop participants were from across Wales and included professionals working both within and outside specialist services for people with learning disabilities. Some were delivering local diagnostic services.

11. The workshop format included short introductory papers from three perspectives: service users, the Welsh process for Assessment & Access and diagnostic practice. Participants identified objectives after considering the existing proposed pathways in the implementation plan and working through some case scenarios. Participants and the implementation local managers have had the opportunity to comment on the paper.

12. The recommendations have been influenced by participants’ visits to specialist services.

13. There is recognition of a lack of agreed outcome measures to evaluate the performance of different diagnostic models.

14. Whilst there is some evidence based diagnostic practice in specialist learning disability services, such provision is planned and delivered without clear infrastructure and governance arrangements.

Specific Recommended Actions

15. Recognition

15.1 Formal evaluation of the evidence base for self and carer/family recognition.

15.2 Evaluation by NPHS of the impact of a time limited screening programme for a high risk population of teenagers in the transition phase; the population would include 14 -18 year olds receiving additional paid support in the classroom with and without a statement; all Welsh children in specialist schools including those in boarding schools outside Wales. If the presence of a statement alone were considered this would give smaller numbers.
However there is evidence of different practices for receiving a statement across Wales.

16. **Children’s Services.**

16.1 An accurate overview is obtained of the systems for diagnosis of autism in children across Wales.

16.2 A clear link is established between the implementation plans for diagnostic services for children and adults. This could capitalise on the current initiatives in place regarding re-modelling services for young people.

17 **Managed Clinical Network**

17.1 An all Wales managed clinical network is established offering a diagnostic service.

17.2 The network would implement across Wales evidence base practice for the early identification and diagnosis of ASD.

17.3 Each new LHB would contribute prescribed clinical workforce to the network. Thus there would be diagnostic expertise within each LHB area.

17.4 The network would be hosted within one LHB, the NPHS or other structures developed within the Welsh NHS for clinical networks. The re-organised NPHS should be an integral member.

17.5 Additional key members should include academic departments across Wales with established expertise in autism including Learning Disability & Autism Network (LDAN) and Professor Sue Leekam, the Cardiff University Chair in Autism Research.

17.6 The network would be responsible for designing the diagnostic model, training its professional members and implementing a clear programme of evaluation. Evaluation would include a strong service user feedback system.

17.7 The network would be subject to professional and organisational regulatory arrangements.

17.8 Users of the diagnostic service would receive pre and post counselling and support services within a designated pathway. Local and regional ASD implementation managers would be key to the design of this area.

17.9 An additional function could be to provide specialist training to all relevant professionals in early recognition and diagnosis of autism. This training would be limited to highly specialist training.

17.10 The network as a whole would include expertise to provide diagnosis in complex areas of differential diagnosis and co-morbidity e.g. ADHD, personality disorder, mental illness. Network infrastructure would allow the
strategic development of particularly specialist areas with cross referral possible within the network.

17.11 The network would function within the framework of Unified Assessment Process (UAP) and Care Programme Approach (CPA).

17.12 The network development should be informed by initiatives and programmes such as those offered by Association of University Centres on Disabilities (AUCD), University Centres for Excellence in Developmental Disabilities Education, Research, & Service (UCEDD).

17.13 Links would be made with existing centres in the U.K. e.g. Autism Research Centre, Cambridge; National Autistic Society, Lorna Wing Centre for Autism.

**18 Organisational Processes.**

18.1 Reviews of the UAP process should acknowledge the place of specialist assessments and try to reduce duplication.

18.2 The review of CPA implementation in Wales specifically includes consideration of the needs of people with ASD.

**19 Training**

19.1 General awareness training needs to be evidence based and linked into local, regional and national systems. Awareness needs to include appropriate referral for diagnosis and understanding of the impact of diagnosis on future service delivery. Without such work there are risks of the managed network being overwhelmed with development of long waiting lists.

**Costings for recommended actions.**

**20. Recognition.**

20.1 Self recognition.

20.1(a) Seek contact with WAG funded research opportunities to influence research priorities.

20.1(b) Evaluation of possible impact of targeted screening of adolescents in transition phase.

20.1(c) Evaluation could be part of current NPHS workload. Discussions with the NPHS indicate they would be able to take this on in their work plan for the next year.

20.1(d) Initial discussions with academic colleagues suggest an early involvement in the work would be appropriate. The evaluation would need to consider both potential therapeutic and cost benefits. The programme if
implemented would require robust evaluation as it would potentially inform clinical practice both in Wales and internationally. The costing of such an evaluation using a research method needs to be included in the NPHS’s evaluation.

21. Children’s services

21.1 Description of current diagnostic practice for children in Wales (not costed)

21.2 Link with children’s part of ASD implementation plan via network of regional and local ASD leads?


22.1(a) Assumptions

- 125 new assessments per year. There will be a need a formal review process at end of first two years and for future funding requirements to be based upon empirical analysis of this service
- pathway would have access to some multidisciplinary assessment in each area. Costings below would be to enhance such services
- aims to initiate were to provide high quality diagnostic services
- host organisation would provide basic/personnel & governance arrangements without any start up costs
- each LHB would receive directive to ensure service promoted stronger interface working between existing specialist mental health and learning disability services
- LHBs would be directed to promote clear linkage with any ASD diagnostic services for children

22.1(b) Please see Page 18 for estimated costings.

22.1(c) Review of UAP and CPA to include consideration of autism – part of existing reviews.

22.1 (d) Estimates for training costs to mental health and learning disabilities workforce. This would provide all mental health and learning disabilities professionals enhanced awareness and basic competency relevant to their area of practice. This would be at a higher level than the basic awareness aims of the education and training aspects of implementation plan. Training would include appropriate referrals to diagnostic services. If this recommendation was accepted it could provide foundation for future activities over a three year programme to establish genuine enhancement in workforce competency levels. Future events could address training needs in co-morbid areas e.g. treating ASD and mental illness. Indicative costings would come from experience in recent training events to implement Mental Health Act (MHA) and Mental Capacity Act (MCA). This was £9,000 for each “old” LHB and local authority in Wales.
23. Priorities

- Linkage with Children’s ASD.
- Implementation of diagnostic clinically managed network.
- Enhanced training for mental health and learning disabilities professionals.
- Evaluation of screening programme for young people in transition.
- Influencing research funding priorities.
### Diagnosis and Pre-Post Diagnostic Counselling Service

<table>
<thead>
<tr>
<th>Cost Category</th>
<th>1 Year £</th>
<th>Costs over 3 Years £</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Start up training costs</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Costings based on DISCO/ADOS, ADi-R training</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Allowance made for accommodation &amp; travel</td>
<td>15,000</td>
<td>30,000</td>
</tr>
<tr>
<td><strong>Governance arrangements</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specialist training in co-morbidity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical governance – audit, clinical/case discussion. Three one day meetings per year to attend (to come out of existing SPA sessions of consultants)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Each meeting costing</td>
<td>£3,000</td>
<td>9,000</td>
</tr>
<tr>
<td><strong>Central costs of network</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Central administrator @ A&amp;C Level 4</td>
<td>10,000</td>
<td>30,000</td>
</tr>
<tr>
<td><strong>Pre/post counselling service in each LHB area</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Costed at same level as current genetics pre/post counselling level. To be delivered within existing genetic service or alternatively as 2 posts shared across LHB’s.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>117,026</td>
<td>351,078</td>
</tr>
<tr>
<td><strong>Diagnostic sessions</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Costed at level of 2 sessions of NHS Consultant Psychiatrist time per assessment</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>41,409</td>
<td>124,227</td>
</tr>
<tr>
<td><strong>Multidisciplinary diagnostic input to enhance current provision.</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Costed at level 7 A&amp;C</td>
<td></td>
<td></td>
</tr>
<tr>
<td>100 professional sessions per annum</td>
<td>6,687</td>
<td>20,061</td>
</tr>
<tr>
<td><strong>Network lead at rate of 2 additional Consultant Psychiatrist sessions per year</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>16,563</td>
<td>49,689</td>
</tr>
<tr>
<td><strong>Costs for host e.g.</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical governance, personnel, office costs.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>10,000</td>
<td>30,000</td>
</tr>
<tr>
<td><strong>Generic MH &amp; LD Training</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>30,000</td>
<td>90,000</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>255,685</td>
<td>752,055</td>
</tr>
</tbody>
</table>

*All Salaries are at mid point.*
APPENDIX (ii) : SUB GROUP REPORT ON ACCESS TO SERVICES

Introduction.

1. The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales clearly recognises the importance of those issues that influence access to services and the process of assessment.

2. There are particular concerns that adults with Asperger syndrome may experience difficulty in accessing services and support. In some cases this may arise from a lack of information and awareness of services available (or indeed not available) but in others may also result from the failure to meet eligibility criteria.

3. Therefore a sub-group was formed by the Adults Task & Finish Group to explore this very difficult area and to make specific recommendations back to the core group. There were two means of collecting this evidence.

4. Firstly, a workshop took place on the 26th January 2009 to explore the situation that currently exists across Wales in relation to adults with autistic spectrum disorders. Participation included contributions from a range of practitioners from statutory and voluntary sector services. The workshop sought to establish whether key issues could be identified and how they might be addressed.

5. Secondly, additional information has been elicited by sub-group members, and there is cross-referencing with evidence and recommendations of the community and monitoring subgroup.

Current Framework for Assessment

6. From the outset it is important to acknowledge that the Health Service and Social Services should provide services based on individually assessed need. There are specific requirements to consider in respect of the Unified Assessment:


   b. Assessment Process - Enquiry – where significant needs described or suspected. Contact assessment – components of independence and information about need gathered.
Overview assessment – need explored across domains of the unified assessment. Specialist assessment – where triggered by particular domains.

c. Care Planning and Review - Care plan is the outcome of the assessment where eligible needs have been identified. Review determines whether outcomes met, re-assessment of needs and continued eligibility.

Process of Evidence Collection.

7. The workshop approach was based on the following objectives:

- Presentations to provide technical and research information.
- To utilise the knowledge and skills of participants.
- Establish key issues and consider possible recommendations.

8. It was recognised that there are a number of components that can be considered in respect of access and assessment. Views were gained from both professional and organisational perspective. A starting point for discussion was based on the Welsh Assembly Government Guidance “Health and Social Care for Adults: Creating a Unified and Fair System for Assessing and Managing Care”.

9. The relevant sections of The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales were also used as a reference point and these include:

- Raising Awareness (pages 9-11)
- Assessments of need for services (pages 16 – 19)
- Care Assessments/Services for Adults (pages 36-43)

10. The National Autistic Society presented their own research although it was recognised within the group that there is a comparatively limited evidence base to draw upon.

11. Since the workshop, sample case vignettes have been provided by one Welsh LA’s Lead Officer for Adults with ASD and these are presented in Paragraph 14 below.

12. Issues considered:

a. Eligibility Criteria

b. Access

i) Information provided about services would benefit from greater consistency across Wales.
ii) Bilingual information should be more readily available.
iii) Review available information to establish effectiveness.
iv) Improve sharing of information between organisations.
v) Establish better joint working between organisations.
vi) Develop training/awareness for staff within the Health and Social Care sectors.

c. Assessment.

i) It is necessary to recognise that there is an element of local determination in respect of eligibility and assessment but agreement about the use of more consistent assessment ‘tools’ should be addressed.

ii) A review of the unified assessment process should be progressed as indicated in ‘A Strategy for Social Services in Wales over the next decade – Fulfilled Lives, Supportive Communities’.

iii) Develop knowledge and skills of practitioners.


v) Clarify assessment processes within the Criminal Justice system.

vi) Develop audit process to assist with the consistency of assessment.

13. Recommended actions.

a. Evaluation of current information in terms of effectiveness.
b. ASD Awareness-raising and training of those involved in the assessment process
c. Development of ASD specific guidance to inform the assessment process in relation to adults with ASD
d. Development of current IT systems if additional specialised assessment tools are to be included.
e. WAG guidance concerning the assessment processes to Local Authorities with regard to autistic spectrum disorders. The assessment process will need to take account of the inherent life-long difficulties in inflexibility in thinking and behaviour, social and communicative functioning and the consequential pervasive impact upon an individual’s capacity to cope in everyday life and this will cut across several areas including, employment, education and housing.

14. Examples of people who have ASDs but experienced difficulty getting an assessment of support needs:

- MS. 27 years of age. This person was treated throughout his teens and early adult life for depression. He was seen by an educational psychologist during secondary school (he thinks three times) He was diagnosed at 23 with Asperger syndrome. His mother requested an
assessment of support needs because family situation is breaking down and he needs to move out. The referral went to CMHT but was sent back to the family doctor without anyone from the team even seeing the person concerned.

- **TA.** 20 years of age. This person was diagnosed with Asperger syndrome at 13 following withdrawal from mainstream schooling. He attended special residential college for students with Asperger syndrome but was asked to leave at 18 prior to taking ‘A’ levels. He is on the transition social workers case load at CTLD. CTLD have tried to pass case management to adult team but they have refused. No assessment of his adult support needs has been made.

- **BA.** 23 years of age. This person was diagnosed with Asperger syndrome at 20 following a long period of depression and self isolation. His details were held on the CMHT case load initially but he was not assessed or seen and subsequently signed off. His mother and father both have significant health problems, and he has a younger brother with LD. A referral by the LA officer for Adults with ASD was turned down by CTLD, CMHT and adult team on eligibility grounds.

- **MJW.** 30 years of age. This person went through mainstream schooling, but in an SEN class. He was diagnosed at 25 with Asperger syndrome. Initially he was with CMHT but was signed off. He was taken back on following a referral by the LA ASD officer but signed off within 6 months. At risk of arrest for threatening behaviour towards disabled people, medicated without knowledge by parents and with a long history of violence and aggression towards his family, all attempts to get one of the teams to allocate a case worker were unsuccessful. He is now with the CMHT following a section under the mental health act.

### Access to Services

<table>
<thead>
<tr>
<th>Actions</th>
<th>Yr 1</th>
<th>Yr2</th>
<th>Yr 3</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Development of ASD Specific Assessment Tools</td>
<td>10,000</td>
<td>0</td>
<td>0</td>
<td>10,000</td>
</tr>
<tr>
<td>Awareness-raising materials for those involved in assessment processes</td>
<td>10,000</td>
<td>0</td>
<td>0</td>
<td>10,000</td>
</tr>
<tr>
<td>Guidance from WAG to LAs re assessment process for people with ASD</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Totals</td>
<td>20,000</td>
<td>0</td>
<td>0</td>
<td>20,000</td>
</tr>
</tbody>
</table>
APPENDIX (iii) : SUB GROUP REPORT ON COMMUNITY & MONITORING SUPPORT

**Introduction**

1. This group was asked to explore the community and monitoring support needs of adults with ASD.

2. From the outset it is important to acknowledge that there is an undoubted need to increase the ASD awareness and training of all those who work with people with autism and who have associated learning disability, especially those with severe or profound LD and complex patterns of behaviour. The WAG ASD Strategic Action Plan can and will make a significant impact upon the range of practitioners involved in residential, day and outreach settings through the production of easily accessible awareness-raising materials and a greater direction given to on-going ASD training facilitated by the ASD Regional Support Officers and the Local ASD Leads. Furthermore, the evidence collected by the other sub-groups will help inform, direct and improve access to services at both regional and local levels for adults with autism and associated learning disabilities in several areas including diagnosis and housing design.

3. However, this sub-group determined at an early stage to focus on those with Asperger syndrome/higher functioning autism as they felt this was the area of biggest deficit in Wales.

4. The needs of adults with Asperger syndrome/higher functioning autism have often been neglected by service providers in Wales. For these adults it can be extremely difficult to access appropriate and timely support. In fact, 70% of adults with Asperger syndrome/higher functioning autism have had difficulty trying to access support from a local authority or health service. This is often because these individuals do not have a learning disability and therefore do not fit easily into established structures. We know that 41% of local agencies say that the reason they do not provide services for adults with autism is that they do not fit easily into LD or MH services. This is perhaps the biggest issue adults with Asperger syndrome face in terms of access.

5. The difficulty many adults with Asperger syndrome find is that they also often fail to meet local authority/health criteria for accessing services and support (criteria is currently set at substantial or critical in most local authorities in Wales). There are issues about the appropriateness of the current assessment process in identifying the needs of this client group. As there is recognition amongst the subgroup that if individuals undertaking assessments had a better understanding of how to

---

7 NAS Cymru (2008) I Exist: The message from adults with autism in Wales
8 Ibid
communicate with individuals with autism, and assessments took account of the social and communication difficulties of the disability more individuals may be eligible for support. However beyond this, the group recognises that there is also a strong argument for providing lower level preventative support for many adults that feel they require some support to prevent their needs from escalating at a later stage.

6. An example of this would be support around socialisation. Adults with autism find it difficult to understand, and interact with the world around them. The nature of their condition means that they do not have the social ability to navigate the world around them, which can be a very scary and threatening place. People can experience high levels of anxiety with everyday tasks such as undertaking a conversation with a stranger, coping with paying bills, engaging in the community and making friends. This can mean that people remain isolated in their own homes and have little contact with the outside world. There is a real need for preventative services such as social skills training. Social support can be viewed as quite low level in nature. This may be true in relation to the relative cost and time spent providing it, but it is not low level in terms of the impact it has on the lives of adults with autism. It can prevent more complex needs developing in the long term and can help people to surmount the sense of isolation that they feel. It can be a lifeline.

7. The needs of individuals with ASD fluctuate depending on the level of stress and pressures on their lives and the coping strategies available to them to deal with these. This also means that professionals need to have a link with individuals in the community to be able to monitor their stress and anxiety levels and provide an accessible avenue of support that can respond quickly in situations where intervention is necessary to prevent an individual moving into crisis.

“If I had had some support when I was going through tough times, the situation I am in now would have been lessened.”

Adult with Asperger syndrome whose mother helps her with every aspect of her life

8. The group recognises that the speed of movement from low level support to intensive emergency support can be extremely fast and therefore a level of ongoing engagement with individuals on the autism spectrum at a low level can prevent individuals’ needs from escalating. If the person’s needs do escalate, the engagement can provide a link to broker swift and appropriate support when required.

9. A lack of support can lead to the development of greater support needs and can require more costly interventions in the longer term. The challenge is to look at how we can put support in place earlier to prevent adults reaching the stage where they develop more severe difficulties and have to access specialist mental health services etc.
10. The following diagram aims to depict the support issues that adults with Asperger syndrome face.

People may move along the scale during different times of the life and need a point of contact to access timely information, advice and support signposting.

Given timely specialist intervention people may be able to be supported to reduce their anxiety and risk levels.

<table>
<thead>
<tr>
<th>Level</th>
<th>Support Required</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low level</td>
<td>Occasional Contact</td>
</tr>
<tr>
<td>Medium level</td>
<td>Regular</td>
</tr>
<tr>
<td>Intensive</td>
<td>Support imperative</td>
</tr>
</tbody>
</table>

**Figure 1:** The range of support needs of adults with Asperger syndrome and higher functioning autism.

**Pale green:** Low level of need requiring preventative support e.g. monitoring and provision of support through social groups, social skills support etc.

**Light green:** Medium level of need, requiring specialist assessment and a range of services including outreach support to help people live their lives and prevent difficulties from escalating, moving to a risk of developing mental health difficulties. Problems with family unit/partners/complete social isolation.

**Dark green:** Encompassing those individuals currently meeting local authority (LA) criteria -at critical or substantial- for services and support. This could be day activities, residential and/or specialist mental health services. Moving to risk of forensic, criminal justice and serious mental health difficulties that may result in detention under the Mental Health Act.

The diagram shows how the needs of adults with autism are on a continuum. Peoples needs can change over time and move between different phases, requiring different levels of support.
11. Process of data collation

- Data was collected by a subgroup of key individuals from across Wales with an interest and expertise in Asperger syndrome/higher functioning autism. The group met twice to identify the key priority areas for focus and develop proposed recommendations. The group also had an opportunity to comment on the final paper prior to presentation to the main task group.
- Three focus groups were held with adults with Asperger syndrome/higher functioning autism. These groups provided an opportunity to gain the views of individuals about their needs and barriers to accessing services and support at present. Views were also gathered on what types of support they require. The information gained from individuals with autism through our focus group work agreed largely with the views of the subgroup in terms of their priorities for support. The focus group felt that the biggest areas of support for them were: someone to talk to and answer questions, and help them in difficult situations; social skills support; assertiveness training (including developing self advocacy skills); access to advocacy; a helpline/one stop shop; specialist counseling and outreach support to help with things from managing finances etc to supporting people to go out into the community. The rest can be sourced in the focus group report submitted separately to the task group.
- A literature review of key research and case studies in the field was conducted. This review found that little evaluative evidence is available of what works for adults with Asperger syndrome, although some small studies of service provision and individual cases show that good outcomes have been measured from services such as social groups and social skills support for instance. One element of any work the Welsh Assembly Government takes forward therefore should be to incorporate evaluative processes into projects.

Key recommendation actions

12. First stage (Pale green): Preventative/low level support

Summary: providing access to a range of low level information, advice and local support to alleviate isolation and help prevent the development of greater need in the longer term.

12.1 Providing a point of contact and support

- The appointment of autism support advisors. Initially these would be regional posts, with a view to being available locally in the longer term. Each advisor would provide individual support and advice, equipping adults to find and sustain their way through services (both mainstream and more specialist as appropriate) and maintain their lives. They would be supported by a part time administrator.
“***** acted as an intermediary with the social worker to get them to understand my needs”

Adult with Asperger syndrome who receives support from the NAS Cymru Family Services worker and through brokering support - now receives 2 hours outreach support.

*The advisor would:

- Act as a referral point for individuals with ASD and their families
- Make links and establish where individuals with ASD in the community not currently known to services are
- Seek opportunities to develop low level support systems such as social groups
- Provide awareness raising/support to colleagues in a range of agencies regarding the support of adults with Asperger syndrome/higher functioning autism
- Work with local ASD leads to share information about numbers of adults, levels of need and issues to inform the development of local autism action plans

Good practice examples of services in Wales, which could be emulated in other areas:
Ceredigion Social Services Department Adults with ASD Development Officer; NAS Cymru Family Services Worker; SE Wales
Targeted recruitment 2009/2010. These posts would be for an initial period of 2 years.

12.2 In the longer term funding would be tapered to encourage local authorities to take responsibility for developing capacity to deliver these services in the longer term.

12.3 Options:
The group discussed a wide range of options for this post. They felt this was an extremely important post that would have a large impact with relatively little money (particularly in the absence of local Asperger support teams - see below). It was felt this post should be located within a ‘host’ social services department, however could be managed by the voluntary sector to provide specialist input and also a support network. It was felt that this post should ideally be locally based (or joint funded across 2/3 authorities where appropriate) however the group recognised that the current financial climate, in the short term, a regional model should be the first step to develop capacity and expertise.

12.4 It is therefore recommended that there should be a two stage approach to the development and delivery of these posts:

- Stage 1 - these posts will be operated on a regional level, initially funded by the Welsh Assembly Government for 2 years. Posts would be full time with 1/3 time admin support.
• Stage 2 - following the first stage, the success of these posts will be reviewed and ASD regional support officers will be expected to seek to fund these posts at a more local level in the longer term.

12.5 Opportunities for development of social skills
  ➢ Provide guidance to colleges and universities, as well as local authorities (in light of their community education portfolios) to encourage them to make social skills training and support to adults with Asperger syndrome.
  ➢ Work with the National Autistic Society Cymru to support the provision of ‘Social Eyes’ - a social skills support training programme - to enable this to be made available online across Wales. Then promote the facility to key stakeholders and encourage use. Targets - work on online resources, guidance and pilots in 2009/2010, and launch online resources in 2011.
  See further information on the benefits of social skills support in the appendix

12.6 Developing advocacy support in Wales
  ➢ A project to develop materials to support the development of self-advocacy amongst individuals with Asperger syndrome to address some of their assertiveness issues. Mapping of advocates for individuals with Asperger syndrome in Wales and a training programme for advocacy organisations to help them better support adults with Asperger syndrome.

12.7 Awareness and training for referral agencies (we understand work is already taking place in this area but suggest the following be considered as part of this work)
  ➢ A booklet of basic information about autism, communicating with individuals with autism for agencies that may come into contact with adults with autism from, for example, the Samaritans to substance misuse teams. The booklet should include information about how to find out about local support groups/services for adults with autism e.g. NAS Cymru’s Autism Services Directory; telephone helplines; basic information about the ASD action plan etc to help support effective referral routes for adults with Asperger syndrome. Targeted 2009/2010.

12.8 Webpage for adults with autism and their families
  ➢ Providing information about local contacts and advice points in Wales e.g. local autism advisors, voluntary organisation key support contacts e.g. NAS Autism Helpline, the All-Wales Autism Resource (www.awares.org); the forthcoming WAG autism information website being developed on HOWIS etc.
13. Second Stage (light green): Medium level need

Summary: Support for social care and health staff to appropriately assess individuals with autism; a clear route for adults with Asperger syndrome

“I don’t need a lot of support in a lot of areas, but the ones I need it in, I need a lot”
Adult with Asperger syndrome, currently receiving no services or support.

13.1 Link with diagnosis and assessment subgroup
- Training is needed for staff undertaking assessments to enable them to better communicate with individuals with autism and consider how to identify their needs. Ideally this should be supported by a specialist assessment for adults with autism. This training should include a copy of the bilingual resource: Undertaking Assessments for Social Care Staff (NAS Cymru) to be made available to all social care staff. Target 2009/2010.

13.2 Clarity over responsibilities
- Although this is an area being covered by the 'diagnosis and assessment' sub-group, our group (along with the individuals in the focus group/s) felt that this is the fundamental issue in provision of services to adults with Asperger syndrome in Wales. We would therefore like to propose that clear direction is given from the Welsh Assembly Government regarding responsibilities around individuals with Asperger syndrome, and that a clarification is given to remind authorities they should not be basing service criteria or individual support decisions on IQ.

13.3 Specialist assessment (see below)
- Capacity to develop specialist assessment services should be developed. Where local agencies struggle to identify an individuals needs and/or develop an appropriate care plan, specialists should be available to support. The National Autistic Society Cymru currently funds a specialist autism manager to undertake this in south Wales, however demand currently outstrips capacity. Therefore the group recommends that an assessment of evidence of need in this area is a priority for ASD regional support officers, with a view to consideration of the need to commission such posts in other areas of Wales in the future. If funded, ideally, these individuals should work closely with regional diagnostic teams (as proposed by the diagnosis and assessment subgroup).

13.4 Regional Asperger syndrome team
- The group suggests that this area should also be a priority for the ASD support officers to take forward. We would like to see a pilot multi-disciplinary team based around one of the new diagnostic individuals (proposed by the diagnosis and assessment sub-group). This team
would provide a specialist service for adults with Asperger syndrome including individuals who are currently undiagnosed. The team would provide a route through diagnosis (as identified and recommended by the diagnosis and assessment sub-group) and in addition support the provision of specialist assessment and care planning.

The team would:

- Provide direct services to individuals on the basis of need
- Take cases to the relevant panel dependent if more significant needs are identified to make the case for support
- Commission local level intervention from local outreach providers
- Provide training to different practitioners and professional organisations including follow on support
- Run social skills training programmes
- Develop social groups etc depending on the needs and wishes of individuals with AS

The team would be multidisciplinary and include a social worker (ASD regional support posts would have to work with authorities to discuss how this would work cross-boundary). Individuals would be able to self refer, or be referred through more traditional routes. Target 2010, pilot for 3 years.

**Good practice examples:**
Liverpool Asperger team; Nottinghamshire Asperger team; Glasgow one stop shop; Edinburgh No.16 one stop shop.

**Good practice example from Wales:**
Newport, Monmouthshire, Torfaen, Caerphilly and Blaenau Gwent local authorities provide an example of regional collaboration as a direct result of the Welsh Assembly Government’s ASD Strategic Action Plan. They are working together to develop a proposal to design services to meet the needs of adults with Asperger syndrome in those local authorities. Their final report is due imminently, and it will include a costed business plan for meeting the needs of adults with Asperger syndrome.

14. **Third Stage: Meeting current criteria**

Responsibility within health: When the new NHS restructure settles it is important that there is a recognised individual responsible for autism within each new LHB. Detail has not been provided here as it will need to be directed from the above.

14.1 **Training for mental health professionals**

- One of the awareness-raising packages being developed by WAG needs to include training for mental health professionals to help them better understand individuals with autism spectrum disorder. There is a need to recognise a mental health from an individual’s autism (which may have been causal) linked with inappropriate support. It is not enough for professionals to note this is part of an individuals condition
without undertaking a proper assessment of risk and needs e.g. counseling etc.

15. Other issues

Summary: Sharing good practice

15.1 Setting the agenda

➢ A conference around adult issues to launch the findings of the Adults Task & Finish Group, along with providing provision of good practice examples etc for consideration at local level. A conference report will also be produced and materials from good practice examples will be made available on the Assembly Government website. Target 2010/11

Community & Monitoring Support

<table>
<thead>
<tr>
<th>Actions</th>
<th>Yr 1 £</th>
<th>Yr 2 £</th>
<th>Yr 3 £</th>
<th>Totals £</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regional Monitoring/Support for Adults with Asperger syndrome (£80,000 per region)</td>
<td>240,000</td>
<td>240,000</td>
<td>240,000</td>
<td>720,000</td>
</tr>
<tr>
<td>All-Wales Practice Conference on Adults with ASD</td>
<td>10,000</td>
<td>0</td>
<td>0</td>
<td>10,000</td>
</tr>
<tr>
<td>Web-site information site for Adults with ASD and Carers (HOWIS)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Awareness-raising materials for practitioners working with Adults with LD &amp; ASD; ASD and co-morbidity; AS/HFA (part of existing WAG-funded packages)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Training for advocacy personnel for Adults with ASD</td>
<td>10,000</td>
<td>0</td>
<td>0</td>
<td>10,000</td>
</tr>
<tr>
<td>Totals</td>
<td>260,000</td>
<td>240,000</td>
<td>240,000</td>
<td>740,000</td>
</tr>
</tbody>
</table>
Support for Adults with Asperger syndrome – a summary comparison between the planned approach in Wales and models existing outside Wales

<table>
<thead>
<tr>
<th>Wales</th>
<th>Models of Support outside Wales</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is taking a national approach through ASD strategy which offers potential for a consistent approach to this client group</td>
<td>Have been developed within a policy vacuum and delivered within relatively narrow geographic areas</td>
</tr>
<tr>
<td>Every authority in Wales asked to establish a local ASD action plan, based upon mapping of need, formation of stakeholder groups, coordinated by local ASD leads, supported to date by £100k for each authority in Wales from Oct 08</td>
<td>No similar coordinated evidence-based local planning, mapping, stakeholder-engagement, nor engagement/resourcing with/by government has yet taken place</td>
</tr>
<tr>
<td>Opportunity to establish a holistic multi-agency approach, providing a service at a level, engaging where appropriate with a range of regional ASD initiatives, and at national level with WAG policy initiatives</td>
<td>Operate outside of established service delivery models</td>
</tr>
<tr>
<td>Respect of, and engagement with, the different skills held by all members involved in the diagnostic and support processes</td>
<td>Self-selects people with AS to come into the schemes, and then provides a diagnostic service before linking clients back into existing services</td>
</tr>
<tr>
<td>Will link into the range of ASD-friendly provision being established through the various aspect of the ASD strategy recommended by the Adults Task &amp; Finish Group</td>
<td>At this stage has no similar capacity</td>
</tr>
<tr>
<td>Standards, clinical practice etc to be monitored and evaluated at local and national level</td>
<td>No similar evidence can be provided</td>
</tr>
</tbody>
</table>
Introduction

1. Autism is a spectrum condition, encompassing people with a wide variety of abilities including people with learning disabilities and individuals with postgraduate degrees. There are over 18,000 adults with autism of working age in Wales today. Some, especially those with associated severe learning disabilities, will find it difficult to enter open employment, however there are a great many who want to work and have a lot to offer employers.\(^9\) Evidence has shown that people with autism can become extremely good employees and the projection of this message is key to promoting a positive profile of autism to employers in Wales.

2. Autism can often be a hidden disability and many people with autism, especially those with Asperger syndrome, may appear very able yet face real difficulties in getting to appointments on their own, coping with a change to routine, or performing well in interviews. Typically, whilst there are certain roles in which many people with autism choose to work, such as IT, engineering, academia and clerical roles, many are also successfully employed in a very wide range of jobs.

3. Currently, the National Autistic Society believe that only 11% of adults with autism are in full time employment\(^10\). 7% of adults with autism are in part time work and 5% in some form of voluntary work. This is much lower that other disabilities which on average is 50%\(^11\).

4. Employment is not a devolved area of responsibility to the Welsh Assembly Government. The challenge therefore is to ensure that the WAG ASD Strategic Action Plan can quickly provide a firm foundation for the development of specific actions which directly lead to improved accessibility and sustainable employment opportunities for people with autism in Wales.

5. The development of local and regional leads for autism can help to create a context for employment within which specific actions can be introduced. These actions should aim to provide increased direction and awareness of the needs of people with ASD and will be of benefit to Businesses, Employers, Careers Wales, Jobcentre Plus and the Welsh economy as a whole.


\(^11\) This is consistent with learning disability and mental illness, which are around 11% also
Process of evidence collection

6. Membership: A WAG subgroup consisted of representatives of the key agencies involved pertinent to people with autism entering the work place:

A meeting of the group was held on 11th December to discuss the barriers adults with autism faced in accessing employment. The group shared ideas about action that could be taken at a Wales level to address some of these issues.

Key Recommended Actions

7. Employers/Businesses

Summary: Awareness-Raising; Local Mapping; National Business/Employers Ambassador for Autism

- **Raising Awareness**: A publicity campaign targeting business and employers in Wales which emphasizes the advantages of employing people with autism (Target 2009/10)
- **Local Needs**: Local mapping of employment needs of people with ASD matched with local employment needs. The existing Local Lead ASD officers can be the conduit for this information-gathering which should be prioritised (Targeted 2009/11)
- **Autism Business/Employers Ambassador**: An initial 2yr secondment to WAG of a national employment advisor for autism. It is suggested that this person may be recruited from the business community in Wales and will already have existing strategic level links with the various aspect of the business community in Wales. Raising the profile of employing people with autism, creating the key links with large and small business to achieve greater potential for access and guidance on successful sustaining employment. For ease of support, the post-holder could be based within a voluntary sector agency (Targeted recruitment 2009/10)

8. Access to Employment

Summary: Employment routes via Careers Wales & Jobcentre Plus

- **Careers Wales** can play a significant role in alerting people with autism to the appropriate employment routes which can meet their needs. The production and delivery of awareness-raising materials specifically written for Careers Wales advisors should be developed and delivered in a consistent manner throughout the constituent six companies. A pilot project has already taken place through a partnership between Mid-Glamorgan & Powys and Autism Cymru (Targeted roll-out: 2009/11)
• **Jobcentre Plus**: Jobcentre Plus is the focal point of contact for people with ASDs seeking employment. It is imperative there are two approaches to awareness-raising for JCP Staff:

  The first is that in-depth training and support should be provided to the **Disability Employment Advisor (DEA)** to be found in Jobcentre Plus. This will be delivered through district DEA meetings. In addition, a workshop will be held at the forthcoming DEA conference in Wales to provide practical advice and support about supporting adults with autism. The National Autistic Society has developed materials/delivered. Targeted roll out 2009/2010.

  The second will be the provision of materials developed and delivered for all frontline Jobcentre Plus Staff in Wales, so there is a recognition of the difficulties inherent for people with ASD accessing the JCP and the methods of support/guidance required. It is recognised however due to the current economic climate that this second stage will be delayed. A pilot project took place in Aberystwyth in 2008 with Ceredigion Social Services/Autism Cymru. Targeted roll-out: (2009/11)

• Jobcentre Plus to run a pilot with WISE and NAS Cymru looking at making the current work prep package more appropriate for individuals with Asperger syndrome. This will be delivered in South West Wales with a small group, using a flexible approach to the current programme to introduce autism specific tools and expertise. The aim is to provide greater support around social interaction and social skills, required as a first step to work preparation.

9. **Social firms/social enterprises**

*Summary: Awareness-raising; Pilot Project*

• Awareness-raising materials to be developed and delivered to the many supported employment agencies that are reported to struggle to support adults with autism spectrum disorder, but who can play a key role in equipping individuals with ASD with coping strategies for the workplace (2009/11)

• Pilot Project: A 1yr Pilot designed to engage, support and troubleshoot with Social Enterprises; Sheltered Employment Agencies and contracting social services departments within a defined region (suggest SE Wales). To link into with Regional Support Officer Roles (WLGA/WAG). A coordinator to be appointed to drive this process forward. (2010/11)

Summary: working group set-up

- This forthcoming area of welfare reform is likely to have a significant impact upon the access and support to employment for people with autism. It is strongly felt that a considered Wales response is essential and therefore it is proposed that a small WAG working group is established to undertake this work.

### Employment & Related Issues

<table>
<thead>
<tr>
<th>Actions</th>
<th>Yr 1 £</th>
<th>Yr 2 £</th>
<th>Yr 3 £</th>
<th>Totals £</th>
</tr>
</thead>
<tbody>
<tr>
<td>WAG sets up its own scheme to employ/support adults within ASD within WAG</td>
<td>0</td>
<td>10</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>Employers’ Ambassador for ASD</td>
<td>60</td>
<td>30</td>
<td>0</td>
<td>90</td>
</tr>
<tr>
<td>JobCentre Plus Awareness-raising &amp; Training</td>
<td>10</td>
<td>10</td>
<td>0</td>
<td>20</td>
</tr>
<tr>
<td>Careers Wales Awareness-raising and training</td>
<td>10</td>
<td>10</td>
<td>0</td>
<td>20</td>
</tr>
<tr>
<td>Disability Employment Advisors</td>
<td>10</td>
<td>0</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>WAG working group to be set up to consider and respond to DWP reforms</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Sheltered Employment awareness-raising/social enterprises</td>
<td>10</td>
<td>0</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Totals</td>
<td>100,000</td>
<td>60,000</td>
<td>10,000</td>
<td>170,000</td>
</tr>
</tbody>
</table>
The Autistic Spectrum Disorder Action Plan and Supported Housing Issues

Introduction

1. There are a wide variety of housing issues for adults with an Autistic Spectrum Disorder. For those adults with a severe learning disability there are the difficulties of obtaining housing and the subsequent challenges of maintaining their accommodation. Since 1983 in Wales there has been a drive to develop supported housing to meet the needs of this group. There is also a significant number of people who are able to function without any statutory support but as a result of their difficulties with communication or their difficulties in thinking flexibly find it difficult to navigate the challenges of daily life such as dealing with relationships with neighbours, landlords or utility companies. Some people may also be easily influenced or manage some of these challenges through the use of alcohol or illicit drugs. These individuals face an increased likelihood of becoming homeless or victims of crime, or their mental health deteriorating to an extent where they require statutory services or entering the criminal justice system.

2. At the time of drafting this paper the Supporting People - Housing Related Support Five Year Strategy is being drafted for consultation early in 2009. The Welsh Assembly Ten Year Homelessness plan has also been recently published for consultation. There are common themes between the three documents which the Welsh Assembly Government would expect to address through the action plan for the Supporting People – Housing Related Support Strategy.

3. In the development of the Supporting People Housing Related Support Strategy expert groups recognised that there is going to be a growth in the numbers of people with a learning disability with a need for housing and housing related support in turn a proportion of these people will have an Autistic Spectrum Disorder. This growth in need will mean that we have to look at new and creative ways of working with finite resources. These issues will raise challenges for the all individuals and organisations involved in meeting the needs of people with an ASD, the role of the Regional ASD Coordinators will play an essential role facilitating and supporting planning activity in respect of these issues.

4. The proposals in the Table summarising actions are not all new as there exists a range of good practice from projects which are specifically designed for people with an ASD such as those managed by Opportunities Housing Trust, Cartrefi Cymru, Autism Initiatives and in South-East Wales by the National Autistic Society. It is hoped that the proposals outlined in this paper
will complement this work and promote consistently high quality service provision across Wales.

<table>
<thead>
<tr>
<th>Issue</th>
<th>Background</th>
<th>Recommendation</th>
<th>Possible Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Housing Design</td>
<td>Adults and young people particularly those with a more severe learning disability can benefit from housing which is designed to meet their needs. There is little or no design guidance at present.</td>
<td>Consider using Social Housing Management Grant to fund a project identifying existing design research and collating into a toolkit to assist architects. There will be consultation with current housing providers to people with ASD in Wales. An approach will be made to the RIBA to explore opportunities for ASD building design to be part of architecture training.</td>
<td>£5,000</td>
</tr>
</tbody>
</table>
| 2. Revenue Funding for housing related support | The current international financial crisis makes it unlikely that there will be significant national increase to funding for housing related support. A number of local authorities and housing related support providers have reviewed existing provision in order to identify how funding can be used more effectively.                                                                 | Review existing housing related support funding within each local authority in order to establish that:
- Funding patterns reflect service user need, and,
- Ensure that there are a range of service models which promote independence and maximise cost benefits.                                                                                                                                                                                                                             | Administrative cost on commissioning activity. |
| 3. Regional Working          | In Wales 22 local authorities serve a population of 3 million there are a number of local authorities with very small populations which puts significant strain on their ability to plan and procure housing related support services.                                                                 | WAG/SSIA/ADSS work in partnership with local authorities, to identify new models of regional working which may help to meet the needs of small numbers with very intensive needs, particularly those who are placed in specialist provision outside of Wales because they pose a risk to themselves or others. | Part of existing regional planning undertaken by ASD Regional Support Officers based with the SSIA/WLGA. Administrative cost on commissioning activity. |
| 4. Supporting Independence – access to housing services for people not adults who are at the lower end of the Autistic Spectrum may not meet the eligibility criteria for support from                                                                                                        | Promote awareness of ASD in frontline housing services. Consider the development of a |

£5000.}
<table>
<thead>
<tr>
<th>39</th>
</tr>
</thead>
</table>

| 5. | **Promote the use of Homebuy as a means to accessing Housing** | The assisted homebuy model represents an innovative and empowering approach to supporting adults with a learning disability to access the housing market, and maximise choice. | Use WAG funded research to develop this model and promote an improved understanding of its value to people with an ASD. | This work is being funded by the Welsh Assembly Government and is being undertaken by Coastal Housing Group in partnership with the Housing Consortium. |

| 6. | **Outcome measurement.** | Increasingly there is a recognition that the impact of service provision should be evaluated in terms of outcomes for service users. The Welsh Assembly Government is developing a set of outcome measures for national policy which will influence future public investment decisions. | Promote the development of outcome based commissioning in supported housing and develop outcome measures to understand the impact of housing related support on the aspirations of service users. | Administrative cost on commissioning activity. |

| 7 | **Improving the quality Service provision** | **Assessment:**
Assessment for housing related support is covered in the Unified Assessment | Work with stakeholders at a national and local level to develop more comprehensive assessment of housing related support needs in | Administrative cost on commissioning activity. |
Process however the depth of assessment is superficial.

Workforce Development:

The Assessment work stream of the ASD action plan has identified that there is a low level of awareness of the communication difficulties faced by people with an Autistic Spectrum Disorder and as a consequence people who experience the condition receive a poor quality of service.

Promote training to raise awareness on the value of good quality communication for front line workers in housing.

<table>
<thead>
<tr>
<th>Housing</th>
<th>Actions</th>
<th>Costs £</th>
<th>Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘ASD Design Toolkit’ for construction industry personnel in Wales</td>
<td>£5,000 via Special Housing Management Grant</td>
<td>WAG/Voluntary Sector</td>
<td></td>
</tr>
<tr>
<td>Regional Planning to meet high-cost low incidence needs</td>
<td>Existing WAG funding to SSIA £0</td>
<td>SSIA ASD Regional Support Officers</td>
<td></td>
</tr>
<tr>
<td>Assess ‘homebuy’ for people with ASD</td>
<td>Existing WAG funded research to be utilised £0</td>
<td>Costal Housing Group/Housing Consortium</td>
<td></td>
</tr>
<tr>
<td>Awareness-raising materials and delivery throughout the statutory and independent residential ASD/LD sectors in Wales</td>
<td>Existing WAG funding for materials as part of the ASD Strategic Action Plan £0 £5,000. Delivery component to frontline housing services/ASD customer care ‘kit’ for housing staff</td>
<td>WAG ‘lead’ with partners</td>
<td></td>
</tr>
<tr>
<td>UAP Housing element to be tailored to meet needs of people with ASD</td>
<td>£0</td>
<td>WAG/LA’s/Voluntary sector</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX (vi) : TERMS OF REFERENCE

1. The Adults with Autistic Spectrum Disorders Task and Finish Group is established by the Welsh Assembly Government (WAG) to:

- Identify and consider the evidence for and provide advice to the WAG concerning Adults with ASD to support the implementation of the ASD Strategic Action Plan for Wales
- Invite and consider specialist submissions to the Task & Finish Group which identify a) weaknesses and gaps in current practice and service delivery and b) models of good practice
- Identify areas of practice and/or service delivery where priority action is by authorities is required
- Prepare, as necessary, proposed draft guidance for WAG to issue to authorities

2. In providing any advice to the WAG on matters pursuant to paragraph 1 above, The Adults Task & Finish Group will, as necessary, include in their advice to the WAG their assessment of any additional costs for organisations in complying with their advice.

3. The WAG will appoint members the chair, vice chair and members of the Adults with ASD Task & Finish Group. Initial membership will consist of representation from:

   The Association of the Directors of Social Services Cymru
   Royal College of Psychiatrists (LD Division)
   Voluntary Sector views to be represented by National Autistic Society
   Welsh Assembly Government (Housing)
   Welsh Assembly Government (Health)
   Welsh Assembly Government (Older People and Long-term Care)
   Vice-Chair
   Welsh Assembly Government (ASD Strategic Action Plan Implementation Manager) Chair

   The WAG has also agreed Observer status for a representative of the Northern Ireland Assembly (DHSS) to attend meetings of the Group.

4. The Adults with ASD Task & Finish Group will hold meetings as and when the Chair considers necessary but shall meet initially on a monthly basis from October 2008 to end of May 2009. At the first planned meeting on 20th October, The Task & Finish Group will prioritise its work schedule and will aim to draw from the submissions of evidence proposed in Annex 1 (to be discussed and finalised at first meeting).

5. A written report of initial evidence and advice in a form determined by the Chair after discussion with members will be made to the WAG before the end of summer 2009. This written report should also, as necessary, include proposed draft guidance for the WAG to issue to authorities.
6. The Adults with ASD Task & Finish Group will identify areas of practice and service-delivery where additional resources are required over a long-term plan.

7. The Adults with ASD Task & Finish Group may, where they consider that it will facilitate the work of the Task & Finish Group, and with the Chair’s agreement, invite non-members to attend for either part or the whole of any meeting and to contribute to the discussions at the meeting.

8. Except where otherwise determined by the WAG or the Chair of the Adults with ASD Task & Finish Group, members of the Adults with ASD Task & Finish Group may, where they believe that this will facilitate the work of the Task & Finish Group, consult with non-members about matters referred to the Task & Finish Group pursuant to paragraph 1 above.

9. The WAG will determine the Terms of Reference for the Adults with ASD Task & Finish Group. The Task & Finish Group at their first meeting and as necessary in future meetings will consider their proposed Terms of Reference and, if necessary, propose to the WAG any changes that they consider should be made. The Task & Finish Group will be consulted about any future changes to the Terms of Reference that may be proposed by the WAG.

10. The WAG will meet any appropriate and reasonable travel and subsistence costs that members may incur in attending meetings of the Adults with ASD Task & Finish Group.

11. General secretariat services for the Adults with ASD Task & Finish Group will normally be provided by officials from the Older People and Long Term Care Policy Directorate of the WAG.

12. The WAG, on a recommendation from the Chair, will determine the date when the Adults with ASD Task & Finish Group will be dissolved.
APPENDIX (vii) : TASK & FINISH GROUP MEMBERSHIP

Chair

Hugh Morgan : ASD Strategic Action Plan Implementation Manager, Welsh Assembly Government

Members

John Carter, Welsh Assembly Government (Older People and Long Term Care)

Jennie Clarke-Moore, Welsh Assembly Government (Nursing Group)

Chris Griffiths, Consultant Nurse, ABM Trust

Nick Haake, National Autistic Society Cymru

Chris Maggs, The Association of the Directors of Social Services Cymru

Helen Matthew, Royal College of Psychiatrists (Learning Disability Division)

Simon Prothero Welsh Assembly Government (Housing Directorate)

Carol Rea : The Association of the Directors of Social Services Cymru :

Sarah Watkins, Welsh Assembly Government (Medical Division)

Liz Withers, National Autistic Society Cymru

Secretariat

Alyson Collins, Welsh Assembly Government (Older People and Long Term care)

The Welsh Assembly Government also agreed Observer status for a representative of the Northern Ireland Assembly (DHSS) to attend meetings of the Group.
APPENDIX (viii) : SUB-GROUP MEMBERSHIP

1) Diagnosis and Access to Services Sub-Group Membership

John Carter, Welsh Assembly Government (WAG)
Jeni Clarke-Moore, WAG
Bridget Craddock, ABMU Trust
Phil Davies, City and County of Swansea
Christopher Griffiths, ABMU Trust
Nick Haake, National Autistic Society (NAS) Cymru
Tony Harris, Torfaen County Borough Council
Glyn Jones, ABMU NHS Trust
**Chris Maggs, City and County of Swansea – Sub-group leader (Access)**
Martine Marshallsay, ABMU MHS Trust
**Helen Matthews, Hywel Dda - Sub-group leader (Diagnosis)**
Hugh Morgan, ASD Strategic Action Plan Implementation Manager, WAG
Carol Rea, City and County of Swansea
Keith Self, Monmouthshire County Council
Dr. Sundari, Gwent NHS Trust
Judith Tomlinson, National Public Health Service
Peter Watkin, ABMU Trust
Sarah Watkins, WAG
Liz Withers, NAS Cymru

2) Community & Monitoring Support Group Membership

Julie Boothroyd, Monmouthshire County Council
Peter Chamberlain, Newport City Council
Christopher Geake, Cartrefi Cymru
**Nick Haake, National Autistic Society (NAS) Cymru – Sub-group leader**
Mary Harris, Vision 21
Claire Lister, Conwy County Borough Concil
Mary Rendell, Ceredigion County Council
Judith North, REACH
Rita Steffenson, Advocacy Matters Wales
Dr Sundari Gwent NHS Healthcare Trust
Liz Withers, NAS Cymru

3) Employment and related issues

Michael Barry, WAG
Barrie Lewis, Jobcentre Plus
Hugh Morgan, WAG
Mike Moss, WAG
Bob Waller, WAG
Bon Westcot, Job Centre Plus
**Liz Withers, NAS Cymru - Sub-group leader**
APPENDIX (ix) : NAS SERVICE-USER FOCUS GROUP MEMBERSHIP

1) Cardiff

Mark Annis
Anon
Carl Joseph
Anon
Collette Morgan
Karen Thompson

2) Bangor

David Abbot
Rowan Crawshaw
John Green
Robert Mann
Robert Murphy

3) Caerleon

Gavin Cashman
Matthew Howard
Aled Lewis
Andrea Sutton
Karen Thompson
Styn Vanerlinden