



Adults with Autism Conference  
10th and 11th June 2010  
The Arts Centre, Aberystwyth

Conference Report

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## INTRODUCTION

In April 2008 the Welsh Assembly Government published its Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales. This sets out how the Welsh Assembly Government expects people with ASD to be supported and how to ensure that support services provided by a range of organisations are delivered appropriately and in a co-ordinated fashion.

Two key actions in the ASD Action Plan related specifically to adults with ASD :

- The establishment of a Task and Finish Group to identify specific issues that adults with ASD face and make recommendations on how to tackle them; and
- The commissioning of research into the prevalence of ASD in older people in Wales and their needs.

The Task and Finish Group's Report was published in February 2010 and in a Written Cabinet Statement the Deputy Minister for Social Services set out how the Welsh Assembly Government intended taking forward the recommendations in the Report.

The Welsh Assembly Government commissioned the Universities of Bangor and Glamorgan to undertake the research into the prevalence of ASD in older people in Wales and their needs. Their Research Report 'The Circumstances and Support Needs of Older People with Autism' was published in February 2010. In response to the recommendations in that report the Deputy Minister for Social Services decided that the Welsh Assembly Government should host a two day Adults with Autism focused conference to enable local ASD Leads, Regional and National Officers, key practitioners and stakeholders to share models of good practice and discuss and plan ways forward to meet the needs of adults with Autism living in Wales.

All the documents referred to above are available for download at <http://wales.gov.uk/topics/health/socialcare/disability/asd/?lang=en>

## CONFERENCE DETAILS

*Day One* focused on Local, Regional and National Development in strategy, commissioning and delivering services.

*Day Two* focused on Older People\* with ASD – research outcomes and developing an agreed plan.

Four voluntary sector organisations in Wales were invited to put on 'lunch and learn' sessions - Autism Initiatives, Cartrefi Cymru, National Autistic Society and Opportunity Housing Trust.

Attendance at the conference was strictly by invitation only with 3 places reserved for each Local Authority (LA) and 2 places for each Local Health Board. Places were also available for

adults with autism and parents of adults with autism – the allocation of these places was left to the determination of each LA.

The up take of places had a mixed end result with some LA's taking up their full quota of places (and requesting more) and some sending less or just on one day rather than both. 18 out of the 22 LA's sent representation. There was no representation from Anglesey, Caerphilly, Neath Port Talbot and Wrexham. There was representation from all 7 LHBs in Wales, Aneurin Bevan Health Board, Cardiff and Vale University Health Board, Cwm Taff Health Board, Hywel Dda Health Board, Abertawe Bro Morgannwg University Health Board, Betsi Cadwaladr Health Board and Powys Teaching LHB.

The conference was organised by Autism Cymru at the request of WAG.

\*The age of an older person in terms of strategies etc does vary. Usually in social services/NHS terms for service configuration it is normally from age 65.

## Keynote Presentations

10<sup>th</sup> June 2010 - Day one of Adults with Autism Conference

**Focus:** Local, Regional and National Developments in strategy, commissioning and delivering services.

**Chair : John Carter** - Older People and Long Term Care Policy Directorate, WAG

**Gwenda Thomas** – Deputy Minister for Social Services opened Conference and gave an overview of the Welsh Assembly Government’s ASD Strategic Action Plan for Wales. The Deputy Minister emphasised the importance of people with autism being the focal point of the strategy and expressed her appreciation to all those working at local, regional and national levels.

### **Hugh Morgan – Implementation of the Strategy**

During Hugh Morgan’s 40 minute presentation ASD Policy developments in other UK nationals, NI, Scotland, England and Wales were looked at, before he focussed on the achieved developments over the last 18 months in Wales. Amongst other things he spoke about the Development of an ASD Infrastructure for Wales, which covers personnel, planning and stakeholder involvement: ASD Research capability increased with the Wales Autism Research Centre, considerable strengthening of the Welsh ASD Strategy in relation to Adults with Autism; and projects underway.

Hugh Morgan’s presentation is available for download at [http://www.awares.org/pkgs/online\\_library/library.asp](http://www.awares.org/pkgs/online_library/library.asp)

### **Mary Rendell – Regional Overview**

In the second keynote speech of the day Mary Rendell, Regional Lead for West and Mid Wales, gave the audience an overview of her region, the presentation looked at the role of the ASD Lead, Stakeholders engagement, mapping of services, the barriers they came across and the solutions. Mary also looked at Key Themes that came up across the region and touched briefly on the what the future may hold.

Mary Rendell’s presentation is available for download at [http://www.awares.org/pkgs/online\\_library/library.asp](http://www.awares.org/pkgs/online_library/library.asp)

### **Colette Morgan – Life of an Adult with Autism**

The third keynote speaker was Colette Morgan, an adult with Autism, who gave an informative and real insight into a Life of an Adult Living with Autism. Colette talked about what she could do, what she found difficult, her rituals and obsessions, her relationship with her husband and children, her experience of employment and what support she would like. To quote Colette ‘For me, life with Asperger Syndrome is normal – it’s everybody else who thinks and acts chaotically, illogically and vaguely!

Colette Morgan’s presentation is available for download at [http://www.awares.org/pkgs/online\\_library/library.asp](http://www.awares.org/pkgs/online_library/library.asp)

## **Keynote Presentations – cont.**

11<sup>th</sup> June 2010 - Day two of Adults with Autism Conference

**Focus:** Older People with ASD - Research Outcomes & Developing an agreed Plan

Chair : **John Carter** - Older People and Long Term Care Policy Directorate, Welsh Assembly Government

### **Professor Ian Stuart Hamilton - Older Peoples Research**

Professor Ian Stuart Hamilton was first key note speaker of Day 2, his presentation entitled 'Hunting more than wozzles – why we must study ASD and other atypical conditions in the older population'. Ian focused on the WAG commissioned research project carried out by the Universities of Glamorgan and Bangor which led to 'The Circumstances and Support Needs of Older People with Autism Report'. The presentation looked at the background to the research, main findings and key actions and recommendations.

Ian Stuart Hamilton's presentation is available for download at  
[http://www.awares.org/pkgs/online\\_library/library.asp](http://www.awares.org/pkgs/online_library/library.asp)

The Circumstances and Support Needs of Older People with Autism report is available for download at  
<http://wales.gov.uk/topics/health/socialcare/disability/asd/;jsessionid=M0H2LZhQgQxcxyZlLkmpRQNWfwsSdCy7vfYv2tLIGQfz71L3NDv!-225497037?lang=en>

### **Dr Gareth Morgan - National Service Framework for Older People**

Gareth Morgan talked about the National Service Framework for Older People and its importance to Wales with the increasing ageing population. The various standards within the NSF were focused on one by one. The importance of the Dignity in Care programme and Phase 2 (2011-2016) and its relevance to autism were touched upon

Dr Gareth Morgan's presentation is available for download at  
[http://www.awares.org/pkgs/online\\_library/library.asp](http://www.awares.org/pkgs/online_library/library.asp)

### **Alun Thomas - Older People's Commission for Wales**

Alun Thomas gave an overview of the 'Who, What and Why' of the Older People's Commission for Wales, and Wales has the only Commissioner for Older People in the UK. Alun identified how they set about to achieve the Vision of the Older People's Commission for Wales 'To see a Wales in which respect for the rights and dignity of older people is a reality in all areas of life, where age discrimination is a thing of the past and where a positive view of ageing and older people prevail'

Alun Thomas's presentation is available for download at  
[http://www.awares.org/pkgs/online\\_library/library.asp](http://www.awares.org/pkgs/online_library/library.asp)

## **Keynote Presentations – cont.**

### **Michael Baron MBE - What Happens Next: Autism and Old Age. A Parent Investigates.**

Michael Baron has a 53 year old son and his talk was titled 'What Happens Next: Autism and Old Age. A Parent Investigates'. It commented on the Department of Health's Adult Autism Strategy for England; but he also referred more favourably to the the Welsh ASD Strategic Action Plan and the Research Project on support needs for the elderly. Michael outlined his hopes and fears as a parent i.e. what we know and what we do not know; the demography of ageing and incidence of the disorder; the Newcastle conference of October 2009; happenings in the USA, Denmark, France and Israel. He concluded by stressing the absolute need for sharing and working together across nations rather than in the separate boxes of today.

### **Short film by Mary Matthews**

Some years ago the BBC in Wales filmed Mary who is a person with autism and a superb pianist about her life. Mary very kindly permitted us to show her short film at the conference and then met delegates over the lunchtime period

[http://www.bbc.co.uk/wales/arts/yourvideo/media/pages/mary\\_matthews\\_01.shtml](http://www.bbc.co.uk/wales/arts/yourvideo/media/pages/mary_matthews_01.shtml)

## Lunch and Learn Sessions:

Four voluntary sector organisations had been invited to hold informal information sessions during lunch time on both days. Attendance to each of the lunch and learn session was voluntary but there was a reasonable attendance to all sessions.

**Opportunity Housing Trust (OHT)** is a non-profit making organisation, which was established in 1985. As well as providing support to people with learning disabilities, OHT provides specialist support to people with Autism Spectrum Disorders. The Lunch and Learn Session on Day One of the conference was **Empowering people with Autism and complex needs to enjoy a valued life in their community**, it set out to describe the steps taken to develop support guidelines. It incorporated the clinical aspects of autism and behaviours that challenge, in order to enable the individual to participate in activities that are recognised as important to the individual.

For further information on OHT please log on to <http://www.oht.org.uk/>

**The National Autistic Society** is a charity working throughout the UK for people affected by autism, and in Wales, NAS Cymru provide specialist advice, services and support. The Day One Lunch and Learn Session was on the **development of Ty Nant, a purpose built, supported living service, developed in response to an over-dependence on out-of-county placements for local individuals with Autism and complex needs**. It explored the development of the service and presented the recommendations and lessons learnt, which were all highlighted in a recent evaluation undertaken by Newport City Council and NAS Cymru.

For further information on NAS Cymru please log on to <http://www.autism.org.uk/>

**Cartrefi Cymru** is a national charity and the largest provider of support for people with learning disabilities in Wales. It has been supporting adults with both ASD and learning disabilities since its establishment in 1989. The Day Two Lunch and Learn Session was on **Designing housing for people with ASD: frontline experiences and lessons** and explored the many environmental features which can help a person with ASD to enjoy their home, or can make it a nightmare for them.

For further information about Cartrefi Cymru please log on to <http://www.cartreficymru.org.uk/>

**Autism Initiatives UK** was founded in the early 1970s in the Merseyside region, Autism Initiatives is a parent led charity and a member of both the Autism Alliance and the Confederation of Service Providers for People with Autism (CoSPPA).

Autism Initiatives have a real understanding of the need for, and the importance of, involving both service users and stakeholders in the delivery and development of their service.

They have developed systems and approaches to facilitate involvement at a level where service users can experience success and gain ownership of their services. Their Day Two Lunch and Learn Session was on **'Being in control through partnership and consultation – a joint perspective'** this session was run by Andy Grainger and Aled James from Autism Initiatives with Val Kewley (service user) and support from Cairi Mckenzie.

For further information about Autism Initiatives please log on to <http://www.autisminitiatives.org/>



## Regional Workshops

During the Adults with Autism Conference, delegates attended regional afternoon workshops. Workshops were split into the three key regions i.e. South East Wales, North Wales and Mid and West Wales. Delegates then attended the workshop that covered their local area.

### **South Wales**

Cardiff, Vale of Glamorgan, Monmouthshire, Torfaen, Rhondda Cynon Taf, Newport, Caerphilly, Blaenau-Gwent, Merthyr Tydfil, Aneurin Bevan Health Board, Cardiff and Vale University Health Board and Cwm Taf Health Board.

### **Mid and West Wales**

Ceredigion, Carmarthenshire, Pembrokeshire, Powys, Swansea, Neath Port Talbot, Bridgend, Powys Teaching Health Board, Hywel Dda Health Board and Abertawe Bro Morgannwg University Health Board.

### **North Wales**

Wrexham, Denbighshire, Anglesey, Conwy, Gwynedd, Flintshire and Betsi Cadwaladr University Health Board.

The Regional Workshops were facilitated by each ASD Regional Support Officer : Mary Rendell – Mid and West Wales, David Poole (covering for Johanna Manikeza) South East Wales and Sharon Walters - North Wales

Each facilitator was briefed in advance on the aims and objectives that each workshop session was trying to achieve. Objectives were as follows:

**Day 1** - Adults with Autism - facilitators needed to focus on 3 main strands for each region - using the information received through the speeches/discussions of the Day One morning:

- where are we now
- what are the challenges that face us
- what are our priorities for this year and next

**Day 2** - Older people - 3 regional groups focused on:

- what is our vision/aims for older people with ASD
- what service/support model can deliver the vision/aims
- what are our priorities for this year and next

Each facilitator gave a 5 minute feedback summary from their region in the main conference room after each workshop session.

## Workshop session from South and East Wales - Day One

### Where are we now?

Key Issues emerging from the South East Wales region were:

- Challenge is becoming joined up across the responsible agencies so that ASD is a collective priority. We need a shared vision across these agencies. Shared performance indicators might assist this.
- Current regions, as designated by WAG/RST, might not be the right ones. Do these need to better reflect the organisational landscape, especially after NHS re-organisation?
- Sharing information between services is a problem – information is held but sharing is inhibited because services are uncomfortable doing so for a variety of reasons.
- Capacity issue is a looming one for the future – a “route map” would show that everything is not achievable all at once, and offer guidance as to what can be achieved and by when.
- Gwent areas have undertaken a study of needs of young people aged 14+ known to Social Services & Paediatrics which has been used to plan future services.
- There has been a significant increase in requests for ASD-related training (say NAS / Autism Cymru).
- Gwent TEACCH may be developing a virtual training team and Monmouthshire have established a virtual multi-agency ASD team.

### What are the challenges that face us?

- Becoming joined up across the responsible agencies so that ASD is a collective priority – see (first bullet point in ‘where are we now’)
- Should the WAG Capital programme reflect the needs of people with ASD?
- A regional approach to enable cross boundary working to suit the compatible needs in local areas.
- Transition arrangements for those in residential placements moving to adult services. Commercial / independent organisations are often easier to use to deliver local services, rather than designing specific local services.
- Early identification of those with ASD. This is possible for those with complex needs, but for those who don’t this is much more difficult as information is not recorded – (see third bullet point under ‘Where are we now’)
- Getting the appropriate services to an individual at the right time.
- There are differences in eligibility criteria for access to services across both delivery organisations and services (eg: mental health and learning disability) in an area and across geographical areas, leading to a “postcode lottery” for service users.
- OHT - Examples of how it works well, but often there are more examples of poor practice/response.
- Information sharing – (see third bullet point under ‘Where are we now’)
- There is a growing trend towards requests for services for those with AS & complex needs. ‘Remove One’ implication for agencies is that AS requires very specialist skills amongst staff. Does this require a new / distinct approach such as the AS Teams Model developed in Liverpool, Glasgow and Nottingham?
- There has been an increase in diagnostic clarification requests in Cardiff, but a paucity of appropriate services to refer individuals into.

### What are our priorities for this / next year?

- Draft a multi-agency care pathway based on the WAG template.
- Use the outcomes / benefits accrued from new training, awareness-raising and identification of need to re-design services – on local/regional/national level.
- Resolve the difficulties associated with the sharing of information across agencies regarding those with ASD.
- Continue the existing work on regional / cross-boundary working regarding ASD services.
- Tackle organisational / geographical differences regarding eligibility criteria for services so as to make this more equitable across Wales.

## **Workshop session from North Wales - Day One**

### Where are we now

Key Issues emerging from the North Wales region were:

- The North Wales group identified the need for more co-ordinated services/joined up services across children and adults. However it was noted that this has improved with the introduction of the ASD Strategic Action Plan for Wales.
- The group felt there was a disjointed approach to service provision for adults with mental health and learning disability in the region. But hopefully the Betsi Cadwaladr University Health Board (BCUHB) operation across North Wales should address this issue.
- There is a need for re-enforcing communication strategies across North Wales. The group identified the need for improving information sharing, for transition to independent living and higher education.
- Discussion around eligibility criteria and problems this presents: It was recognised that adults with ASD are not receiving adequate support and are often unable to access services that are available to other adults. This was not just about diagnosis for adults but a need for more screening to meet the individual's needs. Adults with ASD may not meet the criteria to receive support for either the Learning Disability or Mental Health services
- There is a need for more specialists in the field across a range of service provision. To give support for the whole life experience – social needs and academic needs in the case of Higher Education.

### What are the challenges that face us?

The following challenges that face us in North Wales are:

- The main challenge is the identification of adults with ASD.
- Lack of diagnostic services and multi-agency diagnostic services.
- Ethical issues – do adults want a diagnosis?
- There is a need for information and advice for accessing the appropriate services.
- Develop joint training strategy across agencies
- Support mechanism in place for post diagnosis
- Develop knowledge and skills of the practitioners

- Awareness training for a range of professionals' e.g GP's and making sure this is having an impact.
- Develop joint training strategy across agencies
- Adults with ASD not meeting the eligibility criteria and the need for more signposting.

### **What are our priorities for this year and next?**

The priorities for 2010 and 2011 in the North Wales region are to gather information on the adult population, gain an understanding of their needs in order to inform service provision. This will be achieved with the project covering North Wales - Prevalence of Adults with ASD Development project, Community and Monitoring Support posts and The Betsi Cadwaladr University Health Board (BCUHB) work streams.

The Prevalence of Adults with ASD Development project is a 6 month clinical research project funded by WAG through the ASD Strategic Action Plan which will look at how many adults with ASD live in North Wales. The immediate aims are to identify adults with ASD in North Wales who have substantial unmet needs. This information will help ensure services for adults with ASD are developed in the way that is needed.

### **The Betsi Cadwaladr University Health Board (BCUHB) – ASD Project Board**

The Betsi Cadwaladr University Health Board (BCUHB) work streams will address some of the issues. The group has 4 work streams: Adult ASD Assessment/Diagnosis Service, an ASD Training and Awareness Strategy, Development of a database of people with ASD, as an extension of the developing child database and Service/interventions for adults.

### **ASD development posts working across North Wales**

The proposals have been formulated to employ 3 ASD Development Workers for a period of three years. Each of the three posts will cover two local authorities

The posts will provide an accessible point of information and advice to people with Aspergers/HFA, their families and carers post transition (age range 18-25). The posts will offer assistance/support for people with ASD to achieve personal objectives in areas such as employment, training, housing and social networks.

The North Wales region also identified the following priorities: Improve relationships with criminal justice system, re-enforcing communication strategies across North Wales, recognise there is a tiered approach to services due to the nature of the spectrum with priorities to 1<sup>st</sup> tier and focus on assisting individuals with ASD to engage with ordinary activities of their choice. Consider the benefits of generic approach to social inclusion, health, choice and control, awareness raising and access to training and employment.

A diagnostic pathway with better availability of relevant interventions suitable referral which could prevent deterioration in mental health which if left untreated could potentially lead to criminal justice issues. The development of ASD specific guidance to inform the assessment process and a standardised diagnostic tool across the region.

## Workshop session from Mid and West Wales - Day One

### Where Are We Now? .

- Mid and West Wales felt they had a fairly good knowledge about gaps in services
- Difficulties bridging gap for adults with Asperger Syndrome
- Difficulties mobilising the right people at the right time
- Lack in specialist care in adult services
- Difficult to get CMHT involvement in Wales (noted that National guidance from the Department of Health says that CMHTs have to have ASD within their criteria)
- Lack of strategy in diagnosis – lack of resources
- Need the label to get support
- There is development of good things, like peer support among those diagnosed ( but you need a diagnosis )
- Direct payments = individual choices
- Diagnosis does not equal services
- Ad campaign to raise awareness
- New benefit system difficult for those with autism

### What are the Challenges That Face Us .

- In Adult SMI lack of specialist care
- ASD affects everyone in all walks of life; services need to change so we stop pigeonholing people
  - Mental health issues
  - Learning difficulties etc
- If not put in either category not able to access a service
- “Professionals not listening”
  - Need proof
  - Don't necessarily take on parents word
- It is difficult to get statutory services if you *just* have autism
- There is no integrated criteria within services – different teams need to work together
- Gaps in services
- A lot of services still don't see autism as a mental health issue
- ASD spans siloed services. It is difficult to get MH professionals involved in action planning. (Things are siloed in children's services, but there are structured links between the silos)
- There are services in place that help people get assistance from more appropriate places
- Not enough health professionals attending conferences such as this one – there's no obligation for them to attend
- Communication problems + lots of people + agencies involved
- A lot more drive around children, but situation is improving for adults
- Proposal for:
  - Greater consistency in approach across the board

- Concept that LHBs will work together
- 3 years funding available £752k
- Housing – various live-in carers not able to get support
  - Poor quality of life
  - Neither carer nor individual with ASC is seen as eligible for support – difficult to access assessment
  - Support is available for tenancy related issues = everyone is eligible

#### What Are Our Priorities For This Year & Next? .

- Closer links with and between services
- Services want to influence CEOs in negotiations about the clinical network for adults' diagnosis. As well as better communication between CEOs + services
- More specific information about National planning, a clear line and better links between local + national authorities
- Community monitoring + support
  - Make people aware of what is available + where they can go for advice etc.
- More training – continuing priority. Work on existing initiatives to raise awareness in
  - GPs
  - Community psychiatric nurses
  - Prison workers
- Next step in integrated criteria =
  - Big issue for mental health services
  - Integrated teams = more training needed
  - Work towards one set of integrated eligibility criteria to be used by both learning services + mental health services
- Link workers between the services or joint assessment to determine where case management should lie
  - Can negotiate between two areas

## **BACKGROUND for Day Two workshops**

### The Circumstances and Support Needs of older people with ASD Research – Main Findings

- Relatively few older adults with ASD were found in spite of wide-ranging search
- Levels of unemployment, anxiety and depression are all significantly higher in older adults with ASD, just as they are with young people
- Adults with ASD who are employed need support in terms of greater awareness in the workforce, advocacy and social skills training
- Lower levels of ability in older adults with intellectual disability and ASD are associated with behaviour problems, psychiatric disorder and poorer quality of life
- The problems faced by people with ASD are not insurmountable. They are keen to be as independent as possible, and see themselves as essential partners who need to be actively engaged in decisions about their support needs

## **Workshop session from South and East Wales - Day Two**

### What should be our vision / aims for older people with ASD in South East Wales?

- Raise awareness amongst the general population and professional working with older people with ASD regarding their needs eg public awareness campaign / GP training
- Develop an enhanced understanding of the specific needs of individuals in this group. This should be achieved through further research.
- Better training for professionals / staff working with older people with ASD, so that services provided are able to meet need
- Ensure access to good quality information and guidance about key issues for older people with ASD
- Ultimately, assist older people with ASD live independent lives to the extent possible
- Address the fact that a disproportionately low number of older people are diagnosed with ASD compared to expected levels

### What service / support model can best deliver this vision / aim?

- Older people with ASD should be involved in planning and designing services eg retiree's involved in planning services.
- Training needed for staff in care/ nursing homes. There appears to be a dearth of practitioner knowledge in the area of older individuals due to lack of exposure to people with an ASD above the 50/ 60 age bracket.
- Link with Help the Aged/ Age concern etc. Leaflet distribution/ development.
- Utilise existing infrastructures effectively (older peoples NSF).
- Easily accessible information.

### What should be our priorities for the next year in delivering this vision / aims?

- Face to face contact centres, ensuring information is accessible.
- WASPI (information sharing) awareness training
- Implement Community Monitoring and Support Project across region
- Commission and undertake specific research in this area.

## **Workshop session from North Wales - Day Two**

### What is our vision/aims for older people with ASD in North Wales

- The vision in North Wales is for a society which is inclusive of persons with ASD.
- The group acknowledged there is a lack of data and information on the impact of support needs of older people with ASD traits. The aim in North Wales is to try and improve the identification of older people with ASD. Although it was noted that within the older adult population, the older they are, the more difficult it becomes to identify. There is a need to identify people with ASD to give them the appropriate treatment. The group highlighted the need for more resources, a service to meet all needs and a consistent approach across the region.
- It is important to learn from people with different problems, engage them in discussions about what their support needs are, how best to address them and to gather as much information/history as possible. Also to be aware of their additional needs e.g. learning disability and mental health problems.
- In North Wales they recognise that there are a number of people living in Nursing and Residential homes that may have ASD.
- To help identify older people with autistic spectrum traits the group decided they would need to target primary health professionals and front line workers to raise awareness.
- They also recognised a few barriers to this including: lack of effective diagnostic tools and the need for multi-disciplinary teams a service to meet all needs. There may be a need for developing a protocol for sharing information amongst health and social care services.

### What service/support model can deliver the vision/aims?

Several support models were discussed.

- Supported living keeping older people with ASD for as long as possible in their own homes.
- Low level support - Development and access to self help groups such as social groups or helpline which they could contact whenever they needed help in unexpected situations.
- Internet groups – although it was noted that a large percentage in this age group may not have access to the Internet.
- There is a need for Specialist domiciliary care providers enabling people to live in their communities.
- Bilingual information should be readily available ensuring the availability of Welsh language assessments for adults and older people.
- Improvement of generic approach targeting social inclusion, health, choice and control, awareness raising and access to training and employment.
- Establish better joint working and sharing information across services
- Develop knowledge and skills of the practitioners
- Need for Care Co-ordinators
- Person Centred Approach



## What are our priorities for this year and next?

The priorities in North Wales for 2010-2011 are:

- The North Wales group identified Primary health care workers as a priority. Raising awareness in GP's (it was noted that GP's are often the first point of contact) and all health care professionals including Receptionists and GP Practice Managers. Using the awareness raising materials which will be released shortly and following this through with training. Develop knowledge and skills of professionals explore the possibility of providing the need for job specific training and bespoke training packages.
- It is important to develop links and working closely other existing strategies such as the National Service Framework for Older People and the Care and Dignity agenda.
- Improve engagement with the voluntary sector and the need to improve sharing of information across organisations.

## **Workshop session from Mid and West Wales - Day Two**

### What is our vision/aims for older people with ASD

- .
- Are wages and infrastructure coming out of budgets and using up money leaving less for services (Hugh Morgan gave an explanation of the WAG ASD budget and how it is spent )
- Recognition that people were required to deliver services and therefore ... Some spent on infrastructure
- Spending money on creating positive profile of autism in workplace
- 22 regional projects starting this year of benefit to adults with autism
- Concerns about sustainability after 3 years to keep the regional projects going
- Sums of money being spent on local services to make them hopefully more sustainable
- Important to meet the needs of individuals with autism in your community first
- Difficulties in the integration of adults into services
- Move forward from spending money on research to actually spending it on provisions
- The budget based upon aspiration rather than reality
  - Not much evidence of integrated working in the field of adults
- More awareness = better individual, person-centred approaches
- A lot of services that are already provided are of good quality
  - Supported living for example is often of good quality – people should remain in these environments. They may only need minor adjustments such as more understanding from staff.
  - Minor adjustments could be made regarding awareness of autism in the elderly – increase their positive experience in service + same goes for staff
- If diagnostic/assessment criteria improves, awareness of adults with ASD will also improve(?)
- Need greater understanding of ASD on a sensory level, so chances of adults “slipping through the net” will be reduced
- Get mapping right from point of referral and keeping proper records would set the path for general improvement in diagnostics and appropriate care/access to services

- Better mapping = better, more appropriate services, but how do you improve mapping?
- Improve capacity to diagnose locally
- Diagnosing adults with ASD does not necessarily have a huge financial cost
- Older services have focus on dementia
  - Issues like ASD not seen as particularly relevant to them
- Keep focus on individuals needs and on person-centred planning, it would be a step backwards to house many individuals all together in a village away from their community (unless this is their personal choice)
- Possible a limited place for extra care housing, but only if it's what the individual wants

#### What service/support model can deliver the vision/aims?

- Has to come from integration of health + social services
- Person-centred
- Direct payment
- A system that supports individuals from young adults to adults, including helping them move out of home, become independent and "citizens in their own right"
  - Lots of services involved, plus working with the individuals needs
- Support groups for people on the spectrum
  - 2 in Ceredigion (Mind/NAS)
  - Carmarthen
  - Llanelli
  - Neath
  - Pembrokeshire (?)
- More groups in areas = more choice for carers + individuals on spectrum
- At present tends to have to get to a point of critical need before changes occur
  - Dramatic changes to models not necessary, just alter appropriately
- Clear model for individuals with learning difficulties
  - Supported in their own home
- Many differences between individuals regarding number + type of services required
  - Some things can be done at low cost that will make a huge difference
- Model would have to be very flexible -an individual's needs will fluctuate, but the assistance will need to be long-term

It was noted that in the LD field in general there are issues about ageing to address. If a person with LD requires a nursing home, possibly at an earlier age than is usual, there is often nowhere suitable.

#### What are out priorities for this year & next?

- Train people in residential and nursing homes to look be aware of autism ... IN ALL ADULT SERVICES
  - Raising awareness
  - Accept that many adults with ASD don't want or need anything
  - Targeted training

- Less people going into residential homes
  - costs more to keep people in their homes
  - For this to happen, training is essential
- More provisions in place to assess adults with ASD
- [A working diagnosis can work as much as a formal one in adults. More difficult to be 100% sure if individual wasn't assessed in childhood]
- NEED A STRATEGIC DIRECTION!
  - What next?
  - How ASD will fit into the NSF (ASD and vulnerable groups to be taken up in the second phase)
  - How can this be pushed through?
  - The people who could make it happen not here
- On a local level try to create more interest in the adult with ASD's need
  - But how?
  - Where are they?
- Awareness that traits commonly associated with age may actually be symptomatic of ASD

There may not be much research, but perhaps there is enough and it is time to put the world wide research together and identify what is needed.

Mid and West Wales priorities for this year and the next are:

- Training of care workers and care and residential homes, and domiciliary care – in fact in all adults services.
- Get involved in phase 2 of the NSF for older people
- Develop diagnostic provision

They acknowledge that none of this will be driven forward unless on the back of the WAG ASD strategic action plan so we seek further direction. The big question from our group at the end of the workshop; what next?

## Plenary Session:

### Day One – Thursday 10th June 2010

(Dr Mike Jackson, Consultant Clinical Psychologist, Betsi Cadwaladr University Health Board to Colette Morgan)

**Q: How much has learning so much about AS and autism helped you personally?**

A: Greatly. I felt freakish before, and just wanted to be the same as everyone else. After being diagnosed, I learnt as much as I could about AS and felt relieved that there was nothing 'wrong' with me. It helped remove the feeling of guilt I had surrounding certain behaviours, such as not being able to play with my grandchildren. Researching AS helped me to be able to make sense of certain traits I did not understand. I know I can't blame everything on autism, but knowing what it is provides an understanding.

This was also agreed with by Nicole van Schie who also has AS.

(Dr.Sundari , Consultant Psychiatrist, Aneurin Bevan Health Board to Hugh Morgan, ASD strategic Action Plan Implementation Manager )

**Q: Are there any initiatives to look at how to raise awareness of autism in different regions?**

A: Initial approach = Awareness raising materials. Discussions are ongoing at the Assembly.

### Day Two – Friday 11th June 2010

(Nicole van Schie, Pembrokeshire Association of Voluntary Services to Dr Gareth Morgan, National Framework for Older People)

**Q: How is ASD going to be included in Phase 2?**

A: NSF is going into Phase 2 – it is for all older people in Wales, but there will be a new section in phase 2, need to make sure sub-groups are also recognised, including individuals with ASD.

**Q: How are carers involved in looking after adults with ASD?**

A: Dignity in Care programme is a key theme. Mutually support carers and adults with ASD.

(Adrian Roper, Cartrefi Cymru to panel)

**Q: Do you agree that there is no place in our vision in Wales for 'segregated adulthood to segregated grave'?**

A: (Hugh Morgan): We want small-scale community-based living in Wales. There are WAG guidelines on this. In Wales there is still some very large private sector accommodation. Wales wants to move away from segregated living.

(Chair): There is a need to mutually reinforce housing through registration law. The key = commissioning. Mrs Hart – "First port of call for healthcare = NHS." ...Private care should be a last resort.

(Alan): Wales does not have village communities for the elderly in general. The thought "Out of sight, out of mind" needs changing. The facilities are so tailored for specific needs that it is sad that those using them believe that they need to be separated from society.

It raises the important question: 'What does choice mean?'

End of Report JT