

Foreword

We are very proud to issue this Strategic Action Plan for Wales, which sets out how the Welsh Assembly Government seeks to meet the needs of individuals with ASD and their families and carers. As far as we are aware this is a World first. The Welsh Assembly Government's intention is that this Strategic Action Plan will set the direction to improve the commissioning and delivery of services so that individuals with ASD are supported to reach their full potential in all aspects of their lives whatever their age, wherever they live, whatever their gender, social or ethnic background.

In developing this action plan, the Welsh Assembly Government has worked in partnership with both the voluntary and statutory sectors and we would like to thank all those who gave generously of their time and effort to bring this strategic action plan to fruition including the hundreds of people, including children, young people and adults with ASD, who took part in the consultation exercise. We would also like to thank professionals, particularly those from the voluntary sector, who work with individuals with ASD and their families, for their expert advice.

Partnership working will be the key to success. We are not just talking about partnerships between agencies who commission and deliver services but partnership with individuals with ASD, their families, carers and professionals who support them.

The Strategic Action Plan is the start of a process. There are some actions that are ongoing. Awareness raising is fundamental to future developments, but the mapping of needs and existing services in each local authority area will enable the future development of services where gaps are identified. Some of this work will never have been done before. Some of the findings will require longer term planning but until we take the first step we will never make progress.

We are aware that what is being asked is a challenge. If it were easy it would have been done already. We are confident that the challenge will be met. We will provide support to take this Strategic Action Plan forward in Wales to make the vision a reality and bring about positive, sustainable change that will benefit the individual with ASD, their family and society.



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CONTENTS

CHAPTER 1

Executive Summary	1
Actions.....	2
Resources.....	5

CHAPTER 2

What is autism.....	6
Prevalence of autism in Wales.....	7
Raising awareness.....	9

CHAPTER 3

Early identification.....	13
Diagnosis.....	15
Assessments of need of services.....	16

CHAPTER 4

Commissioning services for people with ASD.....	21
---	----

CHAPTER 5

Services for Children & Young People.....	26
Transition planning and preparation for adulthood and employment.....	33
Care Assessments/Services for Adults.....	36
Family & Carer Support Services.....	41
Generic Service Issues.....	44

ANNEX 1:

How this Action Plan fits with existing policies, strategies, guidance and tools for delivery	50
---	----

ANNEX 2:

Classic Autism with Learning Disability Care Pathway.....	52
---	----

ANNEX 3:

Adults with Classic Autism with Learning Disability Care Pathway.....	56
---	----

ANNEX 4:

Asperger Syndrome Care Pathway.....	58
-------------------------------------	----

ANNEX 5:

Extract from The National Service Framework for Children, Young People and Maternity Services.....	62
--	----

ANNEX 6:

Bibliography.....	65
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CHAPTER 1: Executive Summary, Actions and Resources

Executive Summary

1. The purpose of this Strategic Action Plan is to set a clear direction of travel for the development of services in Wales by ensuring that specific and measurable actions are undertaken and, on the basis of evidence of prevalence and need, commissioning inter agency services at local, regional or national levels as appropriate. It also aims to broaden our understanding of ASD and its prevalence in Wales.
2. It has been developed in collaboration with an All Wales External Working Group on Autism comprising of key stakeholder groups involving parents and professionals both statutory and voluntary. The groundwork that the group undertook is recognised and was fundamental in informing the development of this document.
3. Throughout this action plan, reference will be made to Autistic Spectrum Disorders (ASD), including Asperger Syndrome, to reflect the variation in the nature and severity of the impacts and difficulties posed by these disorders and to cover the consequent diversity and range of needs posed for people with ASD, their families, carers and the statutory, independent and voluntary services. Chapter 2 clarifies what is meant by ASD and deals with awareness raising and prevalence.
4. An increasing number of people are being diagnosed with ASD. We recognise that there is a need to improve our understanding of ASD and in the provision that is made for children, young people and adults with ASD and their families in Wales.
5. ASDs can pose challenges that are often multi-faceted and complex, particularly given the increasing numbers of individuals diagnosed with ASD. The nature of ASD requires a range of professionals and agencies to work together to ensure that needs are properly assessed and addressed. Too often, because of the nature of ASD, people fall into the gaps between services. That is why it is important that services should be available on the basis of the assessed need of individuals and their families or carers. For example, *The National Service Framework for Children, Young People and Maternity Services* (Welsh Assembly Government, 2005) addresses the issue of children and young people with learning disabilities (including those with ASD). It states that children with a learning disability should have access to a network of appropriately skilled professionals that can respond to both their mental health needs and learning disability, according to their assessed need.
6. Appropriate and sustainable improvements in the provision of person-centred services and support arrangements for people who have ASD and their families will be delivered only by effective co-operation at local, regional and in some cases national levels between all those with an interest. The successful delivery of services for people with ASD, and for others with multi-faceted and complex needs, will be a measure of how well professionals and

agencies are working together in partnership at local level and more widely, in the context of *Making the Connections; Delivering Beyond Boundaries* (Welsh Assembly Government, November 2006). Possible legislative changes will also impact on future plans. In addition, the following will help this process:

- *The National Service Framework for Children, Young People and Maternity Services in Wales* has a number of relevant key actions which will already have been measured for either two years if they are developmental or three years if they were flagged for immediate action in 2005/06. This will provide self assessed data from each of the 22 Children and Young People's Partnerships on both a qualitative and quantitative basis to inform the development of family support services at a local level. This information should be used in the mapping of social services in action 8.1 (third bullet point)
- Data from the Children's NSF Self-Assessment Audit Tool is already informing Children and Young People's Plans as per actions 9.1 and 9.4.
- The Welsh Assembly Government has established a task group, chaired by senior officials to advise on improvement of services for disabled children and young people in Wales. This group will provide a basis for assessing the effectiveness of respite care/short breaks for the future.

ACTIONS

7. The following section of this Chapter is a comprehensive list of the first round of actions it is proposed should be taken by the Welsh Assembly Government, commissioners and service providers to set the foundation for better services for children, young people and adults with ASD and their families (for clarity, subsequent chapters are followed by a list of the key actions which have arisen therein.) The Welsh Assembly Government will support commissioners and work with them and stakeholders to develop the next phase of the action plan. It is intended that this should run in 3-year cycles alongside the planning cycles for Children and Young People's Plans and Local Health, Social Care and Well-being Strategies.

8 Mapping prevalence, needs and services

Actions

- 8.1 **Commissioners and service providers** should, through the Children and Young People's Partnerships and Local Health, Social Care and Well-being Strategy groups, and as part of their wider mapping of needs and services and needs assessments:
 - set up systems to identify and record the number of people within their existing client populations who are known to have ASD;
 - estimate current and future demand for services on the basis of the best evidence otherwise (see Chapter 2);

- map services for children, young people and adults as well as family and carer support services, across all statutory, voluntary and independent provision (including self-help support groups). This is to include the full range of services identified in Chapters 4 and 5. Full use should be made of local operational plans, for example the Supporting People Operational Plans and of local directories of services; and
 - identify an ASD champion with sufficient knowledge and seniority, who will work with key stakeholders to promote this work, subsequent planning, service delivery and monitoring.
- 8.2 The **Welsh Assembly Government** has appointed an ASD Implementation Manager to promote regional networks and/or a Wales network to share information and best practice and to take forward work on and develop the action plan – this is in place for the first 12 months with future appointments to be considered following the outcome of the initial work. A steering group consisting of key stakeholders will be established and will meet quarterly.
- 8.3 **The Welsh Assembly Government** will commission research into the prevalence of ASD in older people in Wales and their needs.

9. Commissioning services

Actions

- 9.1 **Commissioners** should ensure that Children and Young People's Plans and Local Health, Social Care and Well-being Strategies, completed in 2008, include an overview of the arrangements for commissioning of services for children, young people and adults with ASD over the lifetime of the plans, including those to be commissioned locally or otherwise.
- 9.2 **Commissioners** should identify where they will make use of their powers to pool resources (including accommodation, staff and financial resources) to commission services.
- 9.3 The **Welsh Assembly Government** will issue guidance to LEAs on the development of the regional provision of goods and services for children and young people with SEN across Wales
- 9.4 **LHBs** should have in place by the end of 2008 arrangements to commission, within the lifetime of the Children and Young People's Plan and Local Health, Social Care and Well-being Strategy, regional provision of diagnostic and treatment services to bring together the appropriate specialisms (including paediatric and adult psychiatry and learning disability) and ensure equity of access across Wales to tier 3 services for those individuals who need them.
- 9.5 **Individual agency** operational plans (health, social services, education, leisure services, housing etc) should support the commissioning, development and delivery of the range of services required.

- 9.6 The **Welsh Assembly Government** will publish the final version of *Quality Standards in Education for Pupils with ASD* in 2008. The quality standards will provide schools and LEAs with guidance on minimum service requirements for pupils with ASD and ensure a consistent approach to meeting needs across Wales.
- 9.7 **Children's & Young People's Partnerships** and **Local Health, Social Care and Well-being Strategic Partnerships** should support the establishment of an ASD co-ordinating group in each local area. This group should be multi-agency, include service users and carers, and inform and support agreed cross-agency approaches to strategic planning for and commissioning of services for people with ASD. Provision for supporting the attendance of users and carers must be considered. Trying is not enough; practical help should be available. Links should also be made to voluntary sector organisations with interests in the area.
10. **Transitional arrangements**
- 10.1 **Commissioners and service providers** should ensure there are clear arrangements for transition between services for children and young people and adult services, in line with the actions set out in the *National Service Framework for Children, Young People and Maternity Services*.
- 10.2 The **Welsh Assembly Government** will produce guidance for schools and LEAs on transitional planning, which will refer to a multi-agency approach as part of the SEN handbook for schools (*Handbook of Good Practice for Children with Special Educational Needs*. Welsh Assembly Government. April 2003). This will include arrangements for transition from school to college at age 16.
- 10.3 The **Welsh Assembly Government** will consider how the arrangements for transitional planning for disabled young people, including those with learning disabilities, might be strengthened to support the actions set out in the *National Service Framework for Children, Young People and Maternity Services*.
- 10.4 The **Welsh Assembly Government** has already secured £1.5m of funding (£500k per year for three years commencing 2008/09) for a number of additional key transition workers to provide support to children and young people (and their parents and carers) with SEN (including those with ASD) as they move through school and on to further education or the workplace. Further guidance is required and this will be produced by a sub group of the External Transition Reference Group which was set up in January 2008 as a result of the former ELLS Committee's review of transition.

11. Services for Adults

Actions

- 11.1 The Welsh Assembly Government will, during 2008, establish a Task and Finish Group who will identify specific issues that adults face and take forward work to tackle them, and investigate, evaluate and report on the evidence for effective interventions and models of services for adults.

12. Awareness raising, information and training

Actions

- 12.1 **Awareness raising and training materials.** Consideration will be given to the development of a web-based, bilingual, self-instructional awareness-training package for families and practitioners in Wales (possibly using existing bilingual web-based routes that are demonstrated by, for example Awaes.org). The needs of black and ethnic minority communities will also be included in considering the range of awareness raising and training materials.
- 12.2 **Commissioners and service providers** in health, social care and education sectors should support the provision of ASD awareness training for all professionals who may come into contact with people with ASD. In addition, professionals in the following services should receive awareness raising information:
- Job Centres, Careers Offices and Employment Training Agencies (particularly on the needs of adults with ASD entering the job market);
 - FE/HE Institutions - a good starting point would be the training of College Disability Officers and their teams;
 - The Youth and Criminal Justice system, in particular Youth Offending Teams;
 - Leisure services.
 - Commissioners of Services
- 12.3 As part of the ongoing development plan for the **Careers Wales** online site, a section will be developed to provide information to employers that provide work experience and jobs to people with Autism.

Resources

13. The Welsh Assembly Government has announced £1.8m in 2008-09 to support the first years actions in relation to mapping of needs and services and the identification of ASD Champions. Future funding will be announced in the coming year.

CHAPTER 2: Understanding Autistic Spectrum Disorders, Prevalence, Raising Awareness

Introduction: This chapter looks at the definition of ASD. It also looks at the numbers of people with ASD in Wales and how data on ASD is collected. The final section deals with the importance of awareness of what it is like to have ASD.

What is Autism?

There are a number of definitions of Autism, but, for the purpose of this Strategic Action Plan, the Welsh Assembly Government has adopted the following World Health Organisation (WHO) definition:

“The term autistic spectrum disorders (ASD) is used to describe the group of pervasive developmental disorders characterised by qualitative abnormalities in reciprocal social interactions and in patterns of communication and by a restricted, stereotyped, repetitive repertoire of interests and activities”.

(WHO, International Statistical Classification of Diseases and Related Health Problems 1994)

1. The autistic spectrum includes people who have severe learning disabilities and little or no verbal communication, through to those people with an average or high IQ. It includes people who have Asperger syndrome.¹ Use of the terminology ASD denotes the fact that there are a number of subgroups within the spectrum of autism. There are differences between the subgroups, but all people who have ASD share a triad of impairments¹ and have difficulties in their ability to:
 - understand and use communication both non-verbal and verbal, difficulty in understanding the communication and language of others and also in developing effective communication themselves;
 - understand social behaviour which, in turn, affects their ability to interact with other people. People with ASD are very literal thinkers and interpreters of language and sometimes they fail to understand its social context; and
 - think and behave flexibly, which may be shown in restricted or repetitive activities. This means that they may not be able to adapt their behaviour to suit specific situations. They will also have difficulty adapting to new situations and often prefer routine to change.
2. Additionally, accounts from people with ASD have reinforced our recognition that many people with ASD experience sensory difficulties and may be hyper or hyposensitive to stimuli. These sensory difficulties warrant consideration, as they form part of the complex and highly individual profile of the condition

¹ Wing L.. *The Autistic Spectrum: A Guide for Parents and Professionals*. Constable. London. (1996)

and may influence the design of settings used frequently by people with ASD, or approaches to services and treatments, for example dental treatment (see chapter 5).

Prevalence of Autism in Wales

3. It is difficult to know exactly how many people have ASD, as it is not always easy to identify. Some people will never be diagnosed. In its mild forms, ASD may be considered entirely usual by some or, in other circumstances, it may be masked by other needs. As our knowledge, understanding and awareness increases, more people with ASD are being identified.
4. The Medical Research Council's review of autism research² suggests that there is fairly good agreement between epidemiological studies that ASD, if broadly defined, currently affects around 60 per 10,000 children under 8 and, if narrowly defined, 10-30 per 10,000. The Public Health Institute in Scotland has also examined a range of epidemiological studies and concurred that the best estimate for the population prevalence of ASD in Scotland was 60 per 10,000 children³. Research conducted by the Office for National Statistics indicates that 0.9% of children aged 5-16 years across Great Britain have ASD⁴.
5. In 2002, the Welsh Assembly Government commissioned a senior trainee in Public Health in Wales to conduct research to estimate the prevalence of ASD in Wales as part of a wider study⁵. The following table shows the estimates by age group (assuming a prevalence of 60 per 10,000).

Age	Population	No. with ASD (60 per 10,000)
1 to 4	138,400	830
5 to 14	388, 300	2330
1 to 14	526,700	3160
1 to 64	2,395,700	14,374

6. More recently in Wales, a study of diagnostic trends in ASD in the South Wales Valleys has been undertaken over a 15 year period by Latif and Williams⁶ (2007) and their work confirms the prevalence rate of 60 per 10,000 of population.

² Medical Research Council. *MRC Review of Autism Research: Epidemiology and Causes*. Medical Research Council. London (2001)

³ Public Health Institute of Scotland. *Autistic Spectrum Disorders: Needs Assessment Report*. Public Health Institute of Scotland. Glasgow (2001)

⁴ Office of National Statistics. *Mental health of children and young people in Great Britain, 2004*. Office for National Statistics. Basingstoke (2005)

⁵ Lowe G. *ASD in Wales: Estimating prevalence, describing current specialist health services and documenting research into autism in Wales*. An unpublished internal report commissioned by the Welsh Assembly Government (2002)

⁶ Latif A.H.A . and Williams W.R. *Diagnostic Trends in Autistic Spectrum Disorders in the South Wales Valleys*. London: Autism; Vol. 11, Number 6; (2007).

7. At first sight, the prevalence of diagnosed autism appears to be increasing. However, although the number of people who are diagnosed with ASD is increasing, it is unclear if this is due to rising awareness and improved diagnosis or an increase in prevalence. Certainly, improved diagnostic services, increased awareness and more specialist provision resulting from a specific diagnosis could account for some of this increase.
8. In Wales, the prevalence of ASD in adults remains unknown. However, a Royal College of Psychiatrists report ⁷ refers to ASD as “A disorder that, although its presentation may change and moderate with age, has a childhood onset and is lifelong.”
9. There are a number of other studies that relate to prevalence that could be listed here; they provide both higher and lower figures of prevalence. So, for the purposes of this report, we use a proxy indicator of 60 per 10,000 to provide us with an estimate of the total population of people who are likely to be within the autistic spectrum.

Data collection, information sharing and research

10. The Welsh Assembly Government has already begun to make improvements in data collection across the statutory services for children in Wales. The new systems of data collection for children in the National Community Child Health Database (NCCHD), the Integrated Children’s System, the Pupil Level Annual School Census (PLASC) and SEN data published annually through statistical bulletins on SEN, will provide data for authorities to plan more effectively. The Lifelong Learning Wales Record (LLWR) collects learner related information from post 16 service providers. Further developments under the introduction of a Common Assessment Framework (CAF) for children will improve data and information sharing on children with additional needs, support communication between practitioners and agencies and early diagnosis and intervention.
11. The development of local services for people with ASD and related disorders should therefore be better informed. Commissioners will need to ensure that they share information to jointly plan to meet the needs of children, young people and adults with ASD.
12. It is acknowledged that further specialist research is needed in this area if we are to improve our knowledge and the evidence-base to inform the future planning and development of services for people with ASD.
 - The Welsh Assembly Government actively supports the Autism Research Co-ordination Group hosted by DfES. This has been established following the publication of *Mapping autism research: Identifying UK priorities for the*

⁷ Royal College of Psychiatrists. *Psychiatric services for adolescents and adults with Asperger syndrome and other autistic-spectrum disorders*. Council Report CR136. London. Royal College of Psychiatrists. April 2006

future (Charman and Clare, March 2004)⁸, which called for Government to play a greater role in co-ordinating information on autism research and identifying priorities for future research. The group does not commission and fund research itself, but meets regularly and brings together a core membership to exchange information and identify links between research activity and areas for further research across the UK.

- As part of Clinical Research Cymru, the Wales Office of Research and Development (WORD) has funded the Welsh Centre for Learning Disabilities to develop a Learning Disability and Autism Network (LDAN). An Autism Spectrum Disorders Research Activities Group will form part of the LDAN.
- The development of a multi-site Welsh Autism Research Centre by Autism Cymru at Welsh universities will also provide relevant data specific for Wales.

Raising Awareness

13. Studies suggest that the lives of children and adults with ASD may only improve if society has a better understanding of their condition. Raising awareness and understanding of ASD is one of the key elements in ensuring that each individual's needs are fully identified and assessed; that all care packages are appropriate to meeting each individual's needs; and that the core education, health and social services required to undertake assessments and interventions are effectively delivered. Failure to take full account of these matters tends to result in provision of relatively generalised services that may not be capable of adapting sufficiently to effectively address an individual's needs or goals. In this context, assessing and addressing care needs may well include local authority housing and leisure staff as well as health, social services and education and independent sector staff.
14. Currently, with the exception of the following, there is a need for more bilingual (Welsh/English) language information available on ASD.
 - In December 2002 Jane Hutt, Minister for Health and Social Services launched www.awares.org, an on-line bilingual information ASD resource for Wales, developed and maintained by Autism Cymru. This bilingual resource provides a rich source of regular news; information; details on autism resources throughout Wales, and contains a library of key lectures, and papers delivered at autism conferences in Wales.
 - *Y Cyfan am Anhwylderau Spectrwm (All about ASD)* for Parents and Carers (Tim Cynnal Plant a Theulu Deredigion & Autism Cymru, 2004). A bilingual booklet for parents in Wales produced by Ceredigion Family

⁸ Charman T. and Clare P.. *Mapping Autism Research: Identifying UK priorities for the future*. London: National Autistic Society (2004).

Support Team and Autism Cymru.

- *My Brother Gwern* (Elin Walker-Jones/Autism Cymru/Welsh Language Board, 2005) – winner of the Welsh Language Children's book in the Welsh Healthcare Awards, 2006. Written for the siblings of children with autism spectrum disorders.
 - *Ydych chi'n gyfarwydd a'r cerdyn yma? (Do you know about this card? – Autism Spectrum Disorders and contact with the Criminal Justice System & Emergency Services)*. Autism Cymru and North Wales Police. Following the success of this bilingual scheme with the Emergency Services in North Wales, it was launched with Gwent and South Wales Police Forces in September 2007.
 - *Apel S4C Autism Cymru 2006 – Beth yw Awtistiaeth? (What is Autism?)* – booklet sent to every school in Wales by S4C during 2006 in support of Autism Cymru, its Charity of the Year .
 - *Gweithio mewn Partneriaeth a phroffesiynolwyr mewn Addysg (Working in Partnership with Professionals in Education)*. Fforymau Ysgolion (Autism Cymru/Three Guineas Trust).
 - *Yr Ysgolion Cynhwysol ac ASA: Prosiect Ymchwil ac Hyfforddi'r Ysgol Gyfan/The Inclusive Schools and ASDs: Whole Schools Training and Research Project* (Autism Cymru/TES Cymru).
15. Information is also available on the National Autistic Society Welsh micro site at www.nascymru.autism.org.uk through their telephone autism helpline and their Advocacy for Education services. The National Autistic Society is also able to provide support through a number of minority ethnic languages.
16. Bilingual practices for adults with ASD appear scarcer than for children with ASD and their families living in Wales today. For example, there are virtually no Welsh language publications written specifically for adults with ASDs and their carers although the web-based www.awares.org does contain a number of Welsh language papers relevant to adult ASD practice from academics, practitioners, carers and people with ASD themselves.
17. As part of the Empowering Teacher agenda, a bilingual e-learning course for special educational needs has been developed by the Welsh Assembly Government, in collaboration with higher education institutions and local education authorities. The course will help teachers and support staff to work more effectively with pupils with SEN and raise awareness of the factors involved in developing an inclusive school. Part of the course focuses on ASD. The course can be undertaken at any point from initial teacher training to continuing professional development.
18. The forthcoming *Quality Standards in Education for Pupils with ASD*, due to be published during 2008 will help raise awareness of ASD issues in schools. In addition, the Welsh Assembly Government is working with providers of

initial teacher training to improve newly qualified teachers' awareness of ASD as part of the Inclusion Policy and Performance Framework. The Welsh Assembly Government is also linking with local education authorities and other agencies to provide continuing professional development across a range of special educational needs including ASD.

19. Alongside the development of Directed Local Enhanced Services (see Chapter 4), the Welsh Assembly Government is funding a disability awareness programme for GPs and practice staff which will include an assessment of how well they are developing disability aware systems. This will be a two-year programme, which will provide recognition for the practices, which have successfully participated, and will measure the progress of the programme across Wales. Bilingual ASD training is already being undertaken by Autism Cymru with health visitors, nursery nurses, and mainstream and specialist schools in Wales.

Actions Arising from Chapter 2

(Taken from the full list of actions in Chapter 1, paragraphs 8. – 12.3)

8 Mapping prevalence, needs and services

Actions

- 8.1 **Commissioners and service providers** should, through the Children and Young People's Partnerships and Local Health, Social Care and Well Being Strategy groups, and as part of their wider mapping of needs and services and needs assessments:
 - set up systems to identify and record the number of people within their existing client populations who are known to have ASD;
 - estimate current and future demand for services on the basis of the best evidence otherwise (see Chapter 2);
 - map services for children, young people and adults as well as family and carer support services, across all statutory, voluntary and independent provision (including self-help support groups). This is to include the full range of services identified in Chapters 4 and 5. Full use should be made of local operational plans, for example the Supporting People Operational Plans and of local directories of services; and
 - identify an ASD champion with sufficient knowledge and seniority, who will work with key stakeholders to promote this work, subsequent planning, service delivery and monitoring.
- 8.2 The **Welsh Assembly Government** has appointed an ASD Implementation Manager to promote regional networks and/or a Wales network to share information and best practice and to take forward work on and develop the action plan – this is in place for the first 12 months with future appointments to

be considered following the outcome of the initial work. A steering group consisting of key stakeholders will be established and will meet quarterly.

- 8.3 **The Welsh Assembly Government** will commission research into the prevalence of ASD in older people in Wales and their needs.

12 Awareness raising, information and training

Actions

- 12.1 **Awareness raising and training materials.** Consideration will be given to the development of a web-based, bilingual, self-instructional awareness-training package for families and practitioners in Wales (possibly using existing bilingual web-based routes that are demonstrated by, for example Awaes.org). The needs of black and ethnic minority communities will also be included in considering the range of awareness raising and training materials.
- 12.2 **Commissioners and service providers** in health, social care and education sectors should support the provision of ASD awareness training for all professionals who may come into contact with people with ASD. In addition, professionals in the following services should receive awareness raising information:
- Job Centres, Careers Offices and Employment Training Agencies (particularly on the needs of adults with ASD entering the job market);
 - FE/HE Institutions - a good starting point would be the training of College Disability Officers and their teams;
 - The Youth and Criminal Justice system, in particular Youth Offending Teams;
 - Leisure services.
 - Commissioners of Services
- 12.3 As part of the ongoing development plan for the Careers Wales online site, a section will be developed to provide information to employers that provide work experience and jobs to people with Autism.

CHAPTER 3: Early Identification, Diagnosis and Assessment

Introduction: This chapter deals with the way in which ASD is identified and diagnosed and how the needs of those with ASD and their families are assessed.

Early identification

1. Research suggests that the majority of children with ASD will display some signs of ASD during the first three years of their life, but their needs may not be identified within this period. Sometimes, this is because the signs of a mild disorder may be difficult to pick up with certainty. In other circumstances, it is possible to recognise and diagnose ASD by the time a child is 18 months old.
2. Children whose communication and academic skills develop at the usual age or who are in advance of their peers in some areas (for example, in maths, reading accuracy and memory for facts) may still have ASD, but it may not be recognised. In these situations, it is usually the case that the condition may not be recognised until after the children begin formal schooling. In some cases, children are not diagnosed or recognised as having ASD until after many years in education. This is particularly true of children with Asperger Syndrome, for which the average age for diagnosis is currently 11 years of age.
3. Early assessment and intervention is central to maximising opportunities for recognising children's difficulties and needs and for improving their emotional, educational, social, and cognitive development and their health. Early action may also help to tackle some of the many social and physical barriers faced by children with ASD and enable their full participation in society. Appropriate plans for their assessment and intervention can enable all children and young people with ASD to achieve their full potential.
4. There are many adults who have ASD that remains undiagnosed or who are only diagnosed as having ASD in adulthood. Recognising the condition, including gaining a diagnosis as early as possible, benefits people with ASD as it helps to focus the interventions and supporting services that they require.
5. Currently, there is no single screening tool for ASD that is used consistently throughout Wales. There are examples of identification and assessment tools in use particularly for identifying children and young people with ASD. For example, the Checklist for Autism in Toddlers (CHAT) is being used in some areas, but reference to the wider body of research literature suggests that this tool does not have equivocal support.
6. Guidelines for screening, identification, assessment and diagnosis of children with autism, commissioned by the Royal College of Paediatrics and Child Health and the Royal College of Psychiatrists have been developed by the National Initiative for Autism: Screening and Assessment (NIASA), an independent, non-governmental, multi-disciplinary group of professionals. In 2003, the group published the *National Autism Plan for Children*, guidelines

for health, education and social services on identifying, assessing, diagnosing and gaining access to early interventions for pre-school and school age children with ASD.

7. The behaviours that professionals look for in determining if a person has ASD are those that are described within the triad of impairments in Chapter 2 (paragraph 1). There is, however, ***no conclusive diagnostic test*** and it is quite common for professionals to disagree over the diagnosis. This can often be very difficult for people with ASD and their families who need assessment of their needs for services and appropriate levels of intervention.

Care pathways:

The care pathways at annexes 2 to 4 were developed by the Autism Task Group and its sub groups. It is considered they will be helpful to commissioners and service providers in planning services and in indicating the range of people who need to be involved and when.

8. In practice, many professionals have important roles to play in recognising ASD and the education services have particular opportunities and roles in not only recognising children and young people who may have ASD, but also in responding to their needs. Paediatricians, psychiatrists, speech and language therapists, clinical and educational psychologists, and general practitioners and other professionals who see individuals and families may contribute to determining if a person has a diagnosis of ASD.
9. For those individuals who require more specialised tier 3 diagnostic expertise, and to provide support for locally based services, arrangements should be made to commission this in Wales in a way which ensures equity of access. Such services have developed in Wales, but are potentially vulnerable. It is proposed these services should be commissioned on a regional basis in future.

The Royal College of Psychiatrists recommends that:

- *“Commissioners should ensure that there is access to local, basic diagnostic expertise that would allow for the firm diagnosis of autistic-spectrum disorders in clear-cut cases. They should also ensure access to a second level of diagnostic expertise for those individuals where there is diagnostic uncertainty.*
- *Services should be well integrated so that clinical diagnosis is not isolated from treatment and that this, in turn, is closely linked to the (non-psychiatric) services that are provided by other agencies.*
- *Psychiatric training should include experience in the diagnosis, assessment and management of individuals with autistic-spectrum disorders. In particular, there should be some supervised experience with adolescents and adults of normal cognitive ability who have these disorders.”*

and....

- *“Commissioners should ensure that individuals who are thought to have autistic-spectrum disorders have access to expertise across a broad range of therapeutic approaches, including those relevant to the psychological management of these specific disorders, delivered through autism-friendly treatment facilities that include the whole range of age and ability and take into account cultural factors.*
- *Referrals should be made within a formal contractual programme (rather than on an individual basis) to ensure that the provider (rather than any individual clinician) accepts responsibility for the care of the individual with the disorder and there should be regional agreement as to the roles of various individual consultants. It should not be assumed that a service can absorb this patient group without specific planning and investment.*
- *As services for those of working age are often poorly developed, it would be helpful if an ‘autistic-spectrum disorders champion’ were identified within each health authority area. This would be a senior clinician with experience of the psychological management of autistic-spectrum disorders, who would have a specific responsibility for advising on treatment options outside of child and adolescent mental health services.”*

Psychiatric Services for Adolescents and Adults with Asperger Syndrome and Other Autistic Spectrum Disorders. Council Report CR136, Royal College of Psychiatrists, London, April 2006

10. It is important that on diagnosis the person with ASD and their family receives appropriate information, counselling and support. It is more likely this will be the case if diagnosis takes place in a multi-disciplinary environment where diagnosis is not a precursor to an assessment of need.

Assessments of need for services

11. The approach to assessing the needs of both children and adults emphasises that assessment is an ongoing process that is designed to identify each person's individual strengths as well as their difficulties. The approach to intervention should seek to enable people to maximise their potential. Assessment should identify areas in the life of each person for which additional services will enable them to:
- enjoy equality of opportunity;
 - have a better quality of life;
 - make best use of educational opportunities;
 - improve their relationships at home and in the wider community; and
 - gain or sustain independence, as appropriate.
12. All assessments should take into account the perspectives of the individuals and their family and carers.
13. People who have been diagnosed as having ASD and their families should have access to multi-disciplinary assessments. The use of multi-disciplinary person-centred assessments that may call on the resources of more than one agency or sector is also often key to successfully diagnosing ASD.
14. Recognition that a person may have special health, education or social needs should lead directly to an holistic assessment.
- For children, social services are the lead agency and the *Framework for the Assessment of Children in Need and their Families* (National Assembly for Wales/Home Office. 2001) and supporting guidance should be used. The *Special Educational Needs Code of Practice for Wales* (National Assembly for Wales. 2002, reprinted January 2004) should also be used where appropriate.
 - For adults, the Unified Assessment Process (UAP) should be used.
15. Speech and language therapists and play therapists have an important key role not only in conducting initial assessments, but also in providing advice about interventions and, particularly, on how children with ASD are managed and the interventions that are made by schools. Assessments may need to take into account direct observations and reports. In the case of co-existing disorders, assessments should take into account all relevant difficulties and/or disorders that are presented.
16. In undertaking assessments of adults using the UAP authorities must utilise the *Practice Guidance for Person Centred Assessments*, Annex 11 of the guidance for local authorities and health services, *Health and Social Care for*

Adults: Creating a Unified and Fair System for Assessing and Managing Care (Welsh Assembly Government 2002). For adults who have a co-existing learning disability, the UAP assessment process must also apply the Welsh Assembly Government's guidance on service principles and service responses (*Learning Disability Strategy: Adults and Older People with Learning Disabilities Section 7 Guidance on Service Principles and Service Responses*. Welsh Assembly Government, August 2004)

17. There is not always clarity between learning disability teams and mental health teams about who will take responsibility for adults with Asperger syndrome/high functioning autism (HFA). This means that people have difficulty in accessing diagnosis and/or assessment and much needed support.
 - Some local authorities are seeking to combat this by creating “vulnerable adults” teams, but eligibility criteria may still exclude many adults with ASD. Local authorities should create a clear route for such people to access assessment. This could be through either a specific Asperger team, an Asperger care co-ordinator, or by developing a protocol between mental health and learning disability teams.
 - The Welsh Assembly Government has made clear to authorities that access to health and social care services for adults must not be based on IQ related criterion. Guidance requires both health and social services to adopt a person centred, outcome based, approach that is needs led. The Unified Assessment guidance requires authorities to determine how assessed needs may undermine an individual's autonomy and independence. In reaching such a decision agencies are required to decide if physical, functional, psychological, social or other needs present a critical, substantial, moderate or low risk to independence. Specialist assessments may also be used to explore specific needs thus enabling access to specialist support and/or services.

Co-occurring impairments and disorders and co-morbidity

18. It is estimated that 70% or so of people with autism will have another or co-existing problem. This poses the following challenges:
 - Co-occurring problems may mask the signs of ASD or the resulting mixture of impairments, difficulties and behaviours may make effective assessment of the various contributory conditions challenging.
 - Some people, and particularly children and young people, may appear to move across a spectrum of problems and disorders over a period of time. Symptoms can vary over the course of the condition. Signs of inattention may appear to predominate at some times while at others; disinhibited behaviour, overactivity and poor sleep patterns may be at the forefront of parents' concerns. At other times, teachers may be most concerned about challenging behaviours in school, including apparent resistance of some young people to modify behaviours that don't fit well

within the rules or with the needs of others.

- All of these matters may delay full assessment and recognition of the needs of many younger people, or lead to changing diagnosis, or only partial responses being made by the agencies to the full range of people's needs.
19. Common problems and conditions that co-occur with ASD include:
- Epilepsy
 - Learning disabilities;
 - Mental disorders;
 - Mental health problems;
 - Neuropsychiatric disorders;
 - Physical health problems including, particularly, neurological impairments;
 - Sensory impairments;
 - Substance use and misuse.
20. Children and young people develop particularly rapidly in the first two years of their lives. This means that ASD may be suspected if children develop in unexpected directions or unexpectedly slowly in respect of their social skills and relationships. However, the ordinary changes that are a part of development may complicate assessment and plans for intervention. Because co-occurring problems, often termed co-morbidity by the healthcare services, are so frequent in people with ASD it is important that holistic, cross-agency and multi-disciplinary assessments can be carried out. For example, a full assessment by a speech therapist may be particularly useful to teachers in knowing how best to intervene with children in school. Their contributions may help school staff to distinguish between children with difficulties that are reflected in their difficult or non-responsive behaviour from children with ASD, who have sometimes subtle difficulties in following instructions, or whose behaviour may appear to lack empathy or who fail to conform to usual expectations.
21. The high frequency with which people who have ASD experience co-occurring problems, the breadth of the problems that stem from having ASD for themselves and the challenges posed for their families and carers support the importance of holistic assessment.
22. While diagnosis may play a very important part in identifying certain components of an appropriate plan of action to address the needs of people with ASD and their families, it describes only part of the wider spectrum of a person's needs. The wider social, daily living, relationship, educational and workplace needs must also be assessed as they have key, and often vitally significant, parts to play in coming to a holistic and comprehensive programme of education, including remedial education, care and other interventions. **For these reasons, formal diagnosis of ASD should be neither a pre-requisite for a full assessment of each person's wider needs nor should it be a reason for not intervening in a timely manner.**

23. Adults with ASD and a co-existing learning disability should continue to be clients of local learning disability services who should follow the approach set out in the 2007 *Statement on Policy and Practice for Adults with a Learning Disability* and the guidance on service principles and service responses (*Learning Disability Strategy, Section 7 Guidance on Service Principles and Service Responses*. Welsh Assembly Government. August 2004).

Delivery

24. Professional staff should have access to appropriate and relevant information to enable them to consider the possibility of a diagnosis of ASD as early as is reasonably possible. Interagency care pathways and care packages should be used to facilitate continuity of care and anticipate service provision for the range of key transition stages.
25. Co-ordinated, multi agency working is vital in order to deliver a holistic approach and meaningful and joined up assessments for people with ASD, parents and carers. It is essential to have effective arrangements in place for co-ordinating the work and contributions of all relevant sectors and agencies.
26. In some instances, particularly those in which a person's difficulties are less complicated, assessment by a professional from a single discipline may be appropriate. However, the majority of people for whom ASD is suspected require a multi-disciplinary assessment that includes both generic and specialist components. All agencies should commission and manage delivery of services to facilitate professionals in conducting holistic assessments.
27. Team working may facilitate a holistic approach. This does not necessarily require re-structuring of services. Teams, whether virtual and task-related or structural, should encompass all the professions and disciplines that can contribute to the assessment processes and should have the knowledge and competencies to ensure that an individual's identified needs are appropriately addressed.
28. A team approach requires the several agencies to recognise their inter-dependency. They must be prepared to accept each other's opinions and, in order to avoid the possibility of unbalanced demands between agencies and services destabilising existing services, they must recognise the need for mutual planning. It is useful for agencies to develop the concept of lead agency and key worker or care co-ordinator. This means that:
- In each phase of a person's assessment, intervention and care, explicit agreements are made by the agencies involved about which one leads, at any particular time, in co-ordinating the assessment, intervention and care for each person with ASD, and
 - Identified staff are empowered to work with families, carers and professionals of people with ASD to co-ordinate assessments, service provision and provide a single point of reference for the family and

carers. Such a link or key worker should usually be a professional who already provides some service to the family or carers and takes on the co-ordination role additional to their core profession.

29. Ordinarily, the link or key worker should come from within the lead agency. Any change in lead agency and link or key worker should be explicitly agreed and be based on the needs of the people who are the clients concerned.
30. To sum up, a formal diagnosis of ASD is not necessarily required before commencing the Assessment Framework or UAP or assessment of SEN, as these processes focus on the risk to an individual's independence and development. For some people, the outcomes from their assessments may be to put in place appropriate contingency care or education plans, to be activated as and when required. All contingency plans must be clear about the circumstances in which the plan is to be activated and how it can be activated. There is nothing unusual in developing contingency plans for people who may need intermittent interventions and they should be subject to review. Regardless of whether an individual has a co-existing learning disability or not, the guidance on fair access to care services applies (*Guidance on Creating a Unified and Fair System for Assessing and Managing Care*. Welsh Assembly Government. April 2002).

Chapter 4: Commissioning services for people with ASD

Introduction: This chapter identifies considerations for those who commission services for individuals with ASD and their families.

1. Local Authorities (LAs) and Local Health Boards (LHBs) are the statutory sector commissioners of local services for people who have ASD. They are best placed to make informed judgements as to the most appropriate balance and spectrum of local services to meet local identified needs and to determine the local level of funding required to address those needs. Health Commission Wales (HCW) is the commissioner on an all Wales basis of more specialised services in the health sector. The Welsh Assembly Government believes that the response of commissioners is a crucial matter on which the success and speed of implementation of this strategic action plan will depend.
2. Reflecting the Government's commitment in *One Wales* to end the market in the NHS, the future of commissioning is at present under review (*Proposals to Change the Structure of the NHS in Wales*, Welsh Assembly Government, April 2008 - <http://new.wales.gov.uk/consultations/currentconsultation/healandsoccarecurrcons/nhswales/?lang=en>). While it is uncertain how the decisions resulting from the review will affect the mechanisms described in this chapter, the process of carefully analysing needs and securing appropriate services to meet them will remain core requirements in the system. Further guidance on these matters will be issued in due course.
3. Children and Young People's Partnerships have a key role in planning services for children and for young adults (i.e. people aged 0-25 years). All authorities must work closely within the Partnerships in securing delivery of some of the key actions outlined in this document. For adults, the arrangements for the Health, Social Care and Well-being Strategy provide a focus for commissioners. To ensure smooth arrangements for transition, appropriate links should be made between the two. It is important to ensure that Community Safety Partnerships also consider the needs of people with ASDs in commissioning services and that appropriate links are made with the Youth Justice Board, Youth Offending Teams, the Prison Service and the Police.

Analysis of needs and service mapping

4. Informed commissioning relies on a full analysis of incidence, of likely needs and a mapping of existing services across all agencies to identify strengths and deficits. The starting point for the development of the approach set out in this document is such an analysis at local level, across Wales and including tier 3 and 4 services outside Wales which are currently used (see paragraph 13).
5. Local agencies should use information they hold on the number of children and young people with ASD to inform their forward planning and

commissioning of services for adults. For example, it is known how many children and young people with ASD are in residential special schools or are in main stream schools with additional needs and that each of these will require transition plans and consideration of future support, education or training, employment and accommodation needs.

6. It is important to involve the voluntary and independent sectors and representatives of people with ASD and their families and carers in formulating effective strategies for commissioning services. The voluntary sector for ASD in Wales holds a considerable body of knowledge, which commissioners can draw upon.

Person centred commissioning and care pathways

7. Local commissioning strategies need to be person centred so that appropriate service and support solutions can be put in place for each person. Commissioners should ensure statements of purpose and operational policies of services, for example respite/short break and day services, demonstrate the services' ability to meet the needs of people with ASD.
8. Additionally, there is a requirement for commissioners to promote the development of fluid and fluent care pathways in which individuals can move between services but also receive elements in their packages of care and intervention from more than one agency at a time. Care and case management are particularly important in co-ordinating this. The care pathways annexed to this document will be of assistance to commissioners and service providers in developing services.

Collaborative commissioning at local level

9. As appropriate, the responsible authorities should explore the options for joint commissioning approaches. The powers contained within the Children Act 2004 and the National Health Service (Wales) Act 2006 provide the legal basis to facilitate this. Guidance on how to set up and manage pooling arrangements to support cross sectoral partnerships is given in *Making the Connections – Partnerships for Delivery* (Welsh Assembly Government. 2008) <http://new.wales.gov.uk/topics/improvingservices/localserviceboards/poolresources/?lang=en>

Inter authority joint or regional commissioning

10. Where relatively small numbers of individuals who need particular services are involved it can be difficult to commission appropriate and cost effective services in a single LHB/local authority area that provide, for example, specialist diagnostic services or services to meet complex or high level assessed care needs. Wherever possible, commissioners should consider the options for inter-authority joint and/or regional commissioning of services.

Working co-operatively may provide part of the solution to providing an appropriate range of services and support to meet the assessed needs of individuals with ASD

11. In looking at such options, commissioners must also consider the impact upon individuals and families, for example, in considering commissioning placements that are long distances from their family homes. In addition, if children are placed a long way from home on a long term basis, the possible implications of providing appropriate support locally to meet the assessed needs of such individuals on their reaching adulthood should be considered.

Education provision

12. Within the Education Act 2002, Wales only clauses were included to enable the development of regional approaches to providing goods and services for children and young people with special educational needs (SEN) of low incidence. Development of regional education provision for children and young people with a range of needs, including ASD, is underway with the development of a continuum of provision in North and, currently, South Wales. To date, this has included a range of provision for children and young people with the most complex of needs and resourced provision for children with Asperger Syndrome. The Welsh Assembly Government is currently developing guidance to give support to local education authorities in the development of regional provision of education services in Wales in accordance with Section 191 of the Education Act 2002. It will offer practical assistance on what is meant by regional provision; what are the legal considerations; auditing of SEN provision and mapping for the future; partnership working and funding for the development of SEN regional provision. It is proposed that this guidance will be launched later in 2008.

A four-tier strategic framework for commissioning services for people with ASD

13. Recent Welsh Assembly Government policy (set out in *Designed for Life: A new strategy for health and social care in Wales*, Welsh Assembly Government, 2005) has taken an approach to developing Wales' health and social services on the basis of a four level strategic conception of their functions. This strategic approach has much in common with the Assembly's CAMHS Strategy document *Everybody's Business* (Welsh Assembly Government, 2001) and the purposes and principles that lie behind the 4 tier approach and is also promoted in the 2007 Social Services strategy paper *Fulfilled Lives, Supportive Communities* (Welsh Assembly Government).
14. People with ASD may have high levels of co-occurring education, social and relationship and health problems, impairments and disabilities. This raises the requirement to bring existing services and commissioning mechanisms and structures together. An effective approach to commissioning services for people of all ages with ASD would fit well into a four tier strategic framework.

15. The advantage of a tiered approach is that it matches the needs of individuals and of populations with the specialisation of service that is required. In particular, it recognises that it is neither appropriate nor feasible that all people with ASD should only be diagnosed, assessed and provided with interventions by the most specialised of services.
16. The nature of the tiered functions would be as follows.
- **Tier 1:** Many people with ASD require direct access to first level services. In many cases, once the balance of need has been ascertained these services may prove sufficient, especially if specialised link workers augment them.
 - **Tier 2:** At times, people are likely to require more specialised but essentially local assessments and interventions from a variety of sectors and particularly so at the time of ascertainment of need and diagnosis.
 - **Tier 3:** A rather smaller number of people with ASD present really complicated problems and particularly those people who have challenging and shifting or variable comorbidities or who present difficult diagnostic and assessment problems. They require access to regional Tier 3 services.
 - **Tier 4:** A much smaller number of people may require more specialised inpatient services or, for children, access to residential schooling and this is likely to apply particularly to those people who have a classic autism syndrome and who have limited verbal communication skills. There are schools in Wales which provide this type of service and these include Ysgol Plas Brondyffryn, Denbigh, Heronsbridge, Bridgend and Ashgrove School in Penarth. It is also recognised that some people with Asperger syndrome have very high-level support needs requiring intensive specialist provision. Some people will require highly specialised health services commissioned by Health Commission Wales.
17. The Welsh Assembly Government will support commissioners in strengthening their commissioning skills (the development of commissioning skills was a key element in the 2007 social services directions paper, *Fulfilled Lives, Supportive Communities- A Strategy for Social Services in Wales over the Next Decade* and in supporting health commissioners in the delivery of *Designed for Life: A new strategy for health and social care in Wales*. Welsh Assembly Government 2005). We will consider further development of the care pathways in annexes 2 to 4 to support commissioners and service providers.

Welsh Language Services for ASD

18. Commissioners will need to establish the demand for services via the medium of Welsh in their area and identify gaps in provision and training. Services must be commissioned in compliance with the Welsh Language Act 1993 and guidance set

out in *Iaith Pawb* - the Welsh Assembly Government's action plan for a bilingual Wales (2003).

Actions Arising from Chapter 4

(Taken from the full list of actions in Chapter 1, paragraphs 8. – 12.3)

9. Commissioning services

Actions

- 9.1 **Commissioners** should ensure that Children and Young People's Plans and Local Health, Social Care and Well-being Strategies, completed in 2008, include an overview of the arrangements for commissioning of services for children, young people and adults with ASD over the lifetime of the plans, including those to be commissioned locally or otherwise.
- 9.2 **Commissioners** should identify where they will make use of their powers to pool resources (including accommodation, staff and financial resources) to commission services.
- 9.3 The **Welsh Assembly Government** will issue guidance to LEAs on the development of the regional provision of goods and services for children and young people with SEN across Wales
- 9.4 **LHBs** should have in place by the end of 2008 arrangements to commission, within the lifetime of the Children and Young People's Plan and Local Health Social Care and Well-being Strategy, regional provision of diagnostic and treatment services to bring together the appropriate specialisms (including paediatric and adult psychiatry and learning disability) and ensure equity of access across Wales to tier 3 services for those individuals who need them.
- 9.5 **Individual agency** operational plans (health, social services, education, leisure services, housing etc) should support the commissioning, development and delivery of the range of services required.
- 9.6 The **Welsh Assembly Government** will publish the final version of *Quality Standards in Education for Pupils with ASD* in 2008. The quality standards will provide schools and LEAs with guidance on minimum service requirements for pupils with ASD and ensure a consistent approach to meeting needs across Wales.
- 9.7 **Children's & Young People's Partnerships** and **Local Health, Social Care and Well-being Strategic Partnerships** should support the establishment of an ASD co-ordinating group in each local area. This group should be multi-agency, include service users and carers, and inform and support agreed cross-agency approaches to strategic planning for and commissioning of services for people with ASD. Provision for supporting the attendance of users and carers must be considered. Trying is not enough; practical help should be available. Links should also be made to voluntary sector organisations with interests in the area.

CHAPTER 5:

- A. Services for children and young people.**
- B. Transition planning and preparation for adulthood and employment**
- C. Care Assessments/Services for Adults**
- D. Family and carer support services**
- E. Generic service issues**

Introduction: This section identifies service issues for commissioners and providers across a range of universal, specialist and high street services. It summarises work already underway in Wales and areas which require further development.

A. Services for Children and Young People

Care Assessments for Children

1. A large number of children with ASD will be regarded as children in need (as defined by the Children Act 1989)

A child shall be taken to be in need if -

a. he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority ...

b. his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services; or

c. he is disabled,

And “family” in relation to such a child, includes any person who has parental responsibility for the child and any other person with whom he has been living.

Children Act 1989 s17(10)

2. As children in need, they are entitled to an assessment of their needs under the *Framework for the Assessment of Children in Need and their Families*.
3. Social Services departments have the lead role for ensuring the assessment is carried out in accordance with the assessment framework.
4. *The Framework for the Assessment of Children in Need and their Families* provides a systematic basis for collecting and analysing information to support professional judgements about how to help children and families in the best interests of the child. Practitioners should use the framework to gain an

understanding of the child's developmental needs; the capacity for parents or caregivers to respond appropriately to those needs; and the impact of wider family and environmental factors on the parents and child.

5. The process of engaging in an assessment should be viewed as being part of the range of services offered to children and families. The provision of appropriate services need not and should not wait until the end of the assessment process, but should be determined according to what is required and when to promote the welfare and safety of the child.
6. Special assessments, including those related to health and education will be carried out as part of and alongside this assessment process.
7. Where children with ASD are not considered to be children in need (as defined by the Children Act 1989), they may still be entitled to assessment and services from agencies other than social services departments.

Education Services in Schools

8. If possible, children and young people should be educated and receive services as close to their home as possible. The Education Act 1996 gives children a strengthened right to inclusive mainstream education if that is appropriate and if parents and young people want it. Likewise, if a parent requests provision for their child in special school, their views must be listened to and considered fully.
9. The SEN Code of Practice for Wales advises the adoption of a range of strategies that recognise the various complexities of need, the different responsibilities to assess and meet those needs, and the associated range of provision which will best reflect and promote common recognition of the continuum of SEN. The existing statutory assessment and statementing framework is currently the subject of a review. The consultation process will continue into 2008. Ultimately, the aim is to improve outcomes for all children and young people with additional learning needs.
10. The graduated response suggests a four-part flexible approach along a continuum to ensure the diverse needs of children and young people are met. The special education needs of the majority of children and young people can and should be met effectively at early years/school action and or early years/school action plus. The graduated response allows for movement along this continuum to reflect a child's needs and progress made.
11. Currently, there are seven residential schools in Wales that are maintained by LEAs that offer overnight accommodation for children and young people with complex difficulties related to ASD. Most of these schools are able to offer between one and four nights' accommodation per week during the school year, but not outside it. The recent regional development of Ysgol Plas Brondyfryn in Denbighshire offers day, 38 and 52 week residential placements in response to meeting a diverse range of the needs of individual pupils.

Currently, there are a number of children who require 52-week care in each year and who are placed out-of-county, often in private sector schools.

Therapies

12. This section of the plan refers to the therapy professionals regulated by the Health Professions Council and which are represented on the Welsh Therapies Advisory Committee. They include:-

- Speech and Language Therapy;
- Podiatry;
- Physiotherapy;
- Orthoptics;
- Occupational Therapy;
- Dietetics; and
- Arts Therapies (Art Therapy, Music Therapy and Drama Therapy)

There is also need for a range of evidenced-based psychological therapies with effective supervision. The role of the psychological therapies (other than the arts therapies) is covered in other sections of this plan.

13. People with a suspected or confirmed ASD present with a range of problems that can be helped significantly by timely and appropriate input from therapy services. Therapy professionals fulfil a unique range of functions in pre-diagnosis, diagnosis, assessment and management that can enhance or sustain the development of children and adults with ASD. They work with individuals and care givers from pre-school, throughout the school years and into adult life.
14. Working within multi-disciplinary and interagency teams, therapists have a key role in ensuring the development of appropriate management plans that encompass all aspects of daily living.
15. Therapists provide specialist interventions specific to ASD, generic interventions for associated problems not unique to ASD, or a combination of both. Their level of involvement is dependent on the presenting issues and symptoms. To ensure each individual's therapeutic needs are met, it is essential that they are fully assessed early in the care pathway and the appropriate specialist and generalist therapy services requirements identified and provided. Speech and language therapists, occupational therapists and dietitians should be core members of the multi-disciplinary team with early referral to the other therapy disciplines being made where appropriate to the specific needs of each individual with ASD.
16. In addition to therapeutic interventions, therapists provide training and support for parents, teachers and other professionals and should also be engaged in supervision, research, audit and service development. They could fulfil the role of and will need to contribute to the education development plans for the local ASD Champions identified in this strategic Action Plan.

17. **Speech and Language Therapy**

Specialist speech and language therapists assess and manage the communication problems and impairments that are central to ASD. They provide interventions and advise on attention skills, sensory processing and social interaction and where appropriate, feeding. Speech and language therapists ensure that multi-disciplinary teams adopt appropriate communication strategies to enable individuals with ASD to meaningfully contribute to their care plan.

- *Working Together – Speech and Language Therapy Services for Children and Young People* (Welsh Assembly Government, 2003) made numerous recommendations for improving the provision of speech and language therapy services for children in Wales, including the potential for joint commissioning of services between health and education. Joint projects between LEAs, LHBs and NHS Trusts were subsequently commissioned between 2005 and 2008 to take these recommendations forward. The outcome of evaluation of these projects needs to be taken into consideration in future planning and commissioning of speech and language therapy services.
- Further speech and language therapy information can be found in the Royal College of Speech & Language Therapists Clinical Guidelines 2005. <http://www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=125079&tabID=288&catID=1115>

18. **Podiatry**

Podiatrists assess, diagnose and treat abnormalities and functional problems of the lower limbs and feet. They assess the need for adapted footwear, orthotics or splint to palliate or correct functional problems or to reduce self-injurious behaviour in individuals with ASD.

19. **Physiotherapy**

Physiotherapists assess and develop therapeutic strategies for children and adults with ASD who present with physical problems including those associated with co-ordination, balance, locomotion and sensory disabilities. Physiotherapists working with children with developmental delay or other conditions may identify early signs of undiagnosed ASD and can refer into the multi-disciplinary team for further assessment where they will continue to contribute to the assessment and on going management.

20. **Orthoptics**

Impairments of visual and auditory perception are frequent in ASD. Orthoptists assess and develop strategies to improve visual acuity and binocular vision and can refer patients to an optometrist or consultant ophthalmologist for refraction tests.

21. **Occupational Therapy**

Specialist occupational therapists assess functional skills across the individual's home, school/work and leisure environments and offer interventions that enable individuals to develop functional skills and pre-requisite foundation skills. Sensory processing problems experienced by

many children with ASD affect their access to learning and skills development and can result in the development of inappropriate behaviours. Occupational therapists assess these difficulties within functional, development and behavioral context and help individuals and their carers to find ways to minimise their impact on learning and skills development. Occupational therapists support adults with ASD to develop and maintain life skills such as budgeting, good tenancy skills, time management, stress and anxiety management, work skills, use of community facilities, social networks and other skills needed to undertake meaningful activities.

22. Nutrition and Dietetics

Specialist dietitians assess the nutritional status of people with ASD and advise on the management of nutritional problems resulting from restrictive or obsessive eating behaviours and/or those influenced by environmental factors. For example, cognitive function and attention spans may be adversely affected by poor nutrition and can be improved by a tailored nutrition plan that ensures children are not hungry at school. Dietitians advise on weight management and access to physical activity for ASD sufferers whose obsessional eating behaviour may lead to excessive energy intake and obesity. Further nutrition and dietetic information can be found in the British Dietetic Association Professional Consensus Statement *Dietary Management of Autism Spectrum Disorder*.

http://members.bda.uk.com/professional_guidance_docs.html

23. Arts Therapies

The Arts Therapies provide an accessible and appropriate form of psychotherapy for people with ASD. They allow individuals with very limited communication skills to identify, address and resolve emotional and mental health issues that affect their quality of life and prevent them reaching their full potential. For example, deficits in early pre-school communication, including the infant/care-giver relationship, can be influenced by music therapy that is focused on the key elements of social interaction.

24. Education and Training

Training and development opportunities for all staff working with individuals with ASD should be incorporated into all aspects of service provision across health, social care, education and the voluntary sectors.

- Therapists who see people with ASD as part of their general caseload must have an understanding of the nature of autism and the principles and practice of behaviour management in order to provide appropriate assessments and advice.

25. Commissioning

The varied and pervasive nature of ASD requires a multi-disciplinary approach throughout the care pathway and over time. Therapists fulfil a unique range of functions in the multi-disciplinary team within which speech and language therapists, occupational therapists and dietitians should be included as core members. Timely access to appropriately qualified therapists from other disciplines as part of the extended multi-disciplinary team should be clearly built into service design and delivery. Health, social care and

education commissioners should work together to ensure that sufficient numbers of appropriately trained therapists are employed within the core and extended multi-disciplinary team.

The role of Chartered Psychology in the management of ASD

26. Chartered psychologists (including educational psychologists, clinical psychologists and those working in other branches of psychology) can play a key role in the identification and assessment of individuals with ASD. In its position paper on working with children and young people with ASD, the British Psychological Society gives details of the potential contribution⁹. This might include: ability to determine when assessment is needed; a knowledge of the key characteristics of children and adults with ASD; a knowledge of assessment tools and guidelines for diagnosis; and skills in establishing a comprehensive developmental and family history. The role may also include the ability to assess behaviour and its function, assess an individual's social communication style and facilitate and take account of the views of children and young people. In an educational context, the role of the chartered psychologist might also take into account assessing learning styles and strengths, identifying barriers to learning and assessing environmental conditions for learning.
27. The chartered psychologist may also continue to play a key role in the delivery of interventions after identification and diagnosis. This role will change over time and will differ according to context. Interventions can be delivered at a number of different levels and can include working with a child's family and support networks and direct work with the individual child. They will often also have a role to play in training and supervision, research and service development.

Advocacy Services for Children and Young People

28. In March 2008, the Welsh Assembly Government announced their plans to implement a **New Service Framework for the Future Provision of Advocacy** over the following two years. This will include setting up:
 - a National Independent Advocacy Board (that will include young people)
 - an Advocacy Development and Performance Unit at the Assembly;
 - a National Advocacy and Advice Service (2009/10), a 'one stop shop' with a single point of contact **for all children and young people**;
 - a local/regional integrated specialist advocacy service commissioned through the Children and Young People's Partnerships - the service model the Welsh Assembly consulted on in summer 2007.

⁹ *Autistic Spectrum Disorders: Guidance for Chartered Psychologists Working with Children and Young People*. The British Psychological Society. Position Paper (2006).

Children and young people with ASD and in need wishing to raise a concern or make a complaint about a statutory service or about other key decisions that affect their life are currently entitled to advocacy services under the Children Act 1989.

A copy of the Ministerial statement can be accessed on <http://wales.gov.uk/about/cabinet/cabinetstatements/2008/nsffuture/?lang=en>

Transitions for children and young people

29. While transition can be viewed as a developmental process, for young people with ASD it may also be a particularly challenging circumstance. There are many transitions that are made by all of us as we grow up and move through our adolescence into and through adulthood. Examples include transitions from school to work, from child-centred to adult services, and from group residential provision to individual accommodation, and so on.
- Transition, and the associated changes in life circumstances, can provoke extreme anxiety in people with ASD, and their families and carers. Existing policies outline a number of approaches authorities may adopt to seek to ensure a smooth transition between pre-school services, mainstream school and special school and post school learning and adult services. Commencing preparation for such transitions well in advance and continuity of service provision are vitally important at all stages of a transition process.
 - The Welsh Assembly Government has recently convened a multi-disciplinary Transition External Reference Group to take forward the recommendations made by the Education, Lifelong Learning and Skills Committee in their review of SEN - part three of which focussed wholly on transition and the Equal Opportunity Committee's review of services for disabled children and young people (*Why is it that disabled young people are always left until last?* Welsh Assembly Government. 2007). It is expected that a range of guidance will issue on a number of transition issues later in 2008/09.
30. The *National Service Framework for Children, Young People and Maternity Services* (Welsh Assembly Government. 2005) contains a specific chapter on transition (see annex 5). The standards in that chapter apply equally to transition arrangements for young people with ASD and in assessing their compliance with key actions using the Self-Assessment Audit Tool, local agencies should include transitions for these young people.

Primary to Secondary Education

31. Transition from primary to secondary education tends to have an educational focus. Procedures outlined in the *SEN Code of Practice for Wales* are explicit in this regard. More recently, the Welsh Assembly Government has convened

a multi disciplinary Transitional External Reference Group to take forward the recommendations made by the former Education, Lifelong Learning and Skills Committee in their review of SEN – part three of which focussed wholly on transition. It is expected that a range of guidance will follow. In addition, transition planning for pupils with ASD is included in forthcoming Welsh Assembly Government *Quality Standards for the Education of Pupils with ASD*. Transition from school to further education necessitates a partnership between schools, Careers Wales and further education and higher education institutions, employers and carers. Transition should be planned well in advance and the plans should have regard to the views of pupils and parents in leading to an assessment of individuals' needs. For pupils with ASD this may involve using a phased or gradual move to the new service or provision.

B. Transition planning and preparation for adulthood and employment

School to Further and Higher Education

32. Young people with ASDs may choose to go on to Further or Higher Education from school and there are adults with ASDs who return to further or higher education. The *SEN Code of Practice for Wales* sets out procedures relating to the process of transition from secondary school.
33. The *SEN Code of Practice for Wales* and the SEN handbook for schools although written for schools and LEAs, are valuable reference documents for other statutory and voluntary agencies, further and higher education institutions, work based training providers and individuals who work with schools to service the needs of children and young people with learning difficulties and/or disabilities.
34. Transition from school to further learning is best managed through co-operation among schools, Careers Wales, post-school education and training providers, employers and carers. This should include social services departments and local health boards where appropriate, and particularly where a placement in post-school residential specialist provision is recommended.
35. It is important that transition is planned sufficiently in advance and that all relevant information is transferred to the post-16 provider in sufficient time to allow that provider to put appropriate learning support in place. Plans should turn on an assessment of individual need and may involve a phased or gradual move to the new service. Joint planning arrangements should identify the elements of planned provision together with the agencies responsible for funding each of those elements, particularly where a placement in post-school residential specialist provision is recommended. The use of different funding criteria by different agencies can create difficulties when securing funding for a single package of educational and non-educational provision in specialist residential further education establishments; particularly when one agency agrees to fund and another does not. Opportunities for improving this situation

in the short and long term are being considered by a sub-group of the Transition External Reference Group.

36. The support needs of people with ASD attending colleges and universities are well recorded, as is the need for awareness raising for teaching, lecture support and ancillary staff in these settings (Mason et al 1996)¹⁰ In Deeside College, a support model was developed for adults with ASD by Neild (2003)¹¹ but in Higher Education institutions in Wales, funding of specific posts to support individuals with ASD has yet to be established. ASD training for university disability officers and their teams would be a very good start in terms of creating an awareness in Welsh universities of the needs of people with ASD undertaking university degrees and other courses.
37. In undertaking assessments for mainstream learning support in further education and training, and for learner financial support, such as the Disabled Student Allowance in higher education, there can often be difficulties if an individual's needs are not properly understood. People making such assessments should have an understanding of ASD and an awareness of how that affects the individual.
38. Education providers should review what support they have in place for people with ASD and consider what provision should be in place such as a specific support worker for ASD or ASD support group. The 14-19 Learning Pathways aim to ensure that all young people including those with learning difficulties receive learning provision that is flexibly tailored to meet their individual needs and aspirations. They also provide guidance for provision at the key stage 4 of the National Curriculum in supporting schools to provide courses suitable for a wide range of learners. Working with local education authority networks in Wales, the 14-19 Learning Pathways set out to provide appropriate opportunities and experiences for young people of all abilities to develop necessary core life and vocational skills. The provision of effective personal and learning coaches support and career guidance is an integral part of the 14-19 Pathways structure.

School to Training and Employment at age 16 plus

39. All young people have the option to leave school at 16 plus to engage in employment or training. If they do so, they cease to be pupils for whom an LEA is responsible. Careers Wales has a key role in ensuring that unemployed young people up to the age of 18 receive timely and effective help to secure and retain suitable placements in education, training and employment. "Youth Gateway" (established by Careers Wales in 1999) provides enhanced assessment, guidance and support to help people in their

¹⁰ Mason L., Edwards G. and Morgan H.: *Developing a support model within a further education college for adults with autism*: Chapter 7 of *Adults with Autism: A guide to Theory and Practice* by Hugh Morgan. Cambridge University Press (1996)

¹¹ Neild P.. *Students with Asperger Syndrome: Stressors within a Further Education College Environment*. Unpublished postgraduate assignment for Birmingham University. (2003).

transition to work, training, education or other opportunities appropriate to their needs and the labour market.

40. The needs of people who are moving into adulthood require careful signposting. Some young people with ASD attend mainstream secondary schools. Most of them will be given the opportunity to undergo work experience in preparation for the future as a part of their education. Suitable placements should be carefully planned and choices of work placement must be realistic. Employers should be made aware of the needs of the people with ASD who may require access to additional services and encouragement during their placements.
41. It is recognised that individuals with disabilities, particularly social and communication difficulties often find it difficult to access appropriate support and training and consequently move into employment. Given the range of difficulties and abilities across the Autistic Spectrum, there needs to be a range of opportunities to provide access to lifelong learning, vocational work and sheltered and supported employment.
42. Estimates suggest that only 11% of adults with autism are in full time employment¹². For those that are able, work brings self-esteem and independence.
43. Individuals with ASD need help and support to find work and stay in work. Job Centre Plus Disability Employment Advisers are able to provide specialist support to people who have any form of disability or work-limiting health condition, who are seeking to progress into training or employment. This includes, for example, Employment Assessment, which can help people find out how their condition might affect the type of work or training they want to do; or referral to a period of Work Preparation, which is an individually-tailored programme designed to help people return to work following a long period of illness or unemployment.
44. A significant percentage of those clients with Statements of Special Educational Needs also have ASD. Careers Wales works with partners as part of the transition planning process from the age of 14 – as set out in the *SEN Code of Practice for Wales*. Careers Wales draws together relevant professional information and assessments to produce a Learning and Skills Plan which sets out the post 16 educational needs of the client and the provision required to meet them. It also leads to the submission of recommendations for specialist further education provision to the Welsh Assembly Government.
45. Information for employers providing work experience and employment for individuals with ASD is currently being tested and will be included on the updated version of the Careers Wales website due to be launched in September 2008.

¹² Withers, L.. Moving on Up?; London, The National Autistic Society (2006)

C. CARE ASSESSMENTS/SERVICES FOR ADULTS

46. Services for adults, including those with Asperger's Syndrome and high functioning autism, are patchy across Wales with a large part of existing services being provided within the voluntary and private sectors. Many adults may not be accessing the care assessment system or their care assessments may not identify any specific needs arising from their autistic spectrum disorders. Authorities need to ensure that their care assessment and management staff receive appropriate training to have a good understanding of ASD and the impact that this can have on people's lives. Such training on understanding ASD should also encompass commissioners and providers of services and other service areas including housing.
47. Effective local co-ordination of information about clients with ASD already known to services will be required as adults with ASD may be found in a variety of service areas including substance misuse; mental health; learning disability; older people and housing.

The Unified Assessment Process

48. For social services and health, assessments will be undertaken using the Unified Assessment Process (UAP). The UAP puts the individual at the centre of the whole process. The purpose of assessment is to describe and evaluate an individual's presented needs and how they constrain or support his/her capacity to live a full and independent life. The impact of a person's needs on his or her independence, daily functioning and quality of life is evaluated, so that appropriate action can be planned. Assessment involves both the person with needs and professionals thinking through different explanations for how needs have arisen, and how different needs interact with each other.
49. Assessment should be carried out in such a way, and be sufficiently transparent, for individuals to:
 - gain a better understanding of their situation
 - identify the options that are available for managing their own lives
 - identify the outcomes required from any help that is provided
 - understand the basis on which decisions are reached
50. One of the key principles underpinning the UAP is that assessment should always be person centred. This means ensuring that the person's views and wishes shape the assessment process. Using methods which help individuals prepare for their contribution to the assessment and having the right information, support and advocacy arrangements (where necessary) available will facilitate this. Authorities will need to review their arrangements for providing access to advocacy services to ensure that they are appropriate.
51. A person centered assessment starts from the individual's perspective of their situation. The assessment should be based on an appreciation of their particular needs and the impact on their independence. Together, the

individual and professional should look at the strengths and abilities that the individual can bring to bear on meeting needs.

52. An evaluation of assessed needs should take full account of the likely progress of people's conditions and health status, their potential to become more independent, given the right help or the likely outcomes if help were not to be provided or was provided in different ways. In thinking through how needs and risks might change over time, professionals should focus on the impact of needs on people's independence both in the immediate and longer term. They should think of the risks involved to the person, their family and others close to them, and which risks cause serious concern and which may be acceptable. Central to an individual's independence is his/her:
- autonomy and freedom to make choices;
 - health and safety, including freedom from harm, abuse and neglect, and taking wider issues of housing and community safety into account;
 - the ability to manage personal and other daily routines; and
 - involvement in family and wider community life, including leisure, hobbies, unpaid and paid work, learning and volunteering.
53. Any assessment of a person's needs should explore the support and treatment/care they are already receiving. Where support from carers is identified, professionals should ascertain the nature of that support, the strength of the caring relationship, and whether the carer requires support and services, either to help them to continue to care for the person or in their own right. Even where carers and others are providing support to an individual, the nature of the individual's needs, and the level of care could be such as to make the individual eligible for community care services.
54. Annex 11 to the UAP guidance contains *Practice Guidance for Person Centred Assessments within the Statutory Assessment Process* which authorities should follow.
55. For adults with a co-existing learning disability, the assessment process must also take full account of the 2004 WAG Section 7 Guidance on Service Principles and Service Responses.
56. The WAG guidance on Fair Access to Care Services also applies to local authorities when carrying out their Community Care duties in respect of all adult groups including adults with ASD.

Physical and mental health needs

57. Local NHS Trusts and LAs need to ensure that the physical and mental health needs of people with ASD are considered within the UAP. Unless these needs are identified and addressed, people may end up receiving often-expensive crisis interventions.

Health checks for adults with a learning disability

58. Adults with ASD who also have a co-existing learning disability and who are on a local authority Learning Disability Register are able to benefit from a health check with their GP. The Welsh Assembly Government has introduced this new service in 2006-07 as a directed local enhanced service (DES) through local health boards.
59. A DES is an enhanced service provided by primary care to meet identified, evidenced gaps in provision, and aims to meet those gaps, and assist local partnerships to use enhanced services to deliver better healthcare to patients. Measurable benefits will include: development of local GP practice registers, a systematic recall approach for patients for further appointments, provision for health checks, improved involvement of carers, support workers and family, and a whole system approach of care with local support services. Reviews will be undertaken to measure the impact of the new directed enhanced services.
60. Adults with ASD who are not on the local authority Learning Disability Registers will not be eligible for this new service. However, it is considered to be good practice that people with ASDs and any co-occurring problem or co-morbid disorder should be offered access to periodic health checks, and this should be taken account of during the assessment process

Training and employment for adults

61. People with ASD should have equal access to the full range of government-funded programmes including education and life-long learning services and other training opportunities. The principle is that all people with ASD should be able to use services that are likely to assist them in their personal development, or provide career opportunities or secure their employment and which should be based on an understanding of their learning patterns.
62. If adults do not achieve the criteria for entry to training or educational services, they may be better served by place and train approaches to gaining paid employment (i.e. supported employment). Effective links should be developed through co-operation among local employers, supported employment services, social services and mainstream Wales employment services. The need for raising awareness of the needs of people with ASDs by Careers Wales, Job Centres, employment training agencies and employers in Wales is paramount. Opportunities provided by placements made by the voluntary sector should be provided as positive in their own right, not just as simpler alternatives to supporting people in paid work. Each person should be linked to a mainstream volunteering scheme, if possible. Many people with ASD are unable to access mainstream training and employment services without support and for those who do go into mainstream employment their long-term success in work will often depend upon the consistency of understanding held by those who work with and employ them. Specialist employment training programmes can assist in this respect by providing suitable training, preparation, support and co-operation with employers,

careers officers and mainstream training providers (Matthews, (1996)¹³). Models of specialist employment preparation agencies which can be drawn upon from outside Wales include ASPIRE (Autism West Midlands) and for those adults with Asperger syndrome, PROSPECTS (NAS). There is a need for all employment training agencies in Wales to understand the needs of adults with ASD seeking to enter the employment market.

Accommodation

63. One of the major life changes in adulthood can be for individuals in moving from residential provision or from their family homes into their own accommodation. The Welsh Assembly Government's funding initiative 'Supporting People' for accommodation for vulnerable people was devised for this purpose. Local Authorities each have a Supporting People Organisational Plan and the Supporting People Planning Group is the strategic link in this area of need. Transition planning arrangements of this kind for adults should be commenced at an early enough stage in advance to ensure that services and each person and their family are properly prepared for the transition. Effective joint working arrangements between the various agencies are crucial to achieving a smooth and seamless change for people as they move between services. Agencies must ensure that they have appropriate information sharing arrangements in place and clear understandings of what are the transition arrangements and the funding arrangements that apply. Agencies must agree which is the lead co-ordinating agency and identify an individual to act as a 'single gateway' for communication with the individual and their families. Our earlier policies on link or key workers and lead agencies also relate to this important matter.
64. In identifying possible accommodation options, local authorities should ensure that pre-placement assessments are undertaken to take into account the suitability of the proposed living environment, including sensory audits. For those individuals with more complex needs, very specialist provision may be required but opportunities for these individuals to live as independently as possible through supported living programmes should be available.
65. Shared accommodation or residential care for adults with ASD exists in Wales and there are several current providers within the public, voluntary and private sectors providing these services, including the Pembrokeshire and Derwen NHS Trust; National Autistic Society; Opportunities Housing Trust; Autism Initiatives, and Beechwood College. In addition to the monitoring of standards within these services by CSSIW (Care and Social Services Inspectorate Wales) and individual sponsoring local authorities, external quality assurance

¹³ Matthews A.; *Employment training and the development of a support model within employment for adults with Asperger syndrome and autism: The Gloucestershire Group Homes Model*; Chapter 8 of *Adults with Autism: A guide to Theory and Practice* by Hugh Morgan. Cambridge University Press (1996)

schemes include the Autism Quality Network, BILD, (see Beyer, (2003)¹⁴) and the National Autistic Society Accreditation Scheme.

Direct payments

66. Young people and adults with ASD form part of the potentially eligible groups for receiving a Direct Payment and the statutory requirement placed on local authorities to offer a Direct Payment to all eligible individuals must be followed. Direct Payments are being used quite successfully by some adults with ASD to pay for services that they have been assessed as needing by their social worker. Direct Payments are not classed as income and do not affect entitlement to benefits. Instead of arranging a service for the person with ASD, a social services department will give them a regular cash payment (ie a Direct Payment) permitting them to arrange and pay for their own care.

Workforce training

67. Workforce training is essential in order to heighten the capacity of services in Wales to understand, respond and to enable adults with ASD to achieve wellbeing. Those arranging services and co-ordinating support need to have a strong understanding of ASD and the impact it has on an individual. This will require commissioning of workers with specialist training.

Meaningful Activities and Social Support

68. Access to local social skills and practical life skills training programmes for adults with autistic spectrum disorders must also be considered by authorities as part of the services and support arrangements to respond to assessed needs. Social skills programmes for adults with autistic spectrum disorders are imperative and the value of social support groups for adults with Asperger syndrome was effectively demonstrated by Macleod (1999)¹⁵. In Wales, the National Autistic Society operates social skills groups in Wrexham, Cardiff and Caerleon. Authorities should also consider whether individuals could benefit from access to local ASD peer or other social groups both in terms of improvements in confidence of individuals in social interaction and in helping address the possible social isolation of some individuals. Experience suggests that, all-too-often, breakdowns of placements or attendance at day facilities and education and occupation programmes are more attributable to the circumstances surrounding a person's social understanding and social skills rather than their failure to succeed in the daytime activity that is provided.

¹⁴ Beyer, S: *The Autism Quality Network : an evaluation of a quality improvement initiative for people with autism*. GAP Journal, 4 (1), pp 35-42. BILD publications (2003).

¹⁵ Macleod A.: *The Birmingham community support system for adults with Asperger syndrome*. Autism Vol 3, Number 2. Sage Publications ; London (1999)

69. The Welsh Assembly Government, will commission research into the needs of older people with ASDs recognising that this has not yet been undertaken in the UK.

D. Family and carer support services

70. Thus far, this plan has focused particularly on the needs of people who have ASD. In this section, we consider the needs of families and carers, including siblings.
71. Families and carers often undertake multiple roles. People with ASD and their families and carers need to have access to up-to-date information relevant to their personal circumstances at all key points of the life of the person they care for. Also, as we have shown in the earlier parts of this Strategic Action Plan, ASDs have impacts on the people who have them, but also impose burdens of a wide nature on their families and carers. Access to an appropriate range of advocacy services is also important for many people with ASD and, separately, for their families.
72. The Welsh Assembly Government recognises that families and carers play an extremely important role in caring, advocating for and generally supporting people with ASD. Also, they make important contributions to the *Framework for the Assessment of Children in Need and their Families*, the SEN assessment framework and the Unified Assessment Process.
73. Carers are entitled to an assessment of their needs in their own right and the Welsh Assembly Government has already issued guidance to authorities on integrating carers' assessments into the children's assessment framework and Unified Assessment Process. In April 2005, the Welsh Assembly Government also commenced use of the powers of the Carers (Equal Opportunities) Act 2004 that places a duty on social services authorities to inform carers of their right to a carers' assessment and also requires authorities, when undertaking assessments, to consider whether the carer works or wishes to work or is undertaking, or wishes to undertake, education, training or any leisure activity.
74. Families of children and young people with ASD living in Wales currently have access, if they so wish, to a wide range of parents' groups and local and national voluntary organisations, including the Public Autism Resource and Information Service (PARIS), an online service developed by the National Autistic Society, and www.awares.org, a bilingual online information source for autism in Wales. The Welsh Assembly Government is currently working to develop additional information for parents, carers and professionals through the provision of Early Support Materials. There are also examples of unsung parent support groups delivering very valuable mutual support services to parents. Parents and carers may receive information about these services in a variety of ways ranging from word of mouth, from voluntary sector organisations to local authority handbooks and websites. There are, however, many examples of parents and people with ASD themselves, who feel

isolated and who are not aware of potential opportunities for discussion, and, in some cases, guidance and support. A locally based ASD co-ordinator as demonstrated by practice in Ceredigion can play a key role in conveying the sources to which parents can refer to gain the best evidence about the efficacy of different methodologies and strategies. In the voluntary sector, charities such as the Welsh Council for Voluntary Agencies, Autism Cymru, the Anglesey and Gwynedd Asperger and Autism Support Group, The Gwent Autistic Society, the National Autistic Society, and the Welsh Autism Communication Centre are examples of good starting points for identifying local support.

75. The availability of objective information concerning ASD in Wales is critically important if those living or working with ASD are to make judgements about accessing or providing appropriate support services for children and adults. Balanced knowledge can also be the access point to exercising rights. Currently, enormous stress can be placed upon families simply fighting to find out what services may or, equally important, may not be appropriate to their son's or daughter's needs.
76. Many of the voluntary groups (including those listed above) have information packs, booklets and leaflets covering various aspects of autistic spectrum disorders. Web-based resources on ASD are also a very valuable source of information, not least the bilingual *All-Wales Autism Resource* (www.awares.org) developed and managed by Autism Cymru and the UK-wide *Public Autism Resource and Information Service* (PARIS), developed and managed by the National Autistic Society.
77. When assessing children with ASD and developing a plan with each person's family, the needs of any siblings must also be explicit. Great care should be taken to provide age-appropriate information and, if required, access to local peer groups and other services because some research has shown that the burden on siblings may be enormous. Attfield and Morgan (2006)¹⁶, describe the needs of siblings and parents in Wales and the West Midlands in *Living with Autistic Spectrum Disorder*. The bilingual booklet *My Brother Gwern* by Dr Elin Walker-Jones, (2005)¹⁷ which has been published by Autism Cymru in association with the Welsh Language Board, is aimed at siblings of children with ASD.
78. There is abundant evidence that families provide the mainstay of day-to-day care for their relatives who have ASD. They should receive effective and appropriate services and support that are flexible and responsive to the breadth and depth of their needs and circumstances. The need for occasional or recurrent short break care arrangements should be considered as part of the assessment process in order to support families in fulfilling their roles in caring.

¹⁶ Attfield, E. and Morgan H. *Living with Autistic Spectrum Disorders*. London. Sage Publications (2006)

¹⁷ Walker-Jones E.. *My Brother Gwern*, Autism Cymru/Welsh language Board (2005).

79. Some authorities provide care in short breaks in the form of family based short term care schemes. They ensure that the same people on a regular basis care for each child or young person with ASD. This is particularly important for children and young people with ASD who are unhappy with changes in their circumstances. Some authorities provide respite/short break care on an hourly basis using support workers.
80. All-too-often family members face high levels of day-to-day stress, especially if they all live in the same home. Lowering stress levels in families is important for the wellbeing of the whole family. Therefore, some family members may ask for access to well informed, but empathic people. Sometimes, this requires access to professionals but, often, the voluntary sector has a pivotal role to play. Self-help groups composed of families in similar situations are also highly important sources of information, support and access to services. The Sage Publication series – *The Autism Support Kit* by Bowen and Plimley (2006/7) (see the bibliography in annex 6 for further details) – which is based upon practice largely in Wales but published for an international audience, asks searching questions of both practitioners and parents and demonstrates the great value of co-operation between the two.
81. In the majority of cases, family members provide a major therapeutic input for the people in their care. Between clinic appointments, attendance at day centres and schools etc, they provide continuity in delivering a variety of intervention programmes at home and in the community. They are also very heavily involved in assisting some people to acquire and develop self-help skills in daily living. Therefore, family members may require training in order to acquire the skills to be able to contribute effectively to a range of activities including, for example, social communication training, administering medication and/or behaviour management. This guidance for families must be available on a continuing basis if it is to respond to the changing needs of people according to their ages and circumstances.
82. Projects exist under the Supporting People scheme in which support can be given to people to develop life and daily living skills on a peripatetic basis. This is available, for example, to young people who are making the transition from education services and from living in their families' homes to employment and homes of their own. This can help to allay the fears of families and carers.

E. Generic service issues

Challenging Behaviour

For the purpose of this strategic action plan, the Welsh Assembly Government has adopted the following definition, as used in the *Statement on Policy and Practice for Adults with a Learning Disability* (Welsh Assembly Government/Learning Disability Implementation Advisory Group, March 2007)

- 9.2 *The term “challenging behaviour” was developed in order to emphasise the interaction between an individual’s behaviour and their social and environmental context, biological state, behavioural repertoire and learning history. The nature of the challenge being emphasised is that of understanding the basis or cause of a person’s behaviour so that action can be taken to help the person behave differently*
- 9.3 *The use of the term “challenging behaviour” is not a diagnostic label, as if the behaviour were solely a property of the person. Challenging behaviour is not intrinsic to the individual; it is a description of an interaction in time and place. Behaviour can vary considerably in different settings and at different times.*
- 9.4 *Behaviours which are defined as challenging are typically those which are perceived as problematic by others. These include aggression to others, destructiveness, self-injury and unacceptable behaviours. However, the extent to which behaviours are seen as problematic is not a constant. Behaviours seen as challenging by some people under some circumstances may not be seen in the same light by others under other circumstances. Training on how to respond well to challenging behaviour when it occurs can give staff, carers and others the confidence to deal with it. Authorities should consider whether a collaborative joint training approach encompassing health and social care staff and family members/carers would be beneficial to avoid inconsistencies of practice.*

83. Within the field of ASD, there have been many approaches to responding to the occasionally, very challenging behaviour and, sometimes, complex needs of people with ASD. Patterns of behaviour shown by people who have ASD can, all-too-easily, be misunderstood. The first step in approaching this is to enable practitioners and services to better understand the perception that people with ASD have of the world around them (see Chapter 2). When working with children with autism, the increased understanding of ASD has led to various approaches being developed to attempt to address problems associated with behaviours that relate to the three broad behaviour patterns of ASDs and any associated challenging behaviour. Several of these interventions are based on structure, some on communication, while others focus on intensive behavioural input. Some approaches are highly child-centred. The success of any intervention depends on the particular needs of each person with ASD, as well as the relevant training and experience of the professional and other external factors.

84. There are several methodologies employed within Wales that seek to give practitioners the skills to manage challenging behaviour safely and effectively, albeit that they have not been developed specifically for people with ASD in mind. Many use behavioural theories as their basis. While the Welsh Assembly Government cannot endorse or recommend any particular intervention, a generic framework was published by the Welsh Assembly Government in 2004 (*A Framework for Restrictive Physical Intervention Policy and Practice*, 2004). The British Institute for Learning Disabilities (BILD) guidelines on physical interventions with people with intellectual disabilities (Harris et al (1999))¹⁸ has also made an important contribution within the learning disabilities and ASD fields.
85. The task of managing challenging behaviours carries with it strong ethical, legal, practical and financial implications. Gaining an appreciation of the thinking and learning patterns of people who have ASD is a good starting point.
86. Alternative intervention methodologies were considered by the working groups that contributed to developing the components of this strategic action plan for 0-19 year olds and were derived from an audit undertaken with LEAs, social services and trusts. Both parents and practitioners contributed to this work. Their endeavours were complemented by the survey conducted by the Welsh Assembly Government of practice in LEAs, social services departments and NHS trusts / LHBs, which asked specific questions on the alternative interventions that are employed locally. This evidence must be set against a wider context in the field of ASD and the work concluded that there is little empirical evidence to support the efficacy of any one methodology over another (Jordan, Jones and Murray DfES, (1998))¹⁹

Involvement in legal processes

87. People with ASD are more likely to be misunderstood when giving evidence as a witness or as a defendant. The UK Government's guidance on *Achieving Best Evidence: Guidance for Vulnerable or Intimidated Witnesses including Children* was issued in response to the report *Speaking up for Justice*²⁰. It describes good practice in interviewing vulnerable and intimidated witnesses, adults and children, in order to enable them to give their best evidence in criminal proceedings.
 - Raising the awareness of professionals who work within the Youth and Criminal Justice system is vital to ensuring equitable treatment and in

¹⁸ Harris J., Cornick M., Jefferson A., Mills R. and Paley S.. *Physical Interventions: A Policy Framework*. British Institute for Learning Disabilities (1999).

¹⁹ Jordan R., Jones G. and Murray D.. *Educational Interventions for Children with Autism: A Literature Review of Recent and Current Research*. HMSO. (1998)

²⁰ Home Office: Criminal Justice, Performance, Justice, Victims and Witnesses Unit. *Speaking up for Justice*. Home Office Circular 58/03 (December 2003)

Wales strides are already made in this area. However, it should also be mentioned that important research into the Criminal Justice System in South Wales by Bro-Morgannwg NHS Healthcare Trust in association with Autism Cymru has demonstrated that adults with ASDs are less likely than those in the general population to commit very serious crime (Allen, (2006))²¹.

- It has also been suggested that health and relationships education for young people with ASD would help them understand what is and what is not appropriate. This may prevent abuse and involvement in the criminal justice system.

88. The Royal College of Psychiatrists recommends that:

“For those individuals with autistic-spectrum disorders who become involved in legal processes, there should be routine access to psychiatric services that can:

- a. distinguish autistic-spectrum disorders from other psychiatric disorders and, in particular, from the personality disorders as well as other neuropsychiatric disorders and learning disability*
- b. recognise the potential impact of these disorders on responsibility, mental capacity, fitness to plead and the ability to bear witness*
- c. encourage awareness of, and provision for, autistic-spectrum disorders in court processes and in subsequent care*
- d. develop appropriate interventions and therapies within secure and forensic settings.”*

(Royal College of Psychiatrists, *Psychiatric services for adolescents and adults with Asperger syndrome and other autistic-spectrum disorders*. Council Report CR136, October 2005)

Protection of vulnerable children and adults

89. Individuals with ASD are potentially vulnerable. Protection of vulnerable people, be they children, young people, adults or older people is paramount. It is important to consider training, including protection for vulnerable adults, when delivering services.
90. The safeguards that are already in place in relation to child protection guidance and the support documentation should be strictly adhered to. *Safeguarding Children: Working Together under the Children Act 2004*. (Welsh Assembly Government. September 2006) gives guidance on how all

²¹ Allen D.. *Asperger Syndrome and Offending Behaviours*. Paper to 2nd Wales International Autism Conference, 8-10 May 2006. Cardiff

agencies and professionals should work together to safeguard and promote children's welfare and protect them from harm.

91. Safeguarding of children and young people is particularly important when considering placements. Further guidance is given in *Towards a Stable Life and Brighter Future: Guidance and Regulations on measures to strengthen arrangements for the: i) placement, health education and well-being of looked after children and young people; and ii) Responsible Commissioner for secondary health care for vulnerable children placed away from home.* (Welsh Assembly Government. June 2007)
92. For many adults with Asperger syndrome whose social isolation leads to a high risk of vulnerability and significant health difficulties, their needs are often not identified in any co-ordinated way. Indeed it is apparent that often no service will accept responsibility for planning and delivering enabling support mechanisms. The need for local strategic direction, co-ordination and the commissioning of services informed by a good knowledge of ASD is essential. Guidance on safeguarding vulnerable adults is given in *In Safe Hands: Implementing Adult Protection Procedures in Wales* (National Assembly for Wales. July 2000).

Oral Health and ASD

93. Although people with ASD do not have any specific oral health problems that relate to their condition, they do have a tendency towards poorer oral hygiene due to sensory problems that can result in tooth decay and gum disease. Untreated decay can lead to abscesses, pain and extraction. Choice of diet and medication also affect oral hygiene. Some medication given to people with ASD can lead to a condition known as dry mouth. Dry mouth can result in increased tooth decay, gum disease and oral infections. Systemic and topical fluoride, professionally applied fluorides, fissure sealants, saliva substitutes, chemical plaque control and more importantly support and assistance can overcome some of these difficulties. Trauma to teeth may also be caused as a result of self-harming behaviour.
94. Dental treatment is an invasive treatment that many people with ASD find particularly distressing. Any dentist who treats a person who has ASD should be aware of the full range of their possible problems and experiences. Guidance on approaches to visiting the dentists and treatment regimes was presented in a workshop to the Wales International Autism Conference, Cardiff City Hall, in May 2004, and is available for downloading on the *All-Wales Autism Resource* (www.awares.org).

High Street Services

95. People with ASD, as all others, require access to a wide range of community-based facilities and services that are provided from premises that are situated along the high streets of Wales. Yet many of these services are not orientated

to be able to respond well to the needs of people with ASD. They include, for example, dentists, opticians and optometrists, and pharmacists. Awareness raising is essential in order to create a more tolerant, supportive and flexible response within our communities; high street services are very good places at which to start this process in Wales.

Leisure services

96. There is great value, especially in the development of social and communicative skills, in the creation of leisure and social clubs by ASD support groups and by schools. People with ASD should be enabled to access and successfully participate in a range of leisure activities from specialist clubs to mainstream interest groups, dependent on individual needs and interests.

Services for individuals from Black and Ethnic Minorities

97. A focus group working on the 0-19 part of the strategic Action Plan looked specifically at this issue and in addition a literature search including those ASD sites operated from Bangladesh, India, Pakistan and the Caribbean, was undertaken to try to identify what models of practice existed both in and outside of Wales. Services for advocacy, training, information and working with communities and parents within their own language are very poor in Wales. Consequently a range of support services for families with ASD from different cultural backgrounds do not currently exist within Wales.
98. In working with ethnic minority families a number of issues need consideration, including language barriers, attitudes towards disability, religion and family relationships. Language issues and not knowing about the services that are available can compound feelings of isolation. There is very little written about the prevalence, incidence, impact and help mechanisms available to people within the ethnic minority populations in Wales and there is a need to prioritise research and data collection in this area to inform Welsh practice.
99. Co-operation across agencies involved with ASD and charitable and statutory organisations relating to ethnic minorities needs to be established. The concept of attending a local parents' group may be alienating to some ethnic minority parents, as would the notion of leaving the home in the evening to go to such a meeting. Culturally significant approaches need to be creatively developed in order to engage far more effectively with ethnic minority families.
100. There is a need to recruit and train more professionals from ethnic minorities to work directly with people with ASD. It is recommended that a series of factual leaflets be published, giving a thorough explanation about autistic spectrum disorders and its possible manifestations. These should include relevant quotations from people with ASD and their families. Useful addresses

of helpful organisations need to be given and these leaflets should be published in a range of languages.

Actions Arising from Chapter 5

(Taken from the full list of actions in Chapter 1, paragraphs 8. – 12.3)

10. Transitional arrangements

- 10.1 **Commissioners and service providers** should ensure there are clear arrangements for transition between services for children and young people and adult services, in line with the actions set out in the *National Service Framework for Children, Young people and Maternity Services*.
- 10.2 The **Welsh Assembly Government** will produce guidance for schools and LEAs on transitional planning, which will refer to a multi-agency approach as part of the SEN handbook for schools (*Handbook of Good Practice for Children with Special Educational Needs*. Welsh Assembly Government. April 2003). This will include arrangements for transition from school to college at age 16.
- 10.3 The **Welsh Assembly Government** will consider how the arrangements for transitional planning for disabled young people, including those with learning disabilities, might be strengthened to support the actions set out in the *National Service Framework for Children, Young People and Maternity Services*.
- 10.4 The **Welsh Assembly Government** has already secured £1.5m of funding (£500k per year for three years commencing 2008/09) for a number of additional key transition workers to provide support to children and young people (and their parents and carers) with SEN (including those with ASD) as they move through school and on to further education or the workplace. Further guidance is required and this will be produced by a sub group of the External Transition Reference Group which was set up in January 2008 as a result of the former ELLS Committee's review of transition.

11. Services for Adults

- 11.1 The Welsh Assembly Government will, during 2008, establish a Task and Finish Group who will identify specific issues that adults face and take forward work to tackle them, and investigate, evaluate and report on the evidence for effective interventions and models of services for adults.

Annex 1

How this Action Plan fits with existing policies, strategies, guidance and tools for delivery

Assembly Government policies are founded on equality legislation. Policies for children and young people, people with learning disabilities and older people adopt the following rights and principles:

- a. In 2002, the Welsh Assembly Government adopted the social model of disability as the foundation for its work on disability. This aims to encourage society to consider the concept of disability in a different way. The basis of this model is that it is not about the person's impairment but how society reacts to it. Disabled people have the right to access the same services, information and resources as non-disabled people.
- b. For children and young people, the Assembly Government set out its approach in *Rights to Action* (2004). This is based on seven aims for children, derived from the articles in the *United Nations Convention on the Rights of the Child*. The Children's Commissioner for Wales has responsibility to protect children's rights as set out in the UN Convention.
- c. For people with learning disabilities, many of whom will require life long services, the Welsh Assembly Government has issued a *Statement on Policy and Practice for Adults with a Learning Disability* (2007). This supports 4 key principles affirming that people with a learning disability are full citizens with the same rights as and equal in status and value to other citizens of the same age.
- d. For older people, the *Strategy for Older People in Wales* (Welsh Assembly Government 2003) takes its key values from *The United Nations Principles for Older People* of independence, participation, care, self-fulfilment and dignity. A commissioner for older people has been appointed to speak up on behalf of older people in Wales, helping to raise their profile and increase awareness of their needs
- e. The Government of Wales Act 2006 confirms our commitment to existing equality legislation and requires the Assembly to "*make appropriate arrangements with a view to securing that its functions are exercised with due regard to the principle that there should be equality of opportunity for all people*".

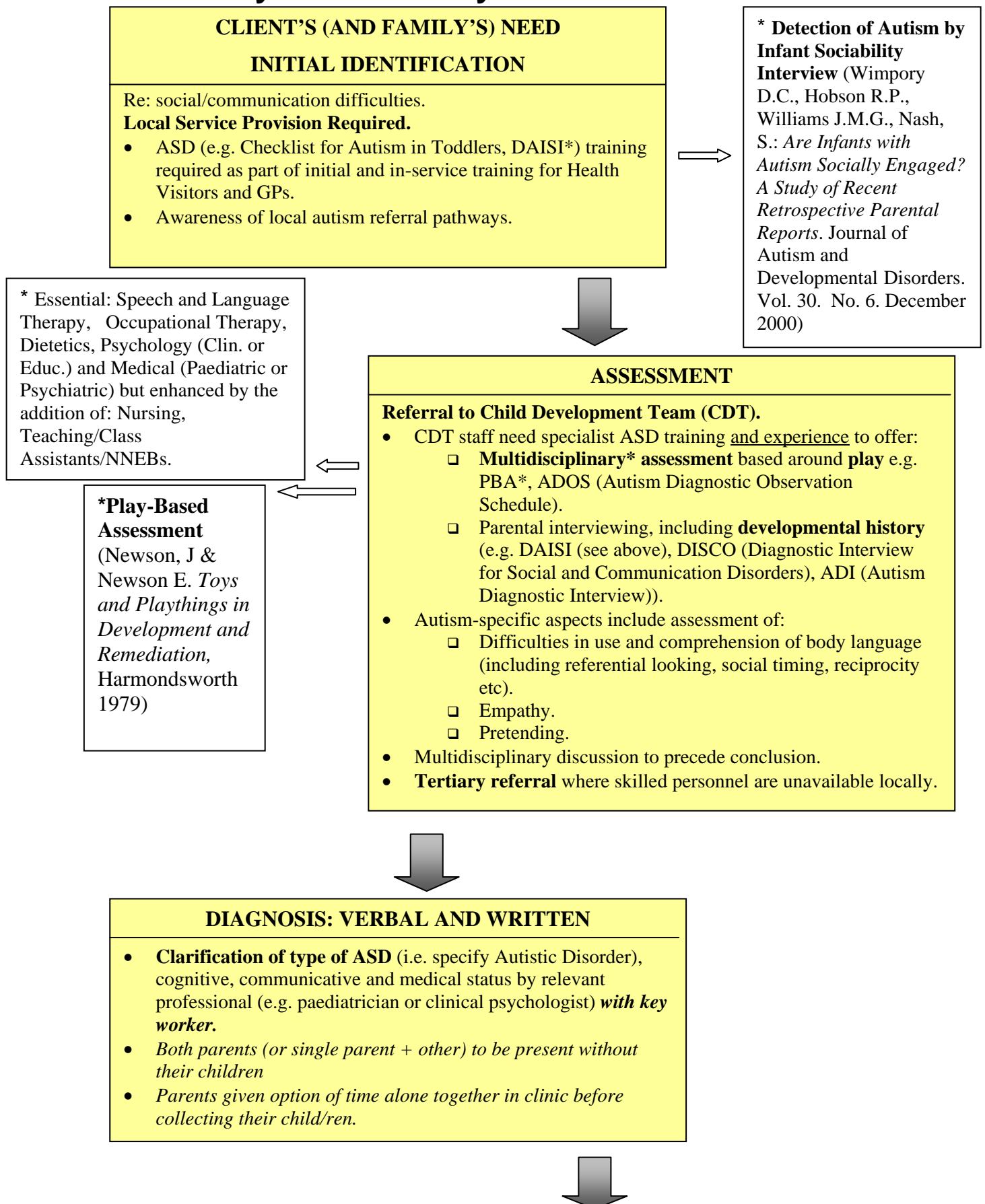
This Strategic Action Plan sets a clear policy direction. Its purpose is to ensure that people with ASD benefit from the wide range of existing policies, strategies, guidance and tools for delivery. It therefore builds on the work of the following Welsh Assembly Government policies and a range of strategies, programmes, guidance and tools:

- Children and Young People's Partnership Plans
- *Designed for life*

- *Designed to Work*
- *Fulfilled Lives, Supportive Communities*
- *Health and Social Care for Adults: Creating a Unified and Fair System for Assessing and Managing Care*
- *Iaith Pawb – A National Action Plan for a Bilingual Wales*
- *Inclusion and Pupil Support Guidance*
- *Local Development Plans and the Local Development Plan Manual*
- *Making the Connections - Delivering Beyond Boundaries: Transforming Public Services in Wales*
- *Making the Connections – Partnerships for Delivery*
- *NHS Commissioning Guidance. WHC (2007) 23*
- *One Wales: A progressive Agenda for the Government of Wales*
- *Planning guidance on Local Health, Social Care and Well Being Strategies*
- *Revised Community Strategy Guidance*
- *Safeguarding Children, Working Together Under the Children Act 2004*
- *the 2004 Section 7 guidance on Service Principles and Service Responses for Adults and Older People with Learning Disabilities*
- *the 2007 Section 7 Statement on Policy and Practice for Adults with a Learning Disability*
- *The CAMHS Strategy, Everybody's Business*
- *the Children First programme*
- *the Framework for the Assessment of Children in Need and their Families*
- *the Handbook of Good Practice for Children with Special Educational Needs.*
- *the National Service Framework for Adult Mental Health Services*
- *the National Service Framework for Children, Young People and Maternity Services*
- *the National Service Framework for Older People*
- *the practice guidance on Person-Centred Assessments*
- *the Special Educational Needs (SEN) Code of Practice for Wales*
- *the Unified Assessment Process*

Much of the evidence-based information gathered from the consultation processes on these and during their implementation provides the evidence base for the Strategic Action Plan. There is also a much wider range of other related policy documents and guidance that are relevant to people with ASD, some of these can be found in Annex 6.

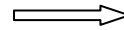
Annex 2: Classic Autism with Learning Disability Care Pathway



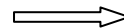


IMMEDIATE POST-DIAGNOSTIC SUPPORT

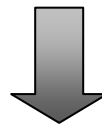
- **Key Worker** duties begin e.g. home visit with notes s/he made at time of diagnosis (re. clarification).
- Parents informed of charity support groups.*
- **Diagnostic report(s)** to include *parental perspective as well as* clarify type of ASD (i.e. **specify Autistic Disorder**), cognitive, communicative and medical status.
- *In respectful lay-language, report should explain the developmental history to date, thereby making sense of the child for the parents.*
- **Parental consent sought** re. contents and recipients.
- Where multiple, reports should be coherently linked.
- **Post-diagnostic counselling sessions** (e.g. <6) offered by Clin. Psych or trained other (e.g. ECS*). This is cost-effective in enabling full parental contribution to subsequent demanding interventions. It identifies other issues which may also need addressing (e.g. mental health referral) and establishes a culture of ongoing support for autism and wider issues.



* Autism Cymru, National Autistic Society or local support group



* e.g. Early Counselling Service, Gwynedd.



* Musical Interaction

Therapy

(Chandler, S. Christie, P. Newson, E. Prevezer, W.: *Developing a Diagnostic and Intervention Package for 2 to 3-Year-Olds with Autism*. Autism, Vol. 6, No. 1, 47-69 (2002). Wimpory, D., Chadwick, P. and Nash, S.. *Musical Interaction Therapy for Children with Autism: An Evaluative Case Study with Two Year Follow Up*. Journal of Autism and Developmental Disorders Volume 25, number 5, October 1995)



EARLY INTERVENTION

- **Pre-school period is crucial** for development; parental involvement essential. *Facilitated by support in multiple settings (e.g. home-based).*
- **Initial focus** on the primary impairment(s) of **sociability/communication** – **should continue** throughout the child's long term education/therapy.
- Support for communication initially facilitates preverbal communication (re. social timing, reciprocity, body language) even in verbal children – as this underpins other symptomatology (empathy, obsessionality etc) e.g. MIT*
- Initial and ongoing **behaviour management** is also often essential (e.g. *Early Bird, Nottingham's Early Communication & Behaviour Package*).
- Referral to other healthcare workers as appropriate



STATEMENT OF SPECIAL EDUCATION NEEDS

Statement should recommend:

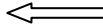
- **ASD-trained staff: child ratio enhanced** beyond that of other children at the same intellectual level.
- **Implementation of strategies re. social communication.**
- If necessary **behaviour management.**



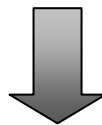


EDUCATIONAL PLACEMENTS: NURSERY, PRIMARY & SECONDARY

- **Pre-school placement** should have **enhanced ASD-trained staff: child ratio** (e.g. 2 or 1:1) to enable sufficient 1:1 work to address **priority needs in communication**.
- If placement is non-specialist then it should be enhanced by appropriately trained staff.
- NHS and Education staff should **integrate services** and reciprocally offer **autism-specific training**.*
- **Additional support for communication** should be available, e.g. *teaching pointing, PECS (Picture Exchange Communication System), ASD-specific Hanen and general Speech and Language Therapy-supported training for parents and staff*.
- General (**e.g. cognitive**) **teaching** should be sensitive to constraints of autism e.g., *TEACCH(Treatment and Education of Autistic and related Communication handicapped CHildren)*
- All staff should be competent in **behaviour management**.
- Any individual behaviour programmes should be considered ethically and always incorporate additional strategies to facilitate communication e.g. *Music and Drama Therapy, Sensory work, ongoing therapist support (e.g. Speech and Language Therapy, Occupational Therapy)*.
- **Subsequent Educational placement** requires a **staff/child ratio enhanced** beyond that of other children at the same intellectual level with flexibility between schools' settings.

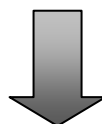


* e.g.s of autism-specific training: MIT (see above) introduced & supervised by Clinical Psychs but provided by Education staff/resources; Child Development Team staff offer in-service training to teachers/classroom assistants.



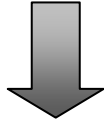
SOCIAL/FAMILY NEEDS

- **Respite** care offered e.g. *swimming, overnight*.
- **Family** (i.e. parent/sibling/grandparent) support **groups/activities**.
- **Ethnic awareness** e.g. countering possible under-diagnosis/**Welsh language provision available where required**.



TRANSITIONAL

- Risk assessment (Yr. 9: 14+) Statutory/Social Care.



OCCUPATIONAL

- *Health and Social Care for Adults – Creating a Unified and Fair System for Assessing and Managing Care.*

Note: The term “parent” also means “carer”.

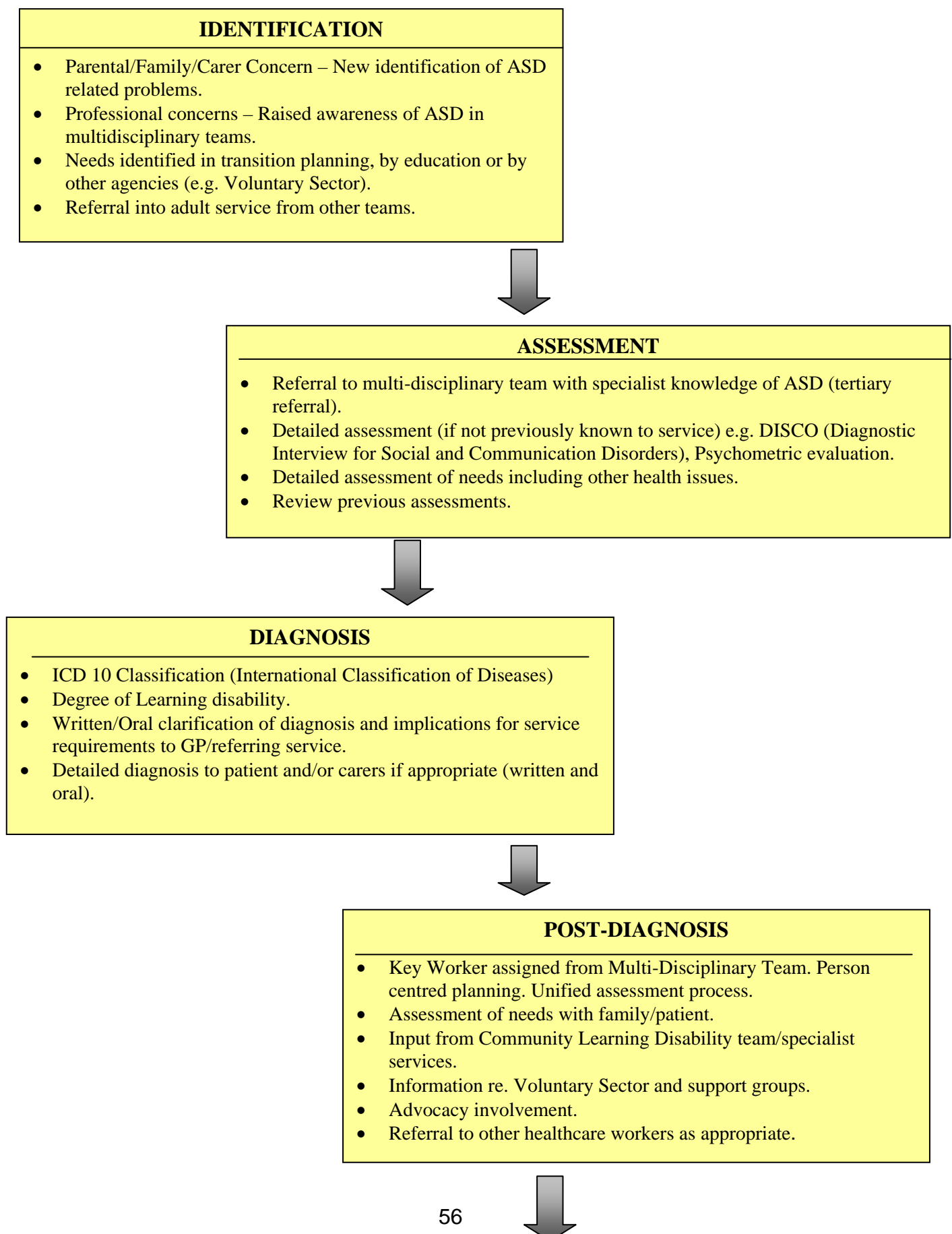
Note: The above suggestions are complementary to the care pathway and service needs for children and young people with autistic spectrum disorder appended to the clinical review “Diagnosis of Autism”, published on the British Medical Journal website (Baird G. Cass H. Slonim V “Diagnosis of Autism”. British Medical Journal. BMJ 2003; 327:488-493. 30 August)

Note: Italics reflect local-based good practice which may be adopted elsewhere.

Other documents consulted include:

- Good Practice Guidelines produced by the Department for Education and Science (www.standards.dfes.gov.uk)
- National Library for Health re. About Integrated Care Pathways www.library.nhs.uk/pathways (see “*What is the difference between an ICP and a Package of Care?*”... “*bite-sized chunks of service or care*”...for brief example on autism).
- Gwent Health Care NHS Trust: Strategy for Services for ASD: Assessment and Diagnosis.
- National Service Framework for Children, Young People and Maternity Services. Welsh Assembly Government 2005
- National Autism Plan for Children on the Individual Educational Plan (IEP). Published by the National Autistic Society for National Initiative for Autism Screening and Assessment (NIASA) in association with the Royal College of Psychiatrists, the Royal College of Paediatrics and Child Health and the All Party Parliamentary Group on Autism (March 2003)

Annex 3: Adults with Classic Autism with Learning Disability Care Pathway





INTERVENTIONS

- Subject to identified clinical need.
- Behavioural management, support from local psychology/behaviour management teams.
- Speech and Language Therapy.
- Occupational Therapy/Physiotherapy/Art and Music Therapy.
- Specific interventions.
- Ongoing monitoring of medical conditions.
- Screening for health problems (Tier 1 and 2 services).
- Awareness and treatment of likely Mental Health problems.



SOCIAL/FAMILY NEEDS

- Assessment of carers' needs – Support Groups, Voluntary Sector.
- Respite Care – Varied Options.
- Social activities tailored to those with ASD, provision of support workers, direct payment schemes.
- Housing, moving from the parental home, suitable client mixes in shared accommodation.
- Planning for exercise, consideration of dietary needs.
- Sexual Health and relationships.
- Old Age/transition into retirement. Links with old age services.



OCCUPATIONAL/EDUCATIONAL

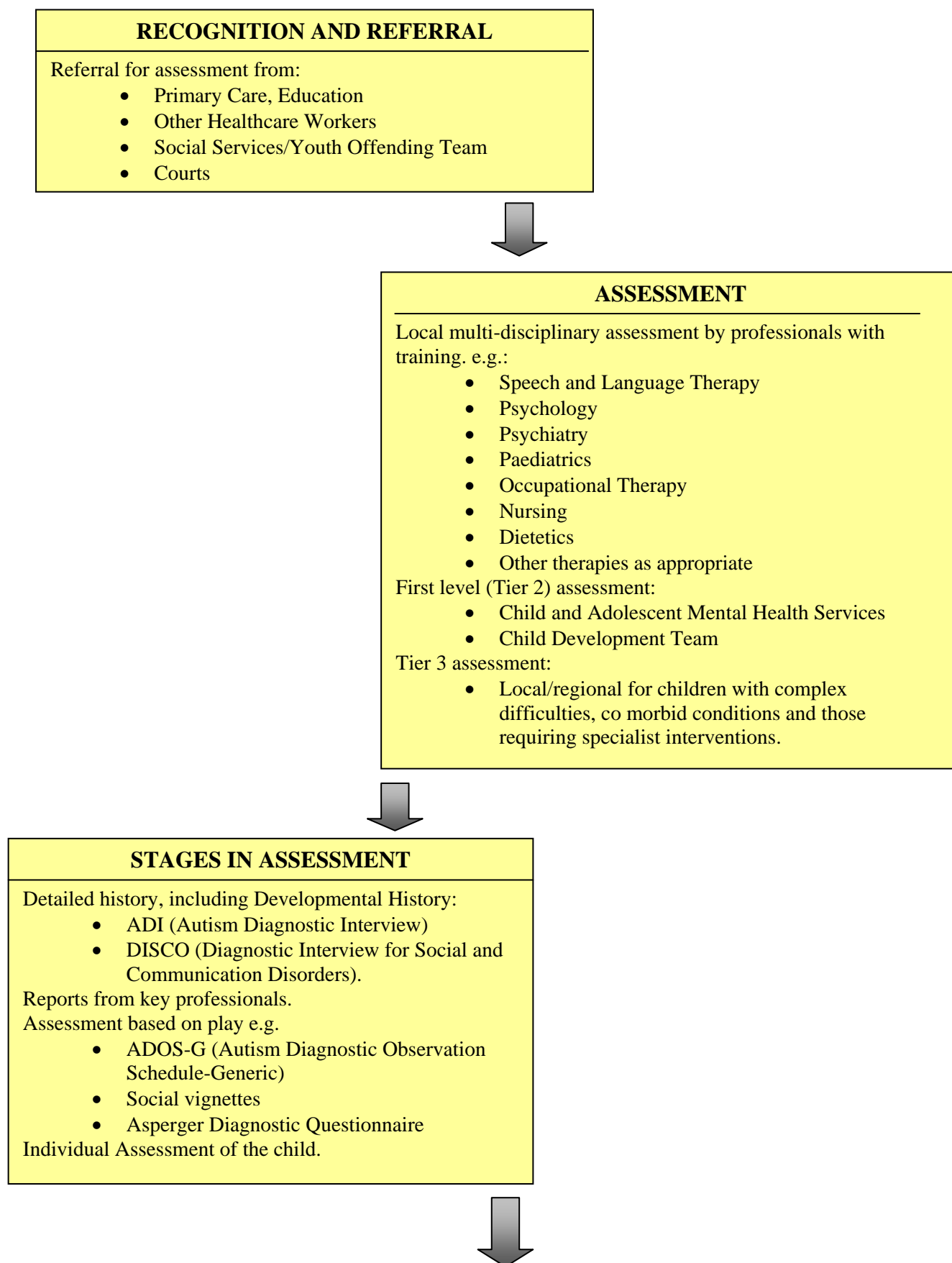
- Jobs.
- Further Education/Skills Training.
- The role of day centres.
- Earning schemes and voluntary work.
- Skills development/Independent living.
- Supported employment/job coaches.



FINANCIAL

- Role of carers, new incapacity legislation/Court of protection.
- Benefits management.

Annex 4: Asperger Syndrome Care Pathway





OUTCOME

- Diagnosis and feedback (verbal and written) - clarification of Higher Functioning Autism/Asperger as synonymous.
- Ongoing assessments to clarify diagnosis.
- Further assessments related to diagnosis
 - ❑ Social Services
 - ❑ Occupational Therapy
 - ❑ Dietetics
 - ❑ Art/Music Therapy
- Sharing information with other agencies (parental consent).
- **Assessment Framework – Allocation of key workers to be discussed at this stage.**
- Post diagnostic support from a suitable trained professional.
- Information on local/national voluntary support.
- Educational care pathway – to meet educational needs initiated by Local Education Authority.
- Parent support – Key Worker.
- Parent training – Diagnosis and behavioural management – multi-disciplinary team.
- Social Care pathway based on assessment of needs.



INTERVENTIONS

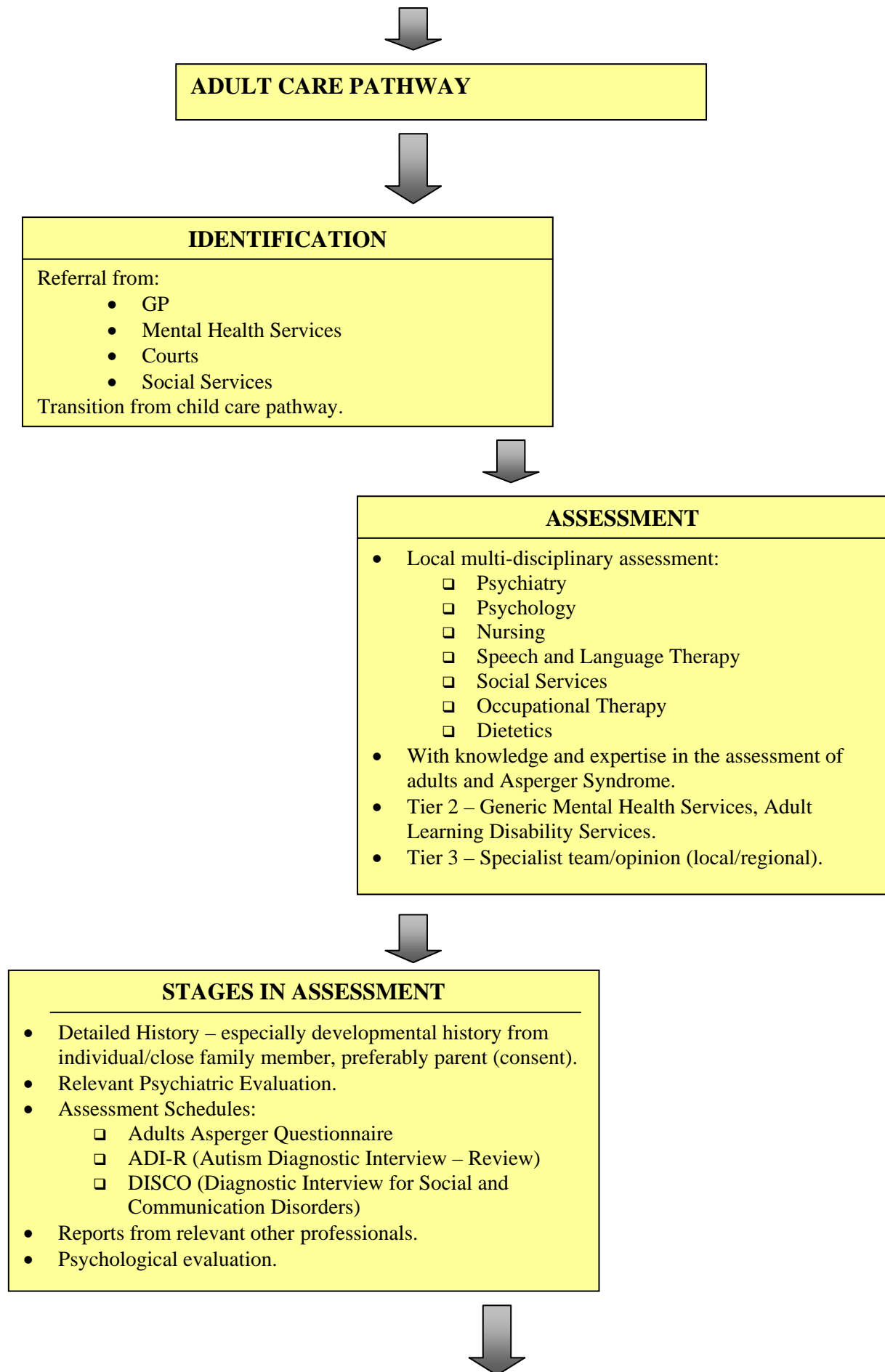
- Ongoing *multi-disciplinary child-centred* assessment.
- At times of *transitions* in various stages of education.
- At key stages in child's personal growth e.g. puberty.
- Transition into Adult Care pathway (planning to begin at 14) Local Education Authority/Social Services Dept.



HEALTH NEEDS/FAMILY NEEDS

- Assessment of child's health needs.
- Tiers 1 and 2 (primary and secondary care) monitoring and shared care arrangements (e.g. Attention Defecit Hyperactivity Disorder/Epilepsy management).
- Tier 2 – mental health needs and family support.
- Tier 3 – complex behavioural difficulties for specialist interventions.
- Referral to other healthcare workers as appropriate.







OUTCOME

- Diagnosis and feedback to individual (written and verbal).
- Ongoing assessments to clarify diagnosis.
- Further assessments to plan interventions – Higher Education, Occupational Therapy.
- Therapies as appropriate to individual need.
- Discussion with individual regarding self-management strategies followed by written information.
- Information on local/national support groups.
- Sharing of information with agencies (with consent) e.g. Employer, College, Social Services.
- If seen in Tier 3, referral back to Tier 2 if appropriate.
- Tier 3 Specialist Team – ongoing interventions.
- Social Care pathway – if individual meets criteria for Social Services.
- Register using Unified assessment centred on the individual with full participation of the service user.
- Family support – respite.
- Education and training – family/service user.



INDIVIDUAL AND FAMILY SUPPORT DURING TRANSITIONS.

- Ongoing need for multi-agency assessments and intervention at key stages of transitions by services who understand underlying impairments such as:
 - ❑ Higher Education
 - ❑ Employment
 - ❑ Relationships
 - ❑ Loss
 - ❑ Parenthood
 - ❑ Retirement
- Ongoing assessment by professionals for mental health needs.
- In-patient/out-patient treatment.

Annex 5

Extract from the National Service Framework for Children, Young People and Maternity Services

STANDARD – TRANSITIONS

STANDARD:

Young people who require continuing services, such as those who are disabled or chronically ill, young people with persistent mental illness or disorders, vulnerable young people and their families and carers, and care leavers, are offered a range of co-ordinated multi-agency services, according to assessed need, in order to make effective transitions from childhood to adulthood.

KEY ACTIONS:

5.32 There is an inter-organisation system to identify children who will require transition into adult services in the year before their 14th birthday (in year 8). This informs the strategic planning for all organisations.

RESPONSIBLE ORGANISATIONS:

LHBs
NHS trusts
LAs

5.33 A **key transition worker** is appointed to all disabled young people at age 14. It is their responsibility to ensure that the young people, their families and all relevant agencies are appropriately involved in the planning process. The **key transition worker** co-ordinates the planning and delivery of services before, during and after the process of transition and will continue to monitor and have contact with the young person until the age of 25 years.

RESPONSIBLE ORGANISATIONS:

LHBs
NHS trusts
LAs

5.34 Information about how to gain access to services and facilities is available to disabled young people in the local community including information about:

- Employment;
- Housing;
- Training;
- Leisure;
- Educational opportunities;
- Access to independent living;

- The process of transition to adult services within the local authority and health service;
- Support to maximise the use of Direct Payments to 16 & 17 year olds;
- Health promotion;
- Support groups and voluntary organisations.

RESPONSIBLE ORGANISATIONS:

LHBs
NHS trusts
LAs

5.35 There is one **joint organisations transition plan** produced for each disabled young person which forms the basis of the **Unified Assessment** within adult services and specifies arrangements for continuing support and services, including:

- Personal assistance;
- Housing requirements (including supported housing);
- Education, training and lifelong learning, including opportunities for work experience;
- Careers including specialist advice;
- Employment;
- Social relationships including leisure activities;
- Short breaks;
- Practical and other skills;
- Health needs including genetic counselling and sexual health;
- Continuing care;
- Appropriate transport;
- Communication needs;
- Domiciliary and day care;
- Financial support (including benefits and direct payments);
- Details of financial arrangements for specialist services required to address particular needs.

RESPONSIBLE ORGANISATIONS:

LHBs
NHS trusts
LAs

5.36 The **joint organisations transition plan** is reviewed at least annually or, in the case of young people who are looked after, every six months in accordance with statutory regulations *Children (Leaving Care) Act 2000*. During the year before their 18th birthday the plan is reviewed each term.

RESPONSIBLE ORGANISATIONS:

LHBs
NHS trusts
LAs

5.37 Aggregated information derived from **joint organisations transition plans** is sent to the area's Young People's Partnerships to inform strategic planning.

RESPONSIBLE ORGANISATIONS:

LHBs
NHS trusts
LAs
CYPPs

ANNEX 6

Bibliography

Legislation

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- Children Act 1989
- Children Act 2004
- Disability Discrimination Act 2004/ SEN & Disability Act 2001
- Education Act 1996
- Education Act 2002
- Government of Wales Act 1998
- Government of Wales Act 2006
- Health Act 1999
- Learning Skills Act 2000
- National Health Service (Wales) Act 2006
- Welsh Language Act 1993

Welsh Assembly Policies, Strategies and Guidance

- *A Therapy Strategy for Wales: The Contribution of Therapy Services to Transforming the Delivery of Health and Social Care in Wales*. Welsh Assembly Government. November 2006
- *Children and Young People's Specialised Services Project* – an ongoing Welsh Assembly Government project to develop Wales standards for Children and Young People's specialised healthcare services. Further information can be found on the project website www.wales.nhs.uk/cypss
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- *Designed to Work: A Workforce Strategy to Deliver Designed for Life.* Welsh Assembly Government. June 2006
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http://members.bda.uk.com/professional_guidance_docs.html
- Further Speech and Language Therapy information can be found in the Royal College of Speech & Language Therapists Clinical Guidelines 2005.
<http://www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=125079&tabID=288&catID=1115>