An Autism Spectrum Disorders (ASD) Database: Regional Pilot for a National ASD Database for Wales.

Match-funded by Welsh Government &

Betsi Cadwaladr University Health Board’s Charitable Funds

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Dr Wimpory's career began as a nanny to young child with autism. Here he is with her now, in his thirties. The current age of the oldest adults within the CCH-based ASD database is 30; they will still be represented there aged 31 years in 2013 etc.
1a) EXECUTIVE SUMMARY

This pilot project begins the development phase of a dedicated database for Autism Spectrum Disorders (ASD), initially within the 6 counties of Betsi Cadwaladr University Health Board (BCUHB), with the potential to evolve into a National ASD Register for Wales.

The primary aim is to enhance the Community Child Health (CCH) database, currently operating within BCUHB and across Wales, for the benefit of people with ASD. Clinicians, service-providers, service planners and potentially researchers, will also be aided by the new ASD Database module, within the CCH database, in terms of improved efficiency and accuracy of recording/retrieving diagnostic information essential to the proper care of people with ASD.

The CCH database records clinical diagnostic decisions following referral of individuals with ASD-type behaviour. It also records record-of-birth and other medical information such as the results of National Screening Programmes e.g. the Phenylketonuria screen that is linked to the newborn heel prick test. The CCH database thus tracks the birth record of all individuals in Wales and has input from, and output to, a range of professionals involved with Child Health. As such, the CCH database was selected as the appropriate electronic depository for diagnostic records on ASD in BCUHB and with All Wales capacity.

The aims of the project were:-

• To provide 100% coverage of the BCUHB child population with accurate ASD diagnostic records, swiftly retrievable electronically, for better informed care.
• To enable organisation of the available data by area, to provide a better understanding of the service needs and ASD status of each BCUHB area independently.
• To gain insight into the nature and number of service users of ASD-evaluation in BCUHB and the staff and service providers involved.
• To generate efficiency in planning the diagnostic services for different BCUHB areas.
• To develop an electronic ASD database for clinical and service development research purposes.
• To prevent the loss of child ASD records as service users reach adulthood and thereby retain early-years records of the service users, i.e. aged 30 years from 2012, 31 years from 2013 etc.
• To link across counties, the regions & potentially the whole of Wales to facilitate development, coordination and dissemination of best practice.
Prior to this pilot development, most ASD diagnoses were not recorded on the CCH database and, even when they were recorded, there was no detailed information on each ASD diagnosis.

The project defined the following **main objectives:**

- To survey ASD diagnoses in the original unenhanced CCH database to measure how well ASD was reported before this pilot. The 2009 BCUHB-wide ASD diagnostic audit was used as a comparison measure.
- To introduce and implement a recording and enforcement plan including a new ASD Report form to ensure all new records of ASD get recorded on the CCH database.
- To survey the levels of recording ASD diagnoses on the CCH database post introduction of enforcements.
- To examine the prevalence of ASD in BCUHB.
- To analyse service provision for ASD diagnosis in terms of diagnostic instruments used and the staff contribution to each diagnosis.
- To analyse the age of the children at the time of diagnosis and how long they waited for their diagnosis.
- To survey the enhanced CCH database for records of disorders known to increase the risk of ASD.

These objectives were met through negotiations of National NHS software developments as well important changes of policy and procedure within BCUHB. This involved senior levels of NHS management and cooperation from diagnosticians.

After ascertaining the suitability of the CCH database (in terms of information technology requirements and costings) for enhancement with an ASD module, ethical approval was gained from Bangor University. BCUHB’s R&D committee subsequently approved the work proceeding under the terms of Service Evaluation. Through consultation with CCH database Coders, BCUHB/All Wales IT Personnel and various levels of BCUHB management, there was an agreement to introduce an ASD Module within the CCH database. This decision was made at The CCH National Meeting in November 2011.

To fulfil the commitment to the complete and accurate recording of ASD, an ASD Diagnostic Report Form was developed and adopted as part of BCUHB’s Minimum Standards for Assessment and Diagnosis of ASD, as agreed during BCUHB’s February 2012’s CAMHS Network Board meeting. Further effort was required to gain compliance from diagnosticians to ensure...
the return of the Diagnostic Report Forms. In support of this process, communication has been shared with BCUHB’s Autism Project Group and Learning Disability/Mental Health Academic Board plus ASD Stakeholder Groups.

The enhanced dataset that was derived from the new CCH database ASD module and the implementation and enforcement of the new ASD Diagnostic Report Forms was analysed to consider a number of detailed measures of diagnostic coverage and the diagnostic process. Levels of ASD (prevalence) within the child population of BCUHB were measured in terms of the original database, the new enhanced database and the levels of ASD to be expected in any UK child population of a given size. The use of ASD diagnostic instruments was analysed for their variety and frequency amongst BCUHB diagnosticians and the numbers of staff contributing to each diagnosis was counted and compared between the BCUHB areas. Disorders that commonly occur together with ASD were also analysed for their prevalence and comorbidity with ASD.

**Findings** presented in this report range from confirmatory, expected measures, to unexpected results that merit further swift investigation. As suspected, the pre-enhancement levels of reporting ASD on the CCH database in BCUHB were very low compared to currently accepted standards. For example 88% of 2009 audited ASD diagnoses were still missing from the CCH database by 2012. This is paralleled by low rates of ASD reporting to the CCH database for the other LHBs of Wales.

Nevertheless, the project has provided a process for ensuring good practice for recording ASD on the CCH database and improvements in the rate of reporting, and a trend towards a more realistic measure of the prevalence of ASD in BCUHB is now seen following the introduction of the enhancements (from 0.35% to 0.5%). However, the prevalence of ASD in the enhanced CCH database is still below the current accepted estimate of 1% but sustained good practice is expected to raise the current BCUHB prevalence. The report highlights the importance of collecting full data sets and shows how the demographic for ASD changes when the CCH database is interrogated after having all the cases reported properly.

The current average age at diagnosis in BCUHB is 8.8 years and the average referral to ASD assessment time is 12 months. In 2012, over 60% of ASD diagnoses in BCUHB were appropriately made by more than three collaborating disciplines. Most frequently, Clinical Psychologists, Nurses and Psychiatrists contribute to ASD diagnosis.
BCUHB clinicians used the standardised diagnostic tool, ADOS, more frequently (65% of cases) in 2012 than the self-reported average across Wales (48%) documented by Leekam et al (2010). 52% of BCUHB clinicians used more than one standard tool for diagnoses in 2012 but only about half of the most frequently-used standardised ASD assessment tools (ADOS & ADI-R) were reported as scored.

Most ASD children diagnosed in BCUHB in 2012 had high/normal intellectual functioning as compared to children with ASD who also have comorbid Learning Disability. The Central area of BCUHB identified proportions (65%) of more intellectually able children compared to East (52%) or West (43%) BCUHB.

Some genetic disorders are comorbid with ASD e.g. Fragile X Syndrome, Tuberous Sclerosis Complex and Phenylketonuria. For each of these disorders, their prevalence in the CCH database is well below expected for the size of BCUHB’s population.

With regards to Fragile X Syndrome, in the 7 cases diagnosed in BCUHB, 2 are reported as comorbid with ASD. In a context of under-reported Fragile X Syndrome in BCUHB (where expected numbers of FXS would be at least 30), it is thus possible that individuals with ASD have the cause of their disorder overlooked, misdiagnosed or simply not reported on the CCH database. Recent advance in the development of drugs to help in the treatment of Fragile X Syndrome symptoms (now under clinical trials) provides momentum to identify ASD cases where the likely cause of ASD is Fragile X Syndrome.

Under reporting of Phenylketonuria (PKU) screening was also investigated, by considering records of the results of the heel prick test for PKU. In the UK, all babies are screened for phenylketonuria (PKU). Phenylketonuria is a diet-treatable metabolic disorder where the level of neurological damage is proportionate to the amount of phenylalanine in the diet. Untreated, PKU leads to Learning Disability often accompanied by ASD. Taking the diagnostic audit year 2009 and the detailed analysis from 2012 together, 19% of children with ASD in BCHUB have no record for the PKU test on the CCH database. As testing for PKU is a screen that all children receive soon after birth, it is unlikely that all these children have not been tested for PKU. Nevertheless, from the analysis of the CCH database alone, the possibility remains that undiagnosed PKU may be accompanying and exacerbating cases of ASD in BCUHB. The enhanced CCH database is capable of swiftly delivering LHB wide ASD statistics and crosschecks. Prior to this pilot however, ASD records on the CCH database have not been adequate in BCUHB (and across the rest of Wales LHBs) to allow proper crosschecks.
**Recommendations** arising from this study address long-term concerns as well as issues that appear to merit urgent consideration:

1) The nature of the CCH database means that the new ASD module can be retrospectively populated with ASD diagnostic reports that are not currently on the database. Regional back-filling of ASD diagnostic reports onto the CCH database is recommended to allow electronic population of the ASD module with records not currently entered on the system. This process would allow retrospective analysis of service development across Wales and show the evolution of recognition and service for people with ASD in Wales over time. Retrospective input would also allow thorough crosschecking of the ASD population with for example, the results of National Screening programmes that have direct relevance to ASD. Regional funding has already been agreed to support backfilling and enhance comorbidity reporting within the North Wales region.

2) National roll out of the CCH database ASD module is recommended and the need for this cannot be over-emphasized. For both the whole of 2009 and the first third of 2012 there were some LHBs in Wales not reporting any cases of ASD in the CCH database. Such information justifies recommendation of progression as outlined in the initial ASD database plan, developed in collaboration with WG, anticipating National roll out subsequent to the BCUHB-pilot phase.

Integration of scientific and clinical analysis into the All Wales ASD Database development is also recommended. Without the scientific back-up to the planning and analysis, the serious situation of approximately a fifth of the audit and recent cases in this report having no CCH record of PKU screening would not have been identified. As outlined earlier, PKU is one of the known causes of Autism and PKU is treatable, so every LHB has responsibility to ensure that its ASD population is 100% PKU-screened (National NHS obligations already require screening of all newborns). National roll out of the ASD-enhanced Module for the CCH database will address this at a service development and scientific level; each are interdependent and similar principles apply to the other forms of ASD comorbidity examined in the current report.

Databases are maximally useful when kept up-to-date, practically complete and accurate. The usefulness and value of the CCH database as a system is evident, however, there are substantial country wide differences in the specific use that the Wales LHBs make of the CCH database for reporting ASDs and these differences exist between the areas within a single large LHB (BCUHB) also.
The transformation of BCUHB CCH database information on ASD cases from incomplete and useful only with caution, to a dataset that is directly useful to clinicians, and suitable for quantitative analysis, could be brought about relatively swiftly in the other Wales LHBs. In the case of BCUHB we have been supported in this by the drive that our Chief Executive has given to this project: to enhance the services for ASD individuals in BCUHB.

It is hoped that other LHBs and their service users may now stand to benefit from an expansion of the ASD Database across Wales. This is recognised as an essential step prior to the cross agency potential of such a database being realised in this flagship project for Wales; a tangible and lasting consequence of The ASD Strategic Action Plan for Wales (WAG, 2008).
1b) Introduction

Preparation of a regional pilot database of an initial one thousand NHS service users with Autism Spectrum Disorder (ASD) was conceived as stage 1 of a three stage process (see excerpt from original funded proposal below).

Welsh Government funded Stage 1 of the database project as the first of 3 stages; subsequent stages were identified as rolling the database across Wales and broadening the database to have a multi-agency function. The plan arose from the need to have precise information about the nature of the service users with ASD. The project, as planned, followed submission of an all Wales Diagnostic Survey report by Professor Leekam’s team for which Dr Wimpory was Consultant (November, 2010; Leekam et al., 2010).

The pilot phase of preparing a database of Autism Spectrum Disorder (ASD) service users for Welsh Government and Betsi Cadwaladr University Health Board (BCUHB)’s Charitable Funds was carried out from November, 2010, to June, 2012. Following extensive discussions/negotiations with NHS managerial, clinical and IT personnel at a regional/national level, an ASD module was created within the NHS’s Child Health Database (CCH). The original electronic 'Child Health Database' was re-launched as 'Community Child Health 2000 (CCH2000)', for clarity within this report it is referred to as the CCH database. The CCH database records information according to ICD-10 an international diagnostic system (WHO, 1992).

1b.i) Excerpt from the original funded bid:

“Pilot project: Development of an Autism Spectrum Disorder (ASD) Database within the Betsi Cadwaladr University Health Board (BCUHB).

**Aim:** The goal of this pilot project is to begin the development phase of a dedicated database for ASD. This database will operate initially within the 6 counties of the BCUHB with the potential to form the first phase of a national ASD register for Wales…

**Project Scope** The work will be carried out in three stages with BCUHB as the first 'pilot' health board. The current pilot proposal relates to work for the first stage only.

**Stage 1** This stage will establish the feasibility of an adapted database. The goal is to enhance the Child Health Database currently operated within the BCUHB. This database is currently used to record clinical diagnostic decisions following referral of individuals presenting with ASD-type behaviours. It also records other medical information. The work will involve design of the data parameters, decisions on data content and analysis strategy. Trials of the database will also be carried out from available data.
The scope for this stage will also include the work related to permissions, ethical approval, intellectual property rights and governance procedures. Work will be carried out in consultation with coordinators of relevant national datasets and with stakeholders from the ASD Action plan…”

This pilot project for WG/Charitable Funds launched the CCH's ASD module regionally (with funding for subsequent back filling of past cases now approved locally – see Chapter 7). The CCH option was selected because all children are registered on it throughout Wales NHS from birth. Parental consent for electronic storage of such information (via Child Health Records/CCH database) is given by parents at each child’s birth. Details of those with special needs are not removed when they reach adulthood; the eldest on the CCH are currently 30yrs old, increasing by one year each year.

1b.ii) Challenges in collecting the data on the 1000 cases analysed for this project have included the following:-

• Gaining ethical approval from Bangor University and negotiating with NHS ethical advisors/R&D committees prior to Service Evaluation status being agreed.
• Consultation with BCUHB’s Caldicott Guardian/Clinical Governance Systems.
• Gaining a BCUHB Letter of Access for Bangor University-employed ASD Database Research Officer to enable him ‘read-only’ access to the CCH database.
• Obtaining the CCH database national meeting’s agreement for software changes to introduce an ASD Module within the CCH database (November 2011).
• Consulting with CCH Database Coders; BCUHB/All Wales IT Personnel; and, through various levels of BCUHB management.
• Making representation to BCUHB’s February 2012’s CAMHS Network Board meeting to gain adoption of an ASD Diagnostic Report Form with BCUHB (see Chapter 3).
• Negotiating incorporation of the ASD Diagnostic Report Form with BCUHB with BCUHB’s Minimum Standards for Assessment and Diagnosis of ASD.
• Gaining compliance from diagnosticians returning the Diagnostic Report Forms
• Maintaining communication with BCUHB’s Autism Project Group, LD/MH Academic Board and relevant ASD Stakeholder Groups.
There follows detailed analysis of the prevalence of ASD and other important attributes of the service users in BCUHB. Understanding the nature of ASDs and the demographics of service users can help the service providers and policy makers to recognize the current needs of the target population and thereby allocate the services as justified.

1b.iii) Constituent datasets and their size

This project includes the analysis of the following sets of data from BCUHB:

- The original unenhanced Community Child Health (CCH) database (1982-2011)
- ASD Diagnostic Report forms introduced to enhance the CCH database from 1.1.12
- An ASD Child Diagnostic Audit in BCUHB for 2009 (showing cases that were mostly unrecorded on the CCH database)
- Enhanced Database: pooled non-overlapping data from each of the above

This report presents analysis of over 1000 identified BCUHB cases with ASD. These comprise the following:

- 795 cases identified to have some form of ASD on the unenhanced CCH database (1982-211). This had 514 child cases and 281 adult cases
- 82 additional child cases diagnosed from 1.1.12 to 30.6.12, recorded on database-linked Diagnostic Report Forms
- 127 additional cases identified through the 2009 audit of clinical diagnoses (and incorporating 18 diagnoses presented in 2010)

The above data set(s) are also considered in relation to all Wales and other Welsh Local Health Boards’ (LHBs) data as recorded on the (unenhanced) CCH database.

1c) Aims and Objectives

1c. i) The Aims of the project were:-
   - To provide 100% coverage of BCUHB child population with accurate ASD diagnostic records, swiftly retrievable electronically, for better-informed care.
To enable organisation of the available data by area, to provide a better understanding of the service needs and ASD status of each BCUHB area independently.

To gain insight into the nature and number of service users of ASD-evaluation in BCUHB and the staff and service providers involved.

To generate efficiency in planning the diagnostic services for different BCUHB areas.

To develop an electronic ASD database for clinical and service development research purposes.

To prevent the loss of child ASD records as service users reach adulthood and thereby retain early-years records of the service users, i.e. aged 30 years from 2012, 31 years from 2013 etc.

To link across counties, the regions & potentially the whole of Wales to facilitate development, coordination and dissemination of best practice.

Prior to this pilot development, not all ASD diagnostic results were recorded on the CCH database and there was no detailed information on each ASD diagnosis. Therefore, and in relation to the aims, the project defined the following main objectives.

1c. ii) The Main Objectives were:-

- To survey ASD diagnoses in the unenhanced CCH database to measure how well ASD was reported before this pilot. The 2009 ASD audit was developed across BCUHB and used as a comparison measure.

- To implement a recording and enforcement plan to ensure all new records of ASD are recorded on to the CCH database.

- To survey the levels of recording ASD diagnoses on the CCH database post introduction of enforcements.

- To examine the prevalence of ASD in BCUHB post introduction of the new ASD Report Forms and enforcements.

- To analyse service provision for ASD diagnosis in terms of diagnostic instruments used and the staff contribution to each diagnosis.

- To analyse the age of the children at the time of diagnosis and how long they waited for their diagnoses.

- To survey the enhanced CCH database for records of disorders known to increase the risk of ASD.

These objectives were met through negotiations of National NHS software developments as well important changes of policy and procedure within
BCUHB. This involved senior levels of NHS management and cooperation from diagnosticians.

1d) Project Team

The project team is led by Dr Dawn Wimpory, Consultant Child Clinical Psychologist, Lead for Autism/ Lecturer (BCUHB & Bangor University) in collaboration with:

- Professor Sue Leekam, Chair in Autism Research, Cardiff University, Wales
  & Dr Wimpory’s Bangor University/BCUHB staff:
- Dr Brad Nicholas (PT Research Officer, Bangor University)
- Oonagh Eason (PT Learning Disability/Research Nurse, BCUHB)
- Marie Burrows (PT Research Project Support Officer, Bangor University)
- Indu Dubey (Temporary Research Project Support Officer, Bangor University)
- Kitty Forster (Temporary Research Project Support Officer, Bangor University)
- Susan Williams (PA to Dr Wimpory)

1e) Cost/Duration

Welsh Government (WG) and BCUHB’s Charitable Funds each awarded the ASD database project £38,000. WG funding was originally awarded to Dr Dawn Wimpory at BCUHB from where some of the funding was transferred to Bangor University. Work commenced in November 2010 following completion of The All Wales Diagnostic Survey, Leekam et al. (2010), as planned. Reporting to Welsh Government was requested for Summer 2012. However, given the longitudinal nature of this project, WG agreed that low level staffing (@0.1FTE) might be employed on continued data collection until end March 2013 and BCUHB’s Charitable Funds have agreed this potentially until end March 2014. In practice WG’s funding will be exhausted by 30.9.12.

Some additional staff time was awarded through Dr Wimpey’s NISCHR part-time Clinical Fellowship (2 days/week running from April, 2011-March, 2014). A part time Research Project Support Officer role was additionally funded by BCUHB’s Charitable Funds to support a variety of Dr Wimpory’s projects including the database. The ASD database module within the CCH database has been developed to be self-sustaining at an NHS level although in practice some allocated staffing would best ensure its continued appropriate use. Current and Future plans and recommendations for the ASD-enhanced CCH database are outlined in Chapter 7.
Chapter 2:

GENERAL ANALYSIS OF ASD CASES WITHIN THE ORIGINAL UNENHANCED CHILD HEALTH DATABASE (CCH) 1982-2012

Contents of Chapter 2:

2a) Introduction 
2b) Prevalence of ASD in BCUHB and its constituent areas 
2c) Prevalence of ASD in children across Wales LHBs 
2d) Sub-categories of ASD and related diagnoses in BCUHB’s original unenhanced CCH database 
2e) Summary of Chapter 2

2a) Introduction

The unenhanced data pertains to children with ASD identified from the overall CCH data up to 31/12/2011. The data from the CCH database was made anonymous to keep it absolutely confidential and safe. Further analysis about ASD was based on the data carefully extracted from the overall CCH database. It was found that only a small proportion of the BCUHB population could be identified from ICD-10 codes as having ASD on the original CCH unenhanced database (see Chapter 2, section b).

2b) Prevalence of ASD in BCUHB and its constituent areas

Using the original CCH unenhanced database, the ASD Database Team analysed the number of BCUHB children and adults, who were recorded when diagnosed in childhood. The former were used to determine ASD prevalence figures for ASD in BCUHB (Table 2-1). The prevalence of ASD in BCUHB’s population (795/678,500) was 0.12% as recorded by the original unenhanced CCH database at the end of 2011. This recorded the prevalence of child ASD in BCUHB as 0.35% (i.e., 514/145,163).
Central BCUHB has the lowest prevalence of ASD in children compared to the other two areas, according to the original unenhanced CCH database. Prevalence for this in each BCUHB area is as follows: 0.26% for Central, 0.38% for East and 0.39% for West (child populations for each at the end of 2011 are 43,533, 62,482 and, 39,148, respectively).

2c) Prevalence of ASD in Children across Wales LHBs

BCUHB is the LHB covering the largest population (678,500) and it has the largest child population (145,163). Comparing the prevalence of ASD as reported in the original unenhanced CCH database for the different Local Health Boards (LHB) of Wales (Table 2-2 and Figure 2-1, overleaf). BCUHB’s recorded ASD prevalence in children (0.35%) is second only to Cwm Taff LHB (0.77%). Abertawe Bro Morgannwg University LHB (ABM) has the lowest prevalence in Wales (at 0.05%).

CCH database-reported prevalence for ASD in children across all of the Wales LHBs (0.27%) is lower than the standard prevalence rate of 1% (as determined from sample screen surveys). Cwm Taff LHB (at 0.77%) is therefore reporting approximately three-quarters of the standard prevalence. Prevalence for ASD in BCUHB children, prior to the 2012 enhancements detailed later in this report, are approaching half the Cwm Taff rate on the following CCH database figures from the end of 2011.

Table 2-1. BCUHB ASD records on the CCH database 1982-31.12.2011, expressed as a % of the total BCUHB Population.

<table>
<thead>
<tr>
<th>Data from original unenhanced CCH database for BCUHB</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of children &amp; adults with an ASD</td>
</tr>
<tr>
<td>Number of adults with an ASD</td>
</tr>
<tr>
<td>Number of children with an ASD</td>
</tr>
<tr>
<td>Prevalence of ASD in child population (&lt;18yrs)</td>
</tr>
<tr>
<td>(514 / 145,163)</td>
</tr>
<tr>
<td>Prevalence of adult &amp; child ASD in total population</td>
</tr>
<tr>
<td>(795 / 678,500)</td>
</tr>
</tbody>
</table>
### Table 2-2: Percentages of children with ASD in the total child populations across Wales’ LHBs. (Includes data from Wales Centre for Health & National Public Health Service for Wales.)

<table>
<thead>
<tr>
<th>LHB</th>
<th>Child pop.</th>
<th>Child ASD</th>
<th>% Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABM</td>
<td>107,160</td>
<td>51</td>
<td>0.05</td>
</tr>
<tr>
<td>AB</td>
<td>132,617</td>
<td>183</td>
<td>0.14</td>
</tr>
<tr>
<td>BCU</td>
<td>145,163</td>
<td>514</td>
<td>0.35</td>
</tr>
<tr>
<td>C &amp; V</td>
<td>107,373</td>
<td>309</td>
<td>0.29</td>
</tr>
<tr>
<td>CT</td>
<td>67,285</td>
<td>521</td>
<td>0.77</td>
</tr>
<tr>
<td>HD</td>
<td>77,751</td>
<td>139</td>
<td>0.18</td>
</tr>
<tr>
<td>PT</td>
<td>25,956</td>
<td>54</td>
<td>0.21</td>
</tr>
<tr>
<td>Total for Wales</td>
<td>663,305</td>
<td>1,767</td>
<td>0.27</td>
</tr>
</tbody>
</table>

(Source: Wales Centre for Health and the National Public Health Service for Wales.)

### Figure 2-1: The percentage of children identified to have some form of ASD in the total child population across the different LHBs in Wales.

To summarise this section, based on CCH database figures from 1982 to 2011 and comparing the prevalence of ASD amongst the different Local Health boards (LHBs), it has been found that:

- The ASD prevalence (or number of adults and children with ASD) in BCUHB within the original unenhanced CCH database is 0.12%.

- The prevalence of children with ASD in BCUHB reported in the original unenhanced CCH database is 0.35%. This is lower than the general established standard prevalence rate of 1%. However, the prevalence for children reported to have ASD within the CCH database across the rest of Wales (0.27%) is even lower than that for BCUHB.
2d) Sub-categories of ASD and related diagnoses in BCUHB’s Original Unenhanced CCH Database.

The data presented in Figure 2-2 is from the CCH database recorded ASD diagnoses over some 30 years. During that period, Autistic Disorder, also known as Childhood Autism (CA), has been the most frequently diagnosed category of ASD. This was followed by Pervasive Developmental Disorder (PDD) and then Asperger Syndrome (AS). However, when the population size of the three areas of BCUHB is taken into account then differences in the distribution of diagnoses across the Autism Spectrum emerge, as indicated in Figure 2-3 overleaf.

![Bar chart](chart.png)

**Figure 2-2.** Number of individuals (children and adults) by diagnostic categories of ASD (not mutually exclusive) across the different areas of BCUHB. (Based on data from 795 ASD adult and child cases from the Original Unenhanced CCH Database, 1982 to 2011.)

Acronyms for Figures 2-2 and 2-3 are as follows: PDD: Pervasive Developmental Disorder; CA: Childhood Autism (also known as Autistic Disorder); AA: Atypical Autism; AS: Asperger Syndrome; Other PDD: Other Pervasive Developmental Disorders; PDD Unspec: Pervasive Developmental Disorders Unspecified.

In Figure 2-3, overleaf, the data shows how the distribution of cases, between the subcategories of ASD, varies for each BCUHB area. For example, the proportion of reported diagnoses of Asperger Syndrome is approximately the same across the three BCUHB areas, as is the case for Childhood Autism. However, there are area variations in the rate of diagnosing Pervasive Developmental Disorder (PDD) and PDD-Unspecified (PDD-U). Central-BCUHB diagnoses proportionally more PDD, and West-BCUHB diagnoses proportionally more PDD-Unspecified and Atypical Autism.
Figure 2-3. Shows the relative levels of diagnosis of the (non-mutually exclusive) ASD subcategories for each BCUHB area, standardised for area population size. East BCUHB has the largest population (100%) while Central and West are approximately 75% and 67% of that, respectively. (Based on 795 adult and child cases from the Original Unenhanced CCH database, 1982 to 2011)

2e) Summary of Chapter 2:

- The original unenhanced CCH database gives reported numbers of ASD cases for BCUHB that are far below the expected levels.

- The ASD prevalence (or number of adults and children with ASD) in BCUHB within the original unenhanced CCH database is 0.12%.

- The prevalence of children with ASD in BCUHB reported in the original unenhanced CCH database is 0.35%. This is lower than the general established standard prevalence rate of 1%. However, the prevalence for children reported to have ASD within the CCH database across the rest of Wales (0.27%) is even lower than that for BCUHB.

- Central BCUHB had the lowest prevalence of ASD in children compared to the other two areas, according to the original unenhanced CCH database. Prevalence for this in each BCUHB area was as follows: 0.26% for Central, 0.38% for East and 0.39% for West.

- In BCUHB East, West and Central areas, Autistic Disorder and Asperger Syndrome are recorded in similar proportions relative to the total number of diagnoses for each area. For other ASDs, the rates are more varied between the areas of BCUHB.
ANALYSIS OF ASD DIAGNOSES IN BCUHB FOR THE YEAR 2009

Contents of Chapter 3:

3a) General Analysis of BCUHB’s 2009 ASD Child Diagnoses
   3a.i) Introduction
   3a.ii) 2009 Audit: ASD diagnostic figures across different BCUHB areas
   3a.iii) Diagnostic Categories of ASD recorded by BCUHB’s 2009 Audit
   3a.iv) Age at diagnosis in BCUHB’s 2009 audit of ASD diagnoses

3b) Comparison of BCUHB’s 09 Child Diagnoses with figures reported to the CCH database
   3b.i) How many BCUHB ASD child diagnoses audited in 2009 were recorded on the CCH database?
   3b.ii) Percentages of BCUHB 2009 ASD Audit Cases Recorded/Missed on the CCH database across BCUHB areas

3c) Analysis of cases recorded on the CCH database in 2009 for BCUHB and other LHBs
   3c.i) Numbers of ASD Cases added to CCH database in 2009: BCUHB in comparison & combination with other Welsh Health Boards
   3c.ii) Age distributions for ASD cases reported to CCH the database in 2009 by BCUHB and other Health Boards in Wales (& for all combined)

3d) Potential for Cross Services Analysis within BCUHB

3e) Summary of Chapter 3
3a) General Analysis of BCUHB’s 2009 ASD Child Diagnoses:

3a.i) Introduction

An audit was carried out in the Central area of BCUHB detailing ASD diagnoses in 2009. Details from the August 2011 report on this audit, as presented to the 2011 Cross Party ASD meeting in North Wales, have been used to contribute to part of this chapter (Griffith et al, 2011). To achieve a complete account of the ASD cases in BCUHB diagnosed in 2009, similar audits were conducted in East and West BCU. The total number of ASD diagnoses recorded in the 2009 total BCUHB audit was 126, this is compared with more recent diagnostic figures in the following chapter. The findings of the overall BCUHB audit of 2009 diagnoses showed that the prevalence of ASD cases was much higher than what was reported in the CCH database (as detailed in 3b below).

3a.ii) 2009 Audit: ASD diagnostic figures across different BCUHB areas

![Bar chart showing the distribution of 2009 audited ASD diagnoses by BCUHB area](image)

Data 2009 audit (126 BCUHB Cases)

**Figure 3-1:** The distribution of 2009 audited ASD diagnoses by BCUHB area

The number of ASD diagnoses audited in 2009 was smallest in West-BCUHB. This is the area with the smallest population and here there was previously a greater focus on the more severe and less common form of Autism: Autistic Disorder. However, in West-BCUHB’s area, subsequent local ASD Stakeholder Group funding has provided intensive diagnostic training that has assisted in the diagnosis of broader, more varied ASDs. Chapter 4 indicates the effects of this training on the quality and quantity of diagnoses, by 2012.

For interest, the current child population figures of each area are approximately: 62,000 for East, 44,000 Central and 39,000 West BCUHB respectively. The numbers of ASD cases in figure 3-1, expressed as a
percentage of these population figures, are 0.08% in East-, 0.15% in Central- and 0.02% in West-BCUHB respectively.

3a.iii) Diagnostic Categories of ASD recorded by BCUHB’s 2009 Audit

ASD describes a range of conditions, also termed Pervasive Developmental Disorders (WHO, 1992). These diagnoses share some common features such that a spectrum of conditions and disorders can be described in terms of the autism features and severity shown by the disorders. ASD includes the more severe, classic presentation of Autism (or Autistic Disorder) and Asperger Syndrome (for intellectually able children without early language problems), whilst broader and more varied presentations are often simply referred to as having ASD.

Current revisions of diagnostic classification systems may change some of these individual terms. However, they were adopted in our analysis of the 2009 data as they can be broadly mapped on to the ICD-10 categories (WHO, 1992) that underpin the CCH database system. For the purpose of this audit’s analysis, ICD-10 codes for Autism, Asperger Syndrome and ASDs were therefore taken as: “F84.0”; “F84.5”; and, “F84.1 to F84.4; F84.8 and F84.9”, respectively.

Each of the ASD sub/categories may have different special needs, areas of deficit and, characteristics. It’s therefore important to identify and understand them individually. The figure below shows number of diagnoses according to these three sub/categories of ASD across the three areas of BCUHB.

![Figure 3-2: Distributions of sub/categories of ASDs as identified through BCUHB’s audit of 2009 diagnoses in different areas of BCUHB. (Data 2009 audit: 126 cases)](image-url)
As would be expected the broader ASD category of ‘ASD’ forms the majority of diagnoses for each BCUHB area within the 2009 audit. In BCUHB’s Central area all diagnoses were made under the broad category of ASD, rather than any more specific diagnostic sub-category.

3a.iv) **Age at diagnosis in BCUHB’s 2009 audit of ASD diagnoses**

Age at diagnosis and intervention can be major factors in predicting the outcome of a developmental disorder. It is therefore important that services that plan interventions are well informed about the age of ASD diagnoses, as analysed here across and within different areas of BCUHB for 2009.

![Figure 3-3](image)

**Figure 3-3:** Average age at diagnosis of ASD across BCUHB and its East, West, Central areas (rounded to nearest year). Source: Data 2009 Audit in BCUHB (126 cases).

Figure 3-3 shows how the average age of diagnosis in BCUHB was 9.3 years (based on 2009 audit of 126 cases). The 2009 audit revealed that the ages at diagnosis for BCUHB ranged over 15 years, i.e. 2 to 17 years old. East and Central BCHUB had an average age of diagnosis of 10 and 9 years respectively, whilst West BCUHB had a much younger average age of diagnosis: 5 years. The data also shows that the age range of diagnosis has been from 3 years 3 months to 17 years 3 months in East, 3 years 0 months to 15 years 7 months in Central, and 3 years 2 months to 8 years 9 months in West. In West BCUHB, ASD diagnoses were more frequently made by Specialist Children’s Services, whose service users are younger than those served by CAMHS. Central and East (specifically Flintshire) CAMHS played a greater role in diagnosing ASD than in the West area. CAMHS throughout BCUHB serves older child service users.
3b) **Comparison of BCUHB’s 09 Audit of Child Diagnoses with figures reported to the CCH database:**

3b.i) How many BCUHB ASD child diagnoses audited in 2009 were recorded on the CCH database?

BCUHB ASD diagnostic audit cases were found to be under-represented in the original unenhanced CCH database. Only 15 (12%) of the 126 audited ASD diagnoses were recorded as having ASD in the CCH database. It failed to record 88% (i.e. 111) of the ASD diagnoses that were identified only through the detailed 2009 BCUHB-wide audit. The rate of CCH recorded ASD diagnosed cases was only 1.3 per month whereas the actual clinical rate of diagnoses was found to be 10.5 per month (each of these two figures and the percentages in this paragraph are rounded to the first decimal point).

3b.ii) Percentages of BCUHB 2009 ASD audit cases recorded/missed on the CCH database, across BCUHB areas.

Figure 3-4 shows area differences for the proportion of ASD diagnoses reported on the original unenhanced CCH database. Although West-BCUHB most reliably reported ASD diagnoses to the CCH database, only 50% of its cases were recorded there. The other BCUHB areas even more strongly highlight the need to improve CCH ASD recording. East-BCUHB recorded 14% and Central-BCUHB recorded just 6% of 2009’s audited ASD diagnoses.

![Figure 3-4:](image-url)
3c) Analysis of cases recorded on the CCH database in 2009 for BCUHB and other LHBs

3c.i) Numbers of ASD Cases added to CCH database in 2009: BCUHB in comparison/combination with other Welsh Health Boards

Although 126 ASD diagnoses were identified through BCUHB’s 2009 audit and 15 of these appear on the CCH database, national analysis shows that in 2009, 50 new records of ASD were made on the CCH database for BCUHB. This is because entries appearing for that year include any children diagnosed with ASD who happen to be retrospectively added in 2009 to the CCH database, for example, because of moving in to an area or, as a result of increased awareness about ASD (such as that prompted by WG’s Strategic Plan for ASD). These entries for 2009 should therefore not be confused with the year in which they may have been diagnosed. These factors underlying the recording of ASD cases for a particular year (in this case 2009) will apply to every Health Board across Wales. It is therefore of interest to compare the numbers of ASD cases recorded for each Welsh Health Board in 2009.

Table 3-1 shows wide variation between Welsh Health Boards for logging ASD cases on the CCH in 2009. Case numbers range from 0-50 (the former being Aneurin Bevan LHB and Powys Teaching LHB, the latter representing BCUHB on the CCH database). This highlights the need for CCH recording to be reconsidered at a national level in relation to ASD (see Chapter 7).

Table 3-1: Number of ASD children recorded in 2009 on the CCH database by different Health Boards in Wales

<table>
<thead>
<tr>
<th>LHBs</th>
<th>CCH-reported ASD in 2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abertawe Bro Morgannwg University LHB</td>
<td>1</td>
</tr>
<tr>
<td>Aneurin Bevan LHB</td>
<td>0</td>
</tr>
<tr>
<td>Betsi Cadwaladr University LHB</td>
<td>50</td>
</tr>
<tr>
<td>Cardiff &amp; Vale University LHB</td>
<td>25</td>
</tr>
<tr>
<td>Cwm Taff LHB</td>
<td>38</td>
</tr>
<tr>
<td>Hywel Dda LHB</td>
<td>12</td>
</tr>
<tr>
<td>Powys Teaching LHB</td>
<td>0</td>
</tr>
<tr>
<td>Total recorded in 2009 on CCH for Wales</td>
<td>126</td>
</tr>
</tbody>
</table>

Data Source: National CCH database entries for 2009
3c.ii) Age distributions for ASD cases reported to CCH the database in 2009 by BCUHB and other Health Boards in Wales (& all combined)

As indicated in 3c.i) and figure 3-5, national data shows 50 ASD diagnoses being added to BCUHB’s CCH database during 2009 (as indicated above, not all of these would have been actually diagnosed in 2009). The ages of these 50 children and comparable age distribution data from the CCH’s representation of other Health Boards is shown below. LHBs missing here have no or almost no data for ASD cases that were recorded in 2009; these are: Aneurin Bevan LHB, Powys Teaching LHB and Bro Morgannwg (which had a single 10yr old recorded with ASD in 2009).

**BCUHB: Number of ASD cases added to unenhanced CCH database in 2009, by age of child**

<table>
<thead>
<tr>
<th>Age of Child</th>
<th>Number of Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
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<tr>
<td>13</td>
<td>3</td>
</tr>
<tr>
<td>14</td>
<td>1</td>
</tr>
</tbody>
</table>

**C&V LHB: Number of ASD cases added to CCH database in 2009, by age of child**

<table>
<thead>
<tr>
<th>Age of Child</th>
<th>Number of Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>4</td>
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<tr>
<td>6</td>
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<tr>
<td>7</td>
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</tr>
<tr>
<td>8</td>
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</tr>
<tr>
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</tr>
<tr>
<td>10</td>
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</tr>
<tr>
<td>11</td>
<td>2</td>
</tr>
<tr>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td>13</td>
<td>1</td>
</tr>
</tbody>
</table>

**CT LHB: Number of ASD cases added to CCH database in 2009, by age of child**

<table>
<thead>
<tr>
<th>Age of Child</th>
<th>Number of Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
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<td>1</td>
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<tr>
<td>16</td>
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</tbody>
</table>
Figure 3-5: Age distributions for ASD cases reported in 2009 to CCH database by BCUHB different Health Boards in Wales. Source: National CCH database (2009 data)

Figure 3-6: CCH age distributions for cases of reported ASD for combined Health Boards in 2009. Source: National CCH (2009 data)

Whilst the age-distributions of cases added to the CCH database across the whole of Wales in 2009 (figure 3-6) may be of interest, the total number of cases represented by this data (as in Table 3-1) principally serves to highlight how inadequately the CCH database was being used for ASD. It recorded a total of 126 cases added in 2009 nationally which is almost the number of ASD diagnoses made-yet-missed-on-the-CCH-database within BCUHB alone (111). Recommendations in relation to this are discussed in Chapter 7. As explained above, data presented for the Health Boards above is based on CCH reported cases of ASD. They should be treated with caution as the 2009 BCUHB audit of actual ASD diagnoses made in that year indicates that 88% of diagnoses failed to be reported to the CCH database.

3d) Potential for Cross-Service Analysis within BCUHB

Service, rather than area, -based analysis of ASD diagnoses is anticipated in future (as discussed in 4e, next chapter) when cases will be more reliably recorded via a Diagnostic Report Form and submitted to the CCH database as they occur. For the 2009 Audit, just 1 ASD diagnosis was recorded for CAMHS West and none was recorded for Wrexham CAMHS (East).
3e) **Summary of Chapter 3:**

- The average age of ASD diagnosis in BCUHB during 2009 was 9.3yrs, ages at diagnosis ranged from 3yrs 0 months to 17yrs 3months.

- The original unenhanced CCH database reported only 12% of the true number of ASD diagnoses found in BCUHB’s 2009 audit i.e. 88% of diagnoses were not reported to the CCH in that year.

- For BCUHB, the rate of CCH-recorded ASD cases for 2009 was 1 per month whereas the actual clinical rate of diagnoses was 11 per month.

- Some other LHBs in Wales did not record any cases of ASD in 2009 on the CCH database.

- According to the 2009 audit, Central BCUHB diagnosed proportionally more cases than did East BCUHB where more cases were diagnosed proportionally than in West BCUHB.

- Central BCUHB’s audit was funded specifically by regional WG funding whereas East and West’s audits were more recent and retrospective (West BCUHB reported just one case whilst Wrexham CAMHS (East) reported no ASD diagnoses for 2009).
Chapter 4:

2012 ANALYSIS OF NEW DIAGNOSTIC REPORT FORMS, COORDINATED WITH CCH DATABASE CHANGES FROM 1.1.12

Contents of Chapter 4:

4a) Introduction: implementing the ASD Module within the CCH database from 1.1.2012.
   4a.i) Excerpt from BCUHB’s Minimum Standards for ASD Diagnosis and Assessment, followed by sample ASD Diagnostic Report Form.

4b) Analysis of BCUHB’s Jan-Jun 2012 ASD Child Diagnoses
   4b.i) Populations and ASD diagnoses for 2012 across BCUHB
   4b.ii) Rates of diagnosis in BCUHB (2009 vs. 2012)
   4b.iii) Time between referral and diagnosis
   4b.iv) Age of diagnosis for 2012 BCUHB cases (& comparisons with 2009)
   4b.v) BCUHB Clinicians’ estimation of Intelligence Levels of ASD children diagnosed in 2012.
   4b.vi) Verbal/non-verbal ASD status at the time of diagnosis.
   4b.vii) Language delay / Non-language delay at the time of diagnosis.
   4b.viii) Subcategories of diagnosis: ASD, Autism and Asperger syndrome.
   4b.ix) Gender ratios

4c) Analysis of Clinicians’ Methods in Diagnosing Children with ASD (Jan-Jun, 2012)
   4c.i) Diagnostic Instruments employed in 2012
   4c.ii) Scoring status of ADOS and other diagnostic instruments
   4c.iii) Degree of cross disciplinary/agency professional involvement in 2012 ASD diagnoses

4d) ASD Child Cases Recorded by CCH Database for the Different LHBs across Wales, Jan-April, 2012.

4e) Potential for Cross Services Analysis within BCUHB

4f) Summary of Chapter 4
4a) Introduction: implementing the ASD Module within the CCH database from 1.1.2012.

The ASD Database Team designed and instigated a new ASD module to identify all BCUHB children diagnosed with ASD from the start of 2012. The new ASD module incorporates details from an evaluation form created by the project for each clinician to complete following each ASD diagnosis made within BCUHB. Submitting the ASD Diagnostic Report Form, to CCH database coders, is now a permanent obligation on all ASD diagnosticians as an essential element within BCUHB’s Minimum Standards for Assessment and Diagnosis of ASD (excerpt overleaf). This development was agreed following lengthy negotiations through senior management/bodies of the Children and Young People’s CPG (e.g. CAMHS Network Planning Board) plus consultations with BCUHB’s Caldicott Guardian/Clinical Governance staff.

The form for recording all new ASD diagnoses includes, for example, dates of referral for ASD assessment and diagnosis, the assessment tools employed (including scores of Autism Diagnostic Observation Schedule (ADOS), Autism Diagnostic Interview-Revised (ADI-R) etc.), aspect(s) of impairment, level of intellectual functioning and diagnostic team details etc. A sample copy of the new Diagnostic Report Form used for the Welsh area of BCUHB for data collection in 2012 is shown in figure 4-1 on page 38 (Welsh and English area specific forms have been made available to all BCUHB ASD Diagnosticians).

The new ASD module, supported by the ASD Diagnostic Report Form, facilitates different types of analysis of the data and comparison across different areas of BCUHB. This facility is beyond what was practicably possible for the original unenhanced CCH or for the 2009 BCUHB Diagnostic Audit. The ASD Database Team developed the new Diagnostic Report Form but also determined several important changes in the software at the CCH database for data storage and its links to the IT report system. The improved software carries the potential to be used for the whole of Wales (as proposed in Chapter 7).

The new ASD module for identification of cases with ASD gives a comprehensive account of the service user’s condition at the very first glance. This pilot database module needs some small adjustment before the number of data builds up beyond 2012. The module has an area for adding subscale scores of ADOS and ADIR. Although these subscale scores are separated by commas, piloting has shown that they are frequently misread by the database as thousands. The module will therefore undergo trouble-shooting adjustment at the next software release (at least annually).
4a.i) Excerpt from:

BCUHB’s Minimum Standards for Assessment & Diagnosis of ASD:

“Completion of Form to Record ASD Diagnosis on The Child Health database.

BCUHB’s Autism Diagnosticians are required from the 1st January 2012, to record all ASD diagnoses on the CCH2000 system using the appropriate forms... This is to ensure that diagnoses are recorded with greater consistency across children’s services that provide diagnostic assessments in BCUHB. In 2011 a Caldicott Guardian/Clinical Governance Consultation considered the status of initial parental signed consent (triplicate form) for electronic Community Child Health recording of later childhood diagnoses; this did not identify the need for further consent being obtained for the recording of this information.

This system will improve ASD database recording and has the support of Welsh Government who have identified BCUHB as the first ‘pilot’ health board to establish the feasibility of an adapted database (CCH2000) in relation to ASD.” (p.14)

A sample area-specific ASD Diagnostic Report Form follows overleaf...
Figure 4-1: Sample of an ASD Diagnostic Report Form as developed and introduced to implement the ASD Module within the CCH database from 1.1.2012:

**ASD recording for Community Child Health records, CCH2000.**

Any professionals presenting an ASD diagnosis within BCUHB (West) have responsibility for completing and returning this form to: Mr Dai Richards, BCUHB (West), The Children’s Centre, Y Lawnt, Dolgellau, Gwynedd, LL40 1DR.

Submitted by: name/service

**Client details (Attach patient label if available)**

<table>
<thead>
<tr>
<th>Surname</th>
<th>D.o.b</th>
<th>Male □</th>
<th>Female □</th>
</tr>
</thead>
<tbody>
<tr>
<td>Forename</td>
<td>Referral date for ASD assessment:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Address</td>
<td>Date of Diagnosis:</td>
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</tr>
<tr>
<td>Postcode</td>
<td>NHS No. (if available):</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**ASD diagnosis**

1. **Tick which one of the following clinical diagnoses best applies?**
   - ASD □ (ICD-10 code F84.1 to F84.4, F84.8 and F84.9)
   - Autism □ (ICD-10 code F84.0 Childhood Autism includes Autistic Disorder, can be High Functioning Autism; Classic Autism; Kanner’s Syndrome etc.).
   - Asperger’s syndrome □ (ICD-10 code F84.5).

2. **Tick which aspects of the triad of impairments are affected?**
   - Social □
   - Communication □
   - Rigidities □

3. **Tick any instrument/s used for diagnosis (If none, tick this box □ & go to Q.4)**
   - ADOS □
   - ADI-R □
   - DISCO □
   - 3Di □

   Use key to enter score/subscale details (even if apparently contradictory):
   - D = Diagnostic Score; S = Sociability; C = Communication;
   - P = Rigidities-Play, including social imagination; B = Rigidities-Behaviour, including pattern of activity;
   - L = Language Delay; A = Autistic Abnormalities pre 36 months. For 3Di write Y/N for boxes L & A.

   Name any other instruments & any overall score? e.g. DAISI

4. **Which professional(s) contributed to the diagnosis?**
   - Paediatrician □
   - Psychiatrist □
   - Clin. Psychologist □
   - SALT □
   - Nurse □
   - Other, please specify e.g. Ed. Psychologist

5. **Intelligence level (Please estimate)**
   - High functioning/normal intelligence □
   - Mild learning disability □
   - Moderate learning disability □
   - Severe learning disability □
   - Non verbal IQ (if recorded) □

6. **Communication at diagnosis**
   - Verbal □
   - Non verbal □
   - Language delay □
   - No language delay □
4b) **Analysis of BCUHB’s Jan-Jun 2012 ASD Child Diagnoses:** Analysis of data from new Diagnostic Report forms as entered into/extracted from the CCH database.

4b.i) Populations and ASD diagnoses for 2012 across BCUHB

![Number of ASD cases](image)

**Figure 4-2:** The number of children diagnosed with ASD in different areas and the whole of BCUHB over the first six months of 2012. For clarity, child populations are also indicated. (2012 Data from new Diagnostic Report Forms (82 BCUHB Cases)

The smallest area (West BCUHB) still diagnoses the smallest number of cases, its diagnostic numbers are greater than they were there in 2009. Whilst 8 children were diagnosed there during 2009, 14 children were diagnosed over the first 6 months of 2012. As indicated in Chapter 3, this may be the result of intensive diagnostic training undertaken in North Wales in recent years with regional and local ASD strategy funding.

In the first 6 months of 2012, East BCUHB has identified almost as many ASD diagnoses (46) as it identified for the whole of 2009 (51). In contrast to the many child diagnoses identified by Central during their 2009 audit (67), fewer were identified in the first 6 months of 2012 (22). However, Central BCUHB still appears to diagnose almost twice as many children as West BCUHB even though its overall child population figures are not very much larger. This may be accounted for by the nature of the ASD clients (age, severity, complexity of presentation etc. and the methods of their assessment, see 4b iv-viii) and 4c) in this chapter). These issues may be elucidated further by future cross services analysis within BCUHB, as considered further in 4e) on page 56.

Data from the new ASD diagnostic report form (figure 4-3) indicate some increase in the rates of ASD diagnoses since 2009: the average number of BCUHB Child ASD diagnoses in 2012 was 14 per month, contrasting with 11 per month in 2009 (based on 126 cases over 2009, and 82 cases for January-June, 2012, in BCUHB). These numbers (and figure 4-3) reflect actual clinical diagnoses. Prior to ASD enhancement, the CCH database recorded a far lower rate of the diagnosed cases for 2009 (88% were missing); this contrasts to the apparent full reporting of diagnoses made in the first 6 months of 2012 in BCUHB monitored for this report. The relative rates of CCH database-reported diagnoses were 1/month for 2009 and 14/month for 2012. Such a dramatic rise in CCH database reported diagnoses has been facilitated by the systematic enhancement of the CCH reporting process.

![Figure 4-3: The rate of actual clinical diagnoses per month across (areas of) BCUHB (derived from Jan-June 2012 Diagnostic Report Forms, 82 cases)](image)

The data from the audit 2009 showed that the Central area diagnosed the highest number (67) of ASD cases that year as compared to East (51) and the minimum number was in West BCUHB (8). If the first 6 months of data from 2012 is doubled to enable comparison, then the relevant figures for Central, East and West BCUHB are: 44; 92 and 24, respectively. Section 4b.i) presents possible reasoning for both these figures and the relative population sizes.

4b.iii) Time between referral and diagnosis

This issue has attracted media attention lately. It therefore seems important to get as accurate information as possible about the time between referral for
ASD assessment and the point of diagnosis. For this reason, figure 4-4 details the response rates for clinicians responding across the three areas of BCUHB.

**Figure 4-4:** Clinician’s response rate to the referral time questions: This indicates the degree of reporting the referral/diagnosis dates, both of which are required for Figure 4-5. (Derived from Jan. to June, 2012, Diagnostic Report Forms: 82 cases)

![Clinicians' response rate re: time to diagnosis](chart)

**Average Time in Months Between Referral and Diagnosis**

![Average Time in Months Between Referral and Diagnosis](chart)

**Figure 4-5:** Time in months between referral for ASD assessment and receipt of ASD diagnosis, for the three areas of BCUHB and BCUHB as whole (Data derived from new Diagnostic Report Forms for 82 cases from Jan. to June, 2012).

From the 2012 analysis, referral-to-diagnosis-time is, on average, longest in East BCUHB. Approximately half of the reports did not have the referral date filled in for this area of BCUHB. It is possible that this means that the waiting time for ASD diagnosis for half the BCUHB 2012 ASD diagnoses could be longer than 1 year 3 months. Better reporting would resolve this question, piloting therefore indicates the need to return and request full completion of diagnostic report forms which lack completion of every detail. (Chapter 6: 6d, on page 71, details further ways in which piloting has informed future plans).

As indicated above, one possible reason for a long period being taken for ASD diagnosis is that other comorbid conditions of ASD such as PTSD or ADHD may need to take priority in the child’s evaluation/intervention, perhaps
before the features of ASD can be fully recognised. In general, the more children that a BCUHB area diagnoses, the longer it is taking to make those diagnoses. Although fewest diagnoses occur in West BCUHB, for example, this is the area where children wait least time for diagnosis once referred for ASD assessment

4b.iv) Age of diagnosis for 2012 BCUHB cases (& comparisons with 2009).

The age at which ASD is identified can have a major influence on the outcome of intervention. The 2012 data show that the average age of diagnosis in BCUHB is currently 8.8 years. In Central BCUHB this is 10.1 years, in East BCUHB it is 9.3 years and in West BCUHB it is 6.9 years. These figures appear to reflect particular strengths in diagnosing older intellectually able children within certain services in BCUHB (4b.v, below). Younger, less able children tend to be more the focus of diagnostic services in West BCUHB where the average age for diagnosis is lower.

The current average age at diagnosis is lower than that of the 2009 audit when the average age of diagnosis in BCUHB as whole was 9.3 years, with the youngest children again being diagnosed in the West. The slight decrease in average diagnostic age over time is positive, especially given the accompanying rise in monthly rates of diagnoses from 2009 to 2012.

When the age range of diagnosis is considered, the data shows that for East the range is from 2yrs 5months to 17yrs 9 months; for Central it is from 2yrs 11months to 15yrs 10 months, and for West it is from 2yrs 9 months to 14yrs 9 months. The data presented below show the number of ASD diagnoses in each age group for BCUHB.

<table>
<thead>
<tr>
<th>Number of ASD diagnoses by age at diagnosis: BCUHB (Jan.- Apr. 2012)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (in years)</td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
</tr>
<tr>
<td>Number of Diagnoses</td>
</tr>
</tbody>
</table>

Figure 4-6: Ages and numbers of children diagnosed with ASD in BCUHB: January to June 2012 Data from new Diagnostic Report Forms (82 Cases)
Figure 4-6 shows that the majority of ASD children were diagnosed at over 8 years in BCUHB during January to April, 2012. Figure 4-7 shows that most ASD cases recorded by the CCH for all Wales LHBs in the first four months of 2012 were also over 8 years. However, age of entry of ASD diagnosis to CCH database does not necessarily equate age at diagnosis. Therefore this data is not directly comparable, as detailed in 4d below.

![ASD age distributions for the cases reported to CCH database for all Wales LHBs, 1.1.12-30.4.12](image)

**Figure 4-7**: Ages of ASD children reported to the CCH database across all Wales LHBs (January to April 2012; National CCH2000 data.)

As indicated earlier, an ASD diagnosis may be made later in cases where the signs are more subtle and/or the child is more intellectually able, in which case initial symptomatology may be masked before age-appropriate social situations become more demanding. The data that follows is therefore of interest as it considers clinicians’ estimates of the intellectual level of the 82 BCUHB children diagnosed in early 2012

4b.v) **BCUHB Clinicians’ estimation of Intelligence Levels of ASD children diagnosed in 2012**

Research indicates that intellectual deficits affect most children with Autistic Disorder (the more severe form of ASD), yet ASD in intellectually average/able children has tended to be underestimated in the past. For BCUHB as a whole, figure 4-8 shows that the larger part of BCUHB’s 2012 (Jan-June) diagnosed population is estimated to have high or normal level of intellectual functioning.
Clinicians’ estimations of intellectual functioning of children with ASD in BCUHB: Percentages of children falling into each category (Jan.-June, 2012 Data from new Diagnostic Report Forms (82 Cases))

Figure 4-9 explores the divisions of children with ASD according to their level of intellectual functioning in different areas of BCUHB.

For each of the three BCUHB areas, figure 4-9 shows that the larger part of BCUHB’s 2012 (Jan-June) diagnosed population is estimated to have high or normal level of intellectual functioning. The ASD children, for whom the level of intellectual function is not reported, are of some concern. Clinicians were given the option of presenting an Intellectual Quotient (IQ) if available. None did so and therefore this element will be reviewed for the form during the extension stage of the project (as discussed in Chapter 6; 6d on page 71).

Clinicians appeared to prefer to respond to the invitation to give a qualitative clinical estimate of level of each child’s intellectual functioning. The further absence of this being recorded for approximately 20% of the children is worrying because some level of intellectual assessment, albeit informal, is required in making the diagnosis of ASD. Diagnosticians need to determine whether it is intellectual impairment that is giving rise to social difficulties or whether there is some specific form of ASD social impairment.
The extension stage of the project will seek clinicians’ feedback to determine why this question was left blank for some children. It may be that it is harder to answer about ASD children who have some level of learning difficulty than it is for ASD children who are of normal or high intellectual functioning. If so, then the approximate 20% of cases for whom this data are unknown would likely represent children with Learning Disabilities.

However, the high proportion of children declared to be at the higher or normal intelligence level does raise concerns that some ASD in children with additional Learning Disabilities may be under-recognised across BCUHB. The data in figures 4-8 and 4-9 indicate that BCUHB’s recently diagnosed ASD child population may be mostly characterised by older, intellectually able children. Such children have more recently been recognised as overlooked in terms of diagnosis. The communicative abilities of the children diagnosed in the first half of 2012 may further help illuminate the issues raised here and in the previous section

4b.vi) **Verbal/non-verbal ASD status at the time of diagnosis.**

![Figure 4-10: The percentages of verbal or non-verbal children in BCUHB as whole and across areas of BCUHB. (From new Report Form data based on 82 cases, Jan.-June, 2012)](image)

Over half the BCUHB ASD children diagnosed in January-June, 2012, for whom there is data, are verbal. Given that communication impairment characterises autism, this finding seems surprising and it is important to enquire further about the language abilities of those verbal children who form the majority here. Even though a child is verbal, he or she may still have some level of language delay.
4b.vii) Language delay / Non-language delay at the time of diagnosis

This section considers the proportion of children with or without language delay, at the time of 2012 diagnosis, (the former includes nonverbal children) in BCUHB.

![Figure 4-11](chart.png)

**Figure 4-11:** The percentage of ASD cases with/out Language Delay at the time of Diagnosis across the areas of BCUHB and for BCUHB as a whole. (From new Diagnostic Report Form data, based on 82 cases in 2012)

The data from figure 4-11 seem to portray a similar picture to the intelligence data presented earlier and qualify the information given in the previous section. For East and West BCUHB and BCUHB as a whole, even though most of the children diagnosed in 2012 (Jan-Jun) are verbal, those with no language delay at all are out-numbered by those with some language delay who may or may not be verbal, as would be expected for ASD. However, the figures from Central BCUHB are surprising in this respect; here verbal children, with no language delay at the time of diagnosis, form the majority diagnosed there. It is of interest to consider whether these children diagnosed within Central BBCUHB are categorised as Asperger Syndrome. Diagnostic sub/categories of ASD are the focus of the next section.

4b.viii) Subcategories of diagnosis: ASD, Autism & Asperger Syndrome.

As outlined earlier, different diagnostic systems such as the International Classification of Diseases (ICD-10) and the Diagnostic Statistical Manual (DSM-IV) divide Autistic Spectrum disorders into different clusters (World Health Organization, 1993; American Psychiatric Association, 1994, respectively). These systems are revised regularly for better understanding of the disorders. The DSM system is undergoing revision (DSM-V is under development) and this may change the way ASD is conceived but the ICD system still focuses on the major divisions of the spectrum in terms compatible with: ASD, Autism, and Asperger Syndrome. The system used by
the CCH database is ICD-10. The new Diagnostic Report Form therefore has sub/categories also compatible with this, as did 2009’s analysis in Chapter 3.

Division of the major categories within ASD on the Diagnostic Report Form and in the CCH database can give additional information about the proportion of the different ASDs in the clinical population. This data can help inform future evaluation and intervention programs.

Figure 4-12: Comparison of percentages of Childhood Autism, Asperger Syndrome in the different areas of BCUHB (new Report Form based data from 82 BCUHB cases, Jan.-Jun, 2012).

Figure 4-12 shows that for East BCUHB, two thirds of the diagnoses are ASD, with the other third being Autism and Asperger Syndrome (2:1 respectively). In Central BCUHB, four fifths of the diagnoses are ASD, with the remaining fifth being Autism and Asperger Syndrome equally. In West BCUHB, half of the diagnoses are Autism, with the other half being Asperger Syndrome and ASD equally.
Therefore, the proportion of ASD children in each specific diagnostic category within the Autism Spectrum differs between the three areas of BCUHB. This could be due to demographics or differences in interpreting the diagnostic categories between the three BCUHB areas by staff. The use of standardised diagnostic instruments in ASD diagnosis and the recording of their results via the new ASD Diagnostic Report Forms will facilitate clarifying this difference and improving standardisation or identification of demographic differences.

4b.ix) Gender ratios.

ASD diagnoses in relation to gender are analysed below for different areas of BCUHB.

**Table 4-1:** Male: female ratios as percentages of the ASD diagnoses in the different areas of BCUHB (from 2012 Data on 82 cases)

<table>
<thead>
<tr>
<th></th>
<th>East</th>
<th>Central</th>
<th>West</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>81%</td>
<td>77%</td>
<td>77%</td>
</tr>
<tr>
<td>Female</td>
<td>19%</td>
<td>23%</td>
<td>23%</td>
</tr>
</tbody>
</table>

All the areas of BCUHB have higher number of male cases identified to have ASD than the female cases in proportions that would be expected for ASDs.

4c) Analysis of Clinicians’ Methods in Diagnosing Children with ASD

4c.i) Diagnostic Instruments employed in 2012

The diagnosis of ASD is often a lengthy process including use of one or more standardised or non-standardised tools; not all of them are used on all the occasions. The following are standardised ASD-specific assessment tools for which training on their administration and scoring is provided: the Autism Diagnostic Observation Schedule (ADOS; Lord et al, 2001); the Autism Diagnostic Interview-Revised (ADI-R; Le Couteur, et al, 2004); the Diagnostic Interview for Social and Communication Disorders (DISCO; Leekam et al, 2002); and, the Developmental, Dimensional and Diagnostic Interview (3di; Skuse et al, 2004). Later in this section are figures representing the number of instruments used in reaching the ASD diagnoses from January to June, 2012, in BCUHB as a whole and across the different areas of BCUHB.

An ASD diagnostic survey report for Wales, submitted to WG, indicates which particular Autism assessment tools were being used by clinicians across Wales in 2010 (Lidstone, Leekam, Wimpory, & Ramsden, 2010). Ten professionals selected from each geographical area were invited and, on average, these respondents estimated that:
• A standardised developmental history-taking instrument was used in an average of 63% of their cases (range 0 - 100).
• The Autism Diagnostic Observation Schedule (ADOS) was used in an average of 57% of their cases (range 0 - 100).

For Leekam et al.’s larger dataset of 118 respondents, the breakdown was as follows:
• ADOS (48%)
• 3di (25%)
• ADI or ADI-R (21%)
• DISCO (7%)
• DAISI (4%)

(DAISI: Detection of Autism by Infant Sociability Interview; Wimpory et al, 2000, Wimpory, 2012)

Whilst Leekam et al.’s figures are based on clinicians’ self-reported use of tools, the data for BCUHB that follows is taken from the actual reported tool use and scoring for specific diagnoses. It seems the practice has changed for BCUHB (shown in the figure below). The figures show that standardised tools are being used more frequently in both in BCUHB as a whole (4-13) and across most parts of BCUHB (4-14). This may be a consequence of the WG regional- and ASD stakeholder group-funded training provided to in recent years to BCUHB’s diagnosticians.

![Figure 4-13: Assessment tools used within ASD assessments: Levels of usage for each instrument across BCUHB as a whole. (Based on new Diagnostic Report Form data: 82 cases from 2012).](image-url)
Figure 4-14: Standardised tools used within ASD assessments: Usage distribution of the instruments by area. (2012 Data from New Diagnostic Report Forms (82 BCUHB Cases).

Figure 4-14 specifically reflects strong use of the ADOS for each area of BCUHB (although this is significantly weaker in Central BCUHB at approximately 34%). West BCUHB uses ADOS for over 85% of diagnoses whilst East BCUHB uses it for approximately 75% of cases and also uses the ADI-R even more frequently than the ADOS.

4c.ii) Scoring status of ADOS and other diagnostic instruments

The scores in different dimensions of a scale can help understanding the areas of major impairment and help in prioritising the treatment goals. When data on more cases is gathered over time these domain scores will enable delineation of subject/group profiles to portray the clinical population more clearly, prioritise areas of intervention etc. But this relies on the tools being administered on the identified cases being scored in a standardised manner. Responses to the 2012 ASD Diagnostic Report Forms indicate that not all clinicians score the tools that they administer for diagnoses of ASD.
Figure 4-15: Comparison of reported scored/un-scored ADOS assessments across East, Central and West BCUHB (Based on data from 82 new Diagnostic Report Forms, Jan.-June, 2012).

Figure 4-15 shows that East BCUHB appears to make scoring and non-scoring use of ADOS assessments, whilst West BCUHB scores these 100% of the time. Further investigation is needed to account for the apparent finding that no ADOS assessments were scored within Central BCUHB. Such details on how thoroughly ASD assessments appear to be conducted may inform BCUHB as to the reasons why more or fewer diagnoses are made over the same time period for different areas.

Figure 4-16: Comparison of reported scored/un-scored ADI/ADI-r assessments across East, Central and West BCUHB (Based on data from 82 new Diagnostic Report Forms, Jan.-June, 2012).

In a similar manner to their ADOS assessments, East-BCUHB appears to balance use of scored to un-scored ADI-R assessments at a 3:2 ratio (figure 4-16). ADI-R is professionally recognised as a thorough, but lengthy, standardised ASD diagnostic instrument; neither West nor Central-BCUHB employed it for their Jan-June 2012 diagnoses.
Figure 4-17: Comparison of reported scored/un-scored 3di/DISCO assessments across East, Central and West BCUHB.

The DISCO is also professionally recognised as a very thorough, though also lengthy, standardised diagnostic instrument. The 3di may be conceptualised as a computerised version of the ADI-R. Figure 4-17 shows how use of the 3di and/or DISCO is always scored in the 2012 reported diagnoses in West-BCUHB whereas use of the 3di and/or DISCO is always un-scored in the 2012 reported diagnoses in East-BCUHB; neither of these instruments is used for parallel diagnostic assessments in Central BCUHB.

For data analysis, it has been assumed that where diagnosticians fail to record any domain scores for the diagnostic instruments that they report they have employed, this indicates their “non-scoring” use of such instruments. However, it may alternatively indicate that the clinicians have simply failed to provide this specific data, despite the ASD Diagnostic Report Form asking them to do so. The ASD Database Team will seek clarity on this issue during extension of the project (see Chapter 6, section e).

4c.iii) Degree of cross disciplinary/agency professional involvement in 2012 ASD diagnoses

The diagnosis of ASD is best made in a multidisciplinary manner and therefore the level of involvement of the different professionals contributing to each diagnosis is reported on the new ASD Diagnostic Report Forms. Paediatricians (Pd), Psychiatrists (P), Clinical Psychologists (CP), Speech and Language Therapists (SALT), Occupational Therapists (OT), Mental Health Practitioners (MHP), Educational Psychologists (EP), Nurses (N) etc. can contribute to ASD diagnosis and the available staff will vary between situations. Figure 4-18 shows the involvement of different groups of professionals in the diagnostic process of the children with ASD across BCUHB as a whole during the first six months of 2012. Clinical Psychologists,
Psychiatrists and Nurses are most commonly involved in ASD diagnoses in BCUHB. Speech and Language Therapists are the fourth most involved profession.

Figure 4-18: The professionals involved in the diagnosis of ASD across BCUHB 2012 Data from New Diagnostic Report Forms (82 cases)

Figures 4-19 shows that Central and East BCUHB take a more multidisciplinary approach to ASD diagnosis. Frequently, and especially in Central BCUHB, more than three professionals are directly involved with an ASD diagnosis.

Figure 19: Cross-disciplinary staffing collaborations for ASD diagnosis across the three areas of BCUHB. (2012 Data from new Diagnostic Report Forms for 82 Cases)

Figure 4-20 clarifies that in West BCUHB the ASD diagnoses are predominantly made by Clinical Psychologists. However, they work with each other in collaboration and invite Educational Psychology colleagues to
diagnostic clinics. Speech and Language Therapist and Psychiatrist involvement is reported as particularly low in West BCUHB diagnoses. Nurses predominate in East BCUHB ASD assessments, where (figure 4-2 shows) the highest numbers and proportions of diagnoses were recorded for 2012. Clinical Psychologists predominate this process in Central BCUHB where there is also heavier reliance on Psychiatrists than in the other areas of BCUHB.

**Figure 4-20**: The professionals involved in the diagnosis of ASD in the three areas of BCUHB. (2012 Data from New Diagnostic Report Forms (82 BCUHB Cases)

It may be that the data collected by the new Diagnostic Report Forms could contribute to finding the best staff to client ratio for ASD diagnosis in terms of staff costings as well as accuracy of diagnosis. The area with the highest numbers of ASD diagnoses for January-June, 2012, East BCUHB, reports most Nurse involvement in the diagnostic process. This may be related to the fact that Nurses are less expensive than Clinical Psychologists and Psychiatrists. However, initial Nurse training does not involve diagnosis as a core skill, unlike the other two professions. Such skills have to be acquired by subsequent training.

4d) **ASD Child Cases Recorded by CCH Database for the Different LHBs across Wales, Jan-April, 2012.**

National CCH data becomes available quarterly, the last period ended 30th of April, 2012. It is therefore possible to compare the numbers of children reported on CCH database for the period January to April (inclusive) for each LHB. These National CCH database figures enable some comparison of BCUHB with other LHBs.
**Table 4-2.** Numbers of children added to CCH database across Wales LHBs, during Jan-April, 2012

<table>
<thead>
<tr>
<th>LHBs</th>
<th>ASD Cases reported on CCH database Jan-April 2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abertawe Bro Morgannwg University LHB</td>
<td>0</td>
</tr>
<tr>
<td>Aneurin Bevan LHB</td>
<td>0</td>
</tr>
<tr>
<td>Betsi Cadwaladr University LHB</td>
<td>30</td>
</tr>
<tr>
<td>Cardiff &amp; Vale University LHB</td>
<td>6</td>
</tr>
<tr>
<td>Cwm Taf LHB</td>
<td>5</td>
</tr>
<tr>
<td>Hywel Dda LHB</td>
<td>4</td>
</tr>
<tr>
<td>Powys Teaching LHB</td>
<td>1</td>
</tr>
<tr>
<td>Total for Wales</td>
<td>46</td>
</tr>
</tbody>
</table>

National CCH data (Table 4-2) show 30 ASD cases being reported to BCUHB’s CCH database during January-April, 2012. Two LHBs show no ASD cases recorded in this same period whilst the remainder show between 1 and 6 cases added (not all of these would have been necessarily been diagnosed in that period, for example, some may have moved into the area).

Although the BCUHB 2012 ASD Diagnostic Report Forms have been implemented from 1.1.12, they were applied retrospectively to the early 2012 diagnoses, as formal BCUHB commitment to the forms dates from February 2012. There was therefore an inevitable initial lag effect for their completion and submission to the CCH database that is reflected in the data that follows. Nevertheless the contrast, in BCUHB’s favour, between BCUHB and other LHB data is impressive.

As table 4-2 shows, BCUHB has almost twice as many entries in 2012 as all the other Wales LHBs put together! (Two of the LHBs did not submit any ASD diagnoses, whilst the remainder report from just 1 to 6 cases each.) This data strongly supports the implementation of ASD Diagnostic Report Forms across Wales, as discussed in Chapter 7.

As indicated above, the data reflect diagnoses reported on the CCH database and these likely under-represent actual diagnosed cases (82 clinical diagnoses were actually registered on the CCH database for the first six months of 2012 in BCHUB). However the enhanced numbers of ASD cases in BCUHB by the end of April 2012 are still indicative of positive effects of an increased focus on reporting ASD diagnoses in this LHB.
As indicated in 4bii above, the relative rates of CCH database-reported diagnoses were 1/month for 2009 and 14 per month for 2012. Such a dramatic rise in CCH database reported diagnoses appears in response to the systematic enhancement of the CCH reporting process, this effect on CCH records would be most welcome across Wales (see Chapter 7’s national recommendation).

**4e) Potential for Cross Services Analysis within BCUHB**

It is anticipated that the continual return of ASD Diagnostic Report Forms within BCUHB (and the corresponding increase in sample size over time) will enable analysis of different services within BCUHB rather than this be limited to the three geographical (ex-Trust) areas as in this report. This will be of interest as BCUHB includes (virtual) ASD teams or ASD-specific services (particularly in East BCUHB) as well as children’s disability services, CAMHS etc. Initial comparisons indicate there are variations in the proportions of diagnoses undertaken by CAMHS as opposed to other services between the three BCUHB areas. For example, in January-June 2012, CAMHS diagnosed approximately 70% of Central BCUHB cases but only approximately 20% of West BCUHB cases.

A limitation on this approach is that the non-CAMHS services across BCUHB are not immediately comparable (including ASD-specific and broader child disability services that may or may not have cross agency integration). Variation on the intervention responsibilities of such services, as well as the profiles of their typical service users, may impact on the numbers of children diagnosed. It may be, for example, that the diagnostic requirements of younger, less able children with more complex needs are more time consuming.

Diagnostic numbers analysed in this chapter reflect Diagnostic Report Forms submitted to CCH database coders and entries in the CCH database. There may be small increases in such figures over time due to possible delays in entering submitted forms for individual children onto the ASD Module. However, the ASD enhanced system, functioning from 1.1.12 and in the future, continues to provide a much more reliable means to record cases than previous auditing methods.
4f) Summary of Chapter 4

- Submitting the ASD Diagnostic Report Form to CCH database coders is now a permanent obligation on all ASD diagnosticians, within BCUHB’s Minimum Standards for Assessment and Diagnosis of ASD.

- In contrast to the apparent full reporting of 82 diagnoses during the first 6 months of 2012, only 12% of BCUHB’s 126 diagnoses were reported to the CCH database in 2009.

- The relative rates of CCH database-reported diagnoses were 1/month for 2009 and 14 per month for 2012.

- Current average age at diagnosis is 8.8 years (i.e. lower than 9.3 years for 2009’s audit). It is 9.3 yrs in East, 10.1 yrs in Central & 6.9 yrs in West.

- On average, it’s 12 months from ASD assessment referral to diagnosis.

- For cases where intellectual level is reported, ASD is diagnosed more often in higher intellectual functioning children.

- ASD diagnoses represent a much greater proportion of the ASD type diagnoses in Central BCUHB than is the case for other BCUHB areas.

- The most frequently used standard diagnostic tools are ADOS and ADI-R. The type of ASD diagnosed and the child’s age and intellectual ability appear related to the methods used and time taken for diagnosis.

- Across BCUHB, Clinical Psychologists are most often the diagnosing professionals. Psychiatrists and Nurses are also frequently involved. Nurses are less expensive and their initial training focuses less on diagnosing, however, their predominance correlates with increased diagnostic numbers.

- Initial diagnostic/area profiles indicate that more children are diagnosed where they are older, more able and verbal, than where they are younger, less able and with more complex needs (the latters’ diagnostic requirements may be more time consuming).

- Future submissions of Diagnostic Report Forms should enable service-, rather than area-, based analysis. CAMHS may play a very different role in diagnosis across different BCUHB areas, e.g., diagnosing approximately 70% vs. 20% of ASD in Central and West areas respectively in the first six months of 2012.
Chapter 5:

ANALYSES APPLIED TO THE MOST COMPLETE DATASETS:
OVER 1000 ASD CASES FROM COMBINATIONS OF 2009 AUDIT, 2012
DIAGNOSTIC REPORT FORMS AND THE ORIGINAL CCH DATABASE

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5d) Summary of Chapter 5 65

5a) Introduction: Outline of the ASD-enhanced CCH database, totalling over 1000 cases and incorporating 2012 and 2009 ASD diagnoses previously unreported on the CCH database.

The data for 2009 was audited and the 2012 data were collected by using the new ASD Diagnostic Report Forms submitted from January to June 2012 (inclusive); these data sets have been added to those from the original CCH database up to 31.12.11, as detailed below and in figure 5-1:

- 795 cases from BCUHB’s original unenhanced CCH (1982-2011, inclusive)
- 127 cases from BCUHB’s 2009 audit previously unrecorded on the CCH database (also incorporating 18 diagnoses presented in 2010)
- 82 completed returns of ASD diagnostic report forms (1.1.12 to 30.06.12)
- Totalling 1004 BCUHB cases (1982-2012)
Increasingly detailed information has been gained on service users over time, culminating in submissions of the 2012 ASD Diagnostic Report Form to the CCH database (detailed in Chapter 4).

![Figure 5-1: The Datasets Contributing to the ASD-enhanced dataset (1004 BCUHB cases from 2009, 2012 & original unenhanced CCH database)](image)

Figure 5-2 indicates that the three areas of BCUHB have been contributing approximately equivalent numbers of individuals with ASD to the original unenhanced CCH database, despite West and Central's populations being much smaller than those of East BCUHB. However, in recent years Central BCUHB’s contribution has been proportionately greater than those of East and West BCUHB when population sizes are taken into account. For interest, here is a reminder of the relative child population figures for these three areas; Central, East and West, 43,533; 62,482 and 39,148, respectively.
5b) Comparison of the recently ASD-enhanced CCH database with the original unenhanced CCH database: ASD prevalence in BCUHB and its constituent areas.

ASD enhancement to the CCH database correlates with an increase in the CCH database recorded prevalence of ASD in BCUHB from 0.12% to 0.15% for Adult and Child figures combined and 0.35% to 0.5% for children with ASD (see Table 5-1 below). Given that the Diagnostic Report Forms are a permanent obligation on BCUHB Diagnosticians (and that Chapter 7 confirms regional backfill funding) it can be anticipated that this rate of increase in the prevalence of ASD in BCUHB’s child population may be maintained until the number of CCH database recorded child cases reaches levels similar to the standard prevalence for ASD (approximately 1%).

Table 5-1: The CCH database recorded prevalence for ASD in BCUHB total population from the original unenhanced CCH database to the ASD-enhanced dataset.

<table>
<thead>
<tr>
<th></th>
<th>Prevalence of Adult &amp; Child ASD in BCUHB</th>
<th>Prevalence of Child ASD in BCUHB</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unenhanced database</td>
<td>0.12%</td>
<td>0.35%</td>
</tr>
<tr>
<td>ASD-enhanced database</td>
<td>0.15%</td>
<td>0.5%</td>
</tr>
</tbody>
</table>

Prevalence for ASD in children has increased, following ASD enhancement of the original CCH database, as follows, for each area of BCUHB: from 0.26% to 0.5% for Central, from 0.38% to 0.52% for East and from 0.39% to 0.45% for West (child populations for each are 43,533, 62,482 and, 39,148, respectively).

5c) ASD Comorbidity:

Some disorders such as Fragile X Syndrome occur together with ASD more often than what would be expected by chance. Disorders that group together like this are termed comorbid. Disorders that are comorbid with ASD include:

5c.i) Fragile X Syndrome (FXS)
5c.ii) Phenylketonuria (PKU) and ASD
5c.iii) Valproate Embryopathy (VE)
5c.iv) Tuberous Sclerosis Complex (TSC)
5c.i) Fragile X Syndrome (FXS)

The primary cause of Fragile X Syndrome is damage to a single gene, the *FMR1* gene. Well-characterised forms of comorbidity (like ASD and Fragile X Syndrome; ASD and Phenylketonuria; ASD and Tuberous Sclerosis Complex) shed light on the complicated biology of ASD. Research shows that damage within a large set of genes can increase the risk of autism. Some of these genes contribute more frequently to the risk of ASD in the general population.

The *FMR1* gene can be checked for damage by a laboratory test and studies have collated the results of such tests to determine a standard prevalence for Fragile X Syndrome. The population size of BCUHB and the standard prevalence for Fragile X Syndrome can be used to determine the expected number of individuals with Fragile X Syndrome in BCUHB.

Table 5-2: Reported & Expected Rates of Fragile X Syndrome (FXS) for BCUHB & constituent areas (based on ASD child cases from the enhanced database; N=727)

<table>
<thead>
<tr>
<th>Child population</th>
<th>EAST</th>
<th>CENTRAL</th>
<th>WEST</th>
<th>BCUHB</th>
</tr>
</thead>
<tbody>
<tr>
<td>Predicted FXS cases (1:4000)</td>
<td>15</td>
<td>11</td>
<td>10</td>
<td>36</td>
</tr>
<tr>
<td>Reported FXS cases</td>
<td>0</td>
<td>3</td>
<td>4</td>
<td>7 (19%)</td>
</tr>
<tr>
<td>Number of FXS cases apparently missed</td>
<td>15</td>
<td>8</td>
<td>6</td>
<td>29 (81%)</td>
</tr>
</tbody>
</table>

By comparing the CCH database reported rate of Fragile X Syndrome in BCUHB with the standard prevalence, it can be determined how well this disorder is being recognised and reported in the CCH database. Table 5-2 shows that the rate of CCH reporting of Fragile X Syndrome in BCUHB is 81% lower than expected and this rate varies dramatically across the 3 areas.

5c.ii) Phenylketonuria (PKU) and ASD

Phenylketonuria PKU is caused by damage to the *PHA* gene. This damage prevents Phenylalanine from being metabolised and maintained at healthy levels. Phenylalanine is normally present in food. In PKU children, Phenylalanine build-up leads to brain damage but early intervention to strictly limit the amount of Phenylalanine in the diet can limit the degree of damage and support typical development. Dietary intervention in late diagnosed PKU can improve the behavioural difficulties and intellectual function.
The incidence of PKU varies, with Irish and Turkish populations having the highest incidence: 1:4,500 and 1:2,600 live births, respectively. PKU screening via the neonatal heel prick aims to catch the baseline incidence. Nevertheless cases still occur, for example, due to birth outside hospital, screening too early, and false negative results. Table 5-3 shows the number of classical PKU cases reported in the CCH database for each of the areas of BCUHB.

Table 5-3. Numbers of Individuals in BCUHB with Classical PKU recorded on the enhanced CCH database (1004 Cases).

<table>
<thead>
<tr>
<th>Actual PKU cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>East</td>
</tr>
<tr>
<td>------</td>
</tr>
<tr>
<td>5</td>
</tr>
</tbody>
</table>

Children who develop PKU often fulfil criteria for ASD in addition to the Learning Disability caused by PKU. Research considering the overlap between ASD and PKU showed a 20% overlap when individuals with both Autistic Disorder and Learning Disability were screened. A 2% overlap was found when an ASD group (excluding Asperger’s Syndrome) were screened for PKU (Knobloch and Pasamanick 1975). In a study group of classic late-diagnosed PKU, all with Learning Disability, 5.7% met ASD diagnostic criteria (Baieli et al. 2003).

This indicates that BCUHB children with both ASD and Learning Disability and no evidence of a PKU test should be tested for PKU. According to the CCH database, 19% of BCUHB ASD children have no PKU screening test result recorded. (Tables 5-4 and 5-5 show the breakdown for these figures over the 2009 and 2012 samples; these figures are combined for Table 5-5)

Table 5-4: Coverage of the PKU screen in BCUHB (2009 audit, 126 cases):

<table>
<thead>
<tr>
<th>% of 2009-diagnosed ASD children missing a PKU screen result</th>
</tr>
</thead>
<tbody>
<tr>
<td>East</td>
</tr>
<tr>
<td>------</td>
</tr>
<tr>
<td>21%</td>
</tr>
</tbody>
</table>
**Table 5-5**: Coverage of the PKU screen in BCUHB: percentages of 2012-diagnosed ASD children missing a PKU screen result (based on 82 cases):

| % of 2012-diagnosed ASD children missing a PKU screen result |
|-----------------|--------|------|-------|
| East            | Central| West | BCUHB |
| 13%             | 21%    | 0%   | 13.4% |

**Table 5-6**: Coverage of the PKU screen in BCUHB: numbers for areas and percentages of 2009- & 2012-diagnosed children missing a PKU screen result (based on 226 cases):

<table>
<thead>
<tr>
<th>No of 2012+2009 ASD children missing a PKU screen result</th>
<th>% 2012+2009 ASD children missing a PKU screen result</th>
</tr>
</thead>
<tbody>
<tr>
<td>East</td>
<td>Central</td>
</tr>
<tr>
<td>17</td>
<td>24</td>
</tr>
</tbody>
</table>

These statistics are concerning; in the much larger population of individuals with Learning Disability in BCUHB, there may be a similar proportion of unconfirmed PKU screen tests.

5c.iii) **Valproate Embryopathy (VE)**

Certain drugs have been found to increase the risk of ASD if taken during pregnancy. It has been shown that Thalidomide and Valproate can each cause autism when taken early in gestation. Whilst these drugs are still clinically useful, women having to take Valproate for epilepsy, for example, inadvertently increase the risk of having a child with ASD if they become pregnant whilst on treatment.

**Table 5-7**: Numbers of children with Valproate Embryopathy for each BCUHB area, (based on BCUHB’s child population of 145,163)

<table>
<thead>
<tr>
<th>Valproate Embryopathy</th>
</tr>
</thead>
<tbody>
<tr>
<td>East</td>
</tr>
<tr>
<td>0</td>
</tr>
</tbody>
</table>
**Table 5-8**: Numbers of BCUHB children with Valproate Embryopathy and ASD for each BCUHB area, (based on BCUHB's child population)

<table>
<thead>
<tr>
<th>Valproate Embryopathy and ASD</th>
<th>East</th>
<th>Central</th>
<th>West</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
</tbody>
</table>

The comorbidity of Valproate Embryopathy and ASD is reflected in the 50% (2 out of 4) cases of Valproate Embryopathy in West BCUHB also having ASD (Tables 5-7 and 5-8). This figure suggests that increased awareness of this comorbidity may help to encourage vigilance.

5c.iv) **Tuberous Sclerosis Complex (TSC)**

Approximately half of all individuals with Tuberous Sclerosis Complex have Learning Difficulties and a similarly high proportion meet the diagnostic criteria for ASD. The prevalence of Tuberous Sclerosis Complex in the general population has been estimated as between 7 and 12 cases per 100,000; over half of cases are likely to represent undiagnosed Tuberous Sclerosis Complex (TSC).

**Table 5-9**: Numbers of BCUHB’s Actual ASD Cases Comorbid with TSC for each area, based on 1004 cases. (60 cases should be expected in total, over half of these are likely to be undiagnosed so it is reasonable to expect ~30 TSC cases in BCUHB).

<table>
<thead>
<tr>
<th>TSC recorded on CCH database</th>
<th>Actual</th>
<th>Predicted</th>
<th>% of cases likely missed on CCH database</th>
</tr>
</thead>
<tbody>
<tr>
<td>East</td>
<td>Central</td>
<td>West</td>
<td>BCUHB</td>
</tr>
<tr>
<td>5</td>
<td>4</td>
<td>6</td>
<td>15</td>
</tr>
</tbody>
</table>

Table 5-9 shows that 15 cases of Tuberous Sclerosis Complex are identified in the BCUHB by the CCH database. This is at least half the expected number for the BCUHB general population and not proportionate to the population size of each area. 50% of BCUHB’s predicted TSC cases are not represented in the ASD-enhanced CCH database.

The role of the Tuberous Sclerosis Complex gene products, TSC1 and TSC2, in the function of the mTOR biochemical pathway in the cerebellum adds to understanding of the gene pathways and brain areas that are likely to be
damaged in ASD. Recent studies in mice with damaged TSC1 and TSC2 genes show that drugs that target the TSC/mTOR pathway can prevent autism-like behaviour that is otherwise displayed by the TSC animals. The success of treatments likely to spin out from this breakthrough will ultimately depend on precise identification of this ASD comorbidity. The ASD enhancement of the CCH database is a step in this direction.

5d) Summary of Chapter 5

- Prevalence for ASD in children has increased, following ASD enhancement of the original CCH database, as follows, for BCUHB as a whole: from 0.35% to 0.5% (and from 0.26% to 0.5% for Central, from 0.38% to 0.52% for East and from 0.39% to 0.45% for West-BCUHB).

- The permanent obligation on BCUHB clinicians to submit ASD Diagnostic Report Forms (in addition to backfilling commitments outlined in Chapter 7) can be anticipated to maintain the increase in prevalence for child ASD in BCUHB, as recorded on the ASD enhanced CCH database (until it is similar to standard prevalence).

- 19% of ASD cases are not recorded as screened for PKU on the CCH database. For some of these cases, screening could identify that remediating treatment is appropriate.

- CCH-recorded Fragile X Syndrome (FXS) cases are far fewer than predicted from the expected rate. BCUHB may therefore be missing 81% of its FXS cases present in the population.

- The prevalence of Valproate Embryopathy and Tuberous Sclerosis Complex does not scale with population size across the three areas of BCUHB suggesting that BCUHB identification/CCH-recording anomaly also exists for these other forms of ASD comorbidity.
Chapter 6:  
SUMMARY OF THE ASD DATABASE FINDINGS:  
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6e) Conclusions from Summary of ASD Database Findings; Basis for Recommendations in Chapter 7 73
6a) Introduction: The Original Purpose of the Database, a Regional Pilot for a National ASD Database for Wales

The ASD Database was designed to determine the feasibility of an ASD Database for Wales as outlined in the original proposal (see excerpt on page 16 in Chapter 1) and envisaged in original WG discussions. At the conclusion of its development phase, this pilot regional database for ASD now operates with over 1000 cases (aged from 2 years up to 30 years) within the 6 counties of BCUHB, reflecting the previous three Health Trusts. All diagnoses from 1.1.2012 will be recorded via the new ASD Diagnostic Report Forms, and their details stored within the new ASD Database module via CCH database coders; a valuable resource for planning the future directions of ASD service development within BCUHB and more widely.

Until the CCH database is ASD-enhanced across the whole of Wales, there is limited data on which other LHBs maybe compared. However, to determine the effect of the regional ASD Database project, prevalence figures etc. have been considered in relation to other LHBs where possible. These findings are summarised, in b) below, along with details of diagnosing ASD within BCUHB and it's 3 constituent areas (in c). They support the report's most important recommendation: To progress the ASD database from regional pilot, to national roll out, as an ASD Database for Wales (as outlined in Chapter 7).

6b) What has been the effect of the regional ASD Database Project on ASD Prevalence and CCH Database Records?

6b.i) Prevalence

BCUHB had very low prevalence of ASD in Adults and Children recorded in the original unenhanced CCH database (0.12% at the end of 2011). Whilst the ASD Database is limited to North Wales, BCUHB's original low prevalence remains paralleled by low rates of ASD reporting to the CCH database by the other LHBs of Wales.

The low prevalence of ASD children in BCUHB was recorded by the original unenhanced CCH database as 0.35% at the end of 2011. This is substantially lower than the standard prevalence rate of 1%. However, following permanent ASD enhancements in BCUHB, prevalence for ASD in children there has improved to 0.5%. This is almost ten times higher than that of the LHB with the lowest prevalence in Wales: Abertawe Bro Morgannwg University LHB (ABM), at 0.05%.
Given that the Diagnostic Report Forms are a permanent obligation on BCUHB Diagnosticians (and Chapter 7’s confirmation of funding of regional backfilling) it can be anticipated that BCUHB’s recent overall rate of increase in the prevalence of ASD in the child population may be maintained until the number of CCH database recorded child cases reaches levels similar to the standard prevalence for ASD (approximately 1%).

Improved prevalence rates for ASD in children following ASD enhancement of the CCH database are reflected in each of BCUHB’s three areas. They improved as follows: from 0.26% to 0.5% for Central-; from 0.38% to 0.52% for East-; and, from 0.39% to 0.45% for West-BCUHB.

6b.ii) CCH-recorded & other measures of Diagnostic Rates for 2009/2012

BCUHB was the LHB with the largest number of ASD cases reported in Wales CCH database during this project’s first comparison period, 2009. However, the CCH database failed to record 88% of the actual diagnoses made in BCUHB during that year. The number of BCUHB diagnoses missed by the CCH database in 2009 almost matched the number recorded by it for all other LHBs combined in Wales for that year. During both the 2009 and 2012 comparison periods, there were some LHBs in Wales not reporting any cases of ASD. In the first 4 months of 2012, whilst the new ASD Diagnostic Report Forms for the CCH database were being introduced and implemented in BCUHB, almost twice as many ASD cases were recorded there as there were in all the other Wales LHBs combined for that period.

Rates of BCUHB diagnoses recorded by the CCH database for 2009 vs. 2012:

These perhaps best reflect the impact of the regional ASD Project on BCUHB. On average, 1 diagnosis/month was recorded in 2009 on the original unenhanced CCH database, whilst 14 diagnoses/month were recorded in 2012 on the CCH database (following ASD-enhancement). Actual numbers and further details relating to ASD diagnoses are presented in the next section.

6c) Summary of remaining findings from within BCUHB & its 3 areas:

6c.i) Numbers of recent diagnoses

These have risen since ASD-enhancement of the CCH database for BCUHB and for all its areas except Central BCUHB where diagnostic numbers appeared exceptionally high in 2009. In 2009, BCUHB diagnosed 126 cases.
The Central area diagnosed the highest number (67) of ASD cases that year as compared to East (51) and the minimum number in West (8). If the first 6 months of enhanced CCH recorded diagnoses from 2012 is doubled to enable comparison, then the relevant figures for BCUHB would be 164 diagnoses over one year with the break down over Central, East and West BCUHB as: 44; 92 and 24, respectively.

6c.ii) Age at diagnosis

Following ASD-enhancement of the CCH database, the average age of diagnosis has dropped from 9.3 years (in 2009) to 8.8 years (in 2012). Age at diagnosis currently ranges from 2.5 to 17.8 years. For East BCUHB, the average age at diagnosis dropped for this period from 10 to 9 years. For Central and West BCUHB, it rose from 9 to 10 years and from 5 to 7 years respectively (figures for areas are rounded off to nearest year).

6c.iii) Time between referral and diagnosis

The average time between referral and diagnosis for BCUHB is 12 months. West-BCUHB has the minimum gap (9 months) between referral to diagnosis whereas this is 13 months and 15 months for Central and East areas respectively.

6c.iv) The extent to which clinicians employ standardised diagnostic tools

52% of BCUHB clinicians use more than one tool for diagnoses. They use the standardised diagnostic tool, ADOS, more frequently (for 65% of cases) in 2012 than what was observed by Leekam et al (2010) who found only 48% of Welsh clinicians used ADOS. Just over half the most frequently used standardised ASD assessment tools (ADOS & ADI-R) were reported as scored in BCUHB.

West BCUHB uses gold standard tools like ADOS in 86% of cases; in East this is used for 75% and in Central-BCUHB this is used for 34%. ADOS is reported as scored in 100% of West cases, 51% of East cases and none of Central’s cases.

6c.v) Professional collaboration for diagnoses

Over 60% of ASD diagnoses in BCUHB are appropriately made by more than three collaborating disciplines. Most frequently, Clinical Psychologists, Nurses and Psychiatrists contribute to ASD diagnosis. Most of the ASD diagnoses are
made by Clinical Psychologists/Psychiatrists across the three BCUHB areas, although Nurses predominate in East BCUHB.

Central-BCUHB works in a multi-disciplinary way (involving more than three different professionals) for almost all their cases, East-BCUHB does so for 65% of cases. West-BCUHB has the highest proportion of diagnoses made by single professional group: usually Clinical Psychology. In practice, these diagnoses are made by Clinical Psychologists working together in diagnostic clinics where other disciplines/agency staff are invited.

It is of interest that the area with the highest numbers and proportions of ASD diagnoses, East BCUHB, relies most heavily on Nurses. Nurses are less expensive than Clinical Psychologists and Psychiatrists but their core training does not focus on diagnosis in contrast to these other two professions.

6c.vi) Clinicians’ estimations of abilities in diagnosed ASD cases.

Over half the 2012 BCUHB diagnosed cases are reported as of normal to high intellectual functioning and a similar proportion are reported as verbal. BCUHB’s Central area reports diagnosing ASD in a greater proportion (65%) of children with higher or normal intelligence than does (East 52%) or West (43%). For cases where data is available, approximately 29% of ASD diagnoses in West and East areas are reported to have mild-severe level of learning disability but, puzzlingly, less than 17% of Central's cases are reported at that level.

Of further concern is that information about intellectual functioning is not known/reported for about 20% of cases across BCUHB (and specifically for 19% of cases in East-, 17% of cases in Central- and 29% of cases in West-BCUHB). Only approximately 15% of all BCUHB cases are non-verbal (this data in unreported for 9% of cases). Non-verbal children are reported for 29%; 14% and 9% of West, East and Central BCUHB diagnoses respectively. These figures appear to reflect relative strengths in diagnosis of older intellectually able children where ASD is generally becoming more recognised.

6c.vii) Subcategories of diagnoses

ASD is the diagnostic category employed for two thirds of East BCUHB (Autism and Asperger make up the rest, 2:1 respectively); ASD is employed for half of West BCUHB’s diagnoses (Autism and Asperger make up the remainder, equally), confirming the picture, indicated above, that are larger proportion of their cases represent younger more severe autism in more disabled children than in the other areas. Four fifths of Central BCUHB’s
diagnoses are ASD (Autism and Asperger make up the remainder, equally). Given that more able verbal cases predominate Central BCUHB diagnoses, it is surprising that there are so few Asperger diagnoses there.

6c.viii) ASD Comorbidity

The major genetic disorders comorbid with ASD include: Fragile X Syndrome, Tuberous Sclerosis Complex and Phenylketonuria (PKU). For each of these disorders, prevalence in the CCH database is well below expected for the size of BCUHB’s population. Another syndrome that justifies increased vigilance is Valproate Embryopathy (a cause of ASD and an inadvertent possible consequence of Valproate being taken for maternal epilepsy during pregnancy).

Improved identification/CCH database reporting of these conditions is required for all BCUHB areas. West BCUHB has slightly better reports: some 2009 and 2012 ASD diagnoses have also been identified to have Fragile X Syndrome or Valproate Embryopathy. PKU is a metabolic disorder that, if untreated, leads to severe Learning Disability often accompanied by ASD. Although 100% of West BCUHB 2012 ASD diagnosed cases were screened for PKU, East and Central areas missed reporting these National PKU Screening Programme test results for 13% and 21% respectively. 19% were missed over BCUHB as a whole for 2009 & 2012-diagnosed ASD cases.

Unfortunately, with no record, it is not possible to say whether the child is positive or negative for PKU or if PKU is the likely cause of their ASD/Learning Disability. From CCH database analysis alone, the possibility remains therefore that undiagnosed PKU may be accompanying and exacerbating cases of ASD in BCUHB, PKU is a treatable disorder.

6d) Limitations of the Pilot Phase; informing improvements to incorporate into subsequent extension(s) of the ASD Database

During subsequent regional and/or national database extensions (see chapter 7), feedback will be sought from BCUHB clinicians to clarify areas of the form that have been less useful or less comprehensively covered during the pilot period (e.g., estimations of the child’s intellectual ability). It is likely that forms without domain scores for ASD assessments can be returned to diagnosticians for completion, unless indication is given that their use was not scored. When data on more cases is gathered over time these domain scores will enable delineation of subject/group profiles to portray the clinical population more clearly, prioritise areas of intervention etc.
Both request for IQ scores and the invitation to say which aspects of the triad are affected will likely be dropped from Diagnostic Report Forms in the future as sufficient data from these was not forthcoming or sufficiently useful. This, and electronic versions, will make the forms less onerous for clinicians and therefore justify their return to those clinicians whose responses on the forms are incomplete.

Increased returns through the on-going ASD Database Module will afford sufficient data for analyses across services as well as across areas, for example, CAMHS in contrast to specific services for children with ASD or broader disabilities. The area-based analysis of the current report reflects the original three health trusts that merged to form BCUHB and historical structures that have evolved for ASD diagnosis.

However, area-based analysis can mask discrepancies across the region. Examples are best provided for Central and West BCUHB where populations are roughly comparable (Child population for Central is 43533 and for West is 39148). For the first six months of 2012, approximately 70% of Central BCUHB’s ASD diagnoses were made by Central BCUHB’s CAMHS whilst approximately 20% of West BCUHB’s diagnoses were reported from this period by West BCUHB’s CAMHS. However, the care pathway in West-BCUHB has previously determined that all cases aged below 9yrs are diagnosed outside CAMHS.

Finer grained analyses may be able to examine the effects of intervention responsibilities on such different services in terms of their impact on diagnostic numbers. In future analyses it may also prove appropriate/possible to add other elements of the CCH database into our analysis. Developmental milestones, for example, a social smile at 6wks, as recorded by Health Visitor assessments within the CCH database, may be investigated as possible early indicators of ASD.
6e) Conclusions from Summary of ASD Database Findings; Basis for Recommendations in Chapter 7:

- It takes 12 months, on average, from referral for ASD assessment to ASD diagnosis in BCUHB.

- The average age of diagnosis has dropped from 9.3 years in 2009 to 8.8 years (in 2012) following ASD-enhancement of the CCH database.

- Most BCUHB diagnoses employ standardised instruments; just over half of these are scored.

- Initial diagnostic/area profiles indicate that more children are diagnosed where they are older, more able and verbal, than where they are younger, less able and with more complex needs.

- The latter may have more time-consuming diagnostic requirements and tend to be diagnosed by disability services where intervention responsibilities may impact on diagnostic capacity. The former are more likely to be CAMHS cases.

- There is wide variation in the proportion of children diagnosed by CAMHS services. Increased sample size from future Diagnostic Report Forms will enable a service-, rather than area-, based analysis.

- 88% of 2009 ASD diagnoses in BCUHB were missed on the CCH database.

- For the 2009 and 2012 comparison periods, some LHBs in Wales were not reporting any cases of ASD (as they should) on the CCH database.

- Enhancements to the CCH database are reflected in increased prevalence of ASD in children by from 0.35% to 0.5% for BCUHB; from 0.26% to 0.5% for Central; from 0.38% to 0.52% for East; and, from 0.39% to 0.45% for West areas.

- BCUHB CCH database-recorded diagnostic rates of ASD are now 14/month (contrasting with 1/month in 2009)

- The major forms of ASD comorbidity are currently under-recorded in the CCH database.

- Approximately 20% of PKU-test results are missing from the CCH database (2009/12). PKU is treatable and a known cause of autism.
Chapter 7:

PLANS AND RECOMMENDATIONS FOR THE FUTURE OF THE ASD DATABASE, WITH COSTING CONSIDERATIONS

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7a) Introduction

This chapter outlines the current position as the ASD Database project nears the end of its initial regional pilot phase, with respect to remaining commitments and funding. It presents two recommendations: The first is for regional developments and has had recent funding approval from BCUHB’s Charitable Funds. As was the case for Stage 1, BCUHB’s Charitable Funds have made their contribution in the hope that it will at least be matched by WG. In practice, the second recommendation, for progression to Stage 2 as National ASD Database for Wales, would require substantially more funding, as outlined below.

The chapter covers justifications as well as practical, planning, implementation, academic support and costing issues relevant for transition from Stages 1 to 2. It thereby outlines development of an All Wales ASD Database, as originally anticipated as a subsequent stage for the original Charitable Funds/WG-funded bid (see excerpt on p16 in Chapter 1).

7b) Current remaining commitments/funding

WG and BCUHB’s Charitable Funds each agreed no-cost extensions (till 31.3.13 & 31.3.14, respectively) enabling maintenance of minimum data collection by a very part-time staff member (1 day/wk) whilst the project’s next stages are clarified. In practice, this will exhaust WG’s Stage 1 funding by 30.9.12. As mentioned earlier, NISCHR awarded Dr Wimpory a Clinical Fellowship of two additional research days each week enabling her to focus specifically on genetics analysis of the ASD Database from 1.4.11 to 31.3.14. This fellowship therefore supports the regional and potentially some of the national developments outlined and proposed here.
7c) **Recommendations**

The recommendations, based on Chapter 6’s summarised findings, are as follows:

**Recommendation 1 (Regional):**
To improve on ASDs’ comorbidity-reporting within CCH database and back fill BCUHB’s database regionally

**Recommendation 2 (National):**
To progress from Stage 1, the pilot regional ASD Database to Stage 2, a National ASD Database for Wales (a subsequent stage originally envisaged in planning of the regional pilot with WG/BCUHB’s Charitable Funds)

7d) **Funded Plans for the Regional Extension of ASD Database Developments, supporting (Regional) Recommendation 1:**

Stage 1 findings have inspired further developments in North Wales; funding has been agreed (from local funders in combination with NISCHR) to extend the database regionally, from 1.1.13, by:

7d.i) **Populating the CCH database ASD module retrospectively** with diagnosed cases, from recent years across the region (Charitable Funds) and from recent decades in North West Wales (NWW Stakeholder Group); and,

7d.ii) **Improving reporting/analysis of comorbidity factors** within BCUHB (Charitable Funds).

Investment in the latter is in response to concerns that, for example, there are no screening CCH database PKU screening reports for a fifth of BCUHB’s 2009/2012 ASD cases, despite PKU being a known cause of ASD with
Severe Learning Disability; furthermore, PKU is treatable. Financial details from this paragraph are available on request. They confirm the commitment to fulfil the regional recommendation (1) of this report.

7e) Justification for Recommendation 2: Progression to Stage 2, a National ASD Database

Prior to this project, only a small percentage of BCUHB records of ASD cases were recorded on the CCH database and this remains the case for Wales other LHBs. The regional ASD Database pilot has now provided a process for ensuring good practice for recording BCUHB ASD cases and improving the prevalence and diagnostic rates of ASD in the CCH database. Without nationwide implementation of an ASD-enhanced CCH database, there is no comparable all Wales NHS data to consider in terms of the range of important findings from BCUHB (such as time from referral to diagnosis, average age at diagnosis, quality of assessment procedures, etc.).

The regional pilot findings highlight the growth in information on ASD diagnoses and their management that could be anticipated across Wales following national roll out of the CCH ASD Module. In the face of widespread under-reporting of ASD and related issues on the CCH database (some LHBs were not reporting any cases of ASD for the 2009/2012 comparison periods), there is an urgent need for its ASD enhancement across the whole of Wales rather than such developments to be limited just to North Wales.

The ASD Database Team already spans from Bangor to Cardiff. It is well placed for this role; BCUHB is the largest LHB and already has experience and recognition in nationally leading for Autism through the Adult ASD Network. Progression to Stage 2 will enhance early identification, recording and analysis of ASD cases, thereby facilitating better care and consistency across Wales.
7f) Planning Issues for Recommendation 2; Progression to a National ASD Database:

7f.i) Transition from Stage 1 to Stage 2

In anticipation of Stage 2 of the ASD database, the ASD Database Team have worked with national CCH information advisors to create an All Wales ASD module at a software level. This will be All-Wales compatible once national ASD reporting is implemented at a clinician/coder level. The extension stage of the ASD database project will involve some trouble shooting adjustment at the next software release (at least annually). Clinicians’ obligations could be facilitated through the provision of electronic versions of the Diagnostic Report Forms. There will be need to implement this at both managerial and clinician/coder level, the latter involving approximately 100 diagnostic/coding staff in each LHB.

7f.ii) Initial Details of Implementation Requirements for Stage 2

Regional pilot work showed that one of the most time-consuming aspects of the work is negotiating at LHB senior management level, for example, to gain agreement that completion of the diagnostic report form is compulsory for all ASD diagnosticians (now within BCUHB’s Minimum Standards for ASD Diagnosis and Assessment). It is for this reason that is recommended to offer LHBs database training and to negotiate with appropriate bodies and personnel throughout Wales, including approximately 100 diagnostic/coding staff in each LHB. Educational feedback of database findings is seen as a significant means to motivate staff’s continued cooperation/fulfilment of obligations for the project. This could usefully range from conference style presentations to 1:1 tutoring at specific LHB venues.

Dr Wimpory’s permanent joint post, as Consultant Clinical Psychologist – Lead for Autism (BCUHB) and Lecturer, positions her well for leading this cross-Wales extension of the ASD database. Her current NISCHR Clinical Research Fellowship already supports her database role for two days a week
until 31.3.14, and future plans for national roll out of the ASD Database would need to support that role thereafter. Her post is well-placed both to support: i) submission of a paper to the meeting of LHB Chief Executives, justifying and requesting commitment to a national ASD Database and, ii) supervision of the implementation of such a paper thereafter, at managerial and diagnostician levels, with appropriate NHS/academic staffing.

(Concluding Comments follow overleaf.)
7g) Concluding Comments:

7g.i) The importance of integration between implementation & academic components of the ASD Database (eg, the PKU and FXS findings)

It is important to recognise the essential integration between the implementation and academic components of the recommendation to progress to Stage 2 (national roll out). Without the scientific back up for planning and analysis, the serious situation of approximately a fifth of the audit and recent cases in this report having no CCH record of PKU screening would not have been identified. Similarly, there are no reported cases of the most prevalent heritable cause of ASD, Fragile X Syndrome, in two of BCUHB areas. Consideration of the standard prevalence for this syndrome indicates this is almost certainly a reporting problem and not a demographic anomaly. PKU and FSX are known causes of ASD and PKU is treatable, so every LHB has responsibility to ensure that its ASD population is 100% PKU-screened (National NHS obligations already require screening of all newborns).

National roll out of the ASD-enhanced Database Module for the CCH database would address these anomalies at an interdependent service development and scientific level. As indicated earlier, Dr Wimpory’s post incorporates permanent employment contracts, with both the NHS and Bangor University, for ASD Research and Service Development.

7g.ii) Experience from Stage 1’s Pilot Project: Support for investment in Wales current infrastructure through ASD-enhancement of the CCH database:

Databases are only really useful if kept up to date with full data sets i.e. no data is omitted for reason of no submission of a report. It will have been a massive financial investment to implement the CCH2000 database revision and its usefulness and value is evident. However, there are substantial differences across Wales in the specific use that the LHBs make of the CCH
database for reporting ASDs. The analysis in BCUHB shows that these differences of usage exist between the areas of a large LHB also.

This project and report highlights the importance of collecting full data sets and shows how the demographic for ASD changes when the CCH database is interrogated after having all the cases reported properly. It is likely that on an individual level, BCUHB children with ASD are receiving the care they need from the NHS. However, this report’s data suggests that medium term, middle management decisions that depend on ASD data have not previously been well served by the CCH database in BCUHB (and are currently not well served by the CCH database in other LHBs across Wales). This is primarily due to omissions in the reporting of cases to the database exacerbated by the previous lack of facility for recording ASD diagnostic information on the CCH.

Stage 1 has started resolving this situation with the implementation of the ASD Database module.

The regional ASD Database project found that the primary obstacles and workload in instigating better reporting and IT enhancements to the CCH database in BCUHB, (apart from planning and strategy) were governance/ethics-related and administrative. The transformation of BCUHB CCH database information on ASD cases, from incomplete and useful only with caution, to a dataset that is directly useful to clinicians, complete, and suitable for quantitative analysis, can be implemented relatively swiftly where there is support for such change. The regional ASD Database project has been supported in this by the insight and drive that BCUHB’s Chief Executive has given to enhance the services for ASD individuals in BCUHB.

It is hoped that other LHBs and their service users may now stand to benefit from an expansion of the ASD Database across Wales. This is recognised as an essential step prior to the cross agency potential of such a database being realised in this flagship project for Wales; a tangible and lasting consequence of The ASD Strategic Action Plan for Wales (WAG, 2008).
References:


Acknowledgements

With thanks to everyone who helped completion of the project, all from BCUHB unless otherwise indicated:

- Alan Banks,
- Dr Roger Banks,
- Mary Burrows,
- Professor Linda Clare (Bangor University),
- Ruth Doyle,
- Joanne Fullerton,
- Marie Garbutt,
- Dr Peter Gore-Rees,
- Bethan Griffith,
- Gemma Griffith (Bangor University),
- Iona Griffiths (Derwen Integrated Team for Disabled Children)
- Yvonne Harding,
- Dr Brendan Harrington,
- Dr Janet Horn,
- Patrick Howells,
- Dr Mike Jackson,
- Dr Val Klimach
- Gillian Knight,
- Samira Lalani,
- Samantha Leonard,
- Dr Jane Lidstone (Cardiff University),
- Gareth Llwyd (Anglesey County Council)
- Dr Sian Owen,
- Dr Mary-Anne Pasteur,
- Andrew Pearce (NHS Wales Informatics - CCH2000),
- Professor Michael Rees,
- Dai Richards,
- Louise Richardson (NHS Wales Informatics - CCH2000),
- Janet Roberts (Gwynedd County Council),
- Julia Roberts,
- Dr Rossela Roberts,
- Dr Elin Roberts-Puw,
- Dr Corinne Scott (NISCHR),
- Kate Shakespeare,
- Mark Tracey,
- Dr Richard Tranter,
- Dr Elin Walker-Jones,
- Dave Williams (Aneurin Bevan Health Board )
- Irfon Williams,
- Dr Rebecca Williams,
- Caroline Winstone,
- Angharad Wright,
- Dr Vikram Yadav