Data collection on the numbers and needs of adults and children with autism

Dr Dawn Wimpory's response to specifically to Questions l) & m) in the proposed Autism Bill's Consultation Document (p. 6).

l) Do you believe that Local Health Boards and Local Authorities in Wales should be required to establish and maintain new data collection practices around the numbers and needs of children and adults with autism spectrum conditions so that local areas can plan services accordingly?

I strongly strong support for the idea of a requirement that Local Health Boards and Local Authorities in Wales should be required to contribute to data collection practices around the numbers and needs of children and adults with Autism Spectrum Conditions so that local areas can plan services accordingly.

m) Do you have a view on how data can most effectively be gathered, on the numbers and needs of children and adults with autism spectrum conditions in different Local Health Board and Local Authority areas in Wales?

WG has already funded the development of a database to record diagnoses of Autism Spectrum Disorders (ASDs), led by Dr Dawn Wimpory, Consultant Clinical Psychologist for ASD & Lecturer, BCUHB & Bangor University) with Professor Sue Leekam, of WARC in Cardiff University, as co-PI on the original stage of this pilot for an ASD Database, for children in Wales. In 2012, the ASD database module was established within the Community Child Health 2000 database (now transitioning/transitioned to CypRIS). Although the software is already in place throughout NHS Wales, via CCH2000/CypRIS, the 6 counties of BCU Health Board are those where data collection has taken place since 2012. Although only children's diagnoses have been entered, those children who become adults are retained within this ASD database.

Dr Dawn Wimpory is currently working with the Neurodevelopmental (ND) National Steering Group (hosted by Les Rudd of Public Health Wales) in an initiative to develop a cross-agency development of this original (and still functioning) database via WCCIS, for initial cross-agency trial in Powys. This development is deliberately compatible with the original ASD Module so that the first 6yrs of data

collection in BCUHB can be used as a baseline against which to compare the consequences of WG's more recent Neurodevelopmental (ND) initiatives for ASD. Experience in BCUHB/Bangor University indicates that some clinically-informed research staffing is an essential element of such an enterprise. The WCCIS developments outlined here could well enable inclusion of adults with ASD in the future.

Whilst LEA data can contribute to such database records, the Bangor team's experience is that there is greater diagnostic accuracy about which cases should be included, where diagnoses are logged by the agency primarily responsible for those diagnoses, in this case, the NHS. Calculations about the proposed costs should recognise that diagnoses are sometimes made at a higher rate than the 1% (point 32, p 11) and this could impact on actual database development costs. However, Wales' diagnostic rates cannot be compared with published standard prevalence rates, established through research, unless Wales has an adequate ASD database recording system.

It is hoped that any new relevant developments will build upon, and therefore be strengthened by, the existing progress and developments outlined above. Areas of data recorded on ASD since 2012 (and still on-going) include the following: incidence & prevalence; clients' gender, intelligence and communication levels, age at diagnosis; diagnostic service involvement (CAMHS vs non-CAMHS etc, including waiting list times; use of diagnostic tools/scores; clarification of cross-agency professional groups' involvement) and cases' comorbidities. Communication/collaboration with Dr Dawn Wimpory on these issues is therefore strongly encouraged (dawn.wimpory@wales.nhs.uk).

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