National Policies and Workshop Reports

ENGLAND

BACKGROUND

Summary

The 2010 adult autism strategy (Fulfilling and Rewarding Lives[1]) and statutory guidance (Implementing Fulfilling and Rewarding Lives[2]) under the Autism Act (2009)[3] set out what local authorities and the NHS have to do to improve services for autistic adults in England. These duties include a diagnostic pathway in every area, training for key professionals, local plans and a local autism lead. The strategy and statutory guidance were reviewed in 2013 and a refreshed strategy (Think Autism[4]) and updated statutory guidance[5] were published in 2014 and 2015 respectively. More recently, the government published a Progress Report on Think Autism[6]. Alongside the refresh, £4.5 million was invested in local projects. Local implementation of the strategy is regularly monitored through a self-assessment questionnaire filled out by all local authorities. The implementation of the strategy is overseen at senior level by a cross-departmental Adult Autism Programme Board, led by the Department of Health (DH)[7].

In children's services, NICE Guidelines[8] set out recommendations for what local pathways to diagnosis should look like and the types of support that should be available post-diagnosis. Autistic children with special educational needs (SEN) are entitled to an assessment to identify the support that they or their family might need from children's social services, but this does not automatically entitle them to provision. Children may receive an Education, Health and Care Plan (EHC Plan)[9] that looks at their needs across education, healthcare and social services. In education and health there are specific statutory duties to make the provision available, but in social care there is no equivalent duty. When it comes to education, children on the autism spectrum are covered by the Children and Families Act (2014)[10]. The Department for Education (DfE) recently committed to include autism in Initial Teacher Training (ITT) while training of existing teachers is through the Autism Education Trust[11].

Chronology

Supported by the National Autistic Society (NAS) and other autism charities, Cheryl Gillan MP took the Autism Act (2009) through Parliament as a private member's bill. The Act

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[1] http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113405.pdf.

[2] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216129/dh_122908.pdf

[3] http://www.legislation.gov.uk/ukpga/2009/15/pdfs/ukpga_20090015_en.pdf

[4] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf

[5] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf

[6] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/492011/autism-progress-report.pdf

[7] https://www.gov.uk/government/groups/aapb

[8] see documents listed at https://www.nice.org.uk/search?q=autism

[9] see for example http://www.autism.org.uk/about/in-education/extra-help-in-school/england/ehc-assessment.aspx

[10] http://www.legislation.gov.uk/ukpga/2014/6/pdfs/ukpga_20140006_en.pdf

[11] http://www.autismeducationtrust.org.uk/

placed two key duties on Government. The first was to produce a strategy for improving services for adults on the autism spectrum. The second was to produce statutory guidance that sets out duties on local authorities and the NHS on what they have to put in place to help deliver the strategy.

Among other things, the national strategy secured the following:

- Autism is now included in standard data returns from local authorities on who locally receives social care services
- The development of NICE Guidelines on identifying, diagnosing and managing autism in adults
- A range of training resources and materials

Fundamentally though, as a result of the Act, statutory guidance means that local authorities and NHS bodies:

- have to develop a clear pathway to diagnosis and assessment for adults with autism
- cannot refuse a community care assessment for adults with autism based solely on IQ
- have to provide autism awareness training for all staff
- have to provide specialist autism training for key staff, such as GPs and community care assessors
- have to appoint an autism lead in their area
- need to commission services based on adequate population data
- should involve people with autism and their family in planning local services

The existence of the legislation has been key in ensuring leadership from the DH on autism and an ongoing focus from Government on improving the services and support available for autistic adults. The Act also sets out that the strategy and statutory guidance have to be regularly reviewed. The first strategy committed the Government to a review in 2013. As a result of this review, the new statutory guidance in 2014 made expectations around training much clearer for different types of staff. The review also resulted in £4.5 million of funding for local projects.

Over the last year, as a result of the NAS' *Autism Diagnosis Crisis* campaign[12], the national programme board that oversees implementation of the adult strategy has been particularly focused on diagnosis and bringing down waiting times. The DH and NHS England have identified the need to better record diagnosis. This will help provide a clearer picture of incidence and need, but also clearer NHS accountability for waiting times. The NHS are currently developing the means to do this effectively.

Pressure around the impact of late diagnosis and also evidence of the high prevalence of mental health problems among autistic children and adults resulted in the DH including tackling health inequalities among those with autism as part of its 'Mandate' to NHS England[13]. This is the document that sets out the Government's priorities for the NHS.

In practice, the actions that the NHS is taking forward on this are around the Transforming Care agenda[14], which is focused on supporting adults with complex needs to move out of in-patient units and into the community. It is important to note that in no small part because of the key focus that the existence of the Act provides, Transforming Care covers those on the spectrum regardless of whether they also have a learning disability. The NHS Five Year

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[12] http://www.autism.org.uk/get-involved/campaign/successes.aspx

[13] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/494485/NHSE_mandate_16-17_22_Jan.pdf

[14] https://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf

Forward View on Mental Health[15] also sets out planned activity for putting in place clearer pathways in mental health services for autistic people.

On employment, a taskforce looking at apprenticeships reported in 2016[16] and pilots will be taken forward to look at how apprenticeships can better support those on the spectrum and others. A new Green Paper on disability employment[17], published in October 2016, has the potential to result in more specialist support for autistic adults seeking work.

Evaluation of Progress

At national level, implementation of the strategy was reviewed by the National Audit Office (NAO) in 2012[18]. The NAS ran its own monitoring of progress as part of its Push for Action campaign in 2013[19]. The Government then undertook its own exercise to review the strategy in 2013 and published a revised strategy in 2014 and revised statutory guidance in 2015 as detailed above. In addition, the DH (Public Health England) also regularly asks local authorities to self-assess their progress on local implementation of the autism strategy. In 2016, the fourth self-assessment was undertaken, but the results will not be available until spring 2017.

The NAO found that the majority of the national actions in the strategy were complete, but that the biggest gaps were in building autism into the core curricula for clinicians, in ensuring that training was available locally and in building in improved data collection on autism. In the latest local self-assessments, nearly all local authority reported that they had an autism lead, a partnership board and were including autism in their planning. Some of the biggest areas of challenge were around training, data collection, diagnosis waiting times and post diagnostic support.

For children, we are in the third year of implementation of the Children and Families Act and there have been significant issues in bedding in the new system, which means parents are still waiting too long and having to fight too hard to get the right help in school for their children. Based on prevalence, it has been estimated that only around 75% of autistic children are recognised by the education system and that a high rate of exclusion of autistic children persists. However, on a positive note the exclusions rate appears to be falling, perhaps as a result of the training teachers are receiving through the Autism Education Trust or through the work of the DfE funded exclusions service at the NAS.

Conclusions

The existence of autism legislation in England at a time when budgets at local level are under increasing pressure has ensured a focus on autism that would not have been possible without the Act. In interviews with the NAS, professionals on the ground confirmed that the Act had been essential to getting autism up the agenda and to make sure that there was a clear foundation for the development of local services. However, they admitted that many autistic adults and their families would not have yet seen the changes needed. Indeed, all of the evaluation has shown that local implementation and change has been patchy as

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[15] https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf

[16] https://www.gov.uk/government/publications/apprenticeships-improving-access-for-people-with-learning-disabilities/paul-maynard-taskforce-recommendations

[17] https://www.gov.uk/government/consultations/work-health-and-disability-improving-lives/work-health-and-disability-green-paper-improving-lives

[18] https://www.nao.org.uk/wp-content/uploads/2012/07/adult_autism_strategy_progress.pdf

[19] http://www.autism.org.uk/get-involved/campaign/successes.aspx

evidenced by the third Public Health England survey of local authorities and their partners[20]. Wider pressures on social care budgets are significant challenges here.

There are opportunities in the next few years to improve outcomes for autistic children and adults through work that the DH and NHS England is doing on diagnosis, the Mandate to NHS England, Transforming Care and the employment Green Paper.

RECOMMENDATIONS: PRESENT POLICY AND NEW INITIATIVES

General points from the workshop

Although the principle of intervening early to avoid later problems remains, current psychiatric thinking is that many mental health conditions are episodic and so early intervention will not necessarily prevent future vulnerabilities. The need for research on the impact of early intervention on increasing resilience to mental illness is clearly needed. NICE guidelines set out what a pathway to diagnosis should look like for autistic children and also how to develop the right support plans for them. The guidelines include recommendations on setting up local autism teams and local planning groups to advise on what services should be available. However, NICE guidelines are not mandatory.

Of around the estimated 120,000 school aged children likely to be autistic (based on prevalence data) around 90,000 are known to the DfE. The route for most children to receive support is through the school system. Children with more complex needs can get a combined assessment of their health, social care and education needs in a single plan although there are long delays (outside the statutory guidelines) in some areas. This system has been in place for two years so it is unlikely that Government will respond to lobbying for further change until the system has had time to bed down.

There is a commitment to train all new teachers in autism and around a quarter (108k) of existing teachers have also been trained. Training is through the Autism Education Trust which operates only in England but is a useful model for other countries. Training is focussed on how the teacher can help the child in the classroom and all teachers have access to a special educational needs co-ordinator (SENCO) (who are usually but not always school-based) to help with wider issues. Take up of training is patchy across local authorities (LA's) but Birmingham is a good example of a comprehensive programme and the emerging super-councils might be a good target.

The legislative framework for children does not require a formal diagnosis of autism in order for needs to be assessed but in practice this is often the case. For accessing support from children's social care, autistic children are generally considered under the policy envelope of children with disabilities.

For adults, strategy and statutory guidance are driven by the Autism Act (2009). Statutory guidance sets out clearly that there is a right to assessment and diagnosis irrespective of IQ. It also sets out that autism training should be provided to all health and care staff, with specific levels of training outlined for e.g. GPs and community care assessors. It is clear that where training takes place the number of assessments rises. Every area has to have an autism lead and service planning should be based on population assessments. The guidance suggests using autism partnership boards to take the guidance forward and most areas do have both an autism lead and a partnership board. If these were not in place, there would be grounds for judicial review of the council's actions. The most powerful part of the Act has been the right to access a diagnostic pathway and there are model legal letters that

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[20] https://www.gov.uk/government/news/progress-in-autistic-care-in-england

the NAS helpline can provide that have been used to achieve this where originally refused. The Act has been important in giving ammunition to local champions and advocates.

The DH has mandated the NHS to tackle inequalities in healthcare but the actions so far outlined to achieve this only see this in terms of getting people out of inappropriate residential care such as hospitals under the Transforming Care initiative. 16% of those with autism in hospital care do not have a learning disability. The current focus by government on mental health means that NHS England is working on the development of various care pathways including one on autism. Sustainability and Transformation Plans (STPs)[21] are a new approach to managing NHS resources and it is important to ensure that autism is properly identified in these.

Relevance of the Recommendations

Recommendation 1 - Ensure timely identification and diagnosis

Identification and diagnosis are distinct processes. The NHS Mental Health Services Data Set[22] does not currently record autism, but following campaigning, a proposed indicator (including diagnosis waiting times) is in development. The new round of indicators will be decided in early 2017 and, if adopted go live in 2018. It is disappointing that the average age of diagnosis in children has been unchanged at 5 for ten years despite increased awareness and training[23]. It is unclear whether this is a construct of additional late diagnosis or re-diagnosis or of better management of young autistic children leading to later diagnosis (on the grounds that diagnosis only arises after a problem has been identified). Although there are NICE guidelines on adult diagnosis, the available tools are not perfect and depend on the skill of the clinician. Autistica is starting a new project in Newcastle on adult diagnosis including looking at who should be involved and which methods and measures are the most efficient and effective. The two key challenges are finance and skills. Lack of formal data on waiting time for diagnosis is an issue and the DH is talking to NHS England and NHS Digital[24] about this. There is also a place for reasonable adjustment in processes and DH is working with the Royal Colleges and charities in this area. Data collection on adult diagnosis may start (subject to the above) in 2018. At the moment getting data on what is happening on the ground relies upon self-assessment returns from LA autism leads. The recommendations of the Westminster Commission[25] and our own report should help.

Recommendation 2 - Provide evidence-supported/informed interventions

Lack of interdisciplinary working in intervention is a key inhibitor to good practice. There is a need to agree on the nature of evidence and to test the effectiveness of interventions in a variety of ways in practice. Under the present government, research structures are not fundamentally changing but the Medical Research Council (MRC) is shifting clinical trials type work to the National Institute for Health Research (NIHR). Autistica is mapping current research spending against the James Lind Alliance[26] top ten priorities and working with NIHR on addressing community priorities. The recent call from NIHR for applications to examine the cost-effectiveness of early intensive behavioural interventions (ABA) shows that NIHR does respond to public pressure. The Economic and Social Research Council (ESRC)

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[21] https://www.england.nhs.uk/stps/

[22] http://content.digital.nhs.uk/isce/publication/SCCI0011

[23] http://link.springer.com/article/10.1007/s10803-016-2716-6

[24] https://www.digital.nhs.uk/

[25] https://westminsterautismcommission.wordpress.com/

[26] http://www.jla.nihr.ac.uk/priority-setting-partnerships/autism/

is continuing to fund the seminar programme "Shaping Autism Research"[27] and the next seminar in March is on autistic well-being and the importance of co-production in research.

Recommendation 3 - Make the economic case

There is a lack of data about what interventions actually cost as well as inadequate information on their (cost) effectiveness . In other health areas such as diabetes there are funds available to test whether service provision is cost effective. It may be more practical to focus on particular areas for which there are already relevant models, such as the treatment of epilepsy in autistic people.

We do not know whether early intervention really does reduce costs and given the intense focus on this as the key to good outcomes, this really needs to be investigated. The DH is funding work by Professor Bryony Beresford at the University of York to look at costings and outcomes for autistic people without learning disability[28]. It does not currently include cost effectiveness analyses but these will be introduced in the next phase. It does however identify a number of models for good support. The Transforming Care programme may be being analysed for economic impact.

The DH is encouraging autism leads to get together regionally and the Association of Directors of Adult Social Services (ADASS)[29] could be a target for creating a national forum. The New Local Government Network[30] might be another. There already is an informal network of mental health leads.

Recommendation 4 - Remove barriers to access

The Government has committed to halving the disability employment gap. Although this is going to be very difficult to achieve it does represent an exploitable opportunity for autism and the NAS employment campaign is making good progress. Autistica is working with Deutsche Bank to provide work experience for autistic people in the bank[31].

The Swedish mortality study[32] identifies the causes of premature mortality as inadequate access to either health or social care. While caution is needed in translating this study to the UK, it is likely that the same barriers exist here. In education, the DoE has identified that there are in fact too many sources of information (formal and informal) available to parents seeking the right environment for their child, thus leaving them ill-prepared.

There are simple ways of reducing barriers such as putting a flag on a GP record to show that the person may need special support. The NAS consistently identifies three systematic barriers: lack of training, absence of data and the need for people to talk to each other. The Care Quality Commission (CQC) is trying to develop a cross-directorate approach[33] to looking at the experience of autistic people across hospital and social care environments, and a programme of awareness raising and guidance on inspecting environments from an

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[27] http://www.shapingautismresearch.co.uk/

[28] https://pure.york.ac.uk/portal/en/projects/nihr-hsdr-shape--supporting-adults-with-highfunctioning-autism-and-asperger-syndrome-mapping-and-evaluating-specialist-autism-team-service-models(f5912dbc-5cb3-40a7-8d74-f14d19278099).html

[29] https://www.adass.org.uk/home

[30] http://www.nlgn.org.uk/public/

[31] https://www.autistica.org.uk/deutsche-bank-autistica-internships/

[32] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M. et al. (2016). Premature mortality in autism spectrum disorder. Brit. J. Psych. 208, 232-238.

[33] http://www.cqc.org.uk/content/coordinated-care

autistic perspective. Hampshire has an Autism Ambassadors scheme working in doctors' surgeries.

Recommendation 5 - Tackle environmental and other stressors

Autistica has been working on an anxiety tool that aims to make the home environment less stressful[34]. There are sensory assessment scales but these are based on observation not systemic testing of sensory responses. Work on cognitive disability and building standards is going on through the British Standards Institution. Minor changes in the built environment could have a big impact but other standards such as Building Control can act as a barrier to change. The NAS has an accreditation scheme for autism friendly buildings and the Trafford Centre in Manchester has shown a reduction in disruptive behaviours after making adaptations.

Recommendation 6 - Fight discrimination

Research from the Equality and Human Right Commission (EHRC) showed that autistic people are more likely to be victims of crime than any other disability group[35]. They are particularly vulnerable to financial abuse. The Time to Change initiative[36] aims to fight discrimination and increase understanding of mental health and the NAS is seeking similarly to improve public understanding of autism with its *Too Much Information* campaign[37]. In order to maximise its reach, it would be keen to partner with Government, but funding has not been forthcoming. The campaign is already making a difference. Public polling has shown that 16% of the public have an increased understanding of why public places can be difficult for autistic people. This mean the campaign has reached a million people. Autistica is working on helping parents of newly-diagnosed children in Bedfordshire to avoid discrimination[38]. Discrimination in BME communities may be a greater problem and could be a bar to seeking diagnosis. Indifference is also a form of discrimination e.g. the Southern Health NHS Trust scandal[39] and Mencap's report Death by Indifference[40]. Discrimination by exclusion in schools is important and DoE funds an exclusions adviser employed by the NAS. Since this person was in post exclusions of autistic children have fallen. However, it should be noted that Equality Act (2010)[41] does not refer to autism in its description of disability and may therefore actually discriminate against autistic children because they can be excluded for aggressive behaviour without their autism being taken into account.

Recommendation 7 - Ensure better transitions

Planning in advance and ensuring the availability of services are the key requirements while peer support and mentoring is likely to be very important in helping people through transitions. There is transition support up to 25 in education but transition from children and adolescent mental health services (CAMHS) to adult services at 19 means that some young people then fall out of the system because they fail to meet the higher threshold for support in adult mental health care. For university entry, Bath University runs a summer school for

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[34] https://www.autistica.org.uk/hackathon-autism-deutsche-bank/

[35] https://www.equalityhumanrights.com/en/publication-download/research-report-103-crime-and-disabled-people

[36] http://www.time-to-change.org.uk/

[37] http://www.autism.org.uk/get-involved/tmi.aspx

[38] https://www.beds.ac.uk/news/2016/october/first-ever-study-to-help-families-cope-with-the-stigma-of-autism-is-launched

[39] http://www.bbc.co.uk/news/uk-england-oxfordshire-34548638

[40] https://www.mencap.org.uk/sites/default/files/2016-08/Death%20by%20Indifference%20-%2074%20deaths%20and%20counting.pdf

[41] http://www.legislation.gov.uk/ukpga/2010/15/contents

incoming autistic students and the University of Kent has created an alumni group. The NAS is working with Brain in Hand[42] team at Southampton University. There is a project at Cambridge looking at how transitions affect mental health. Employment support is very localised but the Department of Work and Pensions (DWP) is consulting on its new Work and Health Programme[43] (in England, Wales and Scotland) to provide specialist support to disabled people in work.

Recommendation 8 - Coordinate action across sectors

For children, EHCPs (Education, Health and Care Plans)[44] integrate support across sectors and evaluation of who is doing this well and who is not is expected shortly. The local STPs (Sustainability and Transformation Plans) in adult health and social care are the current opportunity and there are some vanguard areas in this. The key issue is the reluctance to share health data with social care data. The University of York research (see Recommendation 3) may help with this but there are questions about leadership and ownership that need to be addressed and whether the Autism Leads in the local authority are always effective.

Recommendation 9 - Build better information systems

There are too little data being recorded on autism and the needs and outcomes of autistic people. As any new data recording is developed, there will be a need to ensure that autistic people and their families understand why data are being collected and for what purpose. There needs to be appropriate data protection particularly when data are shared across sectors.

Recommendation 10 - Increase funding of autism research

The Adult Autism Programme Board met recently to discuss autism research. EU funding will no longer be available when current projects such as Innovative Medicines Initiative project EU-AIMS come to an end. A question was raised about whether there had been any research into the outcomes of the various SEN initiatives in autism. More research is needed on why the average age of diagnosis has not fallen from 5 years. Evidence on peer support and mentoring is weak and needs expanding. Research is needed on whether either a label or formal diagnosis of autism is a help or hindrance in challenging discrimination.

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[42] http://braininhand.co.uk/

[43] https://www.gov.uk/government/news/work-and-health-plan-to-help-disabled-people-into-employment

[44] https://www.gov.uk/government/publications/send-code-of-practice-0-to-25

NORTHERN IRELAND

BACKGROUND

Summary

The Northern Ireland Autism Strategy (2013-2020) and Autism Action Plan (2013-16)[45] are underpinned by the Autism Act (Northern Ireland) 2011[46] which protects autistic people from discrimination by public services and mandates the implementation of a cross-departmental strategy for autism that is lifelong. Its scope is far wider and more holistic than its predecessor, the Northern Ireland ASD Health Strategy (2008-11). A NI Autism Strategy Research and Advisory Committee (NIASRAC) was established in 2013 as part of the Autism Strategy with the intention of providing evidence to inform the cross-departmental delivery of the action plan. The restructuring of the Health and Social Care sector in Northern Ireland following the Bengoa report in October 2016[47] will reshape and revise the delivery of services on the basis of population needs rather than with the aim of maintaining services which are not sustainable in the long term. There is currently no outcomes-based evaluation or ring-fenced autism budget in place to support delivery of the Action Plan.

Chronology

For well over a decade, campaigning spearheaded by Autism NI[48] (formerly known as PAPA) has been the consistent driver for the development of policy and legislation for autism in Northern Ireland. The initial outcome, the Northern Ireland ASD Health Strategy, was launched in December 2008, and was supported by just over £2m over three years. Located in the Department of Health, its focus was mainly around the development of regional responses, coordination, identification and service-pathways for children, with a small proportion of funding used to support adult diagnosis. It was a starting point. But a lack of cross-departmental influence and ownership led to the need for an all-age strategy underpinned by legislative requirement for all the departments within the Northern Ireland Executive to work together in order that the all-age autism strategy could be devised and implemented.

Legislative changes therefore became the next step forward. Significantly, the NI Disability Discrimination Act 1995[49] was amended to specifically include autism and the introduction of the well-constructed Autism Act (Northern Ireland) 2011 gave, for the first time, parity of entitlement to services for people with autism in line with others. Although still located in the DH, the subsequent introduction of a cross-departmental Northern Ireland Autism Strategy (2013-2020) and Action Plan (2013-16) sought to fulfil the requirements of the Act by identifying eleven themes matched to strategic priorities. These were: awareness, accessibility, children, young people and family, health and well-being, education, transitions, employability, independence, choice and control, access to justice, being part of the community, participation and active citizenship.

In recognition of her role in bringing forward the Act, Dr Arlene Cassidy MBE (CEO, Autism NI) was appointed chair of the NIASRAC committee established by the Minister for Health to assist and inform departments with research and best practice findings. Ulster University will

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[45] https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/autism-strategy-action-plan-2013_0.pdf

[46] http://www.legislation.gov.uk/nia/2011/27/contents/enacted

[47] https://www.health-ni.gov.uk/sites/default/files/publications/health/expert-panel-full-report.pdf

[48] http://www.autismni.org/

[49] http://www.legislation.gov.uk/ukpga/1995/50/contents

further add to the autism research focus in Northern Ireland with the launch in 2017 of the Autism Research Hub which has its origins in the longstanding partnership with Autism NI.

Whilst NI Executive funding for the strategy since 2013 has not been ring-fenced, programmes for care related to autism delivered by the five regional Health & Social Care Trusts[50] through Mental Health and Learning Disabilities funding streams totalled almost £885,000 between 2013 and 2015. In February 2016, the Health Minister allocated a further £2m.

The restructuring of the Health and Social Care sector in Northern Ireland following the Bengoa report will reshape and revision the delivery of health and social care services with coordinated workforce and service planning carried out on the basis of the population's need rather than with the aim of maintaining services which are not sustainable in the long term. The positioning and resourcing of autism will require consistent, creative and coordinated advocacy if the opportunities of change are to be made relevant and valid.

Evaluation

A self-assessment of progress was published by the NI Executive in September 2015[51] with areas of progress identified across a number of the themed areas identified above. A subsequent statement by the Minister responsible for the autism strategy reported that progress had been made in training, advice, access to travel, employment, and processes designed to streamline clinical diagnosis. However, the Minister further cautioned that increasing prevalence and heightened demand for assessment without the necessary resources in place was likely to impact negatively upon the capacity of the action plan to deliver its ambitions relating to early intervention.

Conclusion

The strengths of the autism strategy in Northern Ireland lie in its roots and ownership with community action and lobbying underpinning well-thought out legislation, remarkable cross-department responsibility and the introduction of a research committee to advise and inform on evidence and practice. Its critical weakness lies in the lack of a defined and ring-fenced budget for autism. This results in an inadequacy to objectively scrutinise and evaluate cost-benefits and outcomes for people with autism and their families, and therefore ultimately to fully address the requirements of the legislation.

RECOMMENDATIONS: PRESENT POLICY AND NEW INTIATIVES

Relevance of the recommendations

Recommendation 1 - Ensure timely identification and diagnosis

Adoption of the Bengoa report's recommendations will have an impact on identification and diagnosis of autism although this could take 2-3 years to take effect. Currently diagnosis is seen as the gateway to support but demand for assessment of children outstrips the capacity of the system. In the new framework model, the focus will be on needs assessment by a multidisciplinary team which includes nurse practitioners, health visitors and parents. Diagnosis would follow for those assessed as having special needs such as autism. In principle, the idea of basing provision on needs first and foremost rather than on the

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[50] http://online.hscni.net/hospitals/health-and-social-care-trusts/

[51] https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/autism-strategy-progress-report-2015.pdf

diagnostic label is attractive, but will require some adjustments, for example, retraining of professionals in the new model. Furthermore, the Health and Social Care Trusts will need to be held accountable for implementation and the 2-3 year wait for this to take place will put huge strain on existing arrangements.

Recommendation 2 - Provide evidence-supported/informed interventions

The Centre for Autism in Middletown[52] is a cross-border agency that promotes best practice with a particular emphasis on practice-based evidence. It publishes research bulletins and conducts its own research, for example, in parental training to reduce anxiety. NIASRAC set up by the N.Ireland government also has a role in promoting use of evidence-supported interventions.

Educational methods for autistic children are outcomes-based.

Recommendation 3 - Make the economic case

There are no economic analyses completed in N. Ireland.

Recommendation 4 - Remove barriers to access

The 2011 Autism Act required the establishment of an autism awareness campaign but this was not taken up by the Department of Health so the voluntary sector has filled the gap. Through the efforts of Autism NI in particular, there have been a number of initiatives aimed at helping autistic people access services as well as training to alter attitudes and to improve the environment (e.g. the Impact Awards[53]).

Recommendation 5 - Tackle Environmental and other stressors

As with Recommendation 4, it has fallen to the voluntary sector to take the initiative through schemes such as the Impact Awards which put the onus on the neurotypical to take steps to make the work environment, for example, more accessible to autistic people.

Recommendation 6 - Fight discrimination

Mencap (NI)[54] coordinates the effort on discrimination including hate crime but this is not specific for autism nor particularly relevant to those autistic people without a learning disability. Otherwise, the voluntary sector efforts described above are relevant.

Recommendation 7 - Ensure better transitions

The new post-Bengoa framework referred to earlier will operate across the Health, Communities and Education departments and should deal better with some of the transitions important for autistic people.

Recommendation 8 - Coordinate action across sectors

There is certainly provision in NI for coordination between sectors to be effective. The Autism Act (NI) 2011 mandates the delivery of the cross departmental NI Autism Strategy and Action Plan. The implementation panel is made up from representatives from all government departments. The NIASRAC members come from R&D, two universities, the Middletown Centre for Autism, Autism NI, the Education Authority, Research Autism and the Department of Health. The new framework proposals are to work across three government

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[52] https://www.middletownautism.com/

[53] http://www.autismni.org/impact-award.html

[54] https://www.mencap.org.uk/northern-ireland

departments. The Children's Services Cooperation Act (NI) 2015[55] mandates cross departmental cooperation on children's services.

Recommendation 9 - Build better information systems

Again there is provision in place for gathering data on autism in NI. The Department of Health in 2012 held pre-consultation engagement workshops across NI capturing very rich data which has not been fully exploited. Furthermore the Autism Act (NI) 2011 mandates the five Health and Social Care Trusts to gather data on autism to share across Trusts and to inform the NI Strategy for autism. However, present information systems are not adequate to capture autism data reliably even on incidence. However, the new framework will be underpinned by a new information strategy which should help to address the problem.

The Department of Health produces a prevalence paper annually based upon school census data, and incidence data are available on the Department of Health website[56]. However the data are not linked to ICD 10 diagnostic criteria.

Recommendation 10 - Increase funding of autism research

Currently only the Queen's University Autism Research and Treatment Centre[57] (dedicated to Applied Behaviour Analysis /Board Certified Behaviour Analysis) is pro-active in acquiring grants for autism-linked research. However, the Ulster University Autism Research Hub to be launched in March 2017 will increase the profile of autism research, and facilitate cross university partnerships internationally for the first time. There is much work to be done to increase funding for research into autism from the NI Executive and to ensure the quality of what is funded. As an example, the BASE report (Benchmarking Autism Service Efficacy)[58] funded by the Office of the First Minister and Deputy First Minister is actively being criticised at present for its lack of rigour and its bias.

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[55] http://www.cypsp.hscni.net/wp-content/uploads/2016/01/DSCUpdate-NewCYPStrategy22-01-2016.pdf

[56] https://www.health-ni.gov.uk/sites/default/files/publications/health/asd-children-ni-2016.pdf

[57] http://www.qub.ac.uk/quart/

[58] https://www.qub.ac.uk/research-centres/CentreforBehaviourAnalysis/Research/BenchmarkingAutismServiceEfficacyBASE/

SCOTLAND

BACKGROUND

Summary

In November 2011, the Scottish Government, working with the Convention of Scottish Local Authorities (COSLA[59]), launched the Scottish Strategy for Autism[60], a 10 year strategy which aimed to address the needs of people with autism. Since the launch of the strategy, over £17 million has been invested in autism services and provisions throughout Scotland. Funding has been utilised to improve diagnosis, post-diagnostic support, awareness raising, training for all professionals, improvement in transitions and the sharing of best practice. The strategy outlined 26 recommendations to ensure that progress is made across Scotland in delivering high quality services for people with autism and their families. Responsibility lies with the Directorate of Population Health in collaboration with the Learning Disabilities Team and other government departments. These recommendations were streamlined into an Autism Outcomes Framework which identifies key policy priorities between 2015 and 2017[61].

Chronology

Autism had been the subject of a number of initiatives over the decade preceding the launch of the Scottish Strategy for Autism, with considerable efforts made to improve diagnosis and assessment, create consistent service standards and to identify appropriate research and training opportunities. In January 2011 the Autism (Scotland) Bill[62] was brought to Parliament by former MSP Hugh O'Donnell and supported by the National Autistic Society Scotland (NAS), as well as a coalition of autism organisations. The bill failed to pass through the Scottish Parliament but set in motion plans to implement a nationwide strategic course of action to improve the lives of people with autism.

The Scottish Strategy for Autism was agreed with stakeholders who were lobbying for an 'Autism Bill' as an alternative way forward and was launched by the then Scottish Minister for Public Health, Michael Matheson in November 2011. The strategy puts emphasis on the importance of true collaboration and innovation across organisations and local authorities to improve services and provide support for people with autism.

The strategy budget has been used to support the implementation of a range of initiatives. The Autism Development Fund[63] provided £1.5 million for a range of organisations to implement and develop improvement in autism services. The Scottish Government has also provided £2.7 million over the last three financial years to pilot and support six One Stop Shops[64] throughout Scotland. The model of the One Stop Shops was developed to offer people with autism, their families and professionals, information and advice about autism and help people gain access to local support services as well as addressing gaps in local services.

Stakeholders from across the country have participated in the process of planning and implementing the key recommendations: the Scottish Government; Scottish Health Boards and Scottish Local Authorities; Third Sector organisations providing autism services, along

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[59] http://www.cosla.gov.uk/

[60] http://www.autismstrategyscotland.org.uk/

[61] http://www.autismstrategyscotland.org.uk/strategy/key-documents.html

[62] http://www.parliament.scot/parliamentarybusiness/Bills/17844.aspx

[63] http://www.autismstrategyscotland.org.uk/development-fund/autism-development-fund.html

[64] http://www.autismnetworkscotland.org.uk/one-stop-shops/

with education and training providers and representatives of the autism community across Scotland. Progressive discussions between stakeholders addressed gaps and improvement areas required within the strategy and culminated in discussions which led to the outlining of strategic priorities for 2015-17.

Publications have been produced to support the implementation of the strategy. In line with recommendations 10 & 11 of the original strategy in 2013 the Scottish Government produced *The Menu of Interventions*[65]. It provides information regarding the challenges faced by people with autism, and suggests the types of services that might address these issues. With Scottish Government funding, one of the key Government's stakeholders, ARC Scotland, is producing a series of Principles of Good Transitions[66] guides highlighting the important issues surrounding transitions, and to bring them to the forefront of policy and practice relating to children and young people.

Legislation to implement health and social care integration came into force on 1 April 2016[67]. This brings together NHS and local council care services under one partnership arrangement for each of 31 areas. It is hoped that this will have a positive effect on delivery of support services for autism. In addition, the Scotland Act 2016[68] devolved new powers to the Scottish Government for employment support which will result in new services for disabled people and long term health conditions in 2017.

Scotland continues to share its work on improving the lives of people with autism to a global audience. Dr Janine Robinson and Ms Marie Claire Shankland from NHS Education for Scotland (NES) have published in the Australian Clinical Psychologist[69], outlining the Scottish Strategy context and the work carried out in collaboration with the autism community. Particular attention was directed within the paper towards the NES training framework, which was the result of contributions from practitioners, organisations and the autism community, on the firm foundations of a national autism strategy.

Evaluation

Policy responsibilities for monitoring and administrating the strategy falls to the autism policy team within the Directorate of Population Health. The team works in collaboration with the Learning Disabilities policy team and continues to develop cross policy relations with colleagues in various other Scottish Government departments including Mental Health, Education and Primary Care. Cross policy collaboration has allowed input into strategic plans outside the normal scope of the autism policy team and taken onboard strategic thinking from other policy areas.

Whilst the strategy was helping to address the needs of people with autism, discussions began to take place to look at identifying priorities within the 26 recommendations listed in 2011. Following consultation with a range of national stakeholders a priority action plan was developed. The action plan recognised gaps in the strategy and looked at prioritising the recommendations initially produced whilst analysing areas for progress that had been raised since the strategy had been launched

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[65] http://www.autismstrategyscotland.org.uk/strategy/key-documents.html

[66] https://scottishtransitions.org.uk/7-principles-of-good-transitions/

[67] http://www.gov.scot/Topics/Health/Policy/Adult-Health-SocialCare-Integration

[68] http://www.legislation.gov.uk/ukpga/2016/11/contents

[69] Robinson,J. and Shankland, M.C. (2015) Engaging with the autism community: beyond tokenism? Australian Clinical Psychology 1, 44-47.

These priorities are reflected in the reframed Autism Outcomes Framework[70], which focus on four key outcomes; A Healthy Life; Independence; Choice and Control and Active Citizenship. The reframing of the Strategy aligns it with current national Scottish Government priorities and provides a rationale for what work is taking place and why. The outcomes framework identified previous shortcomings including barriers to access to services, community facilities, education, employment and social activities, the need for better understanding and knowledge of autism among professionals, and better transition from school to adult life. Key policy priorities therefore encompassed diagnosis, post diagnostic support, awareness raising, training for all professionals, improvement in transitions and the sharing of best practice. The outcomes framework is the Scottish Government's implementation plan for 2015-2017.

Work will shortly commence to identify priorities for the implementation period for 2017-19 and discussions with a range of stakeholders will ensure that the goals of the strategy continue to be evaluated and progress is made.

Conclusion

The Scottish Strategy for Autism is half way through its ten year strategy and much has been accomplished through a sustained commitment from the Scottish Government and the autism community to address the needs of people with autism. The reframing of the strategy for 2015-17 has identified the major issues concerning the autistic population and reframed the original workings of the strategy. Key third sector partners have played a significant role in ensuring the strategy continues to achieve its goals. Stakeholders have identified strategic areas for improvement in diagnosis, education and local implementation which have been recognised within the reframed outcomes framework as key objectives for the 2015-2017 period. Engagement with these stakeholders will continue to shape the next stage of the strategy implementation process to help achieve the goal of improving the lives of people with autism.

RECOMMENDATIONS: PRESENT POLICY AND NEW INTIATIVES

General points from the workshop

Payback on initiatives unfortunately takes longer than the time scale of government and periods of financial constraint encourage short-termism. LA commissioning of services is driven by financial considerations so getting engagement at local level on better practice is a challenge. For example, services are geared to the "typical" autistic person and additional support is only made available when there a problem arises such as self-injury. There is also variation from LA to LA.

The integration of Health and Social Care which came into force in 2016 brings together NHS and local council care services in 31 partnerships across Scotland. This should have a positive effect on the delivery of support services for autism.

It was suggested that evaluation of practice would benefit from a model that would allow use of the Research Domain Criteria (RDoC) research framework introduced by the National Institute of Mental Health[71] and from Comparative Effectiveness Research (CER)[72] findings from current and future US research (see Recommendation 10).

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[70] http://www.autismstrategyscotland.org.uk/strategy/key-documents.html

[71] https://www.nimh.nih.gov/research-priorities/rdoc/index.shtml

[72] https://www.hsph.harvard.edu/comparative-effectiveness-research-initiative/definition/

Relevance of the recommendations

Recommendation 1 - Ensure timely identification and diagnosis

Identification is the responsibility of the Early Years and Childcare Workforce and a national training programme exists to support workers in this sector, training being identified as a key issue. Other important national policies, outcomes and indicators include *Getting it Right for Every Child* (GIRFEC)[73] and the *Early Years Collaborative*[74]. The *Autism ACHIEVE Alliance* (AAA) is a Scottish Government funded multi-disciplinary collaboration to investigate waiting times in the diagnosis of ASD[75]. Most services for children work well but slowly, while adult services are more variable - many people throughout Scotland who do not have a co-occurring learning disability or a mental health problem have no access at all to a diagnostic assessment. Even so, the National Diagnosis Assessment Service from Scottish finds that large numbers of young adults (18-20) are coming for assessment, mostly high-functioning and referred from mental health services which was probably their first contact with service provision. The implication is that timely identification and diagnosis is still problematic for the high-functioning adult, the majority of whom self-present to general practice. Referral numbers are very much influenced by media coverage. AAA has created a national action plan to address the causes of the delays and how to reduce them, and has worked with adult services to implement this plan.

Recommendation 2 - Provide evidence-supported/informed interventions

The creation of a *Menu of Interventions* follows the recommendations of the Scottish Autism Strategy. It provides general guidance for 14 categories of "ASD Challenge" to define the types of interventions to be considered, the service provider, the referral path and the desired outcomes. It would be fair to say that the guidance is vague as to which interventions are most effective, recognising the weakness of the current evidence base. The *National Training Framework* for autism[76] has been developed for all sectors of the workforce and could address several of our recommendations.

Much emphasis is placed on practice-based evidence as opposed to evidence-based or supported practice. In 2014 Scottish Autism established The Centre for Practice Innovation[77] to promote research minded approaches to practice and to encourage the academic community to support the concept of practice-based evidence through the development of new methodologies that could generate credible evidence.

In schools, government sets the context for the curriculum. There is a presumption of inclusion in mainstream schools, and through the Autism Toolbox[78], the government provides a resource to support autistic children in mainstream schools.

The *Right Click Programme* from Scottish Autism[79] is another example of national activity to support informed interventions: it offers advice and support for parents and carers, particularly in the period following a diagnosis, and has recently been extended to provide a dedicated resource for women. In March 2017, a series of *St Clements' Practical Autism*

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[73] http://www.gov.scot/Topics/People/Young-People/gettingitright

[74] http://www.gov.scot/Topics/People/Young-People/early-years/early-years-collaborative

[75] http://www.gov.scot/Publications/2014/10/7066/12

[76] http://www.knowledge.scot.nhs.uk/media/9595218/asd%20web%20final%20(2).pdf

[77] http://www.scottishautism.org/about-autism/research-and-training/centre-practice-innovation

[78] http://www.autismtoolbox.co.uk/

[79] http://www.scottishautism.org/services-support/support-families/online-support-right-click

videos offering advice for parents, teachers and support workers will be promoted by the Scottish government and released on line for free use[80].

Recommendation 3 - Make the economic case

The most promising basis for evaluating the economic case in Scotland is the *Microsegmentation Study* funded by the Scottish government which will identify subgroups within the ASD population who present with different needs, costs, and life courses, information which will be critical to developing a more effective and appropriate assessment, intervention and support infrastructure across Scotland. This will enable calculation of the escapable costs of autism, that is, those which would not be incurred with early and appropriate interventions, and to provide the evidence base for which more timely and effective services can be provided to optimise care across the country within the available budget. Such an analysis requires better data on prevalence and learning disability. While this work will not be able to provide definitive cost/benefit analysis of interventions, it will identify where the costs are and what targets would offer the best chance of success.

Recommendation 4 - Remove barriers to access

Healthcare access for autistic people is an issue. Specific training for GPs in Scotland is limited and while there is a good learning difficulties curriculum for continuing medical education, uptake is variable. Likewise, the Royal College of GPs has identified autism as a clinical priority but it is probably too early to assess its impact. NHS Education for Scotland has published a web resource for GPs and primary care practitioners[81].

In education, many autistic children do well in mainstream, but the presumption of inclusion may not be the best solution for some. Special school provision is severely limited in the numbers that can be admitted compared with the potential need. Specialist tertiary education should not be seen as a strategy of last resort - crisis placement because of inadequate planning or resource is far more stressful on the child and family and ultimately results in far greater public sector costs.

In 2017, further devolution will enable the Scottish government to set up its own employment schemes to help the unemployed and the disabled, an opportunity to address barriers to access and inequalities in this sector. However, increasing opportunities for employment may have to deal with the difficulty of terminating the employment of the disabled under current employment and disability legislation. Other issues include the additional stress that employment may place on the home life of autistic people and the common attitude of employment services that people with learning difficulties are only suited for voluntary work.

A particular Scottish problem concerns expert provision for the community living in the large rural areas.

Recommendation 7 - Ensure better transitions

Key transitions such as from school to further education or employment would work better if the current mechanisms were applied more fully. Legislation is just a first step, then something has to happen and be done correctly. The Children and Young People (Scotland) Act[82] legislates for a Named Person or State Guardian to advise parents and carers and help them access services. This service may well help with transitions although there is the view

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[80] http://www.highland.gov.uk/news/article/10036/introducing_st_clement_s_school_s_practical_guide_to_autism

[81] http://asd.nes.scot.nhs.uk/

[82] https://www.cypcs.org.uk/policy/children-young-people-scotland-act

that this top down policy undermines the parent and the money might have been better spent in strengthening the working partnerships between local authorities and families already in place under the GIRFEC policy. The future of this initiative is in doubt following a Supreme Court ruling that it is in conflict with the right to private and family life.

Recommendation 8 - Coordinate action across sectors

The integration of health and social care should or could address some of the cross-sector issues but implementation at local level will be the issue. In education the GIRFEC principle should drive better coordination.

Recommendation 9 - Build better information systems

Scotland has a number of systems for gathering, holding and managing information. The Information Services Division (ISD)[83] is part of NHS Scotland and holds health administrative datasets on many areas of health including mental health. The Scottish Learning Disabilities Observatory[84] holds data on both learning disability and autism, including information on prevalence, health, education, housing and employment. The Farr Institute of Health Informatics Research[85] and the Scottish Public Health Observatory[86] are other data systems available in Scotland. There is need for a proper national database to enable the large amount of data routinely collected by ISD to be used to greatest effect in improving early identification and in implementation of evidence-based approaches as the evidence is gathered. Currently the systems do not allow simple translation from or use of data published where individuals have RDoC profiles or DSM 5 diagnoses or to make use of CER results.

Recommendation 10 - Increase funding of autism research

Little of the research spend in the UK is devoted to practice-based research or implementation in contrast with the US, and there is a need to increase research activity that has a direct impact on the lives of autistic people. This includes people who are in receipt of services and those living in the community. There is no substantive research on the benefits or otherwise of specialist v generic services, yet specialist provision is being dismantles and with it, the knowledge infrastructure that supports it.

Basic research is still important, but there needs to be a change in approach and focus to enable better understanding of both the interpersonal and environmental components of good autism practice.

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[83] http://www.isdscotland.org/

[84] https://www.sldo.ac.uk/

[85] http://www.farrinstitute.org/

[86] http://www.scotpho.org.uk/

WALES

BACKGROUND

Summary

On 4th December 2002 the Welsh Government became the first country to announce the development of a national autism strategy, and in 2008 launched and commenced implementation of the resulting national strategic action plan[87], believed to be a world first. Since then over £15m of ring-fenced government funding has been allocated to support the delivery of the resulting action plan which underwent a 'refresh' in 2013/14. Almost all this funding has been used to support initiatives in the public sector with a sustained focus on capacity-building and coordination at national, regional and local coordination levels, assessment and diagnostic facilities, advice and information. A notable additional achievement was the fundraising effort by the charitable sector to establish the Wales Autism Research Centre[88] in Cardiff University and the appointment of the UK's first named professorial chair in autism as its Director in 2010. In 2015, an interim enhancement to the autism action plan was announced[89], addressing better assessment and diagnostic services for children, and a new all-Wales National Integrated Autism Service was launched in 2016[90] and will be rolled out over the next 3 years supported by £6m of government funds.

Self-assessment and implementation updates were published by the Welsh Government in 2011[91] and by the Welsh Government and Welsh Local Government Association (WLGA) in 2012. Outcomes and cost-based evaluation of the impact made by the Welsh Government's ASD Strategic Action Plan for people with autism and their families has yet to be made, though reports have been periodically published, including a Welsh Government evaluation report containing several key recommendations in September 2016[92]. The Welsh Government, in November 2016, rejected calls for an Autism Act for Wales, believing developments from the refreshed ASD Action Plan and the Social Services and Well-being Act 2014 will support individuals with ASD and families effectively.

Chronology

'Community Care' magazine (2003) referred to the development of the Welsh national autism strategy in Wales as a 'seismic shift' not just in policy terms but by ensuring that autism became to be seen in policy terms as a condition in its own right rather than being subsumed under the catch-all of learning disabilities. The political agenda for the introduction of a national autism strategy derived from strategic lobbying by Autism Cymru, a charity established and funded by The Shirley Foundation. The resulting Welsh government national autism strategy was intended to be a ten year strategy and implementation of the action plan for the first three years was supported initially by £5.4 ring-fenced funding and eventually launched on 28th April 2008.

Located in the Welsh Government's Health and Social Care Department; funding focussed mainly around capacity-building via the development of local authority infrastructure for autism and regional coordination provided by a new team located in the WLGA. Running alongside these actions, two Task and Finish Groups were set up by the Welsh Government

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[87] http://www.asdinfowales.co.uk/resource/k_k_WAG_ASD_Strategic_Action_Plan_2008_-_2011.pdf

[88] http://sites.cardiff.ac.uk/warc/

[89] http://www.asdinfowales.co.uk/resource/150518_ASD-interim-delivery-plan-2015-16.pdf

[90] http://www.wales.nhs.uk/news/40600

[91] http://www.asdinfowales.co.uk/resource/k_m_ASD_SAP_Evaluation_Report_Final_18_3_2011__2_.pdf

[92] http://gov.wales/docs/caecd/research/2016/160218-evaluation-autistic-spectrum-disorder-strategic-action-plan-en.pdf

to explore the circumstances and needs of adults with autism, with its recommendations[93] leading to an additional award of £740k over three years to establish a diagnostic network for adults with ASCs in Wales including pre and post diagnostic counselling; and £720k to establish regionally-based community-based and monitoring advice and support for adults with Asperger syndrome. Funding for other benchmark projects relating to adults included the creation of a Wales Autism Employment Ambassador whose task was to work at strategic levels with private business across Wales. In late 2013 the Welsh Government re-aligned funding between the regional community and monitoring support and the local authority infrastructure. It then made an additional funding announcement in 2015/16 of £2m prioritising the treatment and assessment of neurodevelopmental conditions in children and young people up to age 18[94].

Outside of funding for the autism action plan the Welsh government committed £60k as a contribution to Autism Cymru and Autistica's substantial fundraising endeavours which eventually raised a further £690k of charitable grant funding to establish the Wales Autism Research Centre in Cardiff University. This included the appointment of the UK's first named professorial chair in autism, who became the Director of the Centre upon its launch in December 2010.

Evaluation

Evaluation of the foundation phase was published by the Welsh Government in early 2011 highlighting some initial progress but also areas needing to be strengthened especially around diagnosis for children. The WGLA published an implementation update in late 2012 based upon local authority self-assessment and the Welsh Government 'refreshed' the strategy between 2012/14 including commissioned research on employment opportunities. In 2015 an interim enhancement to the autism action plan was announced seeking to improve assessment and diagnostic services for children, and in March 2016, the Welsh Government announced plans for a new wales-wide service to improve services for children, young people and adults with autism funded by £6 million over three years. A Welsh Government evaluation report containing several key recommendations was published in September 2016. Almost all of the £16m plus allocated to date to support the delivery of the action plan has been allocated to the statutory sector and to the WLGA who coordinated delivery. As yet there has been no empirical measure of how this cost benefit has impacted directly upon the experiences and outcomes for people with autism and their families. Lobbying from third sector organisations for an autism act for Wales has heightened in recent months, though as has already been seen in England autism-specific legislation has not necessarily been followed by an increase in resources and services.

Conclusion

The strengths of the Welsh Government's ASD Strategic Action Plan derived from its community-based roots and extensive national engagement in its development and subsequent refresh some four years later. The commitment to sustained ring-fenced funding for implementation of the action plan within the public sector has been impressively sustained from 2008-16 and there have been significant developments such as the appointment of autism leads in all local authorities, and information and training materials developed on a wide range of topics. However, a 'whole nation' approach which progressively includes the third sector as key partners in its funded-delivery programme and an objective examination of outcomes for people with autism and the cost-benefits resulting from delivery of the action plan, is not in place. The absence of autism-specific legislation

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[93] http://gov.wales/docs/dhss/publications/100210autisticspectrumdisordereporttaskandfinishfroupen.pdf

[94] http://gov.wales/newsroom/health-and-social-services/2015/10182787/?lang=en

means that government initiatives lack statutory force resulting in an inability to require local authorities to implement the strategy in full.

RECOMMENDATIONS: PRESENT POLICY AND NEW INTIATIVES

General points from the workshop

The key aims of the Wales national autism strategy were to map prevalence and needs; commission services for the transition from child to adult; develop adult services, and raise awareness through information and training. Education has always engaged less with the strategy than health, but the main weakness has been a lack of output measures and the inability to coerce local authorities as noted previously. This could result in the training of teachers and mental health staff remaining patchy. There were supposed to be triennial reviews of the strategy, but the external review conducted by Holton and Lloyd-Jones in 2012 was only published in 2016[95].

Relevance of the Recommendations

Recommendation 1 - Ensure timely identification and diagnosis

Service provision is varied; in some areas a diagnosis is needed to unlock services, in others not. Despite the new Care and Support (Wales) Regulations (2015)[96], there is still assessment of needs based on the presence or absence of learning disability which means that people are not offered needs assessments appropriately, and personal independence payment (PIP) assessments are often refused if behavioural traits are not evident during interview. The Transforming Care programme[97] does not apply in Wales.

Recommendation 2 - Provide evidence-supported/informed interventions

In parallel with the new integrated autism service, an initiative called *Together for Children and Young People*[98] (akin to the CAMHS service in England) contains a neurodevelopmental workstream with £2m of recurring funding attached. It has proved possible to draw health boards together and create a new pathway for autistic children. Built into this is a data capture mechanism within the Wales Community Care Information System (WCCIS)[99] that will track interventions and their outcomes. Dr Dawn Wimpory at Bangor University has also developed and used an autism database module[100] as an enhancement to the National Community Child Health database[101] to improve efficiency in reporting and data quality.

The notion of practice-based evidence (as opposed to evidence-based practice) is not currently discussed in Wales and information on adult intervention is very thin. Decisions about interventions are different in different parts of the country but it is important to recognise that the picture for autistic children today is very different from 20 years ago and that adult outcomes are therefore likely to be different in future. The presumption is that children will go into mainstream schools with some specialist provision in units or otherwise in dedicated schools. Choice is parent-driven and there are many home-schooled children.

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[95] http://gov.wales/docs/caecd/research/2016/160218-evaluation-autistic-spectrum-disorder-strategic-action-plan-en.pdf

[96] http://www.ccwales.org.uk/regulations-and-codes/

[97] https://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf

[98] http://www.wales.nhs.uk/documents/Framework%20For%20Action.pdf

[99] http://www.wales.nhs.uk/nwis/page/74221

[100] http://sites.cardiff.ac.uk/warc/files/2014/06/ASD-Database-Project-Report-October-2010.pdf

[101] http://gov.wales/statistics-and-research/births-national-community-child-health-database/?lang=en

The number of exclusions of autistic children and those with learning disability is rising whilst other exclusion rates are falling. Language is a further complication in this bilingual country.

There is a huge need to understand what autistic people think works for them. Outcome surveys have been trialled but they are finding that autistic people really struggle with these as they cannot readily isolate the impact of a specific intervention from that of their broader life experience in order to assess its effect.

Recommendation 3 - Make the economic case

A number of pilot signposting projects have been run ahead of the launch of the integrated service from which it is clear that line management structures are the key to success, but no economic data has been collected. Work done in Gwent to bring people back from out-of-county placements and support them locally produced both life improvements and reduced costs. The original strategy did include some funding for service design but this is no longer ring-fenced and so some money has been spent on service provision rather than design. There are Regional Partnership boards between LA's and health across Wales[102] and some work has been done on right-sizing services, for example, looking at local rather than out-of-area provision.

Recommendation 4 - Remove barriers to access

Generic mental health services are not designed for autistic people, for example, the offer of group CBT for depression. GPs can be a barrier particularly where autism training, which is not compulsory, has not been taken up. They may be a case for considering incentives to improve uptake. Getting a diagnosis can be a very lengthy (in Pembrokeshire it can take up to 7 years) but under the new neurodevelopmental initiative (see above) it will be possible for parents to self-refer to a single point of contact. Parents can also ask their LA for a carers' assessment. In June 2016 an initiative was launched by Learning Disability Wales[103] to establish supported employment agencies in North and South Wales for 16-25 year old autistic young people and those with learning disabilities, targeting 800 employers and 1000 young people. This *Engage to Change* scheme provided 6 months paid employment, funded by the government, and help from job coaches. Autism Spectrum Connections Cymru has had some success in getting people into employment.

Recommendation 5 - Tackle environmental and other stressors

Sensory and language issues are recognised in Wales, but anxiety issues less so. More girls are now being diagnosed than in the past, and there is an increase in the numbers of men and boys with a 'female' presentation of autism i.e. autism that is well disguised. There may be a link with transgender issues. Standards for new build social housing are good and stress-reducing for autistic people but school environmental standards need attention.

Recommendation 6 - Fight discrimination

Discrimination on the grounds of IQ is still common. Children's services receive recurrent funding while adult services do not and treatment within the criminal justice system is inadequate, with poor awareness of autism. Professionals should have the right to attend safeguarding meetings. Parents of autistic children can be vulnerable to unwarranted social service intervention if they are honest in telling social services about challenges with their children.

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[102] http://www.assembly.wales/laid%20documents/sub-ld10399/sub-ld10399-e.pdf
[103] https://www.ldw.org.uk/projects/current-projects/engage-to-change.aspx#.WK23jPmLQdU

Recommendation 7 - Ensure better transitions

The transition out of education services in Wales is moving to 25 as in England but given the current lack of provision up to 19 within the current system there is no great expectation of change. There is an advisory service for SEN children from age 13 (Careers Wales[104]) which looks at future education and social care needs. The SEN Code of Practice[105] also highlights the importance of the Review in year 9 (age 16) and the need to draw up a Transition Plan. The Social Services and Well Being (Wales) Act (2014) covers both children and adults so in theory transitions should be easier but there is a lack of capacity and a lack of understanding in the system which results in poor outcomes. There is a transition protocol between child and adult services which is currently being reviewed but schools are transitioning children out without a proper understanding of where they are going.

Recommendation 8 - Coordinate action across sectors

There are health and social care integration initiatives but education is often left out. LA autism leads are not consistently placed – some are in health, some in social care, some in education.

Recommendation 9 - Build better information systems

The National Centre for Mental Health in Cardiff[106], funded by NIHR, underpins clinical research in Wales. There were two mapping exercises on autism in 2009 and 2011 but these did not use the same databases. There may be information on people receiving mental health care and the Waterloo Foundation[107] is funding a new children's database as part of a study of 800 children with overlapping diagnoses and needs.

Recommendation 10 - Increase funding of autism research

There is a need for funding of family research (i.e. the impact of the family environment on outcomes) as well as the involvement of families in research.

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[104] https://www.careerswales.com/en/your-career/features-1/my-future/
[105] http://www.snapcymru.org/wp-content/uploads/2014/09/SEN-Code-of-Practice.pdf
[106] http://www.ncmh.info/
[107] http://www.waterloofoundation.org.uk/ChildDevelopmentWhatWeFundResearch.html