

## **ES/J02080X/1: Developing a Research-Policy-Practice Hub for Autism Spectrum Disorder**

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### **Narrative Impact Report**

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder that affects at least one percent of the population. This ESRC Knowledge Exchange grant supported the development of an *Autism Research Policy Practice Hub (Autism RPP Hub)* <http://www.autismrpphub.org/> designed to promote the translation of research knowledge of autism and encourage dialogue and collaboration across research, practice and policy sectors.

This knowledge exchange project was not a standard research grant. Its impact included contributing to new research and to awareness-raising in policy and practice. A full report of impacts during the lifetime of the grant is provided in the evaluation report of outcomes and impacts. <http://sites.cardiff.ac.uk/warc/files/2014/06/EvaluationRPPHub-8th-Aug-2014.pdf>. The current narrative report will draw on the key points of that report and provide updated impact information for the period April 2014-2015.

#### **Summary of the impact**

The project contributed to knowledge capital, by enhancing knowledge of research in the public services and third sector, and by enabling new communications and partnerships between researchers and professionals in non-academic sectors. In addition, the online RPP Hub provided a catalyst for debates on effective service models and informed the work of the Welsh Government (WG) when evaluating and refreshing the WG ASD Strategic Action Plan.

#### **How the work supported by the grant has been used and impact achieved**

##### **1. Use of the Autism RPP Hubsite**

###### *During grant period*

Google Analytics statistics were used to record the use of the hubsite. Statistics showed that from 19<sup>th</sup> Sept 2013 to 25<sup>th</sup> July 2014 (hub launch date until date of Key Findings Report) there were 45,000 page views by a total of 9,496 users. Users viewed an average of 4 pages per session and were predominantly from UK (63%), US (16%), Australia (8%) and Canada (5%) but included 5% users in the European countries of Ireland, Spain, the Netherlands, Italy, and 2% in India and Japan. The site contained News, Discussions, and Articles and Resources, the content of which were designed around stakeholder requests and research survey data (See Key Findings Report). During the grant period, the three online seminar events; *Diagnostic Interview Methods*, *Employment Hot Topic* and *Policy Conversation* together attracted 16,630 reads. The articles and resources repository contained more than 190 items, read on average 400 times, including certain key articles read over 2000 times.

###### *After end of grant*

The grant ended in April 2014 and, due to absence of further grant income, the site has been minimally maintained without added online seminars, or regular 'news' updates. Therefore, a drop in its use is to be expected. The Google analytics results from July 2014 until 22<sup>nd</sup> April 2015 show a drop in use by 50%. Nevertheless, there were 20,394 page views, made by 4,461 users that came from UK (53%), USA (28%), Australia (8%), Canada (6%) and India (4%). The average number of page views per user was 3 pages and the site flow showed that most users predominantly moved to access content from the Articles and Resources section after entering through the front page of the site. This level of self-sustainability of the Autism RPP Hub indicates that it has 'seeded'. It is still

being actively used by as many as 2,390 users in the UK and 2,000 users in other parts of the world, even with minimum active promotion of the site. Interestingly, of the total traffic through the RPP website during this period, 21% was accounted for by Mobile and Tablet (e.g. iPad) use. Future active use of the Autism RPP Hub in 2015-2016 is planned by linking it to a new ESRC Seminar Scheme, of which Leekam is a Co-I. The RPP hub will be promoted again and new content and facilitation will be provided. See <http://www.shapingautismresearch.co.uk> for more details.

## 2. Impact of Research Policy Practice Hub

Impacts on stakeholders are discussed in detail in the evaluation of outcomes and impacts in the following document: <http://sites.cardiff.ac.uk/warc/files/2014/06/EvaluationRPPHub-8th-Aug-2014.pdf>. A summary is given here highlighting examples of the impact in the employment sector.

The launch of the Autism RPP Hub brought together stakeholders from the research, policy and practice communities, providing a networking opportunity for the influence of research on public policy. The Welsh Government's Deputy Minister for Social Services, Gwenda Thomas AM, launched the hub at a formal meeting and reinforced the link between policy development, good practice and academic research in her speech. Once the hub had been launched the Deputy Minister also contributed an article setting out the achievements of the ASD strategic action plan and priorities for the future. The Research Policy Practice Hub was subsequently used and cited by Welsh Government officials when they were preparing the draft 2014 version of the Welsh Government's Strategic Action Plan for Autism Spectrum Disorders.

The opportunity to use the Autism RPP Hub to bring together autism policy leads in governments was attractive and set as an early objective. We used the Autism RPP Hub to construct the basis for dialogue and exchange of ideas between the four governments of the UK in the *Policy Conversation* online event Nov 6<sup>th</sup> 2013. This event created the first opportunity for ASD policy leads from Wales, Scotland England and Northern Ireland to meet in a public forum. The RPP Hub discussion directly resulted in a joint visit by officials to Scotland which took place on 16<sup>th</sup> January, 2014. The purpose of the visit was to discuss together a service model that had been successful in Scotland. Government officials representing England, Scotland, and Northern Ireland attended and visited One Stop Shops for autism in Edinburgh and in Dunfermline. The visit was hosted by the Scottish Government together with Autism Initiatives and Scottish Autism.

It should be noted that the employment agenda was earlier featured in posts on the Autism RPP Hub with several mentions of the need to encourage employers/business to become more open to employ people with autism. One direct consequence of the on-line seminar hosted by the RPP Hub on the 6<sup>th</sup> of November 2013 was the invitation by the Northern Ireland Government to the Wales Autism Employment Ambassador, Robert Lloyd Griffiths, to speak to a meeting hosted by the NI Minister for Employment in *Stormont* (26<sup>th</sup> January, 2014). This was followed with a debate on autism and employment in NI Assembly held on 10<sup>th</sup> April 2014, promoted by the NI Assembly's All-Party Group on Autism. In Wales a project funded by the department for the Economy, Science and Transport in Wales was established to raise the profile and employment opportunities for people with autism throughout the 45 leading 'anchor' companies in Wales. The RPP hub played a significant role in bringing policy makers in UK governments together, for the sharing of knowledge and experiences, and practice influenced as a consequence.

Corroborating statement from CEO of Autism Northern Ireland

*'The series of online discussions was a particularly useful tool to Autism NI. The policy discussion brought together the respective government ASD Policy Leads from Wales, Scotland, England and Northern Ireland for the first time ever. Autism NI had identified this need and had encouraged the*

*need for such dialogue for some time through the Celtic Nations Autism Partnership (CNAP) so this RPP Hub initiative was a very effective and acceptably independent forum to make it happen. The impact has been significant. During this contact an invitation was extended by the Scottish Executive ASD Policy Lead to facilitate visits in Scotland to a service model much debated and misunderstood in Northern Ireland: the one stop shop. In addition, the follow up networking opportunity that this afforded has ensured an ongoing relationship and information exchange that is government driven rather than voluntary sector motivated.’ Dr. Arlene Cassidy, CEO, Autism Northern Ireland.*

In a later online seminar *Employment Hot Topic* in December 2013, we were able to capitalize further on the ASD employment agenda, with the agenda focused more directly on research and the use of evidence. A discussion was opened on the Autism RPP Hub on employment issues in autism, led by Dr. Beatriz López (Senior Lecturer in Psychology, University of Portsmouth). A number of people joined the discussion including Robert Lloyd-Griffiths (Wales Autism Employment Ambassador), Dr. Sue Fletcher-Watson (University of Edinburgh), Prof Elizabeth Hill (Goldsmiths College, University of London) and Equalities and Diversity, Cardiff University. People with autism provided their own experiences. A series of discussions ensued concerning latest research and evaluation on employability programs and postings were contributed by people living with Asperger syndrome and autism, highlighting the psychological challenges faced when living with the condition and attempting to find employment as well as the importance of employer awareness.

The online *Employment Hot Topic* enabled new communications and partnerships between researchers and professionals in non-academic sectors. Many new contacts were created for the first time between researchers at universities and non-academic professionals. One specific outcome was a research survey designed for the Autism RPP Hub by Dr Beatriz López that led to key recommendations to local authorities who based their proposals on Dr López’s research survey results. The result was the creation of an employment service, the *Autism Centre for Employment (ACE)*, and further successful funding applications for research related to this service.

Corroborating statement by Dr. Beatriz López, University of Portsmouth

*The Hub has been invaluable in sharing information about employment (i.e. the report from Ruth Townsley on Welsh government). It enabled me to conduct a large research survey on the Autism RPP Hub, on barriers to employment for people with autism. I wrote a report with the results of the survey which has been circulated to local authorities (Portsmouth, Hampshire), National Autistic Society and Autism Employment Alliance. Four local authorities and the university of Portsmouth based their successful bid, to the Innovation Fund (from ‘Think Autism’), on this report to set up the Autism Centre for Employment (ACE). This employment service provides assessment of individual needs, person-centered training to employers with recommendations of adjustments and work placements. My survey was also the basis for another successful research bid to Research Autism to continue the activities of ACE. An additional bid has been submitted to the Peter Cruddas foundation. Academic publications are currently being prepared for publication.*

Dr. Beatriz López, Associate Head, Dept Psychology, University of Portsmouth

Other impact - The resources provided by the Research Policy Practice Hub have also been used by a range of communities. These include Health Boards, local special schools for Autism in Wales and the Latvian Autism Association. In early April 2015 we were also contacted by the project leader of a non-autism charity, Shelter-Cymru, who has been accessing research summaries and government resources on the Autism RPP Hub to gain more information about the effects of ASD in people who are homeless.

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