Integrating Research, Policy and Practice in ASD

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Introduction

Background: Research in ASD has helped to advance our knowledge about evidence-based methods for identification, diagnosis and intervention in ASD. However, much of the new knowledge emerging from this research is not reaching the people who need it. Many users of autism services, practitioners and policy-makers are not aware of research evidence and how to evaluate it, though they are increasingly expected to use evidence-based practice. Likewise, some key issues affecting individuals with autism that are being articulated by government agencies, third-sector organisations and service users are not impacting on research.

Objectives:
1) To facilitate sharing of expert knowledge across areas of research, policy and practice
2) To increase awareness and understanding of evidence-based scientific research in the non-academic community
3) To promote engagement with users of future research through consultation and participation.

Materials Developed

1) A web-based electronic forum was developed to promote the sharing of expertise between practitioners and researchers for specific topics (e.g. diagnosis, sensory symptoms)
2) Two ‘research aware’ resources were designed, a ‘research aware leaflet’ for parents and a ‘research toolkit’ for practitioners, each focused on enhancing research knowledge about intervention.
3) Familiarisation resources were designed for potential users of researchers; a booklet and DVD about neuroimaging research. A model of the head coil from the MRI machine was made, so that potential participants could look at it and try it.

Evaluation of Materials

1) The web-based electronic forum for practitioners and researchers generated debate and discussion between more than 100 researchers and practitioners, including discussion in advance of two international meetings. Qualitative and quantitative evaluation data revealed a) difficulties in site navigation and b) greater suitability for more focused discussion topics with clear incentives for users
2) The Research Aware Booklet: Results from a small sample of parents (N = 15) suggested that 75% would be more likely to ask for research evidence for an intervention having read the booklet. 81% found the booklet useful
3) The Research Toolkit is a 10,000 word book. Plans to develop it further are underway.
4) The DVD depicted a young man with Asperger’s coming to the Brain Imaging Centre at Cardiff University and taking part in a study. The film follows him arriving and progressing through the study. It is now on Youtube (http://www.youtube.com/watch?v=umTqNN60Djo) and has been viewed 169 times. The accompanying booklet has been distributed to 760 and an electronic version is available (http://psych.cf.ac.uk/warc/docs/warc%20booklet%20(leaflet).pdf). In a small user sample, positive responses were received. Evaluation data showed that watching the video and reading the booklet, changed views in the majority of cases in terms of both increased understanding about the role of neuroimaging and increased interest in potential participation
5) Consultation with potential users of the ‘research aware’ resources identified aspects of research methodology that would be benefit from further explanation, such as the time scale of research projects, the limitations and uses of some techniques e.g. MRI scanning.
6) Engagement with users of research through the familiarisation resources resulted in half of them expressing an interest in participating in future neuroimaging research.

Outcomes

Results of the electronic forum activity helped to identify patterns of user activity informed the development of a larger scale online networking area – The Research Policy Practice Hub. Further work is needed to increase understanding of research evidence and willingness to incorporate it into decision making in policy and practice. Increasing engagement and participation in research will be accompanied by improved dialogue and two-way communication between researchers and users of ASD research.

Developing a Research-Policy-Practice Hub for ASD

The new project, funded by the ESRC and the Welsh Government capitalises directly on the original project. It builds on the team’s experience of usability challenges in online contexts and focuses on working across both practitioner and policy communities. The project also consolidates collaborations with charities and with Bangor University and involves policy consultant placement visits at Cardiff University.

The project will create a policy and practice platform (‘Hub’) that provides a mechanism for:
• Promoting dialogue between different communities of researchers, policy makers and practitioners in ASD.
• Facilitating increased understanding of scientific research in the policy making and practitioner communities.
• Creating the conditions for the translation and exchange of knowledge and practice between researchers and the two other communities.

How will Knowledge exchange be achieved?

Knowledge exchange will be achieved via a set of coordinated online and offline activities that provide elements of the Hub in its first stage of development.

These include development of:
• Networks of expertise
• Visits by two policy consultants once a month to Wales Autism Research Centre. They will have a key role in the strategic planning and development of the Research-Policy-Practice Hub
• Contribution to communication, training and support packages and will encourage visits to WARC by prominent political figures within the National Assembly for Wales and the Houses of Parliament.
• Online infrastructure
• This will give those from the communities of research, policy and practice an opportunity to have dialogue around the areas of diagnosis and intervention via the use of information, discussion forums, news feeds etc.
• Communication, training and support
•There are some diagnosis training packages as part of this project, with the expectation that learners will use the online hub as part of their training experience.

RFF-Hub will coordinate with other UK online communities of practice e.g. Network Autism. The Hub is currently the only UK network which will connect all three communities

Links will also be made to other international specialist websites and news blogs e.g.

RFF-Hub will connect across these and other interfaces, and also have an opportunity for questions related to the implementation of research related policy and practice.