

How can we prioritise autistic wellbeing in biomedical research?

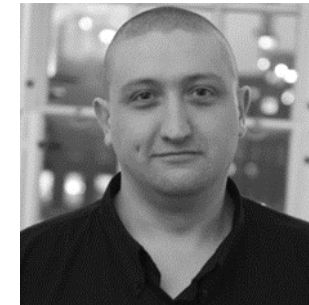
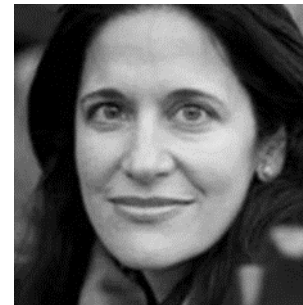
Ginny Russell

Biomedical research consortium



- Strong specialisation in research methods- genetic, neuroscience, animal models
- Importance of publication and citation rate
- Undervaluing of patients experiential knowledge- PPI is required, however.
- ‘Targets’ are symptoms of autism, ‘outcomes’ lessening of symptoms

- Ethics Advisory Board



The standard model



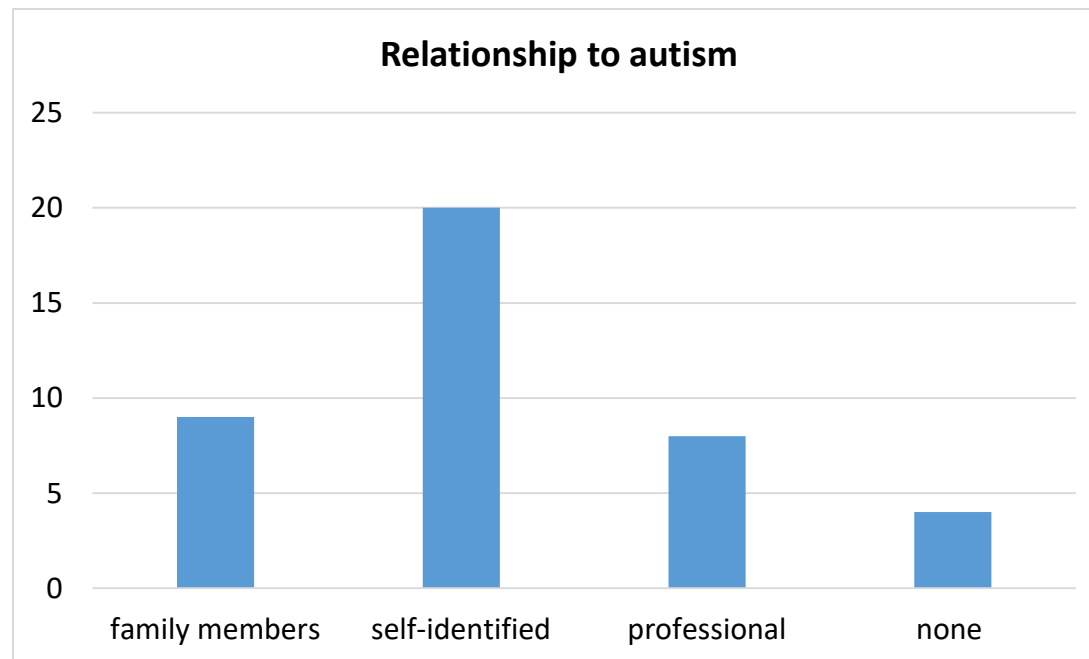
‘What parents wish for their children is often that they “find happiness”, where this would typically be found in having an interesting and well-remunerated job, good friends, a loving partner with whom to start a family, and in having a life free from debilitating sickness and long enough to enjoy one’s grandchildren.’

Is this appropriate for children /adults with autism?

Rodogno, R., Krause-Jensen, K., & Ashcroft, R. E. (2016). ‘Autism and the good life’: a new approach to the study of well-being. *Journal of Medical Ethics*, 42(6), 401–408.

Stakeholder survey: methods and sample

- 2 public events , 2014, 2015. 24 months in.
- Call for comments with video prompt.
- 66 respondents.



Findings

- 'Autism' not a suitable target for treatment.

*Autism is such an inseparable part of our identity, and eliminating it (if that is even possible) would mean eliminating the individual. **Autistic adult***

*To what extent is it possible to talk in global terms about treating autism, given the wide heterogeneity of the condition and given the existence of disparate comorbidities? **Parent***

- Specific issues causing difficulties might be suitable targets.

*Are the researchers aware of the conceptual distinction between treating autism (as defined by its core features/diagnostic criteria), and treating the difficulties that some autistic people and their carers have identified as being the key impairments to their wellbeing? **Professional***

- Well-being considered an important outcome for pharmacological treatment.

Findings

- Agency
- *Antipsychotic drugs are sometimes given to people who display unusual behaviour to improve the experience of the carers rather than that of the patients themselves. I worry that drugs to treat autism would be used in the same way.*

Autistic adult

- Critical voices not the whole story
- *If my son could take a pill for his autism and thus get rid of all the problems he contends with and is going to fight with, I would almost force-feed him with such a pill! I cannot understand the desire to 'protect' a handicap for handicap's sake!*

Parent

Did autistic well-being become a priority in bio-medical research?

- Presented to biomedical consortium

Blocks:

- Well being not easily quantifiable
- Currently funding applications assessed by scientific rigour by other by other biomedical scientists.
- Infrastructure of biomedical funding does not require a range of patient views, just patients' views.
- Targeting autism symptoms or autism is best for a viable commercial product.



Recommendations

- Early engagement with range of views in community
- Funders responsible
- Mechanism to ensure patient views influence to basic research (?)
- Autistic wellbeing needs to be defined & measurable before it can be adopted as an outcome.
- Research avenue- find correlates of well-being in autistic population?



Our research in Exeter



Autism and Neurodiversity

Exploring Diagnosis

Our research is not biomedical but on lived experience of autistic adults.

Mostly qualitative research.

- How to find out about autistic wellbeing ?
- Services/treatment/accomodations –what has been helpful?
- Focus on strengths



Who QOL Bref

		<i>(Please circle the number)</i>				
		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
For office use F6.4 / F8.2.2	19. How satisfied are you with yourself?	1	2	3	4	5
F13.3 / F17.2.3	20. How satisfied are you with your personal relationships?	1	2	3	4	5
F15.3 / F3.2.1	21. How satisfied are you with your sex life?	1	2	3	4	5
F14.4 / F18.2.5	22. How satisfied are you with the support you get from your friends?	1	2	3	4	5
F17.3 / F21.2.2	23. How satisfied are you with the conditions of your living place?	1	2	3	4	5
F19.3 / F24.2.1	24. How satisfied are you with your access to health services?	1	2	3	4	5

- How would you rate your quality of life?
- How satisfied are you with your health?
- To what extent do you feel your life to be meaningful?
- How safe do you feel in your daily life?
- Do you have enough energy for everyday life?
- How satisfied are you with yourself?