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Ethics and autism: where is the autistic voice?

Commentary on Post et al.

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In their recent Brief Report, Post et al. (2012) described the development of the Stony Brook Guidelines, a document outlining treatment-related ethical and social issues for autistic people, their families and professionals, developed, they claim, through extended discussions between professionals and those primarily “affected”.

Although we very much welcome efforts by professionals, researchers, and families to consider the social and ethical issues relating to the lives of autistic people, we have serious concerns both with the way in which Post et al.’s discussions took place and the resulting Guidelines. Indeed, we believe that they threaten to send entirely the wrong message to professionals regarding the “ethics of the care of people with autism and their families”.

The authors claim that their guidelines are “based not on ‘top-down’ imposition of professional expertise but rather on ‘bottom-up’ grass roots attention to the voices of affected individuals and families”. Yet they provide no indication of how the views of “affected individuals” were elicited. There were no autistic voices on the committee of 17 professionals, who derived the Guidelines, half of whom were parents or siblings of autistic individuals. While non-autistic parents and professionals might claim that they are best placed to speak for autistic individuals, especially those who find it difficult to speak for themselves, this cannot be accepted on face value. We believe that human dignity requires us to make every effort to access the views and perspectives of autistic people. The absence of any sustained attempt to represent the views of autistic individuals themselves reflects a paternalistic approach to the ethics of care and threatens further to disempower those already frequently overlooked in key decision-making processes that shape their lives.

Furthermore, the tone of this Brief Report is deeply patronizing throughout. The research aims are primarily discussed in terms of the “impact” of autism on family members, while autism is defined solely in terms of a functional deficit within a medical model narrative. In this way, the authors appear to either ignore or are unaware of social models of

disability and autistic self-advocacy. For example, issues regarding quality of life and happiness are framed within a normalising perspective, including “hopes for a cure” – something that many autistic people either do not want and/or see as an unrealistic goal to pursue, or even as supporting an eugenicist agenda. Indeed, little weight is given to the value of autistic autonomy or to the commentary of autistic authors and researchers over the past 20 years (e.g., Arnold, 2010; Lawson, 2008; Milton, 2012; Sinclair, 1993; Williams, 1996).

We must do better than this. The ethics of the autism research should encompass the various perspectives and best interests of both autistic people *and* their families. We therefore need to devise ways of developing mechanisms that both place the perspectives of autistic people “at the centre of the autism conversation” (Ne’eman, 2011) and are attentive to the diversity of voices within the autism community. Such mechanisms must also be truly participatory (see Pellicano, Ne’eman, & Stears, 2011), actively seeking to overcome the power differentials that exist between autistic people and established authorities. This will not necessarily be easy: disagreement will be inevitable, especially when tackling deeply contested issues like challenges to autonomy. But it offers the only ethically acceptable way forward.

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