Social Science & Medicine 75 (2012) 1642–1649

Contents lists available at SciVerse ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

Diagnosis as a social determinant: The development of prosocial behaviour before and after an autism spectrum diagnosis

Ginny Russell [a,b,*], Susan E. Kelly [b], Tamsin Ford [a], Colin Steer [c]

[a] Institute of Health Services Research, Peninsula College of Medicine and Dentistry, Exeter, UK
[b] ESRC Centre for Genomics in Society (Egenis), University of Exeter, UK
[c] Centre for Child and Adolescent Health, University of Bristol, UK

ARTICLE INFO

Article history:
Available online 16 July 2012

Keywords:
UK
ALSPAC
Autism
ASD
Sociology of diagnosis
Diagnosis
Social determinant
Child health
Developmental trajectory
Pervasive developmental disorder

ABSTRACT

Jutel and Nettleton (2011) discuss diagnosis as not only a major classification tool for medicine but also an interactive social process that itself may have ramifications for health. Consideration of diagnosis as a social determinant of health outcomes led to the formulation of our research question: Can we detect a change in the development of prosocial symptoms before and after an Autism Spectrum Disorder (ASD) diagnosis? We examined the developmental trajectory of prosocial skills of children, as impairment in social skills is given as a core symptom for children with ASD. We used a validated scale measuring prosocial behaviour for a sample of 57 children where the measure was repeatedly recorded over ten years. We plotted the developmental trajectory of the prosocial trait in this sample who were enrolled in a longitudinal birth cohort study based in South West England. Multi-factorial fixed effect modelling suggests that the developmental trajectory of this measure of behaviour was not significantly altered by ASD diagnosis, or the consequences of diagnosis, either for better or worse. Further analysis was conducted on a subset of 33 of the children who had both pre-diagnosis and post-diagnosis information, and the same result obtained. The results indicate that prosocial behaviours may be resistant to typical 'treatments': provision of educational and specialist health services triggered by a clinical ASD diagnosis. The implications of this for considering diagnosis as a social determinant are discussed.

Introduction

In their introduction to a special issue of *Social Science & Medicine* on the sociology of diagnosis, Jutel and Nettleton (2011) consider diagnosis as not only a major classification tool for medicine but also an interactive social process that itself has ramifications for health. Diagnosis plays the important role of organising illness – 'identifying treatment options, predicting outcomes, and providing an explanatory framework' (Jutel, 2009, p. 278). Jutel and Nettleton identify three areas in which diagnosis may exert a socio-political influence on patients: diagnosis as a method of categorisation, diagnosis as a process, and diagnosis as an event with consequences for health. We turn our attention to the last of these with regard to outcomes in child health; can we detect whether diagnosis itself acts as determinate of outcome? More specifically, if diagnosis is a social process, can it be identified as a social determinant of outcome for symptoms of a childhood condition? In order to examine this question we ascertain whether a diagnosis of an autism spectrum disorder (ASD) is associated with improvement in the developmental trajectory of social skill, a key symptom of autism. Is diagnosis associated with an improvement in social skills, a deterioration or no effect? We situate this analysis within the developing 'sociology of diagnosis' field, whilst additionally drawing on psychiatric and educational literatures.

Straightforward medical models are often challenged in child psychiatry where symptoms are behavioural in their nature. This is particularly true for 'contested' conditions (Dumit, 2006), where often diagnosis itself is not wholly determined by symptoms but is also dependent on social factors such as the impact on carers (American Psychiatric Association, 2000; World Health Organisation, 1993). A childhood autism diagnosis, for example, has been described by some as medicalisation of extreme behaviour (Timimi, Gardner, & McCabe, 2010). A clinical diagnosis in childhood of a neurodevelopmental disorder such as ASD or attention deficit hyperactivity disorder (ADHD) has been shown to have ramifications for children and carers beyond determining

---

[*] Corresponding author. Institute of Health Services Research, Peninsula College of Medicine and Dentistry, University of Exeter, Veysey Building, Salmon Pool Lane, Exeter EX2 4SN, UK. Tel.: +44 077 8888 4100.

E-mail address: g.russell@ex.ac.uk (G. Russell).

0277-9536/$ – see front matter © 2012 Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.socscimed.2012.06.019

treatment and the categorization of symptoms into a diagnostic class (Singh, 2011). The ASD diagnosis is therefore the focus of our analysis, but as diagnosis cannot be separated from its consequences (be they positive or negative), we also follow the outcome of interest (social behaviour) for several years before and after diagnosis in order to detect change.

The symptoms of ASD, which are behavioural, lie on a spectrum or continuum in the general population. Individual symptoms of autism do not always appear to be strongly linked, or be inherited together (Happé, Ronald, & Plomin, 2006; Ronald et al., 2006), leading some to question the validity of the diagnostic category itself, and call for research that focuses on trajectories of individual component traits of ASD, rather than the diagnostic class (e.g. London, 2007). It is well established that there is no clear demarcation separating pathological severity from common traits that are seen in non-clinical populations (Constantino & Todd, 2003). Behavioural symptoms of ASD therefore lie on a continuum, which diagnosis then converts into a binary categorical group, defining the boundary between 'sickness' and 'wellness' (Jutel & Nettleton, 2011). We therefore distinguish between a lack of prosocial behaviour, which is symptomatic of ASD, and ASD as a diagnostic class; as a categorical description, which we may consider as itself a potential social influence on behavioural or 'symptom' outcomes. Wispé (1972) first proposed the term "prosocial," meaning to create an antonym to the term "antisocial". Several studies have addressed the link between prosocial skills and life outcomes, and have shown that low prosocial scores are associated with a range of negative outcomes in adults, from lack of employment through educational attainment to successful relationships (e.g. Eron & Huesmann, 1984).

Some scholars have argued that aside from the outcomes associated with underlying behavioural symptoms, being given the ASD diagnosis itself could be, or should be, associated with altered outcomes. The philosopher Hacking distinguishes between 'natural' kinds and 'interactive' kinds. The latter may be transformed by their classification into groups, where 'natural' kinds are not. Hacking describes people classified with autism spectrum disorders and other interactive kinds as:

> Moving targets because our investigations interact with them, and change them. And since they are changed, they are not quite the same kind of people as before. The target has moved. I call this the 'looping effect'. Sometimes, our sciences create kinds of people that in a certain sense did not exist before. I call this 'making up people' (Hacking, 2006, p.23).

Although Hacking considers behaviours symptomatic of autism to be biological and genetic in origin, he argues that the conceptualisation of the categories 'autism' and 'ASD', may feedback after the diagnostic categorisation is made, influencing subsequent childhood behaviours. Autistic children might 'inhabit the identities they have been ascribed' as Nadesan puts it (2005, p150). Thus the diagnostic act or event can be considered a social determinant of health outcome.

In the past, some sociologists, psychiatrists and psychologists have questioned the merits of diagnosing mental health conditions in children at all (Conrad & Schneider, 1992; Scheff, 1974). Theorists argued that diagnostic labels may engender different reactions from others and lead a person who is diagnosed or 'labelled', to be treated differently, and they may act to fulfil the character they have been attributed (Scheff, 1999). Such self-fulfilling prophecies may undermine the use of medical models and the positive outcomes that might follow from diagnosis and interventions following diagnosis. There is a tradition of empirical work, particularly in education, showing that self-fulfilling prophecies do take place and can have negative effects on academic outcomes, particularly with regard to teacher expectations (Jussim & Harber, 2005). However, there is little empirical evidence to support the claims of labelling theorists in relation to the application of a childhood diagnosis of neurodevelopmental disorders such as ASD, although one recent study of ADHD showed that children with hyperactive symptoms who were identified (by researchers) to teachers had worse outcomes at follow-up than a group who were not identified (Sayal et al., 2010). Harris, Milich, Corbitt, and Hoover (1990) looked at boys' dyadic relationships and found if a bogus label of ADHD was ascribed, it led to negative reactions. However a follow up study found the effect of actually being diagnosed with ADHD, and displaying hyperactive behaviours, had a greater effect (the reactions of other boys became even more negative) than being incorrectly labelled by experimental manipulation, even when perceivers were unaware of the diagnostic labels (Harris, Milich, Corbitt, Hoover, & Brady, 1992). Generally, there is a dearth of research that situates childhood diagnosis itself as the site of analysis.

Despite the argument that diagnosis could have negative effects on developmental outcomes, both clinicians and parents would hope to see an improvement in symptoms of autism after diagnosis and remediation. The American Academy of Pediatrics Committee on Children with Disabilities describes the goals of ASD treatment:

> To improve the overall functional status of the child by promoting the development of communication, social, adaptive, behavioral, and academic skills (Committee on Children with Disabilities, 2001, p.7).

The rationale often given for ASD diagnosis is to identify suitable treatments. 'Treatments' for ASD are not pharmaceutical but generally take the form of behavioural interventions and increased educational resources. In Europe and the North American countries, a clinical diagnosis of ASD usually triggers access to services for the child and his or her family. ASD diagnosis is often framed as a way for parents and children to access important health and educational services and other forms of support. Mansell and Morris (2004) provide a useful summary of typical interventions and services that are adopted after an ASD diagnosis is given in the UK. These include extra educational support in the classroom or special schooling, parents' support groups, speech and language therapists, school psychologists, psychiatrists, respite care and focused access to information such as books and academic journals. Special units and schools were rated as the most useful source of support. Many studies have examined the efficacy of various treatments for ASD with mixed results; there are no robust data favouring one approach over the others (Francis, 2005). While some interventions that support social skills do have empirical support (e.g. Dawson et al., 2010), there is a lack of consensus on the most successful intervention strategies (Feinberg & Vacca, 2000). Some approaches work for some children, in controlled settings, but it is not possible to make predictions about efficacy for all children with autism.

Practitioner guidelines strongly advocate clinical diagnosis (Filipek et al., 1999). However parents and educators face considerable dilemmas when faced with the prospect of a diagnosis (Russell & Norwich, 2012). Although diagnosis may lead to access to services, respite and a partial explanation for a child's behaviour, parents also consider that potential devaluation, stigma and rejection may result. A diagnosis can 'vindicate and blame, can legitimise or stigmatise' as Jutel and Nettleton (2011, p. 797) point out. The diagnosis therefore represents a double-edged sword for many parents, and so establishing likely outcomes associated with diagnosis is crucial. Al-Qabandi, Gorter, and Rosenbaum (2011) point out that if long-term outcome is not modified, emphasis on the importance of diagnosis and intervention for ASD may be misplaced.