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Title: Becoming able to see anomalies

by

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In his still-authoritative history of science essay, Kuhn (1970) showed that scientific discoveries commence with awareness of anomaly which researchers initially struggle to notice. Kuhn drew on a psychological study to illustrate the problem. Bruner & Postman (1949 cited in Kuhn 1970: 63-64) asked people to name playing cards on brief exposure. Most cards were normal but some were anomalous, such as a red six of spades and a black four of hearts. On brief exposure all participants fitted the anomalous cards unhesitatingly into their existing cognitive scheme, identifying them as, for example, a six of spades or a four of hearts. With longer exposures subjects began to hesitate: ‘That’s a six of spades, but there’s something wrong with it’. Further increases in exposure resulted in more hesitation. The correct identification came quite suddenly to most people: having noticed a few anomalous cards, they were then able to identify the others without difficulty. Yet even with 40x exposure, a few people continued to express confusion and discomfort while remaining unable to make the cognitive shift.

We cite this in justification of examining a single policy topic, choice, while also seeking to promote a Deleuzean account which entails multiplicity. Kuhn’s history indicates that in order to persuade the necessary critical mass of research colleagues to explore a multiple and relational paradigm, they need first to have noticed anomalies between the thoughts and actions of people involved in ID and policies with which they are required to engage.

We studied people with ID as they left school less because this transition is persistently reported to be troubling than because transition pauses briefly the service flux that obscures the way people on the ground respond to changing policies. School-leaving creates a pinch-point that makes moral imperatives, and people’s concerns and responses, visible to research.

Our study has revealed anomalies between the thoughts and actions of people involved in ID and the policies with which all parties are required to engage, by analysing policy issues one at a time: inclusion (Clegg et al 2008); risk and the navigation of moral terrain (Almack, Clegg & Murphy, 2009); adulthood (Murphy, Clegg, & Almack, 2011); and differences between the needs of young people
with ID and their parents (Pilnick et al 2011). In this final analysis published by PPP, we examined the outworking of choice policy but also went beyond simply adding to the growing chorus of criticism being directed at neoliberal individualism. We introduced a Deleuzean lens to show how this conceptual alternative can shed greater light on the data, and to indicate where this paradigm could take the field. We accept the observation that a Deleuzean account of a life leans back towards neoliberal individualism when only one concept or attribute is examined, and look forward to working with others to develop an account of the ID life that incorporates multiple perspectives.

Whether it is possible/desirable to do without with the administrative category ‘ID’ altogether is a more complex issue. There is growing evidence that ID becoming ‘dedifferentiated’ has had negative consequences for individuals and their families. Dedifferentiation is a term from biology which describes the process by which structures or behaviours that were specialized lose their specialization. Bigby & Ozanne (2001) were amongst the first to argue that, while dedifferentiation would address some problems deriving from stigmatisation, it would also result in loss of knowledge. Current studies show that parents criticise mainstream services for having no knowledge of the health needs of children with unusual syndromes (Tunnicliffe & Oliver 2011); and that adult mental health services are (1) reluctant to accept people with ID into their service (Donner, Mutter & Scior 2010), (2) unsure how to work with adults who have ID (Hemm, Dagnan & Meyer, 2015: systematic review), and (3) not considered sufficiently competent (Flynn, 2010; Sheehan & Paschos, 2013) to treat the mental health problems experienced by people with ID.

Bigby & Ozanne (2001) further predicted that dedifferentiation would bring a loss of commitment to social and political change; shift responsibility back onto parents who already carry a huge burden of care; and result in a return to congregate care with people who have different disabilities being combined within one large setting. The challenge posed to the neo-liberal stance of treating everyone the same is that homogenisation risks reducing equality of outcome, and reinforces exclusion. Recent evidence from Scandinavia (Tøssebro et al 2012; Miettinen 2012) shows that
changing from state-mandated specialist services to local, generic services has indeed resulted in larger homes, and in the development of large congregate care services for a mix of people: those with ID, dementia and other problems of aging, and mental ill-health. Such services have been shown to offer poorer quality of care which, as predicted, encourages parents to continue caring for their relative with ID at home. In similar vein, while there is consistent international evidence that mainstream education works well at primary school, the competitive environment of secondary education results in pupils with ID experiencing significantly greater ridicule and exclusion (Cooney et al, 2006; Popovici & Buica-Belciu, 2013; Kim 2013) and being less likely to access supportive community services they want and for which they are eligible (Olsson et al 2015). There is also evidence that most countries fail to meet their commitment to Article 11 of the United Nations (2006) Convention on the Rights of Persons with Disability, which states that signatories must ensure the protection and safety of persons with disabilities in situations of risk. People with ID have been found to be particularly vulnerable during conflict (Rohrweder, 2013): ‘IDs are hard to diagnose, understand and support…. the amalgamation of persons with disabilities in general obscures [people with IDs] and their specific needs’ (p779).

We agree that the category ‘intellectual disability’ is a moving target. Hacking’s (2007) observation that different kinds of people are referred to as definitions change has been explored by one of us quite recently, in a history of British clinical psychology’s engagement with ID (Clegg, 2015). Yet movement in and out is largely confined to people at the margins (see in particular Burns, 2015, for description of the impact of people outside the category gaining entry fraudulently). We accept Somers-Hall’s concern that a vitalist, Deleuzean account of life does not sit easily with conceptions of the individual human, but unless we can reconcile fluid and multiple understandings of life with the administrative realities of welfare systems, we lack confidence that the 1.5% of the population with significant intellectual impairments will obtain the support that their substantial needs warrant. Contemporary philosophers such as Smith (2013) have argued for ‘thick’ concepts that can encompass parallel understandings. Similarly, Sadler, Staden and Fulford (2015) argue that late
twentieth-century turf wars between medical and social models of practice must give way to twenty-first century negotiation between a diverse range of parties and perspectives, not least the co-production of services with users and parents.

In sum, since people working within a dominant ‘normal science’ need considerable exposure to anomalous data before they are able to recognise the anomalies that precipitate change, each of our transition studies examines only one policy topic. Thus in this article we examined a single issue, choice, and also construed the data through a Deleuzean lens. Simpson (2016) & Somers-Hall’s (2016) succinct and helpful commentaries have articulated important issues and caveats for our project, particularly the latter’s account of relationality and the life rather than the individual human. They have provoked us to further thought about our project which we conceived as a whole, and will now integrate its findings. In the company of other researchers also rethinking ID (such as, but not limited to, Clifford Simplican, 2015; Goodley 2014; Hall, Simpson, & Philo 2012; Wiesel & Bigby, 2015) we look forward to generating, collectively, a paradigm fit for the twenty-first century.

References


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