

Editorial

Introduction to theme section on geographies of intellectual disability: ‘outside the participatory mainstream’?

Abstract

This paper introduces the following theme section on *Geographies of Intellectual Disability*. It outlines the historiography of geographical work on intellectual disability, noting in particular the contributions of Wolpert (Transactions of the Institute of British Geographers 5 (1980) 391) and Hall and Kearns (Health and Place 7 (2001) 237), before tracing claims made about both the ‘institutional’ and ‘deinstitutional’ eras in the changing geographies confronting and experienced by intellectually disabled people. This account, highlighting the tendency for such people to remain ‘outside the participatory mainstream’ in almost all circumstances, offers along the way an introduction to the four contributions that follow.

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Absences and agendas: a quick historiography

In our models we dwell upon this rational expectation of competency and pay less attention to the range and deviations. Institutions, programmes and policies generally operate according to a model which presumes competency and directness. The incompetent and the inadequate are outside the participatory mainstream. The issue, of course, is that the notion of competency results from a process of labelling rather than from any inherent differentiation. Competency is evaluated in relation to an ever-increasing and ever-more-demanding technology and institutional structure which, each year, places more of us in the incompetent group. There are fewer and fewer things, for example, that even mildly retarded people can do any longer, though they have not changed (Wolpert, 1980, p. 397).

Writing in 1980, Julian Wolpert was arguably the first to tackle intellectual disability in a high-profile outlet for academic geography, the *Transactions of the Institute of British Geographers*. Drawing upon his interest in ‘issues of threat and conflict’, which had ‘led [him] to study groups labelled deviant, including mentally handicapped populations,¹ and the implications of their re-entry into

urban communities’ (eg. Wolpert, 1978, 1987), he mused on the changing character of the ‘risks’ that confront everybody in their daily lives. The legal literature on

(footnote continued)

older lexicons to ‘feeble-mindedness’, ‘mental defectiveness’ and ‘mental subnormality’ in the later nineteenth and early to mid-twentieth century; to ‘mental handicap’ and ‘mental retardation’ from the middling years of the last century through, albeit with reservations, to the present day; and to a range of terms used more recently such as ‘learning difficulty’, ‘developmental disability’ and ‘intellectual disability’, the situation is totally bewildering. Behind these labels, there is presumably a core of people with genuine mental differences that has maintained some stability across the centuries, but it is difficult to escape the conclusion that to a large extent what we confront here is a variable social construction open to confusion, dispute and even potentially dubious manipulation. In the papers below, the authors discuss their own take on terminology, but in this introduction we follow the example of Hall and Kearns (2001) in talking about ‘intellectual disability’ and ‘intellectually disabled people’. What we will note is that intellectually disabled people are not necessarily physically ‘unhealthy’, although in practice the bodily differences linked into intellectual disability *do* all too often bring with them unfortunate additional health problems (see Smith (this issue) when discussing certain ‘quality of life’ implications). Nonetheless, it might be possible to ponder whether a journal concerned with *health* is indeed the right place for studies of intellectual disability.

¹The terminology here is the subject of intense expert and often ‘political’ debate. From ‘idiocy’ and ‘imbecility’ in much

such risks tends to stress matters of ‘competency’ and ‘dangerousness’, so he noted, and in the process we all become objectified in terms of our respective competences to cope with potentially dangerous situations. A problem is that according to many ‘models’ of competency, virtually all of us end up seeming *incompetent* relative to the ‘rational’ responses that we *ought* to show when confronted with the increasingly complex ‘technology and institutional structure’ surrounding us. This problem is then ratcheted up several notches for intellectually disabled people—‘the incompetent and the inadequate’, as Wolpert termed them in a vocabulary at once perhaps unfortunate but also starkly exposing the negative portrayals to which such people are commonly subjected—who are seemingly more unable than most to exhibit the appropriate rational responses. Wolpert critiqued this state of affairs for all of us but specifically for those with intellectual disabilities, arguing that there is a certain ‘dignity’ in risk, in accepting the risks that ordinary living cannot but bring. The implication was that a certain *indignity* lies in being sheltered from many of these risks. Most of us retain such dignity, even if rational planning systems strive to reduce the risks facing us, but for intellectually disabled people this dignity is much reduced, since so many mechanisms serve both to protect such people from harm and to prevent them doing possible harm to others. Wolpert (1980, p. 397) duly hinted at ‘the placement’ of this population: the need for it ‘to be displaced for the public good’ to a ‘protective zone’ in order ‘to provide protective security to those who would otherwise harm themselves or be harmed by others’, adding that they are cousins of ‘dangerous people’ like ‘criminal offender populations’ as apparently unpredictable agents who might indeed also do harm to others.

With these fragmentary remarks, Wolpert evoked key themes resonating through subsequent work on the geographies of intellectual disability: the will of wider society to exclude intellectually disabled people on the grounds of their ‘irrationality’, ostensibly as a protective move but also perhaps as one with controlling ambitions linked to a fear of such irrational difference. The purpose of Wolpert’s (1980) paper was not to establish a new subfield of geographical inquiry, and it would be wrong to suggest that it acted as such a catalyst, but it nevertheless stands as a temporal entry-point to a small body of inquiry that has gradually accumulated over the past quarter century. To some extent surfacing as a footnote to a more sizeable literature on the geographies of mental health, illness and services (see Philo, 1997, esp. pp. 82–83 and endnotes 29–30; Wolch and Philo, 2000, esp. footnote 3), studies began to cover institutional provisions for intellectually disabled people, particularly in historical perspective, as well as the shifting spaces of provision, both as structured from without and as experienced from within, associated with

a more recent era of deinstitutionalisation. Despite past elisions in practices directed at both ‘idiots’ and ‘lunatics’, there are important differences between the conditions of intellectual disability and mental ill-health integral to the differing geographies embroiled in these two different, if sometimes overlapping, states of being human. Whereas mental ill-health is often temporary and episodic, meaning that individuals may at times escape medical intervention, routine care and stigmatisation, thus enjoying fuller engagement with the ‘participatory mainstream’, intellectual disability—with its more evident rooting in bodily difference—is usually permanent and hence fixed in a round of more-or-less cloistered spaces set apart from this mainstream. In Wolpert’s terms, the people involved are all too readily cast as even more ‘incompetent’, ‘inadequate’ and dependent upon others, a state of affairs that the emerging small corpus of geographical studies on intellectual disability rapidly came to acknowledge. While concentrating largely on North America, Britain and parts of continental Europe, the situation in other parts of the world—see Inge Komardjaja’s ‘Report’ below on Bandung, Indonesia—has displayed similarities, albeit with differences such as the more muted onset of deinstitutionalisation arising from the overlay of regional cultural effects on to (in certain but not all parts of the world) enduring ‘colonial’ structures.

An early attempt to review the subfield was an unpublished paper by John Radford (1985a) entitled ‘Some issues in the geography of mental handicap’, which emphasised the ‘precarious position’ occupied by ‘the mentally handicapped’ both historically and in contemporary society. Radford underlined continuities between those officially regarded in this category, being labelled as such, and many of the rest of ‘us’ in wider society whose intellectual capacities may fall below some assumed norm. This is a significant point, seeking to scramble the simple ‘us’ and ‘them’ binaries that too easily creep into much thinking, whether academic, applied or everyday, about the phenomenon of intellectual disability. More specifically, though, Radford proposed four research questions that the geography of mental handicap might address. The first—sticking with Radford’s own terminology—asked what, if any, spatial patterns can be detected in the incidence of mental handicap, thereby wondering about the spatial epidemiology of intellectual disability (a topic still virtually untouched in the geographical literature: but see Giggs, 1977, pp. 484–490, 1979, p. 97). The second asked how mentally handicapped people relate to their environment, and what are their spatial and environmental needs, further wondering if it is indeed appropriate that ‘the mentally handicapped’ are sometimes defined as people who cannot interact ‘adequately’ with the environment (recalling Wolpert’s (1980) claims). The third asked about public attitudes to mentally

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