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The meaning of ‘community’ in the lives of people with intellectual disabilities: an historical perspective

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Abstract

This paper critically examines the term ‘community’ as applied to people with intellectual disabilities over time and aims to describe its shifting conceptualisation from the eighteenth century to the present day. Unpublished documentary sources from Old Bailey criminal trials in the eighteenth century, the Earlswood Idiot asylum in the mid-nineteenth-century and early-twentieth-century government reports have been used to explore historical changes in the concept of community. The word community is historically contingent both in its past and present uses. Its meaning has been adapted to strengthen and justify professional claims to own, treat and manage people with intellectual disabilities. Inclusion and community acceptance were normative in the eighteenth century. In later medicalized institutionalization programmes the meaning of community was subverted to endorse and vindicate professional claims. It has been further adapted since deinstitutionalization to support contemporary claims for the social model of community inclusion. Today’s language of inclusion emanates from these historical conceptual shifts, masking a set of unconscious assumptions and meanings attached to the status of intellectually disabled people. The modern concept of community is based on an assumption that people with intellectual disabilities have always been excluded. In the collective memory, it has been forgotten that they were, before the asylum, natural members of community embedded within social, economic, and familial networks. It is communities themselves that must adapt and remodel rather than trying to remodel those people they originally excluded.

Keywords

asylums; community inclusion; history of intellectual disability; institutionalization; medicalization; social model of disability

Introduction

With few exceptions the study of the history of intellectual disability has concentrated on the asylum period from the mid-nineteenth century and the subsequent shift to ‘community living’ that continues today. This has helped to create a distorted, binary debate about the

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concept of community in relation to people with intellectual disabilities. The focus of discussion has been on creating networks of services, as part of the current normative social model of disability, supporting people who have previously been excluded from living in the community. Organizations talk about ‘accessing community-based opportunities’, while commentators refer to people living ‘in a community learning disabilities context’ (Barnes and Summers 2012) or a ‘community-based intellectual disability service’ (Doody 2012). They refer to the process of people with intellectual disabilities living in communities as one of ‘social integration ... resettling into community provision’ (Ager *et al.* 2001) or ‘acculturation’ (Minnes *et al.* 2002). This language suggests a notion of a community that people with intellectual disabilities visit, or to which they are ‘acculturated’, from a liminal service space neither fully within nor fully outside it. When ‘community’ is talked about in this way it refers to a space to which ‘we’, the non-intellectually disabled, belong, and which ‘they’, the intellectually disabled, are given support to ‘access’, a process managed and negotiated through a series of quality of life assessments, risk profiles, funding decisions, and personalized plans.

Our skewed historical understanding of the lives of people with intellectual disabilities, which assumes a permanent saga of exclusion from the arenas occupied by the rest of us, contributes to this artificial, professionalized concept of community. It has constructed an assumption that it is now the job of the well-intentioned intellectual disability bureaucracy to enable some limited form of access and tenure in this previously unoccupied territory, a ‘gift’ model, where those who do not belong are allowed to have some form of belonging. Services make communities ‘inclusive’ so that people with intellectual disabilities can be ‘included’. However, the institutional asylum programme was in full operation for less than 150 years. The full-state asylum building programme did not begin in earnest until the 1840s, and the asylum system began to be fully dismantled in the 1980s. For hundreds of years before the asylum era began, people whom we might today categorize as having intellectual disabilities, and who at that time belonged to a broad category of ‘idiots’, lived within the communities where they were born (it is acknowledged that historical terms for intellectual disability are often offensive to modern ears, but for reasons of historical accuracy, terms such as idiot are used from this point in un-apostrophized form, with no offence intended). It is exclusion therefore that is the anomalous exception in historical terms, and the idea of inclusion is not a modern paradigm shift imagined by late-twentieth-century reforming advocates but represents rather a return to a societal norm. The modern idea of community that has been constructed around people with intellectual disabilities is simply that, a constructed idea.

Institutionalization destabilized the meaning of community, which has shifted radically at different times since the asylum era began. These changes in meaning have often linked with changes in terminology used by those claiming authority to treat, manage or support people with intellectual disabilities, be they medical practitioners, psychiatrists, psychologists, social care practitioners or advocates. The early histories of intellectual disability, written by the very medical men managing the asylums into which so many people had been confined, sought to demonstrate that, before the institutions they had pioneered, the life of the idiot at large in the community had been so marginal and wretched as to be not worth recording. In 1904, Martin Barr, an eminent American asylum superintendent, characterised idiots as a

‘despised and neglected class’ a form of human who ‘sees nothing, feels nothing, hears nothing, does nothing and knows nothing’ (Barr 1904). He saw the breakthrough for this abused and tormented class as the emergence from a French forest in 1800 of Victor, ‘the wild boy of Aveyron’ and his delivery into the hands of the Parisian medical profession, who eventually diagnosed him as an idiot. Barr wrote: ‘the savage of Aveyron may be likened to a guidepost reading two ways. Standing at the beginning of the nineteenth century, a literal symbol of the parting of the ways for his caste, in this uncouth figure is represented all the cruelty of the past and the beneficent influences of a new era’ (Barr 1904). The ‘new era’ was the era of the trainable, educable idiot in the asylum, pioneered by the French physician Seguin at the Paris Bicêtre from the 1830s. In 1964 another doctor, Leo Kanner, located the beginning of intellectual disability history firmly in the early nineteenth century, when ‘almost suddenly, interest in the mental defectives began to flare up’ (Kanner 1964). The person with an intellectual disability, according to Kanner, only became an historical entity when the medical profession began to study and care for them. Life previously had simply been that of despised brutes, ill-treated, whipped and chained or living the lives of savage beasts in the forests. Community, for them, had not existed.

Barr and Kanner were of course setting out the medical claim to treat and manage people with intellectual disabilities and their historical account must be contextualized accordingly: the presentation of community life as sordid, miserable and dangerous for the idiot strengthened and justified the move towards institutional hegemony. If the idiot was understood otherwise, as a person who could participate and survive in family and community life, then this would call into question the whole institutionalization programme. An examination of the historical record suggests that the lives led by the so-called idiot population before the nineteenth century were far more nuanced and varied than these early medical writers asserted. One insight into lives led by people characterized as idiots in the eighteenth and early nineteenth century is given by evidence from felony trials at the Old Bailey in London over this period. Summaries of these trials were published in the *Old Bailey Proceedings*, providing an important, and rare, source of historical information about the lives and thoughts of the plebeian classes of London of this period. The Old Bailey was the central London court for felony, or criminal trials, ranging from theft to violence and murder. All felonies were capital offences under the severe ‘Bloody Code’ of the period and therefore, all defendants were effectively on trial for their lives, although in practice many were acquitted or found guilty of non-capital ‘lesser offences’.

In 50 felony trials over the eighteenth and early nineteenth century, defendants were described in court testimony as ‘idiots’, ‘simple’, or ‘foolish’ and testimony in these trials therefore offers important information about how those characterized in this way were understood and perceived by others. Overwhelmingly, this evidence suggests that people seen as idiots (or similar) were far from marginalized figures excluded from their communities. Informal community bonds of obligation and support were extended to those seen as vulnerable and with a deficit of intellect, who lived in families, often worked and were supported by largely protective neighbourhood networks. Even in court, this sense of community protection was visible, when idiot defendants were invariably acquitted or treated leniently. They lived at the heart of their communities rather than in institutions, in domestic settings with spouses, parents or employers or in shared lodging houses,

surrounded by neighbours and workmates who knew them. A high level of intellectual deficit was no obstacle to marriage. John Thomas was described by his father-in-law as ‘a simple lad, little better than an idiot’ (OBP February 1723). Sarah Holloway, a married woman, was ‘silly ... and when anybody has given her a farthing, she has stood laughing for half an hour’ (OBP May 1798).

The majority of defendants worked, the women predominantly as servants or charwomen. These included servant-girl Ann Wildman, ‘next-akin to an idiot’, whose mistress pledged to re-employ her if she was cleared of theft (OBP November 1762) and the ‘half-natural, very silly creature’ Mary Radford who cleaned for rich households (OBP January 1723). Most of the men also worked: Peter Cunniford, an idiot since ‘his head was torn to pieces by a dog when he was about two or three’ had worked as a building labourer for twelve years, viewed by workmates as a hardworking, honest fellow (OBP February 1759). Some were in skilled occupations, such as bricklaying or carpentry or involved in running small businesses: John Bullock kept a public house in Essex but as he was ‘a silly innocent sort of a fellow ... the management of the business lay altogether upon the wife’ (OBP July 1737). Idiots, therefore, as encountered in Old Bailey trials, were people who worked in many settings, from menial jobs to skilled occupations and idiocy alone did not define them. They were also seen as contributing workers with rounded personalities who were embedded in the economic and social life of the community.

Nicknames were common: Foolish Tom Gloide, Mad Nan, Silly Bill Saunders, and Foolish Johnny all appeared in court. Although callous and objectifying to modern ears, these typify the directness that characterized Georgian Londoners of all classes. They were not the sole descriptor of these individuals. Mad Nan was also ‘an inoffensive person if not insulted, harmless in her way’ (OBP May 1774), while Silly Bill Saunders was a person ‘my mistress always had a good opinion of’ (OBP January 1784). The public demonstrated a keen sense of differentiated levels and types of intellectual deficit. No formal medical codified language to describe gradations of intellectual deficit had been introduced at this time, but Londoners used a rich range of descriptive language, pinpointing the extent of a person’s idiocy. As well as idiot, words and terms such as ‘silly’, ‘half natural’, ‘soft-pated fellow’, ‘of a weak understanding’, ‘half an ideot’, ‘not so sharp as others’, ‘a good deal weaker in his intellects’, and many more were applied. Witnesses strove to encapsulate a person’s capacity in relation to some sort of norm. Sometimes they used illustrative examples such as, ‘if anyone gave him a piece of bread, he would sing and dance for an hour together’ (OBP April 1766). This complex language suggests idiots as a subtly defined group conceptualized by all strata of society through broadly shared community assumptions.

There should be caution about romanticizing community as an inherently ‘good thing’. Community has been described as a ‘warmly persuasive word to describe an existing set of relationships ... (which) seems never to be used unfavourably.’ London’s communities at this time were ‘an association of neighbours, a unit of identity and belonging ... defined by processes of inclusion and exclusion’ (Withington and Shepard 2000). Those perceived as vulnerable or undesirable could easily be ostracised or attacked. Trial evidence shows that cruelty and ridicule were factors in idiots’ lives: ‘I have seen ’em black his face, and carry him about in a basket, and then throw him out into a kennel’ (OBP December 1732), ‘he is a

poor silly fellow, laughed and jeered at by the rest' (OBP June 1825), 'people used to push him about and ill-use him' (OBP January 1828). However, in all such incidences of bullying violence, there was a response from other community members who stood up for the inclusion and protection of the idiot concerned. Their place in the community was contested but over time retained its stability, even when under attack from those who were contemptuous or violent towards them. Trial evidence suggests people characterized as idiots in the eighteenth century could be accepted and contributing members of their families and communities. Their strangeness and difference were acknowledged openly, but seen as part of multiple, complex characteristics forming the individual idiot's personality and character. Despite instances of violence and exclusion, informal community rules defined and supported their status in a largely benign way with the support of significant sections of that community.

Trial records indicate changing attitudes towards idiots as the new nineteenth century began. In 1800, a judge, presiding over the trial of a young man accused of theft, known as 'Foolish Johnny Leck', warned the jury they must determine 'whether this man, by his natural endowments, has that kind of understanding as to know when he is doing wrong; if he has that kind of understanding, then he ought to be made answerable for this act'. They must do this 'for nothing can be more mischievous than that ... this half-witted man, going by the name of foolish Johnny, should be suffered to go about, and committing depredations of this sort ... however the neighbourhood may be inclined to indulge him, or soften his actions by calling him foolish Johnny'. Leck should be punished if he knew what he was doing, and if not then 'it is the duty of the parish, where they have idiots, to lock them up' (OBP July 1800). This judicial assault on the indulgence of 'neighbourhoods' towards the idiots living amongst them was just one signifier of an important change that was taking place in the idea of what community should mean for idiots, and attitudes hardened noticeably as the new century progressed, with more guilty verdicts and harsher punishments.

State and communities were becoming less willing to tolerate deviant behaviours in groups who were acquiring outsider status. Increasing numbers of idiots were moving into institutional life away from the communities they had formerly inhabited. An 1808 Act allowed counties to build lunatic asylums and from 1845 asylum treatment became compulsory in every county. Idiots were included amongst the lunatic population of the new asylums (probably about 1,000 out of 15,000 by 1850) while larger numbers, as many as 10,000, were in workhouses (Wright 2001). The long-term presence of idiots in these institutions was causing concern and pressure grew to create specialist idiot asylums on the model of Seguin's work at the Paris Bicêtre (Conolly 1849). The era of the specialist idiot asylum took off in 1855 with the 500-bedded Earlswood Asylum in Surrey, the world's first such institution built exclusively for idiots (Wright 2004). More idiot asylums opened across the country and by the 1870s the idiot, until recently understood as someone who lived, worked and eventually died in their community, became a type needing medical supervision in a specialist institution. As institutionalization gathered pace the concept of community, and what it meant in terms of the life of an idiot, needed reinvention.

John Langdon Down, an ambitious young doctor, was an early superintendent of Earlswood and, keen for recognition in his field, he sought to promote interest in this new 'community'

behind the walls of the asylum from those in the community they had left behind. He referred to the idiots over whom he held jurisdiction as 'the family' and talked about how this bringing together within the 'spacious walls' would bring many advantages, one of which would be 'the possibility of effecting a classification of the pupils, based on the degree of their intelligence and capability of intelligence' (Earlswood 1859). The community to which this group now belonged was purposefully created and controlled, consisting only of idiots, and became in its own right 'a family', an object of observation, scientific enquiry and display. A subversion of language began to occur in which words such as 'family', 'community', 'spacious', and 'pupil' acquired new meanings entirely separate from those they held in society outside the walls.

Down published his classification system, '*Observations on an ethnic classification of idiots*' in 1867 (Down 1867). Mainly remembered today for its identification of 'Mongolian imbecility', (later Down's syndrome), in fact his paper outlined a wider ethnic classification comprising not only Mongolian imbeciles, but also Ethiopians, Caucasians, Malays and Americans (or Aztecs). He claimed that although all his idiot family were of Caucasian parentage 'a considerable number can be fairly referred to one of the great divisions of the human family other than the class from which they have sprung'. His theory was that this puzzling emergence of alien ethnicities amongst the idiot offspring of Caucasian parents was the result of atavistic degeneracy which, for some reason, allowed ancient, degenerate racial types to emerge in a more advanced population (Wright 2011). By arguing this, Down cleverly incorporated his thinking about idiocy and its causes into the raging contemporary public debates about the origins of mankind (Darwin's *Origin of Species* had been published in 1859). While his speculation about Mongolian imbecility led to the identification of the (non-racial) condition of Down's syndrome, Down's other racial musings have been quietly forgotten.

The community of idiots now became a separately maintained and observed construct of the science of medicine, bearing no resemblance to the community in which they had previously lived. In 1862, Earlswood hosted the annual meeting of the British Association for the Advancement of Science (Earlswood 1863). By inviting the members to observe the Earlswood family he was conveying a message that here, in this small asylum in the Surrey countryside, the five races of man could be studied and observed. He put on displays of his 'multi-ethnic' community of idiots outside and inside the asylum. Far from being an isolated place invisible to the outside world Earlswood, and the other idiot asylums, were very public spectacles. Every year there were large fêtes in its grounds attended by hundreds lured by cheap railway tickets. Patients performed 'acts of agility' and processions 'rendered gay by flags and banners'. The civilizing effect of the Earlswood regime on the community of idiot 'savages' was noted: a newspaper praised their civilized behaviour, comparing it favourably with that of rougher outside elements (Earlswood 1862, 1867, 1881). Down introduced a fully-uniformed asylum band which comprised attendants and patients in order to support events inside and outside the asylum. In 1869, 273 inmates travelled by rail to Brighton and all the males marched along the shore to bathe in the sea. In the same year the band accompanied hundreds more on a march to Redhill and even accompanied a group who marched off for a local picnic (Earlswood 1859, 1867, 1871). Down's presentations of his 'multi-racial' idiot family were intentionally very public displays, as exotic as anything that

could be seen at the zoo or an ethnographical exhibition. The local idiot, previously known to their community and informally supported by it, now paraded back as a strange, exotic outsider.

Down, and others, had stripped the word community of its generic meaning and endowed it with a constellation of medical, anthropological and scientific sub-texts that insinuated barriers between the idiot group and the mainstream society in which they had once lived. Its meaning was to transform again from the 1880s as the eugenic doctrines of degeneration criminalized the idiot and imbecile population, now perceived as a dangerous threat to racial health. As ever, new professional perceptions and claims to management and treatment brought new terminology; idiots and imbeciles now became mental defectives. The 1913 Mental Deficiency Act specified that defectives must either be closely supervised in the community or maintained in new mental deficiency colonies, providing lifelong settlement in isolated rural environments. Close control and supervision in the community meant that people with intellectual disabilities were simultaneously part of and outside the community in which they lived. The Central Association for Mental Welfare, reporting to a new Board of Control, sent volunteers and officials to identify defectives and visit them under statutory supervision, a particular concern being the prevention of sexual relationships and marriage (Walmsley *et al.* 1999).

The new mental deficiency colonies aimed to remove the mental defective from the sight, consciousness and memory of mainstream communities and the defective breeds would be allowed to disappear, sterile and unproductive, in these closed, walled, self-sufficient communities. Each was a small, self-contained world with up to 1,500 people living in detached ‘villas’ housing up to 60 people, grouped around a central administrative block. The block always formed a barrier between male and female villas, as separation of the sexes was deemed essential (Board of Control 1930). This was a community whose aim was to eradicate those who comprised it, to ensure that the class of defectives would wither away and die in isolation. The colonies would live on until the 1990s, re-named as mental handicap hospitals. It was from these and other institutions that the great community resettlement programme of the 1980s took place.

In conclusion, historical shifts in community conceptualization have led people with intellectual disabilities from a position in the eighteenth century where their status as community members was never strongly questioned, although they were perceived as different, to a situation today where community belonging is problematized because it is understood as something which is not naturally theirs. This problematization has arisen from a medicalized institutionalization programme which recreated them as a separated ‘family community’, requiring care, treatment, scientific enquiry, and display. Consequently this transformed to a concept of ‘total community’, where any idea of involvement in mainstream society was replaced by enforced lifelong isolation and separation for many, while invisible walls of community control and segregation were constructed around those remaining outside institutions. A further social revolution pronounced institutions a mistake and proposed a transformative programme of community inclusion supported by a raft of services, including housing, day centres, social workers and community nurses, psychologists, and psychiatrists. With this support, people with intellectual disabilities

would ‘access communities’ as they ‘developed community skills’. In the collective memory, it was forgotten that this class of people had previously been natural members of community, and had not had to ‘access’ them because they were embedded within their social, economic and familial networks. It was communities that needed to adapt and remodel themselves rather than trying to remodel those people with intellectual disabilities they had originally excluded. Community is always a historically contingent term and today’s language of inclusion emanates from these historical conceptual shifts, masking a set of unconscious assumptions and meanings attached to the status of people with an intellectual disability.

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