



# Intellectual disability

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*'Intellectual disability' is a widely used psychiatric category that conceives of certain minds as impaired in their development. By approaching intellectual disability from a cross-cultural perspective, anthropology demonstrates how the condition is culturally variable. It shows, in particular, how intellectual disability is produced by different social expectations of 'normal' mental development and different ways of responding to adults who do not meet those expectations. Anthropology thus offers a way to analyse this seemingly biological deviation from a universal path of mental development as a growing lack of fit between culturally specific expectations for maturation and a person's own life course through society. Anthropology also provides innovative research methods that enable a closer understanding of the experiences, lives, and self-narrations of people categorised as having intellectual disabilities themselves—in particular, demonstrating how they develop and exercise agency in spite of considerable constraints. In this way, anthropology gives us a deeper insight into how people become and remain classified as having an intellectual disability, what it is like to live under such categorisations, as well as what such classifications leave out about them as people.*

## Introduction

This entry does not discuss all potential forms of disability that might relate to cognition (i.e. dementia, autism, brain injury, or mental illness) but focuses on the specific clinical category of 'intellectual disability' that was originally formulated within Euro-American psychiatry (McKearney & Zoanni 2018)<sup>1</sup>. The entry explores how work on the cross-cultural variation of this condition complements biomedical and professional understandings of it, filling in the blind spots of those perspectives and challenging their assumptions.

The widespread use of 'intellectual disability' in many contemporary states—in biomedicine, psychology, welfare distribution, and legal proceedings—naturalises a distinctive way of categorising certain minds as impaired and gives the impression that people diagnosed as intellectually disabled 'have' a biological condition (Levinson 2010; Altermark 2018). The term has been most precisely defined within psychiatry, where it can refer both to the cause and to the outcome of mental impairment. The former use gives the misleading impression that people permanently 'have' this condition in the way they might have a genetic condition or temporarily have an infectious disease. Contemporary psychiatry more precisely defines intellectual disability as a state, the aetiologies of which are diverse and often unknown (Mackenzie 2010). The prognosis is not always certain either, making it possible for a person to cease to be intellectually

disabled in the future. For this reason, it is preferable to use the term 'intellectual disability' to refer to the outcome of mental impairment.

The most recent edition of the American Psychiatric Association's *Diagnostic and statistical manual of mental disorders* (DSM-V) recommends someone be diagnosed as having an intellectual disability if they: 1) have deficits in intellectual functions that can be measured by psychometric tests; 2) have deficits in adaptive functioning that result in a failure to meet developmental and sociocultural standards for personal independence and social responsibility; and 3) if these deficits began during the developmental period of life—i.e. before the age of eighteen rather than, for example, as the result of a later accident (APA, 2013).

Anthropological work demonstrates that there is significant variation in the 'social-cultural standards for personal independence and social responsibility' which the DSM-V refers to and how they expect people to develop the mental capacity to reach them. These standards are especially likely to be different beyond the professional and institutional contexts in which the category of intellectual disability originated and is used, by professionals and lay-people. What people must 'adapt' to, furthermore, varies depending on how people in a society communicate, organise relationships, and manage to live independently—if, indeed, living independently is required at all.

So the DSM's seemingly straightforward definition of intellectual disability, in fact, raises a series of empirical questions that are not sufficiently answered by medical and psychological science. What kind of diversity exists among those who end up categorised as intellectually disabled? What are the different causes of this categorisation, including those that are non-biological? Is it coherent to demarcate intellectual disability as separate from physical disability, mental illness, or a putative 'normal' cognitive functioning? If what is considered 'normal' cognitive functioning and development varies socially and culturally, is intellectual disability and its development also variable?

Anthropology has yet to fully answer such questions. While there is a robust body of anthropological literature on cross-cultural variation within mental health, and an emerging one on physical disability and sensory conditions like Blindness and Deafness, there is not such an elaborated tradition in relation to intellectual disability (Edgerton 1970). This dearth echoes a wider social and scholarly marginalisation of intellectual disability (Kulick and Rydstöm 2015). The result is that anthropology has not yet fully developed a cross-cultural conversation about intellectual disability that would enrich and challenge a psychiatric understanding of it.

One reason for this neglect is internal to anthropology as a science of social and cultural difference. Anthropologists work on the assumption that seemingly puzzling behaviours do not issue from a lack of intelligence, but rather require deeper ethnographic understanding (Geertz 1975; Shore 2000). This premise of mental equality has enabled them to demonstrate the coherency, intelligence, and sophistication of different forms of life, and thus to undermine arguments about 'natural' differences in intellect between

human groups (e.g. Evans-Pritchard 1976; Levi-Strauss 2021). But this same standpoint has unintentionally thwarted investigation into potential differences at the level of the mind itself (McKearney and Zoanni 2018; McKearney and Zogas 2021).

Overcoming this trend, there is a small but important strand of anthropological work on intellectual disability that began in the latter half of the twentieth century. The first major engagement with the subject in the discipline was a collaborative and longitudinal research project in California, which remains the largest conducted to date. An additional research tradition in North America and Europe emerges out of feminist concerns with reproduction, care, and dependence. A third body of literature we discuss includes arguments about how intellectual disability is socially produced and how studies from outside of Euro-America enhance our understanding of its cultural variation.

Anthropological work on intellectual disability reveals just how particular are the social and cultural conditions that support the psychiatric framing of intellectual disability. It also shows the limits of describing people's lives solely or primarily in terms of this category, regardless of context and circumstance. Anthropology has innovated methodologically to get closer to the experiences, lives, and self-narrations of people themselves. This enables us to gain a fuller understanding of what it is like to live as someone classified as intellectually disabled, as well as what such classifications leave out about them as people. In doing so, anthropology contributes significant missing pieces to the puzzle of just how people become intellectually disabled, as well as how and why that might vary socially and culturally. Anthropology offers a way to analyse what psychiatry treats as a pathological deviation from a universal path of mental development as, instead, a growing lack of fit between culturally specific expectations for maturation and a person's own particular life course through society.

### **Early studies and methodological innovation**

Anthropology's first engagement with intellectual disability emerged in the 1960s alongside other critical social scientific studies of the professional treatment of those classed as having mental conditions in medicine, psychology, social services, and charities within North Atlantic welfare states. Robert Edgerton's monograph *The cloak of competence* (1967) presents extensive data on the lives of disabled people in urban California who had been discharged from a residential institution. Edgerton demonstrates the incredible efforts these people undertake to confront 'the shattering stigma' of being regarded as 'retarded' by working to conceal, through a 'cloak of competence', their difficulties navigating life outside of institutions (1967, 205). This, in turn, entails confronting the psychological scars of humiliation, loss, and fear resulting from their former confinement. It includes also finding ways to navigate the poverty they typically face. This often happens through constructing ad hoc relationships of support, including with friends and especially romantic partners. At the same time, however, many people in Edgerton's study were forcibly sterilised and feel permanently and irrevocably undermined by their inability to have

children.

Edgerton treats 'mental retardation' as not just a biological condition but also a social status that has stigmatising effects on people quite apart from their own mental capacities. His study also aims to 'see people through their own eyes and to hear them through their own words' by exploring their thoughts, actions, and feelings (Edgerton 1967, 6). The same approach characterises the subsequent works produced by the large research group Edgerton headed at the University of California, Los Angeles (UCLA). The team conducted a series of thorough and detailed longitudinal ethnographic studies by tracking many of Edgerton's original cohort of informants, and others besides, across diverse settings and into their older years (see Edgerton 1984b; Edgerton and Gaston 1991).

L. L. Langness and Harold Levine's *Culture and retardation* (1988a) is significant among this work for its systematic focus on life history as a methodology for studying intellectual disability. It departs from standard parentally-focused life-histories that present a person with disabilities as 'aspects of a man who might have been' (Langness and Levine 1988b, 1-3). The book's detailed portraits of the complexity of disabled people's lives shows them to be protagonists with agency, individuality, and richness. It challenges the clinical reduction of disabled people to their mental impairments, and thus to 'a single homogenous group best characterized as an I.Q. range' (Langness and Levine 1988a, xiv).

This volume demonstrates how difficult it is for those with intellectual disabilities to access the contexts in which others learn social roles. It argues that they are, instead, actively socialised into 'incompetence'. For instance, they are confined to atypical social contexts in which they cannot access the kinds of social learning through which others of a similar age and gender transition to adulthood (Langness and Turner 1988; Kernan, Hubbard and Kennan 1988; see also Mitchell-Kernan and Tucker 1984, 186). Acquired incompetence is even worse for those who have only ever lived in institutions:

Once one has lived as retarded, been systematically denied information about the everyday world, provided with false information, his or her chances for subsequent normal development are slim (Langness and Levine 1988a, xiii).

Demonstrating the effects of socialisation reveals how problematic it is to take a person's capacities at a given moment as a read-out of their innate abilities. A long-term perspective on their development over the life course is required (Langness and Levine 1988b, 8).

This demonstrates the necessary role ethnography plays in looking beyond simple casual relationships between single factors in people's lives and facile quantitative measures of 'success' for people with intellectual disabilities. Standard professional measurements of the causes and effects of disability on people's lives are not only narrow but attempt to stabilise a picture that is constantly 'in process' (Edgerton 1984a, 2). Ethnography allows researchers to become embedded in the wider context of people's lives,

rather than operating in contrived experimental situations or clinical and psychometric assessments. Ethnographic research is essential if we are to avoid simplistic pictures of intellectual disability.

A subsequent tradition of ethnographic inquiry further developed new ways of ethnographically and analytically centring the lives, perspectives, and voices of intellectually disabled people themselves. One landmark study focused on two individuals in the US, Ed Murphy and Patty Burt, who had previously been labelled ‘retarded’ and institutionalised (Bogdan and Taylor 1982). The book relates several extensive and wide-ranging interviews in which Ed and Patty articulately and thoughtfully narrate how they moved through various kinds of institutions and independent-living arrangements over their life courses. This perspective challenges the professional and research perspectives that dominated understandings of ‘mental retardation’ at the time. Ed, for instance, remarks that to understand people like himself ‘you need experts’. ‘Experts,’ he goes on to say, ‘are people who have lived it’ (Bogdan and Taylor 1982, 30; see also Hartblay 2019). Indeed, Robert Bogdan and Steven Taylor are critical of the very category of ‘mental retardation’, which they take to be a construct that is not only scientifically vague but also has devastating effects on people’s lives.

Ed and Patty’s lives are, like Edgerton’s narratives, ‘stories of lost opportunity brought about by institutional confinement’ (Bogdan and Taylor 1982, 219). But the book also shows them as multidimensional human beings that are constantly exceeding their categorisation as cognitively incapable (Bogdan and Taylor 1982, 210-14). Bogdan and Taylor end with a strong concluding plea to abandon stigmatising labels and to ask what is wrong with society, rather than disabled people, by focusing on what can be done to make it more accommodating and, indeed, dignifying for these individuals (Bogdan and Taylor 1982, 224-5; see also 1992; Edgerton 1993, 228).

Michael Angrosino similarly sought ways to narrate the lives of people with intellectual disabilities in the US from their own perspective by asking, ‘what does it feel like to *be* mentally disabled and to make one’s way in the world with that condition?’ (1998, 8). Against commonplace aspirations to objectivity, he aims to facilitate people with intellectual disabilities telling their stories in their own ways (Angrosino 1994, 26). For example, he describes a bus trip with Vonnie Lee, a resident of a group home Angrosino was working at. He reads Lee’s seemingly incoherent and insignificant comments on the trip as a way of assembling and narrating significant emotions, values, places, and relationships. Angrosino treats the bus as a legitimate context in which to tell one’s life history. By accompanying Lee as he travels across the urban landscape, the memories incidentally evoked become a coherent form of narration—and it turns out there is nothing ‘disordered’ or trivial about what Lee says (Angrosino 1994, 26-7). In subsequent work, Angrosino (1998) goes further by writing ethnographically-based semi-fictional narratives. The characters are fictionalised composites of people he met volunteering at a nonprofit residential community for people diagnosed with an intellectual disability (1998, 25-6).

Angrosino contends that anthropology's resourcefulness at deciphering seemingly 'exotic' symbols ought to be applied to understand forms of disabled activity that might otherwise seem meaningless (Angrosino 1994, 26). He explores the self-presentations of people with intellectual disabilities as strategies for managing their dependency upon others (Angrosino 1999). People's way of presenting themselves, he argues, are neither innocent facts nor efforts to cover up who they really are (1998, 269). They are 'extended metaphors of the self', produced by feeling, thinking, and interacting agents (Angrosino 1994, 24). People with 'mental conditions' hold these as much as anyone else, to the point that we ought to question the position from which we are attributing intellectual disability to anyone in the first place.

Developing an ethnographic mode of attending to the lives of people diagnosed with intellectual disability is one of the most important contributions of this research tradition (see also Cascio and Racine 2019). By combining scrutiny of official categories with detailed empirical work with the people themselves, this work reveals the complexity and challenging nature of the social worlds these people must navigate, as well as how many seemingly 'pathological' or 'disabled' forms of action are frequently strategies for negotiating those worlds (e.g. Koegel 1988a; Whittemore 1988; Goode 1992; Todis 1992; Levinson 2010).

### **The social production of intellectual disability**

Alongside a tradition of historical scholarship on intellectual disability (Wright and Digby 1996; Thomson 1998; Goodey 2016), scattered anthropological works on the Global North show how particular economic, political, and institutional arrangements make the category appear as something that seems natural, stable, and objective.

Educational institutions play a central role in naturalising intellectual disability, as they differentiate between intellectual capacities and stratify people based on the kinds of minds they have. Could it even be that the educational system does not *find* these differences but instead *creates* them (McDermott 1993; Gleason 1989; Mercieca 2013; Avery 2020; Rapp and Ginsburg 2011b)? Classroom tasks and, most of all, tests can make people appear as disabled, given that they foreground and stigmatise 'differential rates of learning' (McDermott 1993, 272; see also Avery 2020; McDermott and Varenne 1995; McDermott et al. 2006). If it is not simply different learning speeds that cause the diagnosis, but rather the diagnostic system that causes something called 'disability' to appear as notable, different, and defective in the first place, then educational settings may well produce 'intellectual disability' as a seemingly natural fact.

State institutions continue to shape the lives of people with intellectual disabilities after leaving school, primarily through the care system. This system typically prioritises their basic needs over the facilitation of their lives more broadly, making it nearly impossible for these people to achieve culturally valued forms of adulthood (Mietola and Vehmas 2019; Vehmas and Mietola 2021). Staff who care for people with intellectual disabilities, especially in institutions, often view 'pathological' forms of behaviour as the direct

result of these disabled people's defective psyches (Johnson 1998; Goffman 1968; Bogdan and Taylor 1992). The cruel irony is that this behaviour is rarely innate but often the response to the inexperienced, even abusive, ways in which the care itself is managed. Anger and violence, for example, are frequently a protest against confinement, neglect, and coercion (Johnson 1998; McKearney 2021a, 2022). When residents are exposed to these conditions (and to the resulting aggressive behaviour of other residents), it ought to be no surprise they too may become aggressive. Put simply, it is often the care itself that transforms people into the, at times, violent beings that they are expected to be in these contexts.

Across these contemporary state institutions, there are tensions between contrasting ways of governing people with intellectual disabilities that pull them and their carers in opposing directions (Redley 2018). On the one hand, intellectual disability marks out particularly dependent people as legitimate recipients of state welfare. On the other, it identifies them as subjects whose rights are in danger of being overridden. Even if it might be possible to resolve this tension in theory (see Redley and Weinberg 2007), anthropologists demonstrate that the two aspirations of receiving welfare and having rights can lead carers and people with disabilities themselves into conflicts they cannot resolve (Todis 1992; McKearney 2021a, 2022; Davies 2002, 1999; Levinson 2010).

### **Dependence in Euro-America: Beyond the institution**

Anthropologists ask whether a person's incapacity to be productive and independent only leads to social exclusion in certain contexts. Might intellectual disability manifest differently, or at all, outside of these state institutions? Could intellectual disability be the product of the way in which capitalist societies organise labour markets, and deal with those who are judged to be unproductive? A body of work draws on feminist scholarship to analyse alternative forms of care, principally within the family, as lessening the necessity of and the value placed on autonomy, capacity, and independence. By focusing on relationships of care, it asks: what becomes of intellectual disability in contexts more accommodating of dependence?

Take as an example the transformations that parenting an intellectually disabled child brings (e.g. Hubert 1991; Rapp 1999; Rapp and Ginsburg 2011a, 2018; Landsman 2009; Mattingly 2010; Jackson 2021). Within the United States, everyday expectations about childhood development and the frequently assumed 'worthlessness' of an intellectually disabled life can devalue children with intellectual impairments. These expectations can also stigmatise parents, particularly mothers. In the face of this, mothers of disabled children have been shown to rethink their own life and that of their children, imagining new familial futures with integrity, meaning, and value. In practice, they develop new social networks with other parents of disabled children and develop daily care practices that can stretch over a lifetime, rather than ending with a child becoming an adult (Landsman 2009; Rapp 1999). Similarly, the families of intellectually disabled children often become forces for 'cultural innovation' that build new models of and for kinship, education, and citizenship. For example, parents actively work to support scientific work on the conditions



their children have (Rapp 2011), advocate for more inclusive school programs (Rapp and Ginsburg 2011b), and produce new forms of media that foster greater disability awareness (Rapp and Ginsburg 2011a).

Creating hopeful possibilities can even take shape in professional caring relationships beyond the kinship group (Vehmas and Mietola 2021). Professional carers in the Netherlands are meant to pursue an ideal of autonomy in their work, presuming that those with intellectual disabilities are able to ‘govern their own lives’ (Pols, Althoff and Bransen 2017, 781). But, in practice, when, for example, people with intellectual disabilities engage in substance abuse, carers may think their choices are ‘not good for their own well-being’ (Pols, Althoff and Bransen 2017, 777; McKearney 2020). In these instances, the ideal of autonomy risks guiding carers towards neglect. Therefore, carers attempt to persuade care-recipients away from bad decisions towards better ones. Such care breaks with ideals of independence in liberal societies, and assumes that minds are predominantly relational rather than self-sufficient, not closed systems but open to ‘influence’ (Pols, Althoff, and Bransen 2017, 781; see also McKearney 2021a).

Sexuality is another arena in which the form care takes makes an enormous difference to the possibilities of people with intellectual disabilities. In Denmark, caregivers facilitate sexual intimacy for physically and mentally disabled adults in need of long-term support. This is made possible by an expansive welfare state and progressive disability legislation, enabling kin, professional carers, and sex workers to render sexual encounters possible for people with intellectual disabilities. The case of Denmark sits in striking contrast to its neighbour, Sweden, which likewise has a robust welfare state but nonetheless suppresses rather than facilitates the sexual lives of disabled adults in care settings (Kulick and Rydstöm 2015; see also Vehmas and Mietola 2021).

The contrast between Denmark and Sweden suggests that more research is needed to understand how various social, political, and legal conditions support or constrain the sexual, romantic, and reproductive lives of disabled people. Yet research suggests a wide trend of suppressing, ignoring, or trivialising the sexuality of people understood to have intellectual disabilities across a variety of very different countries, to which Denmark is an exception proving the rule. This is evident even in countries with very different histories (e.g. Soniya 2022). In Brazil, for example, there was not the widespread institutionalisation which took place in North America and much of Europe, yet no less than in Europe and North America did Brazilian educators and caregivers discourage and even actively prevent the sex lives of people considered to have intellectual disabilities (Block 2002; see also Ramawati and Block 2020).

Another domain where the kinds of support and care people receive make a big difference is communication and language. Insofar as intellectual disability may mean that people do not speak or communicate in typical ways, educators, parents, and disabled people themselves have experimented with assistive technologies to foster alternative means of communication, ranging from simple books with pictures and phrases to complex computer programs. Such efforts are controversial, with critics raising



doubts about who is actually communicating in the practice of ‘facilitated communication’. Anthropological studies of these assistive technologies demonstrate the ways in which all communication is facilitated, for disabled and non-disabled people alike, while showing how particular communicative technologies can help build disabled personhood and enable meaningful interactions, exchanges, and relationships (Rutherford 2021; Wolf-Meyer 2020a, 2020b).

This leads to broader questions about the kind of social relations that people with intellectual disabilities can enter into, particularly outside of the context of the large-scale institutions which have fallen out of favour in many Euro-American contexts since the mid-twentieth century. The expansion of relational possibilities is a prominent theme in ethnographic work on L’Arche communities. L’Arche originated as a Roman-Catholic venture in France and has become a federation of ecumenical, interfaith, small-scale residential communities across the world in which those with and without intellectual disabilities share life together (Cushing and Lewis 2002; McKearney 2017, 2018, 2019a; Angrosino 2003; Zoanni 2019). Contemporary social policy in Euro-America typically imagines social life as happening only *outside* of the caring relationship, and thus in a sphere which government-funded care by definition cannot directly influence (McKearney 2017; Mietola and Vehmas 2019; Vehmas and Mietola 2021). By contrast, in L’Arche homes in the UK, the dependence of those with intellectual disabilities is transformed from a barrier to intimacy, belonging, and interaction into the foundation of it (McKearney 2017; 2018; 2019a). People with intellectual disabilities in L’Arche live together with their carers, who are trained to treat the dependence of others as enriching rather than burdensome. The underlying idea is that all people have vulnerabilities and dependencies, and thus all people need care. In such settings, care homes are no longer stigmatised places outside of society that residents need to leave in order to socialise, but sites of vibrant social interaction in their own right (McKearney 2021b; see also Vehmas and Mietola 2021, 87-111). In this way, institutional settings may serve as ‘institutional utopias’ that foster communal forms of support (Block 2007; see also Siebers 2007; R. Jackson 2011).

This work raises the question as to whether there might be whole societies, and not just minority communities, institutions, or individual caring relationships, where intellectual disability is considered less of a problem and perhaps even socially and emotionally productive. Anthropology has long attended to the possibility that other societies might enact relationality and dependence quite differently from the West (e.g. Wagner 1975; Dumont 1980, 1986; Strathern 1990; Mahmood 2012; J. Ferguson 2013; see also Robbins 2013). Might people with intellectual disabilities struggle not only on certain psychometric tests, but also with a specific kind of Euro-American adult life that requires a high degree of individual autonomy?

### **Cross-cultural research on intellectual disability**

In thinking about the lives of people with intellectual disabilities outside Euro-American settings, two

contrasting and very generalising assumptions exist, assumptions which are not yet particularly informed by empirical research. The first, a staple of humanitarian and developmental projects, is that the lives of such people are invariably worse, due to lack of resources, 'backward' attitudes, pervasive stigma, and the like (Rohwerder 2018; see also Ingstad 1995).

The second assumption is that the lives of those who would be grouped under 'intellectual disability' in Euro-American contexts must be much better elsewhere, and perhaps not even recognised as being deficient at all. This assumption grows out of a particular critical social scientific way of thinking about intellectual disability. Social scientists have claimed in a range of different ways that 'intellectual disability' does not refer to anything *other* than a way in which certain Euro-American institutions apprehend people (Goodley 2001; Rapley 2004). At the most general level, scholars have argued that disability in general, and intellectual disability in particular, is simply the product of the demands of modern industrial capitalism, while positing that in other cultures and in 'pre-modern' Europe, people with cognitive impairments led relatively normal lives (e.g. Ginzberg 1965; Oliver 1989). More specifically, other scholars argued that labelling someone as having an 'intellectual disability' is a performative act that does not so much describe a neutral biological condition, but rather socially *makes* someone 'intellectually disabled' (Dexter 1964; Goode 1992; Rapley 2004; Lungren 1999; P. M. Ferguson, Ferguson and Taylor 1992, 296). The fact that IQ is a conspicuously 'invented entity' only deepens this critique's force (Douglas 1980). In particular, and in line with wider developments in social theory, critiques of institutions argue that the classification of people according to 'intelligence' was more than anything a disciplinary project that served to reproduce asylums and the forms of medical expertise and governance they entailed (see Edgerton 1970, 524-7).

Yet there is evidence that something analogous to intellectual disability persists even outside of the formal situations in which it is conspicuous and labelled (e.g. Edgerton 1988). Young adults in one study in California were regarded as impaired outside of school, for instance, when people noticed their incapacity to tell the time, to count money, or to comprehend the stakes of their decisions (Kogel and Edgerton 1984; see also Kernan and Sharon 1984). This raises the possibility that intellectual disability is not entirely a social construction, but reflects a condition of impairment that is 'the product of an interaction between environmental and biological factors' (Edgerton 1993, xiv). In any case, extant cross-cultural ethnographic research by no means demonstrates that intellectual disability is always inconspicuous, better accommodated, or less stigmatised outside of the institutions of the industrialised West (Edgerton 1970; see also Groce 1992).

Cross-cultural research on intellectual disability has only occasionally been gathered together in comparative fashion (Jenkins 1999; McKearney and Zoanni 2018; McKearney and Zogas 2021). But what has been done starts to build a picture of the diversity and complexity of ways that intellectual impairment is responded to outside of the West or the Global North. In the absence of significant state support, care is often organised at the margins of existing kinship structures. In Jordan, Brazil, and India, mothers who are

primarily responsible for their children's care are desperately worried about who, after they die, will look after their offspring (Fietz 2019, 2020; Soniya 2022; Mehrotra and Vaidya 2008; Sargent 2019, 2020, 2021). Although this is also a common worry in the Global North, there is little state welfare in Jordan, Brazil, or India to provide residence or on-going care, thus raising the existential stakes. Even for those families that have the resources, paying for private residential care to be provided by non-kin is a 'relatively uncommon and unpopular option'; indeed, it is one that is often highly stigmatised (Sargent 2021, 1-2; Fietz 2020). Mothers are further uncertain about whether their other children or the child's potential spouses will take on such a responsibility.

In some cases, people work towards the creation of new forms of voluntary institutions for care beyond parents' lives (Aydos and Fietz 2017; Fietz 2020). In stark contrast to societies in which care is expected to be separated from romance and sexuality, marriage is often practised as a way of creating new relationships of dependence with the spouse or their parents (Sargent 2021; Manor-Binyami 2018; see also Craft and Craft 1980; Kulick and Rydström 2015). Indeed, in a context in which everyone remains within hierarchical kinship relations and frequently in complex webs of dependence within the home, people with intellectual disabilities rarely become conspicuous solely for the fact of being unable to operate totally autonomously.

A small body of work on sub-Saharan Africa explores how intellectual disability manifests in interactions between non-typical minds and the wider fabric of social life. Within Uganda, for example, though people in rural areas may not have been exposed to understandings of intellectual disability from the Global North, they still articulate a highly elaborated and often stigmatising set of categories and terms for perceived cognitive impairment (Whyte 1998). In contemporary urban Uganda, understandings of intellectual disability are forged at the intersection of local models of the mind, longstanding patterns of kinship care, and newer forms of Christian charity (Zoanni 2018; 2021). A person may only stand out as 'disabled' when they break particular social expectations about key features of personhood, such as by lacking the ability to speak or the capacity to be socially and biologically reproductive. This leads to different arrangements of care in which, for example, a person with cerebral palsy (which generally entails no intellectual impairment) is offered care in a group home, while someone with Down Syndrome may work as a taxi driver (Zoanni 2021). Outside kinship relations, dedicated care for people with intellectual disabilities is only available within a handful of primarily Christian institutions, which in turn reproduce models of highly paternalistic care that renders the cared-for as 'children'. At the same time, the category of the 'child' provides a socially legible status that affirms disabled people as deserving of care and resources (Zoanni 2019).

Things unfold differently in other African countries. In Botswana, people with a number of severe impairments, including developmental and cognitive ones, are sometimes grouped under the overarching category *mopakwane* (Livingston 2006; Ingstand 1995; see also Ingstad and Whyte 1995, 2007).

*Mopakwane* are typically cared for by their families, and their arrival thus involves a significant rearrangement of expectations for the life course and the kinship group. Parents will likely be blamed for the child's condition, but typically try to move responsibility away from themselves by claiming that it is something that naturally happens, that it was the result of witchcraft, or that *mopakwane* are, in fact, a gift from God (Ingstad 1995).

In these circumstances, the specific way of parsing intelligence behind the psychiatric framing of 'intellectual disability' gives way to alternative categories for comprehending differences, such as people's capacity to care for children, to marry, to do certain kinds of work, to speak, or to comport themselves properly (McKearney and Zogas 2021). Research on Africa further suggests something parallel to the emergence of the notion of intellectual disability in the Global North. Colonial and postcolonial demands for the creation of school systems, new expectations of literacy, and new regimes of testing created conditions that rendered children markedly disabled in a way that was not true for earlier circumstances, especially in rural settings (Whyte 1998; Livingston 2006; Zoanni 2020). This research also demonstrates that alternative forms of social organisation can create opportunities for those with intellectual disabilities: to be less conspicuous, to remain within relations of care, and to access relationships in which they are recognised as full persons.

None of this ethnographic work confirms hopes that different arrangements of social life and alternative expectations about personhood resolve all potential difficulties. The reliance of people with intellectual disabilities upon others troubles expectations about work in Jordan, Uganda, and India. Even supposedly 'manual' or 'menial' work can involve complex demands that not everyone in a society is capable of (Groe 1992; Edgerton 1970). Intellectual disability troubles the kinship systems for organising care in these contexts, and thus the expectations about personhood that they rely on. Even if such societies expect people to be dependent, they tend also to expect changes over the life course in how that dependence manifests and interacts with that of others. In none of these societies, for instance, are others any less concerned than they are in Euro-America about the possibility of those with intellectual disabilities raising children (Craft and Craft 1980; Booth and Booth 1999). In addition, the sense that intellectual disability is a significant enough problem that people need to account for its cause or origins and to distribute responsibility for it is a surprising continuity across many ethnographies within and beyond Euro-America (Mehrotra and Vaidya 2008; Gammeltoft 2014; Sargent 2020; Mattingly 2010; Landsman 2009).

For reasons like these, the various responses to dependence in these ethnographies are not best parsed in terms of whether a society accepts or rejects it. Instead, they more particularly relate to how care is socially organised over the life course. In much of Euro-America, welfare states support kinship care of disabled children during early years through medical and educational institutions. The transition to adulthood produces a distinct rupture as young adults are expected to move beyond their domestic support (Rapp and Ginsburg 2018; Mietola & Vehmas 2019). People with intellectual disabilities struggle to access

further education or work, and to develop the skills for independent living that would lay the ground for such a transition. But the forms of residential care outside the family home, which might replicate independent forms of adulthood and replace kinship care, can only be accessed through an entirely different set of social services.

By contrast, in India, Uganda, Brazil, and Jordan leaving school is rarely correlated with expectations about independent living. Parents struggle to find forms of support beyond the education system, but the more significant crisis is normally the death of the parents. People with intellectual disabilities in Euro-America who do not rely on professional care can often be in similar positions. But there are many, by this stage in the life cycle, who will have already moved to a stable residence and care provision beyond the parental home. In countries without state welfare systems, by contrast, this moment will almost always necessitate finding and relocating to a new form of residence and care. Here, parents, families, and the disabled people themselves rarely have established patterns, structures, and ideas about what that might involve.

Carrying this research forward requires seriously engaging with the way that the psychiatric category of intellectual disability has become globalised, which is likely to be partial and patchy (Zoanni 2021). It is a significant limitation not only of psychology and medicine, but also of the social sciences and history, that we have so little work beyond Euro-American contexts on which to base better comparisons. But if anthropology has not yet furnished us with a wealth of empirical examples, its tradition of research in this area has nevertheless left us with ways we can investigate intellectual disability in a properly cross-cultural ethnographic perspective.

### **Conclusion: Towards an anthropology of competence**

Anthropology offers a way to put into social perspective the individualised concept of mental development that underwrites psychiatric approaches to intellectual disability. The *DSM-V* defines intellectual disability in terms of a lack of progress towards expected milestones, and the failure to attain full mental ‘maturity’. In doing so, it gives passing mention to the fact that such expectations will vary cross-culturally. Anthropological work is well positioned to explore this issue and demonstrate its centrality. Likewise, insofar as many anthropological approaches to intellectual disability emphasise the life course (Langness and Levine 1988a; Mietola and Vehmas 2019), they sketch a path for moving beyond understanding intellectual disability as a biologically-caused deviation of an individual from a universal path of mental development. Rather, they demand analysing intellectual disability in terms of an increasing lack of ‘fit’ between particular expectations for maturation and a person in all their particularity (Garland-Thomson 2011).

In this way, anthropological approaches challenge us to think more broadly than *DSM* categories alone. On this front, Edgerton’s concept of ‘competence’ may be helpful. Existing cross-cultural studies of

competence in relation to intellectual disability shift the emphasis from theoretical debates about the condition's social and cultural construction into an empirical investigation (Jenkins 1999). The concept foregrounds people's capacities, rather than limitations, opens up the definitional gaps of the *DSM-V*, and raises the question of whether individual responsibility and independence are in fact prerequisites of a meaningful life. The concept also focuses our attention on the concrete cultural expectations, political-economic demands, histories of classification, and environmental and material conditions in particular places. All of these factors play a central, yet not easily predictable, role in the way intellectual disability manifests, is experienced, and plays out in practice.

A focus on competence is one way in which anthropology avoids reducing intellectual disability either to a biological pathology residing in an individual brain, or to nothing but a social fiction that is wholly a product of language and categories. Anthropology requires us to investigate ethnographically the normative features of any given setting, the forms of learning that enable people to follow them, and how precisely people end up departing from them. Ethnography allows us to view persons deemed intellectually disabled over time, to attend to what pulls them away from expected developmental paths, and to track how those departures come to be imagined, classified, and responded to. It thereby foregrounds the significance and the complexity of the relational lives of people with intellectual disabilities.

In all of these respects, anthropological research reveals dimensions of the social and cultural life of intellectual disability that biomedical and professional research rarely enquires into, let alone comprehends. An anthropology that developed and expanded its own still-nascent tradition of detailed cross-cultural research in this area would enable us to answer crucial unanswered questions about how the condition is differently constructed, responded to, and lived across the world.

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[1] Past versions of the American Psychiatric Association's *Diagnostic and statistical manual of mental disorders (DSM)* referred to 'mental retardation'. The 2013 DSM-5 changes nomenclature to 'intellectual disability', in line with accepted international academic usage as well as a 2010 US federal statute outlawing the use of the previous term (Wills 2014). This entry uses the term 'intellectual disability' except when referring to historical or academic contexts in which a different term was used.