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Debates about dedifferentiation: twenty-first century thinking about people with intellectual disabilities as distinct members of the disability group^{1,2}

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ABSTRACT

Dedifferentiation describes a shift away from regarding cognitive impairments as the origin of difficulties experienced by people with intellectual disabilities and, instead, regarding their difficulties as socially produced and common to all people with disabilities. This article reviews research evidence concerning the advantages and disadvantages of dedifferentiated policy and service systems for people with intellectual disabilities, the bulk of which addresses education and health service systems. Advantages of dedifferentiation include its avoidance of assumptions about homogeneity, and the stigma of being labelled intellectually disabled; and its support for strong collectives and advocacy that enable people with all types of disabilities to live in the presence of others. For young children, dedifferentiated school and mental health services have positive outcomes not found in similar services for older children and adults. Disadvantages of dedifferentiation include inaccurate or absent representations of unique needs arising from intellectual disability, failure to reduce marginalisation, poor-quality non-specialist mainstream secondary education and health services, and deteriorations in social care. Arguments that dichotomies such as dedifferentiation/differentiation encourage simplification and misconception are reviewed: instead, twenty-first-century thinking negotiates between diverse parties and perspectives. The article makes the case for treating people with intellectual disabilities as members of the broad disability group wherever possible, and for protecting and developing differentiated opportunities, services and research whenever necessary. This requires policymakers and practitioners to balance conflicting ideas more effectively, but it also requires reflection and debate that allow new conceptual tools to emerge. The article concludes by posing three questions intended to encourage reconceptualisation.

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Conceptions of intellectual disability have shifted continually as ideas about society, the family, and social justice have changed over time. While each change has corrected the

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failings of its predecessor, arguably a wholly acceptable response has not yet emerged (Vehmas & Watson, 2014). For the last two centuries, dominant concerns about people with intellectual disabilities have been their vulnerability, dangerousness, or incapacity to meet community norms of educational attainment or economic independence (Thomson, 1998). The distinctive policy and service systems established to support their educational, residential care and community support needs evolved during the twentieth century as ideas changed. They moved away from distinguishing people with intellectual disabilities from other disabled groups as social oppression rather than impairment explained difficulties of disabled people, and inclusion replaced separation as a policy aim.

Since the 1990s, people with intellectual disabilities have become increasingly included in the generic grouping “people with a disability” in United Kingdom, Scandinavian and Australian policy, advocacy, service delivery, and research. Thinking about something new is easier once it has been named. Sandvin and Soder (1996) introduced the unfamiliar word *dedifferentiation* to characterise this change, a biological term for a process whereby tissue that had become specialized evolves back to its simpler form. When applied to intellectual disability, it describes the change away from regarding people with intellectual disabilities as having particular needs resulting from cognitive impairment and, instead, treating them as members of the broader group “people with disabilities”. We examine research evidence about the advantages and disadvantages of dedifferentiation for people with intellectual disabilities, focussing on policy and service systems rather than theoretical or philosophical perspectives.

Method

We searched multiple databases from 2010 for articles, books, and reports that used the terms “intellectual disability”, “learning disability”, or “mental retardation” in combination with any of these keywords: mainstream, specialist, services, disability rights, definitions, policy, education, health. This evidence was amplified by following up references from these sources and by adding theoretical observations that frame the debate. There are four caveats. Wherever possible we refer to strong evidence but also consider “grey” literature that illuminates, for example, the situation of people with intellectual disabilities in war zones where it is not possible to use tight research methodology. Second, we value contributions from all parties involved in intellectual disability, but struggle with the paradoxes that arise when authors question the category while commenting on intellectual disability without describing their population’s characteristics. Consequently, the experiences of one specific sub-group within the category people with intellectual disabilities are sometimes used to represent the whole, or data come from people with lower than average cognitive abilities who do not have intellectual disabilities. Third, much of the evidence originates from a very limited group of developed countries, yet different contexts are highly relevant to thinking through these issues. Finally, there is a tension between identities of people with intellectual disabilities as fluid and constructed, and identities becoming fixed by the very service systems developed to meet their needs.

Evidence about advantages of dedifferentiation

Dedifferentiation has supported beneficial social changes and individual adjustments that increase social justice. Many people with mild intellectual disabilities choose dedifferentiation.

They reject the label of intellectual disability, attribute their experiences of emotionally painful stigma to its impact on their lives, and prefer the social model position that society should change not them (Clifford Simpican, 2015a; Shakespeare, 2013). They object to the assumptions of group homogeneity implicit in differentiation and, in particular, resist being grouped together with people with more severe or multiple intellectual impairment who cannot speak or who use wheelchairs (Goodley, 2010).

Dedifferentiation also avoids the unreliability of identifying intellectual disability, which many argue is an unsatisfactory administrative concept that is difficult to quantify. Psychologists acknowledge that IQ tests contain errors of measurement and cultural bias (e.g., Webb & Whitaker, 2012). Some neuroscientists have called for more complex and sensitive assessments of a broader range of cognitive functions (reviewed in Salvador-Carulla et al., 2011). However, delivering this equitably would require additional professionals and risk diverting scarce resources from more pressing needs.

Goodley & Runswick-Cole (2015) argued that people with all types of disabilities need solidarity in order to resist manipulation by the pharmaceutical trade and powerful “psy” professionals. Dedifferentiation has supported development of the Disability Rights Movement as a collective that can challenge oppressive structures. For example, the inclusion of people with intellectual disabilities in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) has been important in promoting their rights and supporting legal challenges to discrimination. Although the role of law is limited, the equality, support, protection, and socio-economic aspirations of the UNCRPD raise and inform important challenges (Carney, 2013). Appeals based on the UNCRPD have protected women with intellectual disabilities from unnecessary interventions concerning their menstruation and sexuality in many different countries (Roy, Roy, & Roy, 2012). Article 12 has generated debate about the need for law reform and introduction of supported decision-making in Australia and elsewhere (Douglas, Bigby, Knox, & Browning, 2015). Yet for people with intellectual disabilities, rights to autonomy and protection asserted by the UNCRPD need to be balanced by equally important rights to care and support for development, without which, as Dörenberg and Frederiks (2012) have argued, life is meaningless for them

Dedifferentiation intends to increase social justice by increasing the visibility of people with disabilities. Successful challenges to physical and material barriers mean that space is now more likely to be organised in ways that allow people with all types of disabilities to live in the presence of others. Dedifferentiated policies promoting access to mainstream services, primarily health and education, were introduced to most developed countries in the late 1970s: these challenged service providers to be creative rather than look for problems. One of the success stories has been dedifferentiated support to children with and without intellectual disabilities admitted to mental health units. Both groups show clinically significant improvements (Chaplin, Roach, Johnson, & Thompson, 2015), despite the greater complexity of children with intellectual disabilities who had higher clinical problem scores and longer admissions. Inclusive primary education is another success. Pupils with intellectual disabilities attending integrated primary schools generally appear to be happy and accepted by peers, building community understanding and tolerance at no apparent cost to their developing self-esteem (Huck, Kemp, & Carter, 2010). Many pupils with intellectual disabilities and their parents also prefer that they attend mainstream secondary schools (Kim, 2013; Rogers, 2013) although there are shortcomings, which we examine below.

Evidence about disadvantages of differentiation

Four types of disadvantage are described by the literature: inaccurate or absent representations of intellectual disability; failure to reduce marginalisation; unresolved problems in the provision of mainstream non-specialist secondary education and health services; and deteriorations in social care.

Inaccurate or absent representations of intellectual disability

Policy and public discourse often relies on “stand-ins” as close to normal as possible to represent people with intellectual disabilities. Burton and Kagan (2006) showed that in many policies the imagined person with an intellectual disability has mild cognitive impairment, no additional physical or mental health problems, and lives in a welcoming rather than a hostile community. Since few people fully understand what the term “intellectual disability” signifies (Goodley, 2010), inaccurate representation compounds common tendencies to underestimate the impact of limited abstract thinking or the difficulties people with intellectual disabilities have in communication and self-determination. For example, 20% of those with the mildest intellectual disabilities are unable to give a coherent explanation that follows expected communication rules (Kernan & Sabsay, 1983). Close-to-normal portrayals underline the importance of regarding people with intellectual disabilities as having equal human value, but obscure their diversity and the extent of additional needs such as high rates of mental health problems (detailed below).

The disability rights movement has neither engendered relationships nor a sense of belonging for most people with intellectual disabilities beyond the fellowship enjoyed within People First meetings (Goodley, 2014). Shakespeare (2013) argued that people with intellectual disabilities are silent within the disability rights movement, because their access and communication issues have been neither understood nor addressed and they have not been welcomed. Despite the strong stand on service user involvement taken by policy and the rights movement, he cautioned against accepting accounts of the life of people with intellectual disabilities as untroubled:

People with learning difficulties generally reject a sense of themselves as being different or vulnerable... [but] I think an attitude of respectful ambivalence ... is necessary: the fact that they do not interpret their lives using the language of intellectual impairment does not mean that they are correct, (Shakespeare, 2013, p. 108)

Failures of representation and unquestioning service user involvement have resulted in the needs of people with the most severe and complex intellectual disabilities being ignored. Arguably this accounts for the necessity to rewrite England’s Valuing People policy after only eight years, so it more clearly addressed the needs of this group (United Kingdom Department of Health, 2001, 2009)

Implementation of policies to remove disabling barriers has taken little cognisance of the invisible ones people with intellectual disabilities face or the nuanced and often complex adjustments needed to facilitate participation. In Australia, for a long time the actions plans required by the Disability Discrimination Act (1992) reproduced common stereotypes of people with disabilities as using wheelchairs and facing physical barriers (Goggin & Newell, 2005). Under this legislation there have been few individual cases, and only one anti-discrimination class action that resulted in substantial positive change for people

with intellectual disabilities (Australian Government Department of Social Services [DSS], n.d.; French, 2012). Strategies seldom recognise the extent to which reliance on written or web based communication or automated technology systems prevents independent participation by people with mild intellectual disabilities (Nind & Seale, 2009). Failure to acknowledge the need for skilled interpreters of both content and process has led to tokenistic participation in decision-making, research, and political and civil society bodies (Bigby, Frawley, & Ramcharan, 2015; Frawley & Bigby, 2011; Schelly, 2008).

Failure to reduce marginalisation

Social marginalisation or complete exclusion have long been problems for people with intellectual disabilities: social networks have not expanded with dedifferentiation. Improvements in quality of life have focussed on quality of physical environment. Many more people with intellectual disabilities have their own room and possessions, live with only a few other people, and are present in towns rather than living in isolated institutions. However, such changes have resulted in little improvement in the quality of social life for most people with intellectual disabilities (Clegg, Murphy, Almack, & Harvey, 2008).

Marginalisation echoes through all settings, perhaps most visibly in war and civil conflicts where people with intellectual disabilities are often abandoned by families and institutional staff (Rohwerder, 2013). Once abandoned they are either not identified as having an intellectual disability that warrants special assistance or, if recognised, passed from one agency to the next by uncertain staff who believe that some other agency must be better placed to help them. Rohwerder concluded that identification of people with intellectual disabilities and making specialist provision for them in war are essential to fulfil the UNCRPD (2006).

Adults with mild intellectual disabilities who live independently still choose to spend time in specialist refuges at the margins of society, in self-advocacy groups facilitated by people familiar with their needs (Hall, 2004; Jahoda, Wilson, Stalker, & Cairney, 2010). These are almost exclusively held in intellectual disability settings (Clifford-Simplican, 2015a) and accorded great significance by those who attend, indicating the importance of ensuring that people with intellectual disabilities can access forums separate from parents, families, or people with disabilities in general (Anderson & Bigby, 2016; Frawley & Bigby, 2015). It is possible to anchor people with intellectual disabilities into a (rather than “the”) community. However, skilled support is required to facilitate encounters that build into relationships (Bigby & Wiesel, 2015; Schelly, 2008; van Alphen, Dijker, van den Borne, & Curfs, 2010; Wiesel & Bigby, 2015) and the scarcity of longitudinal research in intellectual disability means there is little evidence of what it takes to engender relationships and connections that endure.

Unresolved problems in the provision of mainstream non-specialist secondary education and health services

Education

The disadvantages of dedifferentiated secondary education have been identified by a number of research studies. Children with intellectual disabilities attending mainstream

secondary schools were found to be less likely than peers in specialist schools to access social services that they require, and for which they are eligible (Olsson, Elgmark, Granelund, & Huus, 2015). They experience more name-calling, ridicule, and exclusion than peers attending special schools (Cooney, Jahoda, Gumley, & Knott, 2006; Kim, 2013; Popovici & Buică-Belciu, 2013; Rogers, 2013). Children formally identified as having Special Educational Need are twice as likely to be bullied (12%) as an average pupil (6%), and, unlike the bullying experiences of children without disabilities, their significantly heightened risk of being bullied “all the time” does not reduce with age (Chatzitheochari, Parsons, & Platt, 2016). Longitudinal research shows that childhood bullying has negative social and psychological outcomes in adulthood (Arseneault, Bowes, & Shakoor, 2010; Wolke, Copeland, Angold, & Costello, 2013). Teachers also identified inclusion as a major obstacle to learning because it exacerbates behavioural disruption (MacBeath & Galton, 2004). Parents who challenge dedifferentiation do so because it exposes their child to abuse and unsuitable teaching:

When he went to the special school ... I think life improved overnight and I wished with hindsight I'd done that from the start... he never got as tired or as run down again and I suppose the activities were just paced for him better. I mean nobody was sitting with him any more with a fistful of flashcards hoping that if they did it often enough he'd learn them. (Clegg et al., 2008, p. 85)

Some authors attribute problems to insufficient support: they urge more resource, better teacher attitudes, or de-emphasising competitive school league-tables based on exam results. However, Chatzitheochari et al. (2016) concluded that far from being progressive, dedifferentiated secondary education reproduces social inequalities. Even Warnock, who chaired the 1978 report that introduced educational mainstreaming to the United Kingdom, subsequently argued that different children's needs are often best met in different environments. She described inclusion as “disastrous” for children with autism and with challenging behaviour (2005, p. 22).

Physical health

People with intellectual disabilities are very likely to have additional physical health problems: there are higher rates of epilepsy, obesity, skin disease, sensory impairment, heart disease, and thyroid disorder. Since 84% of people with intellectual disabilities have co-occurring physical and mental health problems, these effects often interact: the way anti-psychotic medications lower epileptic seizure thresholds illustrates why this needs to be taken into account during treatment (Crocker, Prokić, Morin, & Reyes, 2014). Health services struggle with the way cognitive impairments affect subjective experience of pain or ill health and the ability to reflect and report it (Sheehan & Paschos, 2013). This includes difficulties in describing the location and type of physical or emotional pain in ways that support diagnosis. Systematic adjustments tailored to the needs of this group are required to reduce avoidable death and equalise physical health care (Byrne, Lennox, & Ware, 2015; Heslop et al., 2014). A longitudinal perspective is also necessary. Improving the significantly poorer health of people with intellectual disabilities requires interventions that prevent childhood adversities from accumulating (Emerson, 2013).

A small number of conditions not only cause intellectual disability but also have implications for the way the child is best managed. Parents criticise mainstream services for

lacking familiarity with these conditions, which means they have to explain the syndrome and its implications repeatedly (Griffith et al., 2011). They prefer specialist services that help them respond to their child's needs (Tunnicliffe & Oliver, 2011). An example is the fluctuating hormone levels that render people with Angelman syndrome by turns challenging and sleepy. Recommended behavioural interventions for insomnia that prevent daytime sleeping worsen the challenging behaviour: it is more effective to stabilise hormone levels with melatonin (Bird, 2014).

Mental health

Mental health problems affect nearly half (47%) of adults with intellectual disabilities (Lin et al., 2014), double the rate experienced by adults without intellectual disabilities. The main advantage of using mainstream mental health services and admitting people with intellectual disabilities to general adult mental health units, rather than specialist ones, is that the former are closer to home. However, Donner, Mutter, and Scior (2010) reported that parents find it difficult to access help from adult mental health services because they are reluctant to take anybody with an intellectual disability. These parents described adult mental health units as hostile and disempowering places where frequently changing staff made no relationship with their relative. Treatment was almost exclusively through medication as their relatives passed the time alone in their rooms, afraid of violent fellow patients who misuse drugs and alcohol, and who call them names and exploit them.

Rogers (2011) concluded that merging people who have intellectual disabilities and mental health problems with others results in service failure to address their objective physical and mental health difficulties. Similarly, Chaplin (2011) found people with intellectual disabilities admitted to adult mental health units had more severe problems than those without intellectual disabilities. Poor care standards and difficulty obtaining emergency support were evident, and, instead of treatment, people with intellectual disabilities were more likely to be discharged early to an expensive out-of-area service. Carers can become caught in tensions and boundary disputes between different service models, not least that specialist intellectual disability mental health services co-ordinate long-term support while general mental health services focus on short-term treatment and throughput (Venville et al., 2015).

Sheehan and Paschos (2013) concluded that adult mental health services in the United Kingdom are unable to offer high-quality care to people with intellectual disabilities who become mentally ill, and that outcomes from specialist services are more positive. International reviews that compared specialist and mainstream mental health services for people with intellectual disabilities (Cain, Davidson, Dosen, & Torr, 2010; Torr, 2013) found pockets of good practice only in specialist services, which showed good agreement between psychiatrists about diagnosis, good staff engagement, and patients had relatively good outcomes. However, the majority of people with intellectual disabilities were treated in mainstream acute mental health services by psychiatrists and nurses who reported either not wanting to, or not knowing how to, work with adults who have intellectual disabilities. These reviews also found that diagnosis was unreliable in mainstream services, with over-diagnosis of psychotic disorder and over-use of psychotropic medications; and the individuals with intellectual disabilities were exploited by other patients.

A scoping review identified 17 studies that considered the perspective of service users with intellectual disabilities and mental health problems (Venville et al., 2015). It found that while they report experiencing distress in both mainstream and specialist mental

health services, mainstream in-patient settings were the site of the most negative and stressful experiences. Mainstream staff failed to engage and some made negative comments; the service users with intellectual disabilities were afraid of other patients not least because they stole their belongings.

Relatively positive user views of specialist mental health services challenge policy in England, where differentiated mental health services are assumed to provide an ideal setting for abuse, and policy has sought to close them down (United Kingdom Department of Health, 2015). Yet abuse recurs in all settings. History shows both institutions (including hospitals managed by psychiatrists and nurses) and communities to be abusive (Clegg & Jones 2015; Trent, 1994). Research indicates that family members are the most likely perpetrators of abuse (Shakespeare, 2013) with harsh and inconsistent parenting significantly associated with challenging behaviour (Emerson, Einfeld, & Standliffe, 2011). Protecting people with intellectual disabilities from abuse is an ethical issue for all contexts (Fyson & Cromby, 2013).

In Australia, the poor quality of service for people with intellectual disabilities and challenging behaviours led to a call for specialist services (Carter Report, 2006). Specialist intellectual disability professionals can adapt cognitive behavioural therapy to accommodate each person's pattern of abilities, and recognise when therapy needs to be supplemented by practical interventions to address sources of stress affecting the person (Jahoda et al., 2010). Specialists also make effective risk-judgements, particularly for that small number of people with autism and intellectual disabilities who endanger mothers and siblings. Conflicts are more likely in the face of such risks, so structures and processes are needed that allow interpretation and negotiation of conflicting ideas (Pilnick, Clegg, Murphy, & Almack, 2011):

When my brother cried, five people pronounced a different cause. My mother blamed sickness, my father blamed boredom, I blamed my parents, my sister looked to the weather, and the other sister consulted the phase of the moon. Not only did we struggle to determine my brother's needs, but we also struggled with the ways in which our family's distributions of power ... resolved these disputes. (Clifford-Simplican, 2015b, p. 225)

When people with intellectual disabilities experience mental health problems and particularly when this entails aggression, an enormous range of possibilities must be explored through assessment, reflection, and discussion. Common questions include: Can at least some professionals establish an open and emotionally containing relationship that reassures the person? To what degree could poor physical health be compromising mental health? Is embodied distress psychological or does it indicate disease? When somebody is chaotic, which aspects of their physical health, mental health or challenging behaviour should be addressed first? When they are volatile, how can their safety and that of staff, fellow patients, and family be assured? Of course intellectual disability has a dreadful history of abandoning staff in hopeless institutions that, at best, provide no meaningful treatment and, at worst, react to brutal conditions with brutality. Yet there is no evidence that professionals without specialist knowledge find a way to communicate with the person despite confusion or challenges, or a way to negotiate between different and often conflicting family and professional perspectives, while addressing all the possible issues in play.

Specialist professionals with an understanding of intellectual disability and attachment theory offer unique insights into service responses for people with challenging behaviour

(Schuengel, Clegg, de Schipper, & Clasien, 2016). Attachment is a cognitive-emotional system that directs people towards specific others in their immediate social world who are perceived to be wiser and stronger, and willing to share their resources. This system is highly active in young children but also activated in adults whenever life's challenges outstrip personal resources. Patterns of attachment behaviour reflect cognitive-affective processing that emerges from social relationships and (usually) change in response to the development of new types of relationship. Some people with intellectual disabilities show excessive attachment behaviours towards family members or particular members of care staff, and these relationships can provoke challenging behaviour. Services that do not understand their basis in attachment distress tend to respond by separating the person from that family member or staff carer, a short-term solution that ultimately makes the problem worse.

Deteriorating social care

The final disadvantage of dedifferentiation concerns problems that arise as services decentralise and social care deteriorates: recent drops in living standards and service quality are evident in a number of European countries. For example, in 2000 Norway rescinded its previous central mandate that group homes should contain no more than four people with intellectual disabilities. This resulted in average group home size increasing: some homes had as many as 25 and for an incompatible mix of residents, including those with dementia or substance misuse (Tøssebro et al., 2012). Similar service deterioration occurred in Denmark and Sweden.

Miettinen (2012) identified three problems after Finnish localities gained responsibility for service provision as state subsidies were cut: vulnerable people with intellectual disabilities were left unsupervised, staffing levels permitted only minimal care, and lack of in-service training fostered coercion. These changes amplified family mistrust in service systems across Scandinavia, fostering parents' belief that their adult children with intellectual disabilities should remain at home with them. Similar problems were identified in the United Kingdom when dedifferentiated policies coincided with both the transfer of responsibility to local authorities and austerity. A formal United Nations inquiry into the United Kingdom's provision to all people with disabilities (United Nations Committee on the Rights of Persons with Disabilities, 2016) found that people with intellectual disabilities were particularly disadvantaged by benefit sanctions, and by failure to take their high support needs into account. Assessment processes had not been adapted, nor had their additional needs been given appropriate weight in decision-making.

In sum, as service administration decentralised and funding shrank in both Scandinavia and the United Kingdom, dedifferentiation appears to have rendered invisible the additional problems posed by living with intellectual disabilities.

The case for change

The evidence for and against dedifferentiation has a kaleidoscopic quality. Our mind's eye settles onto one perspective or position until new research shows how it is incomplete. There is evidence in favour of treating children with intellectual disabilities as children first, since dedifferentiated primary schools and child mental health services are relatively

successful. There is also evidence that when people with different disabilities combine, they accrue political power, as shown by the successful challenges under the UNCRPD that certainly have improved the lives of people with intellectual disabilities. Yet dedifferentiation is not the only route to political power, since this has also been exerted by impairment-specific groups such as those promoting the interests of people with autism. Sharp focus, a graspable story, and effective campaigning achieved the Autism State Plan for Victoria (Victorian Government Department of Human Services, 2009), and passage of laws that mandate the provision of public support to this particular group in both England and Wales (Autism Act 2009) and the United States of America (Autism CARES Act 2014).

Sandvin and Soder (1996) introduced the term “dedifferentiation” to express concern about dissolution of intellectual disability. Most of the negative predictions about its impact subsequently made by Bigby and Ozanne (2001) have been fulfilled. Knowledge and know-how is being lost; commitment to creating more tolerant and supportive societies has reduced; people with a range of different disabilities are being congregated into the same stigmatising and poor-quality care settings; and greater responsibility for problem-solving has been shifted onto families. There is no doubt that a differentiated approach also falls short of aspirations, but specialist opportunities and services do not have to be segregated, less valued, or poorly resourced. They just need to be tailored for the unique talents of people with intellectual disabilities in the same way as specialist arts and sport facilities are tailored for artists and sportspeople.

While people with mild intellectual disabilities reject suggestions they are vulnerable this does not mean that they do not need help. Their social isolation has not diminished as they have become more present and visible within local communities (Bigby, 2008) and this is not surprising. A considerable body of research into intercultural dialogue confirms that neither community presence nor contact alone increase tolerance between different types of people (Valentine, 2013). Tolerance and acceptance of difference have to be taught and practised throughout childhood; take place in environments where there is authority support; and contact must allow opportunities for meaningful personal communication, equal status, and cooperation (Pettigrew & Tropp, 2006). Dedifferentiated education appears to be ideally placed to achieve these, but so far has struggled to do so.

Community members continue to avoid children and adults with intellectual disabilities in part because their unpredictable mix of expected and unexpected abilities undermines the skills people rely on to ease social encounters (Meininger, 2008). Another problem is the impact of emotional deprivation on the way some people with intellectual disabilities engage socially. This was vividly illustrated by the forgotten men in Hubert and Hollins’ (2010) study: histories of neglect and institutionalisation rendered them so unusual that even the most highly motivated community members would struggle to bridge the interactional gap. Parents also describe the paradox of their child with an intellectual disability being both like and wholly unlike other children. People familiar with intellectual disability are required who can help others come to grips with this strangeness.

Differentiation also ensures that resources and opportunities intended for people with intellectual disabilities are reserved for their use. An incident of misused public resource occurred when most of Spain’s “intellectual disability” Paralympic team in 2000 turned out not have intellectual disabilities: the basketball team was stripped of its gold medal, and people with intellectual disabilities were excluded from the Paralympics until a

reliable method of identification could be agreed. Reinstatement involved developing a robust process of IQ testing plus independent checks (Burns, 2015). This does not negate reservations about IQ as a concept, which reflect Churchill's view of democracy: "No-one pretends that democracy is perfect or all-wise. Indeed, it has been said that democracy is the worst form of Government except all those other forms that have been tried from time to time" (Hansard, 1947, p. 207). This argument in favour of appropriate identification through IQ testing does not dismiss parental complaints about repetitive developmental assessments that generate no new knowledge or resource. Identification must be done in ways that avoid undermining parents' attempts to create a broader sense of their child's personhood.

A central argument for dedifferentiation is that the shortcomings of non-specialist services can be addressed by staff training, yet problems have been attributed to reorganisation rather than lack of training. Flynn (2010) argued that the move away from general to sub-specialist services in adult mental health means that no general services exist that could provide appropriate care to people with intellectual disabilities. Additionally, very few of the disability-related training needs identified by mainstream healthcare professionals are straightforward. The training they requested included topics such as how to manage complex family dynamics (Hemm, Dagnan, & Meyer, 2015), which could not start to be addressed in the limited time available to non-specialist staff. It is thus no surprise that training for assessors and decision makers has been judged ineffective: "Evidence indicates a persisting lack of awareness and limited knowledge of disability rights and specific needs ... particularly of persons with intellectual disabilities" (UNCRPD 2016, p. 18).

The resolution of a similarly polarised situation outside intellectual disability, intimate violence, may be informative (Goldner, 1999). For feminists, violence is a criminal act: the couple should separate so that the justice system can deal with the man while mental health professionals support and treat the woman. By contrast, clinicians argue that couples involved with violence have a complex relationship: men should be held responsible for their behaviour, but inability to contain their rage interacts with the women's inability to separate and keep themselves safe. After 25 years of sharp opposition between these positions, a shared commitment to identify valuable aspects of each perspective emerged. Dialogue enabled both parties to reshape their positions while keeping them distinct. In clinical work with couples who wanted to stay together, the therapist's ability to contain contradictory truths while examining all aspects became the lynchpin for change.

A problem with raising any argument in favour of differentiation is that people take exception to exceptionalism (Haskell, 2000): claims that a group is so unusual that it does not conform to general rules or principles tend to be challenged. Haskell questioned why exceptionalism became associated with parochialism and conservatism that block progress. He argued for a post-exceptionalist position that makes no commitment to either side. In this way, twenty-first-century thinkers urge that dichotomies (medical-social, specialist-mainstream, dedifferentiated-differentiated) which have paralysed debate be abandoned, so that discussion can be "less about polar right and wrong actions, but instead choosing the better action from a range of possibilities" (Sadler, van Staden, & Fulford, 2015, p. 7).

Dichotomies encourage simplification and misconception (Haskell, 2000). A new case is needed that allows people with intellectual disabilities to be treated as members of the broad disability group wherever possible, and protects and develops differentiated

opportunities, services, and research whenever necessary. We agree with Sadler, Staden, and Fulford (2015) that twentieth-century “turf wars” must give way to twenty-first-century thinking that negotiates between diverse parties and perspectives. New models need to be multi-perspectival, nuanced, and creative.

Twenty-first-century thinking about people with intellectual disabilities

The evidence supports neither dedifferentiation nor differentiation as *the* solution to difficulties faced by people with intellectual disabilities. It highlights the protections that legal challenges supported by the dedifferentiated UNCRPD can provide, but also the need to articulate and represent the distinct problems experienced by people with intellectual disabilities, and differences between people with intellectual disabilities. There are three immediate implications for policymakers and practitioners:

- The need to balance conflicting ideas more effectively. Compromises have to be found that address the tensions that arise when people with intellectual disabilities, particularly those with more severe impairments, are disadvantaged when they cannot represent themselves. It must not be assumed that people with mild intellectual disabilities can represent the views of those with severe intellectual disabilities or additional mental health problems more effectively than reflexive, involved people without disabilities; or that people with other disabilities are effective proxies for the many different types of people described as having an intellectual disability. While user perspectives are important, their input must be critically appraised, and considered alongside other forms of knowledge to ensure that the decisions reached are sensible.
- The evidence highlights both successes and problems with dedifferentiation. The shortcomings will neither be addressed through brief training courses about intellectual disability for general staff, nor by resurrecting 50-year-old differentiated approaches. Effective identification and good data are necessary to make the political case for redistributing resource to people with intellectual disabilities, and planning new services (Smith, 2013), but conceptual development at a higher or different level of abstraction is also required. New conceptual tools are needed that can engage with the significant embodied impairment that reduces the wellbeing of people with intellectual disabilities, and can solve some of the moral dilemmas posed (Vehmas & Watson, 2014).
- Solutions must be grounded in the core problem that the social relationships of people with intellectual disabilities are unsatisfactory or non-existent. The very anonymity of dedifferentiation increases the risk that people with intellectual disabilities will float adrift from any connection. Rather than perpetuating liberal individualism by focussing solely on experiences and choices of people who have intellectual disabilities, the issue is not how to enable people to be somewhere (whether differentiated or dedifferentiated) but how to enable people to be someone.

In conclusion, we advocate productive engagement with uncertainty, and envisage the creation of opportunities to bring proponents of different positions into dialogue with one another. The following three questions may help to ignite new thought: we invite

readers to join in creating conceptual tools to shape the next set of policies and support services.

1. *What is required for people with intellectual disabilities to become anchored within a community?*

In an era of *Liquid Modernity*, Bauman (2001) argued that achieving satisfactory recognition is one of the problems of the age, since social ties are unstable and collectives are dissolving. He criticised the deification of happiness as a life goal and choice as the means to attain it. He also criticised the relativisation of quality of life, which pits interest groups against one another as they battle for diminishing resources. Instead, he commends formal descriptions of wellbeing and what it means to live a life of dignity. These ideas were developed further in the new concept of Social Anchoring which links identity, security, and integration for immigrants who have lost their place in the world (Grzymala-Kazłowska, 2016). This is defined thus: “The process of finding significant references and grounded points which enable migrants to restore their socio-psychological stability in new life settings and establish their (subjective and objective) footholds in a receiving society” (2016, p. 134). Anchors may be relationships but also places and objects. This approach is clearly applicable to intellectual disability, inviting research into what Grzymala-Kazłowska called “essential life footholds”.

2. *In what ways should policies and services to support people with intellectual disabilities be adapted to suit those who live in the most deprived localities?*

Forty-eight percent of all contacts between people with intellectual disabilities and psychiatric services concerned people living in the most deprived parts of a city, significantly more than expected from general population data (Nicholson & Hotchin, 2015). Growing evidence of the way poverty and deprivation reduce the physical and mental health of many people with intellectual disabilities must be grappled with: productive engagement with social class is overdue.

3. *Which relational approaches could replace current focus on individual outcomes?*

This question invites thinking that goes well beyond positive behavioural support and person-centred planning, which have become portmanteaus, swallowing up new ideas whether or not they are conceptually compatible until there is no longer a specific intervention that can be applied or evaluated. A broader range of specific approaches needs to be developed that, by suiting different people, reflects the full heterogeneity of intellectual disabilities. The Royal College of Psychiatry’s (2012) Enabling Environments initiative has already begun to broaden thinking by drawing on research into therapeutic communities in order to accredit human service agencies as places where relationships work effectively at all levels. Its built-in flexibility allows schools, prisons, youth clubs, and hospital wards all to attain Enabling Environment status.

Human relationships involve not only connection, but also disconnection, which can be particularly difficult for people with intellectual disabilities who have underdeveloped or damaged socio-emotional skills (Emerson et al., 2011; Sappok et al., 2014). Further

insights into relationship challenges for people with intellectual disabilities derived from attachment theory (Fletcher, Flood, & Hare, 2016) should be another focus for thinking about practice and research.

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