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## **The intellectual ableism of leisure research: original considerations towards understanding well-being with and for people with IDs**

People with Intellectual Disabilities (ID) are considered to be one of the most marginalized, isolated and disenfranchised groups in society. However, recent social prescription intervention programs are being introduced to enhance the physical and mental well-being of these individuals through participation in leisure activities, thus increasing academic interest in research within the area. This paper introduces the theoretical and methodological tensions in applying mainstream scholarly thinking of leisure and well-being to people with IDs, and argues that by failing to acknowledge and address such tensions scholars are at risk of demonstrating intellectual ableism. Layering Kleiber's (1999) components of leisure over Seligman's (2000) PERMA concept of well-being, the paper poses critical questions of how each contributing element of well-being could be reconceptualised for people with neurological diversities. The intersection of leisure, well-being and ID is ripe for research development; however many studies in the domain are falling short of suitable theoretical discussion and methodological rigour. The paper concludes with suggestions on how scholars can reduce intellectual ableism through inclusive design, methodological reporting, acknowledging bias and grappling theoretical dissonance.

Keywords: ID. **Ableism**. Well-being. Positive Psychology. Leisure

## **Introduction**

A vast body of literature supporting the role of leisure as an extensive medium for enhancing human well-being is becoming increasingly relevant in psychological and health sciences (Hood & Carruthus, 2013). Presently, the majority of available literature that attempts to understand and translate the relationship of leisure participation and well-being is overwhelmingly focused on the corporeally typical body and the neurologically typical brain, with few leisure journals publishing studies involving intellectual disability (ID). There is a substantial need for scholars to engage in translational research that seeks to diversify the conceptualization of well-being away from such typical sites. Gradual progress has been made in introducing research concerning the well-being (and associated terms such as quality of life, happiness and life satisfaction for example) of people with lived physical differences into mainstream academic journals that do not have a specific remit of disability. However, the author argues this demonstration of inclusive scholarly activity is not being extended to researching the well-being of people with intellectual disabilities (PWID). Reaffirming the work of Hensel (2001), it is evident that the academic sophistication required to study the topic leaves authors vulnerable to enacting intellectual ableism through the duplicitous hindrance of both an ignoring and an ignorance of the specific considerations of exploring well-being with, for and of PWID. This initial responsibility of eliciting such debates falls upon academics researching ID in order for there to be a ripple effect of better informed in mainstream leisure and well-being literature.

Dodge et al (2012, p.222) argue that “well-being is a growing area of research, yet the question of how it should be defined remains unanswered”. However as this paper is theoretically framed in the work of Seligman (2011), it is appropriate to consider the forthcoming text in regards to his consideration that the topic of well-being “is a construct [that] has several measurable

elements, each a real thing, each contributing to well-being, but none defining well-being” (p.15); these elements being Positive Emotion, Engagement, Relationships, Meaning, and Accomplishment (PERMA). These elements of well-being in regards to PWID will be discussed individually in depth later in the paper. Within critical disability studies, ‘ableism’ is a term with various scholarly definitions, all of which are fundamentally premised on the discrimination and oppression that people with disabilities experience within society (Hehir, 2003). However, the term ‘intellectual ableism’ is yet to be afforded the same academic attention. Therefore, the author presents the definition of intellectual ableism as being the prejudicial assemblage of concepts, actions, practices and structures that favour the more able-minded, resulting in the devaluing, silencing and invisibilizing of the considered lesser intellectual other. For the purposes of this paper, the author shall use the term intellectual disability (as opposed to learning disability) and does so in accordance with the definition provided by the World Health Organization<sup>1</sup> (WHO); whilst simultaneously acknowledging the hypocrisy of issuing a single encompassing term to typecast the very individuals the paper is discussing.

This paper provides scholars working at the intersections of ID, leisure and well-being an overview of the competing theoretical and methodological tensions existing within the three areas when exploring best practice research with and for PWID. Furthermore the paper overlaps questions from critical disabilities studies literature and positive psychology, demonstrating the potential for intellectual ableism, as well as prompting scholars to consider how they might conduct rigorous yet meaningful research with people across the spectrum of ID. Before discussing these tensions, the authors provides a brief consideration of determinants of difference in leisure and objective health for PWID.

## **Recognizing objective health inequalities in PWID**

The work of Emerson et al (2011) provides a detailed consensus review of the five key determinants of health inequalities for PWID; 1) Greater risk of exposure to social determinants of poorer health such as poverty, poor housing, unemployment and social disconnectedness; 2) Increased risk of health problems associated with specific genetic, biological and environmental causes of intellectual disability; 3) Communication difficulties and reduced health literacy; 4) Personal health risks and behaviours such poor diet and lack of exercise; and 5) Deficiencies relating to access to healthcare provision. There is, however, significant opportunity for these objective health inequalities - specifically social disconnectedness, reduced health literacy, personal health risks and behaviours - to be researched through the intervention of social prescribing; particularly through the medium of leisure activities.

### ***The potential impact of objective health inequalities for PWID in leisure activities for well-being***

Research into the well-being of PWID is widely available, and whilst the academic interest in well-being through leisure participation of PWID is growing, there is a dearth of literature explicitly respecting the neuropathological and sociological differences that exist on how well-being might be perceived, achieved, experienced and understood for PWID due to prevalent health inequalities.

The discipline of positive psychology has discussed at length the entangled mutual dependencies of the concepts of ill-being and well-being; often grappling with the conundrum of if well-being is, simply, the lack of something unwanted (or ill-being) (Schultz and Pury, 2018). Brady and Grenville-Cleave (2017, p21) argue that ill-being and well-being should be thought of as “a continuum of fluid being” that spans chronic ill-being, neutrality, languishing and flourishing. Congruent to this, the World Health Organisation define well-being as a central

concept to overall health that represents ‘a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity’ (WHO, 2014). However, the WHO definition of health does little to deliberately understand how the concept of well-being can be understood for PWID as it is highly unlikely that a PWID will ever experience living without some (re)presentation of physical, mental or social ill-being. It is therefore critical to debate to what extent well-being can be philosophically conceptualized when there *is* a presence of often chronic and severe stratifications of ill-being; a topic often ignored in well-being research for PWID.

Some philosophers argue that disabilities are neutral characteristics; mere differences with no average or generally adverse impact on well-being (Barnes, 2014; Bognar, 2015). However, providing health and psychological support for PWID *requires* looking for essential differences; indeed medical practitioners would argue that it is utterly unethical to ignore the extent to which these health differences might affect a person’s capability of achieving well-being (Andric & Wundisch, 2015). A small number of authors have written on the application of well-being (drawn mainly from positive psychology) to PWID (Shogren et al, 2006; Niemiec, Shrogren and Wehmeyer, 2017; Shogren, Wehmeyer & Singh; 2017) and have grounded such research efforts on a strengths based as opposed to a deficient based approach (see Seligman, 2002). However, many studies neglect discussing the pre-existing health conditions that are conjoined with ID that influence or distort well-being; therefore scholars must be aware that PWID frequently begin their well-being experience from a place of ill-being.

It can be argued that it is more complicated to engage in leisure pursuits when an individual experiences ill-being and general health inequalities; be that due to biological, sociological, physical and/or psychological barriers to participation. Overall PWID will experience poorer indicators of health than their non-ID peers (Cooper et al, 2015; Emerson et al, 2016). PWID are

statistically more likely to have an increased risk of visual impairment and some form of ataxic condition that limits or prevents physical movement (Matson & Matson, 2015; Kinnear et al, 2018). This leads to PWID being more likely to be overweight or obese than the general population due to high levels of inactivity coupled with weight-gaining side-effects associated with psychotropic medication (Segal et al, 2016). In addition, PWID are at greater risk than the general population of experiencing mental ill-health (Schützwohl et al; 2016), and of experiencing chronic loneliness and social isolation (Wilson et al, 2017). Furthermore, PWID are likely to be diagnosed with associative Autism Spectrum Disorders (Buxbaum et al, 2016), and potentially exhibit increased behaviour that may be of concern (such as socially striking behaviour that causes distress, harm or drawback to the person or to others e.g., screaming or shouting, aggression towards others) or self-injurious behaviour (Schützwohl et al, 2016). Collectively these co/multi-morbidities will substantially alter the ways in which PWID participate in leisure pursuits, how well-being from such pursuits can be experienced by PWID, and subsequently how that manifestation of well-being can be understood by researchers.

The above paragraphs outline the edges of writings on the debates surrounding how well-being can attempt to be understood for PWID from a medicalised vantage; the body of work available is vast and requires deep engagement to fully consider the health inequality arguments and practical applications of well-being within critical disability studies. However, the medicalised considerations of how ID is known through social constructionist readings remains rooted in deeply problematic normative propositions, and researchers should be aware of their philosophical and paradigmatic positioning in regards to debates of considered abnormality (Vehmas & Mäkelä, 2009). Importantly, the above paragraphs should not be interpreted as ID being a neurological deviation that ultimately reduces well-being; but rather should be read as an

introductory insight into a meaningful and relevant discussion about departure points for undertaking purposeful well-being research with PWID.

### **Overlapping leisure theory and well-being theory for PWID**

Kleiber (1999) comments that the essential defining qualities of leisure create a natural link between leisure and well-being; these qualities being pleasant, intrinsic, freedom, expression and engagement. Using Seligman's (2011) well-being model of positive emotions, engagement, relationships, meaning and accomplishment (PERMA) to theorize the actualization of well-being, there is exceptional overlap between the two concepts and the five components in each. However, when explored through the lens of intellectual ableism, it is evident that these concepts are not fully understood for people with mild to moderate IDs, and furthermore, are partially, if not wholly, debateable to people with moderate to severe IDs. Collectively, the author introduces the potential for intellectual ableism and invites scholars in the fields of critical disability studies, leisure and well-being to begin to unpack the theoretical tensions that exist between the three fields of knowledge.

#### ***1. Pleasant in anticipation, experience or recollection / Positive Emotion***

At the core of well-being studies is the contemplation of what makes a good life; with many scholars concluding that a balance between hedonic and eudaemonic experiences serves the ideal approach to happiness (See Seligman, 2011). The research base for studies that seek to understand happiness for PWID is growing, with a small number of empirical studies elevating the field by acknowledging the demographics and co/multi-morbidities of their participants in their work; but noting that their research only extends so far as exploring well-being for people with mild (or mild to moderate) IDs (McGillivray et al, 2009; Patterson & Pegg, 2009; Araten-Bergman, 2014;

Rossow-Kimball & Goodwin, 2014; Strnadová, et al, 2015; Sexton et al, 2016; Armila, et al 2017; Young-Southward et al, 2017; Boström, Åsberg Johnels, & Broberg, 2018). However, well-being research that extends to people with profound intellectual and multiple disabilities (PPIMD) is somewhat limited. Simmons and Watson (2014) summarise that PPIMD are understood as being pre-volitional, pre-contingency, pre-intersubjective, pre-intentional and at risk of living in a world of confusion. As a result, empirical studies that demonstrate the good life for PPIMD are recondite – therefore intellectual ableism is actioned through the persistent engagement of mild to moderate ID only. A select number of empirical studies have been published that seek to qualify the quality of life for PPWID (Nieuwenhuijse et al, 2017), however the majority of these are concerned with understanding considered displays of positive emotion only (such as temporary changes in facial movements, vocal noises, interactions with the environment and a reduction in concerning behaviour). In addition, these displays of perceived hedonic experiences are reported through a hermeneutic process of researcher observation or proxy voice, demonstrating both a significant epistemological flaw in the data production and an act of intellectual ableism that is seldom acknowledged in such studies.

The pioneering works of Vos et al (2010a, 2010b, 2012, 2013a, 2013b) have explored understanding similarities and differences in the physiological responses of PPIMD against typical responses of people without IDs during considered pleasurable experiences. Whilst these studies are exceptionally useful in determining if and how PWID (and specifically PPIMD) experience and express hedonic states of positive emotion in similar ways to people without IDs, their work does not fully explore the multiple variables that determine the philosophical musings of a ‘good life’. Furthermore, particular studies (Vos, 2010a, 2012) measured positive or negative responses to stimuli (i.e. toys, cuddling, massage, music, personal care, limb manipulation) that were chosen

by proxies and the research team; demonstrating the research as being conducted *on* PPIMD not *with* PPIMD. Nonetheless, these bodies of work are highly important as they introduce initial indicators towards understanding how positive affect is revealed in PWID. However, the good life is more than the repeated experience of hedonistic pleasure; scholarship is increasingly directed towards life satisfaction as the primary contributor of happiness. Therefore the argument regarding eudaemonic experiences for PWID needs to be explored.

## ***2. Pursued for the intrinsic rewards inherent in the activity / Achievement***

The debate of the good life being achieved through eudaemonic experiences for PWID is troublesome; and whilst it is written about significantly from both a philosophical and a medicalized vantage, there remains a dearth of research that seeks to problematize current understandings. When eudaemonic well-being is achieved through concepts such as self-reflexivity, personal growth, purpose and autonomy it is understandable (though not excusable) that studies would favour individuals who have the intellectual capacity to be cognisant of complex variations in time and space in relation to the self. Few studies have explored to what extent PWID experience eudaemonia, especially in regards to psychological aspects that contribute to intrinsic reward and achievement such as self-determination, motivation and goal setting (Shogren et al, 2006); even fewer have explored this with PPIMD.

The concept of autonomy is of immense importance when researching well-being for PWID as conceptual understandings of choice, freedom and agency are fundamental in shaping life satisfaction. As intellectual capacity decreases, so too does the ability of an individual to make meaningful choices about how their life is lived (Wehmeyer & Bolding, 2001; Hatton, 2004) – consequently the role of the proxy response becomes increasingly prominent in well-being research for PWID. Cummins (2002) argues that there is no evidence to support proxy response

as a defensible technique for assessing subjective well-being and should not be regarded as valid under any circumstances, especially as the proxy can only rely on indirect cues and personal knowledge about the individual – both of which are inherently unreliable and fallible (Lacey et al, 2015). Therefore, when exploring well-being for PWID and PPIMD through leisure activities, it is imperative that researchers acknowledge the order of consequence that is required for intrinsic reward and achievement: firstly autonomously making the choice and decision to undertake an activity, then secondly being self-aware enough to internalise positive and negative affect from the experience, followed thirdly by providing justified reasons to undertake the activity again based on recollection, fourthly to make a favourable comparison from past experience to present experience, and finally recognising positive change as achievement. If the first element of this order of consequence is omitted, then conceptual frameworks of eudaemonic well-being need to be (re)considered to congruously deduce intrinsic reward and achievement. Some studies have successfully demonstrated that proxies often misconstrue acquiescence to partake in an activity as autonomous decision making, especially when supporting people with mild to moderate IDs (Beail, 2002; Schelly, 2008). However other studies report how autonomous choice making can actually be learnt by PPIMD through the use of preference assessment and micro-switches (Singh et al, 2003; Lancioni et al, 2005; Tam et al, 2011). Collectively, these studies demonstrate the need for researchers to be transparent when reporting to what extent choice in a leisure activity by a PWID is autonomous, and to what extent intrinsic reward and achievement is recognised by the individual. As is argued by Schalock and Alonso (2003, p. 271): “where people are not able to speak for themselves and others make life decisions on their behalf, such measurement should be clearly identified as another person's perspective”. Therefore, understanding the relationship of the PWID and the proxy is critical in moving the debate forward.

### ***3. Perceived as chosen in relative freedom / Relationships***

The freedom of choice is often a privilege afforded for the more intellectually able. Thus, there is a need to articulate the theoretical dissonance that exists between a fabricated freedom of choice that is partially, if not wholly, enabled or, at times, dictated by others. Kleiber (1999) suggests that leisure is not defined by activity alone; it is truly individual and dependent on the perception of the person involved - thus demonstrating the fundamental problem of the role of the proxy in choice making. Gilmore and Cuskelly, (2014) reflect that PWID (especially PPIMD) are the most socially isolated of marginalized groups, often passing the majority of their time in the company of only one or two other people. The relationship the PWID has with their proxy (be that a parent, caregiver, health professional or teacher) is of huge importance in well-being research, but it is necessary to recognize that the relationship is overwhelmingly loaded with systemic power. Unquestionably, for PWID to carry out conceptions of the good life they may require assistance from people who are in a position of responsibility both for them, and to them. The author argues that if research persists where participants are unable to understand the information proxies report, are unable to challenge proxy views or have no means to communicate their will, researchers are left vulnerable to regressing back to times pre-Philippe Pinels<sup>ii</sup> - reproducing the Foucauldian writ of people with disabilities as passive subjects and conduits of discourses of expert power/knowledge (Tremain, 2015). Worryingly, this expertization from the proxy may lead to dismissing agency, personhood and the humanness of the PWID. Critical disability scholars have attempted to disrupt this inappositeness by calling for the progress of inclusive and emancipatory research, however the aims of extensive participation and collaboration in the research process have manifested in a focus (yet again) on individuals with mild or moderate IDs. Graber (2017) argues that many research domains (bioethics, psychology, medicine, education for example) lack

a satisfactory account of informed consent for individuals with moderate and severe IDs, and that proxy consent should first and foremost be morally justified. Here, the issue of consent needs to be explored two fold – firstly how do proxies gain consent of the PWID to participate in a leisure activity, and secondly how to proxies and researchers gain consent for PWID to participate in research? There is a small collection of literature available on the ethical and methodological challenges of engaging PWID in research (for example see Horner-Johnson & Bailey, 2013; Taua, Neville & Hepworth, 2014), however this work again mainly extends to people with mild to moderate ID, and is rarely routinely referred to as a methodological consideration of published well-being studies for PWID. Troublesomely, the greater the degree of ID the individual has, the less their voice is afforded worth by the researcher - intellectual ableism is at its most prevalent when the proxy is preferred over the person. Indeed, the denial of autonomous choice is incompatible with wellbeing. The PERMA model of positive psychology defines relationships as being authentically connected to others, and so scholars should attempt to explore how the authenticity of the proxy decision making is reflected and manifested in the choice of leisure activity that a PWID participates in. Building from this, once a PWID is participating, there is a need to uncover how leisure activities can promote and facilitate authentic meaning for PWID.

#### ***4. Expressive of essential aspects of the self / Meaning***

The eudaemonic condition of ‘meaning’ is without question one of the most perplexing of topics – the immateriality of life purpose has challenged some of the brightest minds for millennia. Understandably although not excusably, this branch of intellectual ableism is often most detectable within well-being research with PPIMD – the less intellectually capable an individual is perceived, the more likely it is that research will be the result of measurement *without* meaning. The theoretical tension therefore is to understand to what extent the capacity for abstraction is required

to derive meaning and purpose from life. To what extent can an individual with a particular type and degree of ID understand abstractions? For example; let us take the leisure activity of swimming. Due to learnt acquiescence and social desirability (Finlay & Lyons, 2002; Schelly, 2008; Emerson, 2012), and/or to compensate for reduced communication and agency, PWID may not accurately or easily generate answers to abstract questions such as “Do you like being in the water?” – it might be that the individual does like being in water, but at that moment perhaps not in water at *that* temperature, or water at *that* location, or water of *that* colour, or being in the water with *that* particular person. Indeed, abstraction often requires imagining the self or objects in a different location or time to ascertain a change of meaning in an experience – something that some PWID find difficult to action, let alone articulate. However, for a PWID this deduction of abstraction and search for meaning is often formulated by their proxy. Nussbaum (2009, p.347) discusses the proxy as a “mental surrogate” but acknowledges “that there is room for corruption in this process”; the proxy may simply project their own preferences for living the good life to the PWID. Indeed Schelly (2008, p.10), when being a personal assistant to a PWID, acknowledges that by engaging in leisure activities that Schelly enjoyed, there was an “implicit intention [to] change [the PWID] so that he is more like me”. As Oliver (1990) discusses, behaviours such as these are demonstrated efforts to normalize ID, and is based on the assertion PWID can think in the same way as ‘us’ (only to a lesser extent) but cannot necessarily think differently from us.

The conceptual disaccord between well-being, meaning, abstraction and proxy needs much deeper exploration as the subject lends itself to contemporary broader critical disability studies debates in humanness, especially concerning PPIMD. Some prominent philosophers such as Singer (1993) and McMahan (2002) compare PPIMD to the non-human; claiming the level of well-being that can be achieved is psychologically comparable to nothing more than a “contented

dog” (McMahan, 2002, p.153); whilst cognitive evolution scholars such as Hauser (2009), argue that abstract thought is one of four abilities of the human mind that distinguish us from animals (however, this is argued against heavily by Kittay 2005, 2010). If, therefore, a key component of well-being is an interiority of life satisfaction arrived at by abstracting meaning from eudaemonic experiences, intellectual ableism can be reduced if scholars simply acknowledge that this research domain is (perhaps) unobtainable. As a result of the weighty over-reliance on proxy interpretation of measures of well-being, Hensel (2001, p.311) propositions that “there is a strong argument for the abandonment of measures of quality of life in general, and subjective ones in particular” for PWID, especially for PPIMD. Instead, scholars should focus on better determining how proxies can ensure regular and consistent experiences that seek to reduce the potential for unpleasant affect and increase the likelihood of interpreted pleasant affect in both high (i.e. excitement, enthusiasm, pleased), and low (contented, calm, tranquil) states of activation (see Russell, 2003). Circling back to the first topic discussed regarding positive emotion, there is a need to determine more rigorous theoretical and methodological protocols for recognising, measuring, reporting and promoting long lasting pleasurable experiences in a leisure activity for a PWID. Perhaps, the argument therefore is the search for authentic and genuine engagement in the present.

### ***5. Involving a shift in perception and/or engagement / Engagement***

For an individual to experience a shift in perception of engagement, they must have a level of cognitive capacity that can detect both subtle and significant changes in affect, in environment and in activity from one point in time to another. Furthermore, to repeat any shift in perception experienced, the individual must have the intellectual capacity to ascribe reason as to why particular changes caused particular responses at each point in time. The privilege of these cognitive tasks are not often afforded to PWID; indeed the degree of ID can have a significant

impact on semantic memory, episodic memory and future thinking (Lifshitz et al, 2011). Knowing this, there is perhaps a need for a scholars across disciplines to debate if PWID, especially PPIMD, experience a lived-world that is *only* ever the ‘present’; a continuous collection of moments that have limited relational value. The ideology of ‘being present’ is often regarded as being introduced to the Western world by Jon Kabat-Zinn, defining it as "paying attention in a particular way: on purpose, in the present moment, and non-judgmentally" (Kabat-Zinn, 1994, p.2). However, this psychological construct of ‘being present’ is one of the most intellectually ableist concepts within the subjective well-being discipline. Bishop et al. (2004) define the practice as consisting of two individual-level facets: (a) the self-regulation of attention, “so that it is maintained on immediate experience, thereby allowing for increased recognition of mental events in the present moment” (p. 232), and (b) an orientation toward experience in the present moment “that is characterized by curiosity, openness, and acceptance” (p. 232). Being ‘present’ therefore is a conscious choice: it is a purposeful acknowledgement of a differentiation of attention and affect between moments - something requiring significant intellectual capacity. The need to better understand the subtleties of how PWID express moment by moment changes in well-being through activity participation requires deep scholarly investment, and should be consistently reported, assessed and reflected upon to develop a more nuanced and individualised understanding of how and why a PWID’s perception and engagement with a particular activity might shift. This moment by moment accumulation can facilitate a much broader understanding of how the frequency of repeated moments of engagement and associated positive emotions experienced by an individual over time can be tallied as proving the PWID with more lived/felt-experiences of considered well-being than of considered ill-being. Knowing that most PWID begin their well-being journey from a point of ill-being, is the overarching research problem to solve one that explores how PWID have a life

that is filled with more moments that align to flourishing than moments align to suffering? Considering the theoretical tensions that have been exposed thus far, the author argues that there is need to reconceptualise what it means to flourish for PWID, especially when the majority of definitions are associated with time-bound changes in physical, psychological and sociological states of being that simply cannot be realised for some individuals. Thus, there is need to explore how to recognise and report well-being through repeated momentary engagement overtime in leisure activities for PWID, as opposed to static, cross-sectional studies which fail to confront the complexities the phenomenon of well-being in neurologically different people.

### **Reducing intellectual ableism in leisure and well-being studies**

This paper is offered as an original contribution by positioning well-being in leisure as a critical yet underdeveloped area of research for PWID; and whilst the above discussions should be considered as an introduction to the area, the issues raised are salient. Subsequently, the author offers moderate yet achievable research processes that can support the reduction of intellectual ableism within these fields, and prevent a perpetuated body of literature that currently emphasises either proxy over person, or measurement without meaning. The author concludes this paper by offering some precursory guidance for academics wanting to explore the intersections of leisure, well-being and ID.

### ***The need for inclusive design***

The notion of inclusive design has been discussed within the health sciences and the social sciences for a number of decades, and is often called upon as a progressive and needed element of emancipatory research; indeed all vulnerable and marginalized groups need advocacy support to move beyond being solely subjects of studies if their needs are to be genuinely met. Examples of

such models of involvement include Arnstein's (1969) 'Ladder of Citizen Participation' (although Tritter & McCallum [2006] provide critique), Brager and Specht's (1973) 'Ladder of Community Participation', the Shand-Arnberg (1996) 'Participation Continuum', and the Mitchell and Chesters (2004) 'Cell of Exclusion'. However, the inclusion of PWID specifically for well-being research design has been paid exceptionally little attention (Bigby et al, 2014), despite the majority of these studies recruiting participants with mild or mild to moderate IDs only. Frankena et al (2016) discuss in depth the lack of transparency and agreement amongst academics in regards to inclusive research, especially within the context of health, arguing that researchers should be made aware of the possible added value of inclusive research design, and be nuanced about where the involvement of PWID has no added value. As is acutely acknowledged by O'Brien et al (2014), academics should argue for the exclusion of PWID in their research design *instead* of having to argue for their inclusion. Therefore, for academics exploring the meeting of leisure, well-being and ID, the immediate consideration should be to what extent a PWID - regardless of the level of intellectual capacity - can be included to inform and shape the research design from the beginning, with specific details as to why inclusive design has or has not been achieved being explicit.

### ***Recognizing research participants as individual human beings***

Appropriate identification of research participants is critical to the science and practice of well-being particularly for assessing the results, making comparisons across groups, generalizing findings where appropriate, and making comparisons in contextual replications or secondary data analyses. This necessary information includes details regarding major demographic variables, the number of participants, methods of participant recruitment and selection, assignment to groups, agreements made, payments made, and the number of participants who withdrew from the study and why. Unfortunately this is not the case for the majority of research with and for PWID

(Nieuwenhuijse et al, 2017). Of concern, is the regular practice of articles failing to acknowledge any differentiations amongst their participants; instead choosing to homogenize their participants through a reduced socially excluded identity of *intellectually disabled*. Regrettably, whilst research into well-being attempts to humanize PWID, some studies continue to marginalize through maintaining and exacerbating a focus on the considered most prominent deficient. Most often, studies repeatedly fail to see complete human beings - with dis/abilities, gender, age, race, ethnicity, sexuality, and intellectual quotient in consistent complex interaction with society. Furthermore, researchers often ignore the associated co/multi-morbidities of their participants, which only serves to fuel the concept that the term ‘intellectually disabled’ is an all-encompassing biological, social and personal identity. At best, this concept is highly offensive and at worst is severely damaging (Campbell, 2018). The narrowness of terminology demonstrated in such articles perpetuates a dualistic, yet illegitimate, dichotomy of intellectually ‘able/disable’. The author argues that the generic blanketing of an entire collection of individuals as one group through a shared medically and socially prescribed identity permits a level of obduracy across the academic community. Therefore, to prevent misunderstanding in comparison of results of research concerning PWID, Nakken and Vlaskamp (2007, p.83) propose a “multi-axial model-based taxonomy that distinguishes visual and/or auditory impairments, other physical impairments, and mental health problems, in addition to the two key defining characteristics (limited intellect and compromised physical functions)”. Moving forwards, it would be ethical for academics to recognise and report the differentiations of their participants in the same manner that would be afforded to participants without IDs, especially if a leisure activity aimed to address a co/multi-morbidity also (i.e. mental health).

***Transparency of participant consent, proxy voice and researcher bias***

The role of the sociologist is to give a voice to the voiceless (Barnes & Oliver, 1993); an often overlooked aspect of the Cartesian Dualism that permeates disability literature. Physiologically, the voiceless might be those who do not have the capacity (intellectually or physically) to make a noise that is a normatively and typically understood communication. Sociologically, the voiceless might be members of society who find themselves the Othered, the marginalized, the oppressed, the enslaved and/or the impotent. PWIDs often suffer the dualistic restriction of being both physiologically and sociologically voiceless, and unquestionably remain a mute and disenfranchised group (Arthur-Kelly et al. 2008). It is therefore paramount that studies that seek to position themselves as emancipatory do so with ethically sound research aims and justifiable research methodologies. However, studies that have attempted to provide a voice for PWID are not always transparent as to if the work is *giving* voice to the voiceless or if the work is *being* a voice for the voiceless. The processes and procedures for obtaining consent from the PWID should be systematically recognised and reported, such as if the proxy is providing assent for the PWID to participate in research, as well as indicating what methodological protocols have been explored to determine the validity of the data collected (especially if the proxy is the sole data source). For example, if collecting data through observing PWID researcher's should acknowledge their own biases and constructions of assent to determine if the PWID is actually in agreement to being observed (regardless of if the proxy agrees to observation - see Petry & Maes, 2006). Furthermore, any data from the proxy should be cross-examined to ensure the interests, normalcies and assumptions of what makes a 'good life' for the proxy is not bleeding into the life experience of the PWID. The inference and interpretation of behaviours of PWID is an inexact science and should be consistently under review by those who provide care and assistance (Porter et al, 2001);

thus proxy responses should be derived from all those who have a responsibility to provide and contribute to the individual's well-being, with differing perspectives being afforded challenge.

### ***Theoretically informed leisure activity interventions***

The hallmark of research across both the natural and social sciences is that it is theoretically informed; that the research itself contributes to a scholarly meaning that is greater than the data itself. However, theory is not always applicable in a certain context and as Popper (1972, p.6) writes “whenever a theory appears to you as the only possible one, take this as a sign that you have neither understood the theory nor the problem which it was intended to solve”. And so, if the problem to solve is ‘How can the enhanced well-being of PWID be better understood, presented and actualized through leisure participation?’ there are certain questions that academics must address through their theoretical framework of subjective well-being before designing their study. These initial questions might include: 1) can subjective well-being be concluded if eudemonic experiences cannot be determined? 2) can subjective well-being be concluded if life satisfaction cannot be self-reported?; 3) can subjective well-being be concluded if the individual has severely limited capacity to exercise agency? 4) can subjective well-being be concluded if an individual cannot abstract meaning from an experience? 5) can subjective well-being be concluded if the individual cannot distinguish between moments? Whilst there are without question suitable theoretical points of departure for the meeting of research in leisure, well-being and ID, perhaps intellectual ableism has presented itself most noticeably when researchers attempt to explain the well-being of neurologically diverse people through the same theoretical lens as neurologically typical people. The author argues that whilst scholars already in the field (albeit few) recognize the equal importance of researching the good-life for PWID, they do not necessarily recognise the

differences required to theorize and methodologize across the heterogeneousness of the population.

## **Conclusion**

This paper has introduced some of the theoretical and methodology challenges that currently exist within research into the well-being of PWID, and stresses how such challenges perpetuate an intellectual ableism that is preventing the field from fully understanding the expanse of the topic. The notion of what constitutes a good life for PWID (including PPIMD) is labyrinthian; Lyons & Cassebohm (2012) report that it is philosophically and practically problematic. But, this does not mean that academics should shy away from this area of research. Rather, they could, and should, be more transparent about their philosophical positions and pragmatic processes, whilst simultaneously seeking to share knowledge and offer guidance to others in the field. Moving forwards, it is paramount that researchers investigating the phenomenon of well-being in PWID through leisure based activities recognise the need for theoretical drift and atypical methodological approaches that might look to prevent privileging cognitive capacity, and embrace the opportunity to discover the diversification of human happiness.

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<sup>i</sup> Definition available at <http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability>]. Accessed 16<sup>th</sup> May 2018.

<sup>ii</sup> Philippe Pinel (1745 - 1826) was a French physician who was instrumental in the development of a more humane psychological approach to the custody and care of psychiatric patients, often referred to today as moral therapy.