

ABSTRACT

Institutionalised cultures and imbalances of power have been identified within the literature as risk factors for abuse of adults with intellectual disability living in residential services. Governments in the Republic of Ireland and internationally continue to support person-centeredness as a framework of care that can promote cultural change within disability services as a safeguard against abuse. However, there is limited research which seeks to explore if person-centeredness as a framework of care has had much impact in changing cultures within disability services as a protective factor against abuse.

This study aims to explore how adults with intellectual disability living in residential services and staff experience the professional caring relationship and the framework of person-centeredness. The study was based on a phenomenological approach using thematic analysis which enabled six adults with intellectual disability and six staff to participate through one-to-one interviews.

The thematic analysis resulted in three main themes: a) Conflict within the relational dynamic between service users and staff, 2) Challenge to delivering person-centred care and 3) Shared needs. Participants reported that there was conflict within the relationship between service users and staff influenced by relational and cultural issues. Participants also experienced challenges to delivering person-centred care within the service. This study revealed that as a result of wider organisational and cultural influences, person centred cultures, which are vital to underpin changes in power imbalances, were often undermined.

This research highlights that it is not enough to have a system of quality of care guided by the principles of person centeredness alone to ensure a shift in culture and safeguard against abuse for adults with intellectual disability. Rather, consideration of the relational and cultural factors that impact upon their lives also need to be built into the values and practices of services offered to adults with intellectual disability.

Keywords: intellectual disability, disability service, relational needs, abuse, organisational culture, person-centeredness, quality of life.

What is known about this topic:

- Adults with intellectual disability living in residential services are at greater risk of experiencing poor or abusive care practices.
- Transforming organisational culture is of significant importance to advancing change within disability services in the safeguarding against abuse.

What this paper adds:

- This research suggests that adults with intellectual disabilities are limited and constrained in their roles, behaviours, emotions and voice as a result of relational and cultural processes that exist in disability services.
- This study highlights how organisational culture enabled the development of disablist attitudes that resulted in a dilution of expectation, whereby ‘quality of care’ was reduced to ensure basic needs were met and anything else was seen as a bonus.

1. INTRODUCTION

Person centred care is the primary focus of current Irish and international social policy in the field of intellectual disability (HSE, 2018; Department of Justice & Equality, 2017; HIQA, 2013; DOH, 2001). It is the framework that guides how best to improve the quality of life for adults with intellectual disability living in residential services, through the promotion of healthful relationships and person centred cultures within disability services (HSE, 2018).

Within the Irish national guidelines person-centeredness is defined as;

An approach to practice established through the formation and fostering of healthful relationships between all providers, service users and others significant to them in their lives. It is underpinned by values of respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development (HSE, 2018, p. 11).

The guidance promotes the importance of healthful relationships in enabling an adult with intellectual disability to achieve maximum well-being and to flourish in all aspects of their life. It also highlights the need for cultures within disability services that continuously place the adult with intellectual disability at the very centre of their care.

Acknowledging the importance of relationships in the lives of adults with intellectual disability is a significant step in understanding that adults with intellectual disability share the same yearning, as the rest of humanity, to belong in relationship with others and/or to a place or a way of life (Hall, 2010). Clegg & Lansdall-Welfare (2010) argue that one of the major shortcomings in current policy for enhancing the quality of life for adults with intellectual disability is the failure to enhance social relationships. So it is welcome that within the Republic of Ireland there is an effort toward ensuring a coherent cultural shift across services,

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3 whereby the creation of, and enhancement of social relationships, is at the heart of what
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5 services aim to do (Clegg & Lansdall-Welfare, 2010).
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9 Developing person centred practices is aimed through the process of person centred planning
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11 (PCP). Within the international literature there is no agreed definition of PCP; however, in
12
13 the Republic of Ireland the National Disability Authority (NDA) defines PCP as:
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17 A way of discovering how a person wants to live their life and what is required to
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19 make that possible. The overall aim of PCP is good planning leading to positive
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21 changes in people's lives and services (NDA, 2005, p. 12)
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25 Those who are critical of person centeredness warn; however, that evidence supporting PCP
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27 is limited, and does not demonstrate that PCP can achieve radical transformations in the lives
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29 of adults with intellectual disability (Ratti et al., 2016). Despite the on-going emphasis of
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31 PCP, as the cornerstone of care in disability services in the Republic of Ireland, there is scant
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33 research that supports its effectiveness on the quality of life of adults with intellectual
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35 disability (Ratti et al., 2016). While some studies have shown that PCP is linked to
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37 statistically significant changes in certain 'quality of life' domains, research has not shown
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39 any significant impact upon enhancing inclusive social networks for adults with intellectual
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41 disability (Robertson et al., 2007; Clement & Bigby, 2010). Research undertaken by Clement
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43 & Bigby (2010) highlighted that "is it not enough to have good planning meetings that
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45 produce good personal plans - plans needs to be translated into action" (p. 109). This suggests
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47 that it is not the planning system itself that is to blame for not improving the quality of life of
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49 people with intellectual disability, but rather how the system is used (Clement & Bigby,
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51 2010).
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57 Richards (2019) calls for a review of how we think about the concept of person centeredness
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59 in disability services in light of the many cases of systemic abuse this century. Richards
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3 (2019) states we need a “new perspective that encapsulates people first values, which could
4 go some way to ensuring that disabled people are no longer treated and classed as sub-
5 human” (p. 505). Richards (2019) highlights that if disability services are to be truly person
6 centred, we need to understand the contextual factors that limit adults with intellectual
7 disability having full control over their lives, by focusing on the knowledge and experiences
8 of adults with intellectual disability and challenging the cultural and institutional
9 misconceptions of what disability means.
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20 1.1 *The Organisational Context and Culture*

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22 In understanding the social construct of *intellectual disability*, and how an adult with
23 intellectual disability can be further disabled, as a result of their interaction with their
24 environmental and social contexts, it is important to think about the organisational context
25 and culture in which an adult with intellectual disability engages. Felce et al. (1998) suggest
26 that service structures and processes influence service outcomes. Therefore, if organisations
27 supporting adults with intellectual disability wish to achieve positive outcomes in the lives of
28 those they support attention must be paid to how the service is designed and put in to practice
29 (Clement & Bigby, 2010). Clement and Bigby (2010) in their research offer the following
30 example; while group homes for adults with intellectual disability may be equipped with the
31 normal range of domestic equipment, other features can undermine the “ordinary life”
32 aspirations of adults with intellectual disability, such as the use of separate amenities for staff,
33 which promote a workplace environment (pg. 247). If such practices are endorsed by official
34 policy then this creates a culture of distinction, which may influence other informal practices
35 within the service and how adults with intellectual disability are perceived (Clement &
36 Bigby, 2010). Research by White et al., (2003) has demonstrated that there is a correlation
37 between organisational culture and the development of informal practices that may lead to
38 abusive practices developing.
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3 According to the HSE (2014)-
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6 Culture manifests what is important, valued and accepted in an organisation. It is not
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8 easily changed nor is it susceptible to change merely by a pronouncement, command
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10 or declaration of a new vision. At its most basic it can be reduced to the observation
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12 the way things are done around here (p.15).
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16 Therefore, this study argues that in order to promote protective cultures against abuse, there
17
18 needs to be greater awareness and focus of the relational and systemic dynamics that exist in
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20 disability services.
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23 24 25 **2. PURPOSE**

26 The purpose of this study is to explore how adults with intellectual disability living in residential
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28 services and staff experience the professional caring relationship and the framework of
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30 person-centeredness and its impact upon service user's right to have choice and power over
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32 their lives.
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36 37 38 **3. METHOD**

39 40 41 *3.1 Study design*

42 A phenomenological study using thematic analysis was chosen as the best fit for this study's
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44 objectives as it offers a focused systematic and flexible approach to data collection and analysis
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46 (Sundler et al., 2019), and is particularly suited to studying human processes, particularly with regard
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48 to this study, as there are few studies which seek to explore the experiences of adults with Intellectual
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50 disability and staff and how they talk about it. Semi-structured interviews were used to gain an
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52 understanding of participant's experience.
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3.2 *The Setting*

This study took place in a ‘not for profit’ disability service situated in the Republic of Ireland. The service nationally provides day and residential services to approximately 6,500 people presenting with intellectual disability. Service users interviewed were all living in modern homes within local neighbourhoods and had different levels of staff support based on their assessed individual need. The service employs a range of staff who provide individualised and multi-disciplinary professional support across its many day and residential service settings.

3.2 *Ethical considerations*

Ethical approval was obtained from ‘Blinded for review’. Recruitment was carried out amongst the residents and staff of one disability service in the Republic of Ireland. In addition, ethical guidelines issued by the Irish National Disability Authority (NDA, 2009) were followed in designing the study and throughout the research process. Adults with intellectual disabilities and staff who met the inclusion criteria (see below) were identified within the service by the services manager and provided with a letter which contained ‘easy-read’ information regarding the study. Interested participants made contact with the first author (Blinded for review) by phone to confirm interest and seek additional information. All twelve participants agreed to take part voluntarily in this qualitative study and provided informed consent.

3.3 *Participants*

A sample of twelve participants (six adults with intellectual disabilities and six staff) were interviewed for the study. The inclusion criteria for adults with intellectual disabilities were: (a) aged ≥ 18 years, (b) having a mild or moderate intellectual disability and (c) currently living in residential services. The inclusion criteria for staff were: (a) currently employed

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3 within the disability service in which the study was being conducted and (b) be providing
4 support to adults with intellectual disabilities who are current residents within the disability
5 service. Demographic information, provided by the participants are presented in Table 1 and
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8 Table 2, with pseudonyms used for all participants to protect confidentiality.
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13 *3.4 Data collection and analysis*

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15 A semi-structured interview schedule was developed to explore the participants' experiences.
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17 The interview schedule was developed on the basis of the research aim. Interviews lasted
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19 between 30 minutes to 2 hours. The objectives were explored by four broad questions: (1)
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21 what does a typical day look like for you in the service, (2) what do you understand is the aim
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23 of the service and any difficulties with this, (3) what does person-centeredness mean for you,
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25 and (4) can you tell me about your experience of the relationship between adults with
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27 intellectual disabilities and staff. Each interview was recorded using a portable digital audio
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29 recording device and transcribed verbatim after each interview.
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34 Each participant's transcript was analysed using thematic analysis (Braun & Clarke, 2006).
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36 The thematic analysis used to analyse the interview transcripts in this study comprised of a
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38 six-step framework (Braun & Clarke, 2006). Each group was analysed separately developing
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40 initial codes for the service user and staff groups separately. Once initial codes had been
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42 identified the researcher grouped them together with other similar codes developing initial
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44 sub-thematic categories. Both authors (Blinded for review) jointly reviewed the themes for
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46 internal and external homogeneity. The themes were then defined supported by relevant
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48 quotes and named appropriately. Finally, a scholarly report of the thematic analysis was
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50 produced, in conjunction with vivid and compelling extracts from the participant's
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52 interviews.
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4. Findings

Analysis of the interviews identified three overarching themes: *Conflict within the relational dynamic between service users and staff*, *Challenges to delivering person-centred care*, and *Shared needs*.

4.1 Theme I: *Conflict within the relational dynamic between service users and staff*

Three sub-themes emerged; *Imbalance of power*, *Loss* and *Disabling attitudes*, which reflected the conflict which existed in the relationship and how service users were positioned within the service.

4.1.1 *Imbalance of power*

Participants reflect the imbalance of power in the relationship between service users and staff and the role each plays within this relational dynamic. While it is acknowledged that this relationship is significant in enhancing quality of life for adults with intellectual disability, it was strongly voiced by participants that service users have little choice about who supports them. One participant (service user) shared his annoyance when he describes that he must at times accept ‘strangers’ to come and assist him in his home -

“I should have more than a say in that because it’s my house at the end of the day. So it’s up to me to say who I should bring in and who I shouldn’t”.

Another participant (staff) reflected the unnaturalness of this relationship when she describes that staff and services users are ‘forced’ to be in relationship with each other. Participants remarked that as a result of this tension with being ‘forced’ into relationship meant that staff often held the power about how the boundaries of this relationship should be managed. One

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3 participant (staff) describes how she had come to develop practices to ensure the adults with
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5 intellectual disability she supported did not become ‘too dependent’ on staff –
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8 “we usually have two staff, so that people aren’t overly-dependent on one person, so
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10 that there isn’t over-dependency. It gets really messy....”
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14 It seemed that staff were experiencing service users emotional ‘dependency’ upon them as
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16 ‘inappropriate’ and something that needed to be protected against. The description ‘*It gets*
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18 *really messy*’ is reflective of the common conceptualised view that adults with intellectual
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20 disability are not ‘normal’ and ‘functional’ human beings (Goodley, 2001).
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23 24 4.1.2 Loss

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27 Despite the forced nature of this relationship for many adults with intellectual disability and
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29 staff, where relationships had existed over a period of time, it was clear that close emotional
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31 attachment relationships developed. However, the depth of this relationship was only fully
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33 realised when the relationship ended. Again, conflict was experienced by participants about
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35 how such loss should be expressed, managed and supported. One participant (staff) describes
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37 the real pain experienced by a service user she supports who is struggling to cope with and
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39 resolve the loss of a relationship with a staff member due to retirement -
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44 “It’s an on-going loss and a grief that he’s working through, that you or I would. He
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46 has no access to that person. You know we have no kind of “exit policy” around that”
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50 The participant empathises with his grief and acknowledges that it is real in the same way it
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52 is for any of us, but she goes on to reflect how the service has no strategy of support to enable
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54 the person process the loss. This further reflects how the significance of the relationship with
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56 staff is not fully held within the disability service. Similarly, the impact of loss upon staff was
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3 also not held within the service as another participant (staff) reflected the lack of support she
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5 received from her manager-

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8 “I suppose to be honest, and my manager would have said to me once, it’s only a job,
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10 they’re not your family....because actually when a resident died, I was quite upset.
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12 And it was said to me ‘it’s only a job like’....and I said ‘it might be to you but it’s not
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14 to me’”
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19 This participant was not given permission by her manager to be upset and to grieve the loss
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21 of this person she had grown to care about. This raises the question how such a
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23 communication by a manager may serve to dehumanise adults with intellectual disability that
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25 they should not be grieved over like any other person would be?
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28 29 *4.1.3 Disabling attitudes*

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31 The experience of ‘disabling attitudes’ by participants were explored indicating that service
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33 users continue to meet attitudes that are driven by prejudice or stereotype. One participant
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35 (staff) described witnessing a staff member speak to an adult service user as though they were
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37 a young child;
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42 “eat all your dinner or you’re not getting ice-cream” – these are adults – I speak to my
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44 grandchild like that you know”
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48 Similarly, another participant (Staff) described observing a staff member make a decision that
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50 would have resulted in an individual miss out on the end of a movie at the cinema in order to
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52 return home for the administration of medication. Such attitudes reflect the roles that adults
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54 with intellectual disability are often cast such as the ‘eternal child’ and ‘incompetent’. These
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56 de-valued positions have consequences including; low expectations and the provision of
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58 fewer opportunities.
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4.2 Theme II: Challenges to delivering person centred care

The second over-arching theme, challenges to delivering person centred care, encompasses three sub-themes: *No shared understanding of person-centred care*, *There is no choice* and *Funding crisis*.

4.2.1 *No shared understanding of person-centred care*

For many of the participants their understanding of a person-centred care framework was confused with person-centred planning, which is the process of problem-solving used to help adults with intellectual disabilities to plan for their future. Adults with intellectual disability in particular did not have a sense that the framework of person centred care was aimed at delivering for them a service which enables them to live a life of their choosing and in which they were to be central. The struggle in understanding the concept of person-centred care was also reflected on by staff as echoed by one participant (staff) – “People think it’s a plan and people are obsessed with thinking it’s a plan and that plan has to be in date and that person has to have three goals.....we don’t really look at ‘this person is real’”

4.2.2 *‘There is no choice’*

The second sub-theme explores further service user’s experience of not having power and control in how they choose to live their life. As illustrated by one participant (staff) his experience of service users having a choice was almost laughable and an illusion of person-centred care within the service –

“I choose where I live” is normally one that I always....not like laugh at but I kind of go.....ya know this is not happening like....and I don’t know how it will happen”

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3 This sentiment was shared by another participant (staff) who reflects the tokenistic nature of
4 delivering choice “it can sometimes appear tokenism, and that that’s an issue”. Staff seem
5 aware of the injustice that service users have little choice but powerless to change it. The
6 constraints around choice-making was shared by one participant (service user) who seemed to
7 have resigned acceptance that her choice to live independently would likely never happen –

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15 “Well I think that I would like to just live in an independent house if you like, with
16 just one staff...but I don’t suppose that’s going to be possible no”.

20 21 4.2.3 *Funding crisis*

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23 All participants indicated that there were many constraints to delivering person-centred care
24 of which they had no control. The concern about lack of financial resources resonated with
25 every participant interviewed. One participant (staff) expressed her fear that within the
26 hierarchical system senior management had more of a focus on budgets rather than person-
27 centeredness;
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35 “I’m fearful that the organisation is going towards focusing on budget as opposed to
36 people, and when you go to senior management meetings that I find a challenge...that
37 while we’re pontificating person-centeredness, on the other hand we’re saying
38 “budget budget budget”.

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45 Service users too shared concerns regarding the funding crisis. One participant (service user)
46 spoke about how a lack of money was limiting his access to additional home support hours;
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49 “But see the money is not there”.

50 51 52 53 4.3 *Theme III: Shared needs*

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55 The third over-arching theme, *Shared Needs*, encompasses three sub-themes: *Not enough*
56 *support*, *Need for more time*, and *Need for training and supervision*.
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4.3.1 *Not enough support*

All participants reflected the need for greater support and training identifying their parallel needs. Participants indicated that in order to meet the needs of adults with intellectual disability, staff also needed to feel supported in their work highlighting the dyadic nature of professional support; this is illustrated by one participant (staff)-

“But if the emotional needs of staff aren’t met how can we meet the emotional needs of service users”

4.3.2 *Need for time*

There was a sense from all participants that that there was little time to do anything. One participant (service user) described how staff did not have time to support her to engage in community activities-

“No-one brings me...staff have no time to bring me to the cinema”.

This was shared by another participant (staff) who also experienced not having time to engage in a meaningful way with adults with intellectual disabilities -

“I’m coming on at 4.30pm – by the time I pick up four individuals,; drive out to the house where we are; put on dinners; support somebody to use the bathroom; read the notes as I’ve been gone for a week – it’s 6 p.m. before dinner’s over; then you’re into the care plans, toilet plans, whatever... - that’s your day gone! So where in the name of god do you have time...”.

4.3.3 *Need for training and supervision*

Participants were unanimous with their discussion relating to the need for more training. One participant (service user) identifies that in his view staff would benefit from regular ‘training’ to discuss and review the realities of the job so that there was a shared understanding of how best to support adults with intellectual disability-

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3 “I think there should be a training day for a staff...like every two weeks...ya know
4 and then people[staff] will know... exactly what to do ”
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7 The need for training opportunities for adults with intellectual disability was also highlighted.
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9 According to those interviewed; adults with intellectual disability received little training
10 opportunities to enhance their skills toward meeting their needs. There were no group training
11 initiatives to develop skills or develop emotional awareness despite as one participant (staff)
12 highlighted there was a need for bereavement groups for example-
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20 “there’s a need in the service, but whether there’s scope I’m not so sure...but there’s a
21 definite need to focus on it yeah...and as well on specific kind of support for issues like a
22 bereavement group...”
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28 29 **5. DISCUSSION**

30 This chapter focuses on the key findings which emerged from the data gathered from the
31 twelve interviews and considers them in the context of the current models of disability,
32 philosophies of care and previous literature.
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38 *5.1 The need to challenge attitudes which construct adults with intellectual disability as* 39 *‘other’* 40 41

42 The abuse of adults with Intellectual disability who live in residential services occurs within a
43 specific cultural and environmental context (Robinson, 2013). Within the literature (Bigby et
44 al., 2012; Clement & Bigby, 2010; Felce, Lowe & Jones, 2002) there have been many
45 variables identified as to why abuse is more likely to occur in residential services. Of these,
46 organisational culture and the imbalance of power which positions adults with intellectual
47 disability as ‘other’ has been the most commonly identified factor (DOH, 2012; HSE, 2016).
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49 Research by Mansell & Beadle-Brown, (2010) suggests that despite progress towards de-
50 institutionalisation and person-centred models of care disablist attitudes can exist in
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3 community based service settings and alone these changes in service delivery are not
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5 protective factors in safeguarding adults with intellectual disability from abuse. This study
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7 confirms the concerns raised by Mansell & Beadle-Brown (2010) by identifying disabling
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9 attitudes that constructed adults with intellectual disability in this service as 'other'. Of
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11 concern was the finding that staff found it difficult to challenge such attitudes. Staff highlight
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13 how such attitudes are *passed down* and it can be difficult for new staff entering into the
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15 system to challenge these subtle forces that can limit and further restrict the choices available
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17 to adults with intellectual disability living in residential services. Within this service as a
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19 result of such disabling attitudes and prejudices which constructed adults with intellectual
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21 disability as 'vulnerable' this provided justification for diminishing expectations for how care
22
23 was provided within the service. This attitude seemed to reflect a sense of hopelessness about
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25 the outcome of support and reflects what Nunkoosing (2019) defines as "the problem of the
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27 disablement" of adults with intellectual disability lies in the attitudes of staff working within
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29 the disability field and the lack of hopefulness we hold about our work. The challenge with
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31 feeling hopeless is that adults with intellectual disability are devalued and at risk of being
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33 treated as 'other'.
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40 However, staff were more conflicted and anxious about allowing for *dependency* and real
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42 human connection. It seemed managing this conflict was in the hands of staff who exercised
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44 more power and control about how the relationship between service users and staff should be
45
46 constructed. Staff describe their efforts to ensure that emotional distance is maintained in this
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48 relationship by ensuring staffing rosters were rotated. This seemed to occur without
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50 consultation or collaboration with service users. Staff appeared to adopt a '*we know best*'
51
52 approach to managing this relationship. The assumption was that adults with intellectual
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54 disability would not tolerate the loss of this relationship and so it was best to avoid any
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56 closeness occurring in the first place. This reflects an anxiety held about adults with
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3 intellectual disability and their ability to experience and manage heightened emotion. This
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5 reflects similar findings in the study by Dorozenko, Roberts & Bishop (2015a) whereby
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7 adults with intellectual disability can experience assumptions of incompetence which can
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9 limit adults with intellectual disability as being seen as 'normal' and functional 'human
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11 beings'. Such attitudes reinforce the orientation to see the pathological and maladaptive
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13 behaviours rather than seeing the resilient and ordinary lives of adults with intellectual
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15 disability (Nunkoosing, 2019).
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20 This highlights how the emotional security and well-being of adults with intellectual
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22 disability is dependent upon their relationships with staff and raises the importance of paying
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24 more systemic attention to the relational needs of adults with intellectual disability in the field
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26 and the impact of professional-power knowledge upon them.
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30 *5.2 Barriers to creating Person centred cultures*

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33 This study confirms previous research by Marsland, Oakes & Bright (2015) and demonstrates
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35 that there are systemic risk factors that restrict person-centredness, which may contribute to
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37 the continued abuse of adults with intellectual disability who live in residential services.
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39 Challenges to delivering person-centred care were identified by Mansell & Beadle-Brown
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41 (2004) who argued that unless there was a shift in how disability services were funded and
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43 how staff are trained the delivery of person centred care across all adults with intellectual
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45 disability would be difficult. This is confirmed in this study, whereby funding constraints and
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47 the lack of focus on staff training to adequately support the needs of service users were
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49 identified as challenges to delivering person centred care.
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55 Person-centeredness is rooted in the development of healthful relationships, but it seems that
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57 within this disability service there is resistance to relationships and a fear of getting 'too
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59 close' to adults with intellectual disability. This study highlights how in negotiating conflict
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3 within the relationship between staff and service users there is a tendency towards prioritising
4 the practical sides of the job and delivering basic care versus addressing the human emotional
5 aspects of the relationship. As a result this study has shown that there is little space for
6 understanding the psychological realities of adults with intellectual disability and how their
7 emotional lives need to be considered when evaluating quality of care. These results provide
8 deeper insight into how difficult it can be for both adults with intellectual disability and staff
9 to be in relationship and engage in a person-centred approach.

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11 The lack of understanding of what person-centred means within this study amongst a group
12 of adults with mild to moderate intellectual disability, demonstrates how difficult it is to
13 support adults with intellectual disability with more severe to profound intellectual disability
14 to understand the process, as they may not fully understand the choices and decisions being
15 made with regard to their quality of life.

16
17 Furthermore, this study highlights the challenges experienced by staff in delivering person
18 centred care and the immense pressure they experienced from both the organisational context
19 and culture and the interpersonal demands from adults with intellectual disability. Staff
20 experienced a pull from the organisation to provide objective measurements regarding quality
21 of care and a pull from adults with intellectual disability to meet their subjective needs in
22 fulfilment of their quality of life. This pull in opposite directions left staff feeling
23 disempowered and disabled in their roles within the service. The consequence of this was the
24 development of disabling attitudes that saw the job of providing care to adults with
25 intellectual disability as an 'impossible task' and a dilution of expectation, whereby 'care'
26 was reduced to ensure basic needs were met and anything else was seen as a bonus.

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3 This study gives a valuable contribution to the growing body of qualitative studies
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5 highlighting the experiences of adults with intellectual disability when it comes to everyday
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7 life and the complexities and shortcomings of a life in residential services (Bond & Hurst,
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9 2010; Haigh et al, 2013). Furthermore, this exploratory study demonstrates how the use of a
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11 qualitative approach is ideal for exploring in-depth under-researched topics and provides the
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13 context for future studies with more generalizable focus. Conversely, the main limitation was
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15 the small scale of this study. This study only sought the experiences of participants from one
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17 disability service in the Republic of Ireland, and therefore, findings cannot be extended
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19 across all disability services or to wider populations. This study focused on exploring an
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21 under researched area in an effort to propose a new understanding of delivering person
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23 centred care in residential services, as a safeguard against abuse, rather than to test whether
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25 the results were statistically significant or due to chance.
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32 **6. CONCLUSION**

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35 This study has shown that it is not enough to have a system of quality of care guided by the
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37 principles of person centeredness alone to ensure the best possible quality of life for adults
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39 with intellectual disability. Rather, consideration of the cultural and contextual factors that
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41 impact upon the relationships held by adults with intellectual disability needs to be built into
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43 the values and practices of services offered to adults with intellectual disability. This paper
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45 highlights the complex and multi-dimensional issues of living in residential services for
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47 adults with intellectual disability and is an important step in contributing to an evidence base
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49 for lived experiences.
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Table 1 Adults with Intellectual Disabilities Participant Demographics

No.	Adult with intellectual Disability (Pseudonyms used)	Age	Gender	Total years living in residential services
1	“Ann”	38	Female	7 years
2	“Robert”	58	Male	38 years
3	“Stephen”	40	Male	17 years
4	“Angela”	65	Female	11 years
5	“Laura”	63	Female	14 years
6	“Michael”	49	Male	18 years

Table 2 Staff Participant Demographics

No.	Staff (Pseudonyms used)	Age	Gender	Role & Years working within the service
1	“Maura”	42	Female	Social Care Worker – 27 years
2	“Breda”	54	Female	Manager – 25 years
3	“Brian”	52	Male	Team Leader – 10 years
4	“Liz”	51	Female	Social Worker – 3 years
5	“Lorraine”	44	Female	Social Care Worker - 18 years
6	“Claire”	40	Female	Supported Living Co- ordinator- 5 years