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Are we Valuing People's choices Now? – Restrictions to mundane choices made by adults with learning difficulties

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4 **Are we *Valuing People's* choices Now? – Restrictions to mundane**
5 **choices made by adults with learning difficulties**
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24 **Biographical details:**
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26
27 Andrea Hollomotz came to academia from a social care and social work background. This paper
28 draws on findings from her PhD study, which was funded by a University of Leeds scholarship.
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Are we *Valuing People's* choices Now? – Restrictions to mundane choices made by adults with learning difficulties

Abstract

Valuing People (Department of Health, 2001, 2010a) has shaped services for people with learning difficulties in the UK for the past decade. Promoting choices and independence are two of the four key principles that underpin this white paper and its subsequent delivery plans. This paper assesses the impact that these changes had on the availability of mundane choices. It draws on empirical evidence from interviews with adults with learning difficulties.

First impressions of the findings indicate that individuals are indeed able to make an increased range of decisions. At closer inspection it does however become apparent that not all of these decisions are based on an infinite spectrum of options. Under the guise of choice-based policy rhetoric some people with learning difficulties are at times presented with a pre-arranged 'menu of choices'. For instance, a person may be free to choose activities at their day centre, but they may have limited control when deciding whether to attend the service in the first place. The wider implications that tokenistic choice-making processes have for the development of personal autonomy are highlighted. It is argued that a lack of control in respect to mundane choices is disempowering and leads to learned passivity.

Key words

Learning disabilities, choice, empowerment, personal autonomy, social care, adult protection

Introduction

McLaughlin's (2012) keyword search within the *British Journal of Social Work* revealed that the term 'empowerment' was first mentioned in an article in Volume 16 (1986). Thereafter, use of the term grew steadily:

It appeared in more than 150 articles and book reviews in the journal between 1990 and 1999, and in over 250 articles between 2000 and 2009. This trend seems set to continue, as there were 90 citations of the word between 2010 and 2011 (McLaughlin, 2012, online).

This is not surprising. Thompson (2012, p. 8) points out that, in our position as mediators between service users and the state, our interventions can either 'help or hinder, empower or oppress. Which aspect is to the fore [...] depends largely on the actions of the social workers concerned'. For decades, this realisation has meant that empowerment was seen as a central concern to those who seek to practice in an anti-oppressive manner.

Enabling people to make their own choices is a central prerequisite for empowerment. This is acknowledged in the White Paper *Valuing People* (Department of Health, 2001) and the

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Valuing People Now delivery plans (e.g. Department of Health, 2010a), which are underpinned by the principles that the rights, choices, independence and inclusion of people with learning difficulties must be promoted. Furthermore, when publishing *A Vision for Adult Social Care* (Department of Health, 2010b) the coalition government were adamant that individuals, not institutions, should take control of the support they need. However, Fyson (2009, p. 19) warns that recent policy is ‘sold under the comforting banners of “independence”, “choice” and “control” in order to mask the less palatable reality of budget cuts’. She points to the considerable risks that arise when the support needs of people with learning difficulties are not adequately addressed.

Armstrong (2002, p. 441) furthermore highlights that a focus on formal documents leaves out ‘the messiness, variety and unpredictability of policies as they are enacted through social practice’. It must be remembered that political, temporal and spatial contexts, as well as the discretion of social actors impact on social practices. This paper consequently aims to explore the actual experiences of individuals making mundane choices, in order to assess to what extent policy rhetoric has affected practice.

Defining and contextualising ‘choice’

Hatton (2004) asserts that researchers seeking to explore choice making processes need to ask themselves the following questions:

- Is choice-making largely a function of the skills of the person, or of restrictive environments?

- Who is in the best position to assess the choices exercised by people with learning difficulties; the person themselves or an informant?
- Is choice a valued end in itself, or a vehicle through which other positive lifestyle outcomes can be achieved? (adapted from Hatton, 2004, p. 337)

Answers to these questions have determined the focus of this research project. They will be made explicit in the following.

This study is committed to the social model of disability (e.g. Oliver and Barnes, 2012). It therefore focuses on social barriers in the lives of disabled people and not on their personal 'limitations'. It furthermore conforms to inclusive research principles. Amongst others this means that people with learning difficulties are included 'as more than just subjects of research. They are actors, people whose views are directly represented in the published findings in their own words' (Walmsley and Johnson, 2003, p. 61f).

For the purpose of this paper choice is defined as an opportunity to make a selection free from coercion, which means that there should be no foreseeable consequences for a selection, other than the consequences of that selection itself (Brown and Brown, 2009). Choice should also be active, which means that individuals' passive acceptance or compliance should not be interpreted as choice (Kishi *et al.*, 1988). Choice can extend beyond selecting between given alternatives to control over the matter in question.

The concept of personal control is closely related to self-determination (Stancliffe, 2001). According to Abery (1999, p. 157) self-determination 'involves a person having the degree of control over their life that they desire in those areas that they value and over which they wish to exercise control'. In the past, a desire to protect people with learning difficulties from the

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2
3 consequences of 'bad' choices served as a rationale for restricting autonomy (Guess *et al.*, 1985).
4
5 Today, we continue to be particularly apprehensive about those choices that may put a person at
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7 risk (Fyson, 2009).
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10 Beck (1992) asserts that the management of predictable risks is at the very core of
11
12 advanced modern societies, which led him to the conclusion that such societies are 'risk
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14 societies'. We are no longer 'primarily concerned with attaining something "good" but with
15
16 preventing the worst, with the result that self-limitation, as opposed to self-realization, becomes
17
18 the goal of both the individual and society'(McLaughlin, 2008, p. 81). We thus often seek to
19
20 establish causal relationships for socially recognized risks. Risk is made predictable and 'brought
21
22 into a social and legal context of responsibility' (Beck, 1992, p. 28).
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27 Within this context, adult protection has become an increasingly prominent policy issue
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29 (Department of Health, 2000; Association of Directors of Social Services, 2005). Consequently,
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31 risk management is at the core of current social work and social care practice. This leads to a
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33 situation in which there is little room for professional discretion. As a result practitioners have
34
35 been observed to have a propensity towards caution (McLaughlin, 2008). In a recent study care
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37 practitioners have commented that they faced negative responses from their agency after
38
39 deciding to support people to take risks (Dunn *et al.*, 2010). Thus, services sometimes get the
40
41 balance wrong between 'protecting vulnerable people and helping people have a life'
42
43 (Department of Health, 2007, p. 77). However, *A Vision for Adult Social Care* (Department of
44
45 Health, 2010b, p. 25) stipulates that 'risk is no longer an excuse to limit people's freedom'. This
46
47 is supported by the *Mental Capacity Act* (HMSO, 2005), which protects the right of people with
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49 learning difficulties to make their own decisions.
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3 To sum up, some UK policy and legislation focuses on an individual's abilities and seek
4 to promote independent choice making. At the same time, an almost separate strand of guidelines
5
6 in the area of adult protection has emerged. *A Vision for Adult Social Care* (Department of
7
8 Health, 2010b) proposes that these areas of policy should be brought closer together. How and to
9
10 what extent this will translate into practice within the current context of a retrenching welfare
11
12 state is yet to be seen. This paper will focus on assessing the impact of the former strand and
13
14 considers to what extent the principles outlined in *Valuing People* (Department of Health, 2001,
15
16 2010a) have affected mundane choice making interactions in practice.
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26 ***Methodology***

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31 Given that disability research engages with oppressed groups, Barnes (1996, p. 110) argues that
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33 'researchers should not be professing "mythical independence" to disabled people [...]. There is
34
35 no independent haven or middle ground when researching oppression: academics and researchers
36
37 can only be with the oppressors or with the oppressed'. Consequently, as stated in the previous
38
39 section, this study is underpinned by the social model of disability, which determined the
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41 questions that were asked, which aspects of disabled people's lives were investigated (social,
42
43 rather than biological factors) and also the choice of research methods.
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48 The social model has been criticised by a range of scholars (e.g. as summarised in Oliver,
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50 2009, p. 48f). However, an in-depth theoretical discussion would be beyond the scope of this
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52 paper. It is sufficient to acknowledge that this author and the research advisors, a group of self-
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3 advocates with learning difficulties, continue to find a focus on social processes in explaining the
4 disadvantages experienced by disabled people helpful.
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8 Semi-structured interviews were conducted with 12 men and 17 women with learning
9 difficulties. These were substituted by participant observations at two day services and two
10 advocacy services. With the exception of one person with South Asian heritage, all of the
11 participants were White British. They were between 22 and 68 years old. Respondents had labels
12 of 'mild' to 'moderate' learning difficulties. About half had additional impairment labels, such as
13 physical impairments, epilepsy and 'Autistic spectrum' labels. Furthermore, half lived with their
14 parents or other family members. About a quarter lived in residential group settings and another
15 quarter lived on their own or with a partner. These figures are roughly representative of the
16 accommodation arrangements for this population (Emerson and Hatton, 2008).
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29 Great care was taken to develop accessible research tools with the help of the research
30 advisors, to ensure that the interviewing schedule did not include complex grammatical
31 structures or concepts (Finlay and Lyons, 2001). Instead, short sentences and simple words were
32 used. In addition, 36 picture cards accompanied 23 question categories. The interviews were
33 recorded and partially transcribed. The data was then processed and analysed with the assistance
34 of *NVivo8*, using thematic analysis. The research advisors helped to determine the focus of the
35 analysis and to interpret the data. Ethical approval for this study has been granted by a local
36 authority ethics committee. Furthermore, all names that are used in this paper are pseudonyms.
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48 This paper explores social processes that impact on mundane choices. Even though there
49 were many examples of good practice, this discussion makes reference to a perhaps
50 disproportionate amount of negative experiences, in order to enable a more in-depth
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3 investigation of disabling processes. Throughout this paper, it is made explicit how case studies
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5 relate to the experiences of the overall research sample.
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8 In the subsequent three sections, it is discussed to what extent contemporary notions of
9
10 empowerment and increasingly choice-based policy rhetoric have affected the control that people
11
12 with learning difficulties have when making mundane choices about food, alcohol and daytime
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14 activities. This is followed by a discussion, which highlights the wider implications of the
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16 evidence presented.
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23 ***Food choices*** 24 25 26 27

28 All respondents reported that they had some control over what they ate. For instance, the lunch
29
30 box that Jasmine (early 50s) brings to the day centre usually contains a variety of food, including
31
32 some vegetables, a sandwich, crisps and a homemade dessert. Jasmine often presents items from
33
34 her lunch box to me and tells me how much she likes them. She does not pack her lunch box
35
36 herself, but her sister always consults her when she prepares it. This morning: ‘She brought a bag
37
38 of biscuits out for, to put in me bread box. She asked us: “Did I want them?” I said “no”, so I
39
40 might, eh, have them tomorrow.’
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45 On first sight, it appears that, in respect to food, most individuals are generally
46
47 encouraged to make choices. This indicates a shift away from a domination of institutional
48
49 practices of force and control (Ryan and Thomas, 1987). However, for five of the 22 respondents
50
51 who lived with family carers or in group settings, external control appears to have slipped in
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3 through the back door of dieting for apparent health reasons. All of these respondents were
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5 female.
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7
8 Sue (mid 50s), who wears UK size 12-14, follows a popular diet regime. She pointed out
9
10 the comparatively lower fat content in diet biscuits in front of her key worker, who smiled and
11
12 said: 'You see, she knows it all herself. It's her choice.' Yet, away from her home at the
13
14 advocacy training, Sue never failed to buy herself a bag of full fat crisps and to ask for a second
15
16 serving of the chocolates and (non-diet) biscuits that were available as refreshments. The fact
17
18 that Sue's eating behaviour is different away from home makes me wonder whether she
19
20 genuinely prefers to diet.
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25 Smyth and Bell (2006) observe that it is often assumed that some choices are harder than
26
27 others and that choices about food are mostly considered to be quite straightforward. They
28
29 disagree with this assumption and point out that choice about food can have significant
30
31 implications for an individual's health and wellbeing and that it is sometimes not safe to allow
32
33 individuals to choose food that will harm their health. Facilitating choice can consequently
34
35 become an ethical dilemma when individuals make selections that do not appear to be in their
36
37 best interest (Brown and Brown, 2003).
38
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41 In Rachel's (early 30s) case it was her mother who initially decided that she should
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43 follow a popular diet regime and staff at her home are enforcing this regime. In contrast to Sue,
44
45 Rachel embraces her diet. Even before the interview, she told me many times what she will and
46
47 will not eat. Although she has not opted to follow the diet by her own initiative, she seems to be
48
49 appreciative of her mother having introduced it to her. Dunn et al. (2010) assert that sometimes
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51 people with learning difficulties require assistance in identifying the whole range of available
52
53 options, to enable them to make *informed* choices. Thus, they would argue in these instances
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3 carers have ‘widened a person’s horizon’. Whereas Rachel may or may not feel that she has
4
5 made a personal choice, this is less certain in Sue’s case. It is also difficult to determine whether
6
7 Rachel would be supported, if she made a conscious and perhaps unwise decision not to diet.
8
9

10 A final facet of the debate about food choices is that of food preparation. Those who
11
12 prepare food will inevitably have more control when deciding what they will eat. Yet, a third of
13
14 the respondents were not engaged in preparing food at all. This was not merely determined by
15
16 convenience or ability. At times rigid institutional guidance, which did not distinguish between
17
18 individuals’ inclinations and abilities, was in place. Josie frankly states:
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24 Josie: We can’t go in the kitchen. ... We’ve been warned about going in the
25
26 kitchen. ... If we get burned, staff are getting into trouble at our home.
27
28

29 Andrea: So you just stay out of the kitchen?
30

31 Josie: Mmh.
32
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34 Andrea: Would you like to go into the kitchen?
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36 Josie: [eyes widen, immediate response, loud] No.
37
38

39 Andrea: Why not?
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41 Josie: [immediate response, loud] You mustn’t get told off by the staff.
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46 This statement signifies some level of learned obedience towards staff. Similar safety
47
48 considerations about hazardous kitchen appliances were voiced by a third of the respondents who
49
50 lived with relatives or in group settings. The fact that these participants assessed mundane risks
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52 to be more immediate than they would be for non-disabled people suggests that they have
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54 become accustomed to the at times disproportionate protection they are subjected to. What is
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3 more, a lack of opportunities to develop and practice domestic skills will indeed lead to
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6 deskillling and increase risk. The assumption of ‘vulnerability’ can thus become a self-fulfilling
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8 prophecy.
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10 11 12 13 **Alcohol**

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19 The *Mental Capacity Act* (HMSO, 2005) stipulates that ‘a person is not to be treated as unable to
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21 make a decision merely because he makes an unwise decision’ (section 1(4)) as long as they
22
23 understand the information relevant to the decision, retain that information and are able to use or
24
25 weigh that information as part of the process of making the decision (section 3(1a-c)).
26
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28
29 Rachel explains that she understands that the quantities of alcohol she enjoys to consume
30
31 at times may impair her judgment and cause her headaches and discomfort the next day, yet she
32
33 likes to drink a lot sometimes. Even though she is aware of these consequences, staff strictly
34
35 limit what she can drink:
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40 Rachel: The staff.. monitor me now. Only two drinks only. For me. But on the
41
42 weekends.. I’m allowed .. two Fridays or Saturday two. .. That leaves
43
44 me four. [...]

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47 Andrea: So, two drinks a night. Are you happy with that or do you like getting
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49 drunk sometimes?
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3 Rachel: [short pause] [laughs] [3 sec's] When I used to be at [other
4 accommodation] I used to drink quite a lot, but when I'm here I can't
5
6 do that, cause the staff are there. [...]
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10 Andrea: Do you sometimes wish you could?
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12 Rachel: Mmh. [nods] ... I used to have vodkas in the house. [laughs]
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18 It is interesting to note that Rachel does not mention her calorie controlled diet as a justification
19 for those restrictions. As far as she is aware, Rachel does not have medical reasons for which she
20 has to limit her alcohol intake. Staff enforce limitations which comply with the current
21 guidelines set out by the Public Health Agency (2009), which limit women's alcohol intake to
22 two to three alcohol units per day. As Rachel is likely to be within this daily limit (two of her
23 favourite drinks equal about three units) she drinks about six units per week. However, according
24 to the guidelines, up to 14 weekly units are 'safe'. In other words: Rachel is limited to drinking
25 only a proportion of the recommended weekly allowance.
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36 Furthermore, public health campaigns enable individuals to make *informed* choices.
37 There is no law that prohibits an adult from drinking more than the *recommended* maximum
38 amount, other than if that person was to, for example, drive a motor vehicle (HMSO, 1988).
39 Much research suggests that there is a substantial gap between healthy living guidelines and how
40 most people choose to live their lives (Lindsay, 2010). Some regularly exceed the recommended
41 maximum amount of alcohol units. Gill (2002), for example, reports that, depending on the
42 research study, 41-51% of male and 17-43% of female undergraduate university students admit
43 to exceeding the 21 (for males) or 14 (for females) weekly alcohol units that were recommended
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3 at the time. Furthermore, Szmigin et al. (2008, p. 365) expose that young people view drinking
4 as almost entirely positive. Reasons for drinking include:
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10 having fun, conforming to peer group norms, letting yourself go, forgetting the
11 frustrations of the day and helping self-confidence in a social situation, also reducing
12 tension, enhancing sexuality and aiding social interaction and 'for fun, enjoyment and to
13 feel good'.
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22 In light of this evidence, Rachel's past drinking was hardly unusual, yet maybe 'unwise'.
23

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25 Staff interference may be explained with reference to pressure they are exposed to. They
26 are expected to conform to service priorities, even if these conflict with individual's choices
27 (Finlay *et al.*, 2008). Stancliffe *et al.* (2000) demonstrate that staff variables, such as attitudes
28 and skills, do not result in significant variations in the level of personal control that individuals
29 are allowed. They conclude that agency policies have a more significant impact.
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37 In other words, even if a support worker thinks that a certain option would be tolerable,
38 they may only allow individuals to opt for it if they feel it will be accepted by their agency. If
39 Rachel was to choose to get drunk, staff could be held responsible for allowing this to happen on
40 an unannounced visit from relatives, managers or inspectors. Thus, as long as an individual's
41 right to make informed choices, some of which will be unwise, does not become a more
42 dominant service priority, options will continue to be restricted (Finlay et al., 2008).
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51 Lee (early 20s), on the other hand, feels in full control about his drinking. He says he
52 likes drinking beers and shandies: 'I like going to pubs, me. Get drunk, get everything. Uhhh!'
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3 For Lee the fact that he can choose to drink alcohol is a signifier of adulthood, a status that is
4
5 often withheld from disabled people (Priestley, 2003):
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9
10 Lee: I was Down Syndrome.

11
12 Andrea: And... are you Down Syndrome now?

13
14 Lee: No.. I'm a man.

15
16 Andrea: How is that different?

17
18 Lee: Because eh, when I was a kid I was, eh, Down Syndrome... Now I am grown
19
20 up.
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27 Lee explains that, in contrast to 'Down syndromes', 'grown ups' drink beer and have girlfriends.
28
29 He associates Down syndrome with a negative educational label. As evidence for his adult status,
30
31 he produces his mobile phone and shows me pictures of him with a pint of beer in the pub and
32
33 pictures of his girlfriend.
34
35

36
37 However, adult citizenship, as it is interpreted by contemporary social policy, does not
38
39 simply give Lee rights (to drink alcohol), but also responsibilities (to behave sensibly whilst
40
41 doing so) (Dwyer, 2002). In fact, there appears to be a distinct shift towards a greater focus on
42
43 responsibilities by the current coalition government (Lister, 2011) and especially following the
44
45 August 2011 riots in major UK cities (e.g. Cameron, 2011). Some people with learning
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47 difficulties will thus require assistance in negotiating citizenship within this changing context.
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Daytime activities

The majority of the respondents who attended day services engaged in a range of activities, such as drama groups, yoga, cooking, women's and men's groups, arts and crafts, domestic skills training, sports, self-advocacy, a library and a shopping group and so forth. They had set weekly schedules. Many liked the activities and the social aspect of coming to the day centre:

Andrea: Do you like coming to the day centre?

Kathy (early 20s): Yeah, good.

Andrea: Or is there-

Kathy: -It feel good.-

Andrea: - is there anything-

Kathy: My friends here, my friends here. [laughs] ... Good yeah.

Andrea: [...] Is there anything that you want to change?

Kathy: No.

Andrea: About, you know-

Kathy: -No.-

Andrea: -One of the groups you don't like?

Kathy: Mmh.. No.

Andrea: All the groups are cool?

Kathy: Cool, yeah.

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3 Individuals generally had some level of control when determining which activities they attended,
4
5 with only five of the 22 respondents who attended a day service stating that they could not
6
7 exercise any meaningful choice. Yet, one staff member expressed her concern about the fact that
8
9 individual's choices are not reviewed regularly and that some consequently end up attending the
10
11 same activity groups for many years without being encouraged to try something new. However,
12
13 without ongoing and meaningful consultation, habitual behaviour can be mistaken for active
14
15 choice, lack of protest for informed consent and resignation for contentment (Shevin and Klein,
16
17 1984).
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22 Leanne (mid 20s) is exceptional, as she is entirely unsatisfied with her day service. She
23
24 states that she would prefer to stay with her mother, or to take up paid employment. Research
25
26 suggests that individuals only perceive they have choices when there are 'at least two available
27
28 alternatives, either of which would meet at least some of the individual's chosen goals'
29
30 (Jenkinson, 1993, p. 366). Ongoing leisure does not meet Leanne's chosen goal of gainful
31
32 employment. Thus, the fact that she can choose between, e.g. bowling and watching TV, does
33
34 not provide her with a choice that is meaningful to her. We spoke to Leanne's key worker after
35
36 the interview. The key worker stated that she knows about Leanne's ambitions to find work, but
37
38 that Leanne has not yet demonstrated that she is 'determined enough', as she often gets
39
40 disinterested half way through activities.
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46 People are 'most likely to have clear preferences in issues that are familiar, simple and
47
48 directly experienced' (Jenkinson, 1993, p. 365). A mere discussion of an option might therefore
49
50 not be sufficient to enable an individual to fully understand it, particularly if they find abstract
51
52 thought difficult. For many people with learning difficulties this means that they should have an
53
54 opportunity to experience their options. For instance, in order to enable Leanne to make a choice
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3 about her preferred daytime activity, she should try out each of the available options before
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5 deciding which one to take up. Facilitating choice making in this way is however resource
6
7 intensive, which is why it may not always be viable to follow this guidance.
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10 About two thirds, 14 of the 22 individuals attending day centres, explicitly stated that
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12 they had no choice about their attendance. Peter (late 50s) explains:
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17 Peter: There's many times that-, if, you know. You're in bed and you think:
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19 'Uuh!' You don't, you don't feel like getting up to go, but, eh... you
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21 know, you have to go. You have to go if transport comes. [...]
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24 Andrea: Why do you have to go?
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27 Peter: [...] My mother said: 'Well you wouldn't stay, you wouldn't be at
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29 home all day.' Cause otherwise all I'd do, all I'll be doing is sleeping,
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31 more or less, so she said: 'Well you'd better go into, better going
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33 out'... I know there's not a great deal to do.
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39 Dunn *et al.* (2010) observe that carers often reason with themselves about their own inclinations
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41 before deciding on behalf of a person. When making a decision for Peter, his mother makes
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43 assumptions about his preferences: 'You wouldn't be at home all day.' Even though such
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45 decisions are made with the best interest of the person in mind, they can result in the individual's
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47 *actual* wishes being overlooked. Maybe Peter would have preferred to stay in bed or to do
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49 something entirely different. Yet, every time we explore an alternative Peter points out risks and
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51 limitations, such as his inability to mobilize outdoors without support, due to his visual
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53 impairment. Peter cuts every suggestion short by stating: 'my mother wouldn't agree to that',
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3 thus implying that he has come to accept and even internalised a notion of assumed dependency
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5 (Oliver and Barnes, 2012).
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8 It is uncertain whether all eight respondents who stated that they attended by choice had
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10 made an informed and free selection about their attendance. Bill (late 50s) lives independently
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12 and has a limited social network. Attending the day centre gives him a rare opportunity to
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14 socialise. Sam (early 50s) attends the day service because he has long given up on seeking paid
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16 employment in a disablist employment market. For such individuals choice is restricted by the
17
18 continuing social exclusion disabled people face in contemporary society. As they have no
19
20 access to alternative daytime activities the day centre simply remains 'somewhere to go' (Barnes,
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22 1990, p. 192).
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27 Conversely, Salina, a woman in her sixties who lives independently, tells me that
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29 sometimes she does 'not really feel like going'. I observed that Salina chooses to stay at home
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31 about once per week. Salina's tendency to make attendance a choice visibly annoys her key
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33 worker, who informs me that Salina ought to attend every working day. Overall, only four of the
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35 22 respondents who attend day services can be said to have been free to choose in this way.
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42 ***Discussion***

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48 This paper set out to examine to what extent contemporary notions of empowerment and
49
50 increasingly choice-based policy rhetoric have affected the control that people with learning
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52 difficulties have when making mundane choices about food, alcohol and daytime activities. All
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54 respondents in this study had opportunities to make selections. However, in many cases not all
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3 choices were based on an infinite spectrum of alternatives. Instead, people were frequently
4 presented with what may be termed a restricted *menu of choice*. This concept can be understood
5 literally as a menu. For example, in relation to choices offered at a day centre, the menu might
6 look like the one displayed in Figure 1.
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Insert figure 1 about here.

(This figure first appeared in Hollomotz (2011).)

Individuals can make a range of selections at the day centre, but at the same time, their attendance of the service means that an infinite list of alternatives becomes unavailable. The options on offer may be restricted and pre-agreed by staff, who remain in control, while an individual's selections from *the menu* are at times tokenistic. McLaughlin's (2012, online) claim that, instead of empowerment encouraging people to have more control over their lives, it has been used as 'a mechanism for drawing people into participating in processes and decisions over which they have little meaningful control' may apply here: When Rachel felt like drinking more alcohol than was recommended, when Leanne declared that she would like to work or when Peter suggested staying at home, these preferences were dismissed. Rachel's *menu* is restricted by a set amount of alcohol units, while Leanne and Peter are merely able to consider existing activities that are on offer at their day services. Thus, the decision making power that was given in these instances is bound within certain parameters.

One of the reasons why some choices continue to be limited is that restrictions serve to minimise risk within an external world that may expose individuals to forces over which, according to the fears of concerned carers and practitioners, they might otherwise have little

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3 control (McLaughlin, 2008). Carers often express the wish to protect people from unpleasant
4 experiences. Yet 'it is these very experiences that help towards human growth' (Deeley, 2002, p.
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10 Beck (1992, pp. 20-21) argues that, whatever preventative measures we take, risk remains
11 a 'primeval phenomenon of human action'. We may wish to predict the outcomes of actions in
12 the social world but the haphazard nature of actual events means that there will always remain an
13 element of risk. Furthermore, this author would like to propose that the removal of one risk
14 factor (such as the outcome of an unwise decision) might serve to create another (such as a lack
15 of skill in decision-making). In particular, it is concerning that some respondents appeared to be
16 acutely aware of boundaries beyond which they cannot exercise control. Some felt a strong sense
17 of obedience to remain within predefined margins. For example, Ryan (late 20s) candidly
18 asserts: 'I've always tried pleasing people in my life, cause that's with my difficulty, that's what
19 I've always thought I've had to do.' Ryan's remark implies that he feels anything but
20 empowered.
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36 What is more, this attitude puts Ryan into a vulnerable situation. Despite safety measures
37 that are now in place, such as the vetting of prospective employees in social support services
38 (HMSO, 2006), there continues to be some risk that a minority of staff may misuse their position
39 of trust in order to exploit those they care for (e.g. BBC Panorama, 2011). Individuals who
40 distinguish available choices on their pre-selected *menu* from options beyond their reach will be
41 less likely to conceptualise speaking up against derogatory treatment, threats and violent
42 intrusions in such situations as an available choice, especially if they have learned to depend on
43 the judgment of carers in their decision-making. On the other hand, increased confidence in
44 choice making can enable a person to respond more assertively.
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3 Hingsburger (1995, p. 22) reminds his readers that the ability to negotiate choices
4 successfully is something all of us had to learn, initially during primary socialisation:
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10 The very first time you looked at your parents and howled something like, “WHEN I
11 GROW UP I’M NEVER, EVER, EVER GOING TO EAT PEAS AGAIN”, you were
12 saying, even as a child that you could envision a future where you would make decisions
13 about your life. Unfortunately, many people with disabilities are still ‘eating peas’
14 because they never grew into a state of independence that would allow them such
15 freedom.
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27 It has been almost two decades since Hingsburger (1995) provided this example. The data
28 presented in this paper suggests that people are by now indeed ‘choosing peas’, but this does not
29 necessarily translate into feeling in control or empowered. Nonetheless, the recommendation that
30 a person who is not a particularly skilled decision maker should receive further support to
31 increase their skills, rather than having decisions made on their behalf, is a principle which
32 underpins the *Mental Capacity Act* (HMSO, 2005).
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41 The cynical reader may rightfully point out that social responsibilities result in all of us
42 operating within restricted ‘menus’ when making choices: We have to abide by the law and if we
43 choose not to, we will be sanctioned. When I choose to become a lecturer, that decision would
44 act to restrict me in many aspects of my life. Like Peter, I sometimes wish I could stay in bed all
45 day. Like Peter, I know this is not an option, but unlike Peter I have chosen what I get up for and
46 should I ever get tired of my post I would seek an alternative. In other words, I feel empowered
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3 to make major choices for myself, even if that means that I then expose myself to the potentially
4 negative consequences associated with this choice (such as lack of sleep).
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8 I *choose between different menus*, in order to select the one I consider the least restrictive.
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10 For instance, I would rather put up with lack of sleep than to be without gainful employment. I
11 am free to make mistakes, to learn from them and to try again. Unlike Leanne, I will not have to
12 convince anyone but myself that my resolutions are ‘determined enough’. I also have the
13 freedom to opt out of ‘menus’ that do not take my fancy. Frankly, if I go to a restaurant and I do
14 not like what I see, I get up and leave. However, when disabled people seek to, for instance,
15 make mundane choices about daily routines and activities in a society that continues to restrict
16 their leisure and employment options, there is often nowhere else to go. As stated earlier,
17 habitual behaviour is then mistaken for active choice and resignation for contentment.
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29 Discriminatory structures in society are consequently one reason why our efforts to
30 empower have so far not been fully realized. A further explanation is offered by Oliver (1992, p.
31 111, citing Freire 1972), who claims that ‘empowerment does not exist as the gift of few who
32 have it to be delivered to those who do not; people can only empower themselves’. To him,
33 empowerment is ‘a collective process of transformation on which the powerless embark as part
34 of the struggle to resist the oppression of others’ (Oliver, 2009, p. 102). In other words, our
35 ambition, as the powerful, to hand down some of our power to the powerless, is a noble, but
36 perhaps unachievable dream.
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52 **Conclusion**

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3 This paper demonstrated that there has been a distinct shift away from restrictive past practices
4 that did not allow people to make even the most basic choices, such as whether or not to eat peas
5 (Hingsburger, 1995). Yet, at times concerns about risk continue to restrict the options available
6 to people with learning difficulties. Assisting in decision-making is therefore often a challenging
7 balancing act between safeguarding and encouraging independence.
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11 According to the *Mental Capacity Act* (HMSO, 2005) those offering formal support are
12 obliged to allow a person who has capacity to make even unwise decisions. However, mundane
13 interactions rarely draw on formal capacity assessments. Whether and to what extent an
14 individual is able to assert autonomy through the choices they make will furthermore depend on
15 institutional and societal constraints, as well as on the discretion of the person supporting them.
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19 Evidently, none of us achieve rationality when making unwise decisions, as otherwise we
20 would have opted for a more sensible option. It is therefore reasonable for an observer to suggest
21 that a person, disabled or not, lacks ‘capacity’ when being unwise and thus to justify an
22 intervention. We have all made foolish, perhaps even damaging decisions against which, upon
23 retrospective reflection, we would have very much welcomed interference. Yet, seeing through
24 the consequences of ill-advised decisions, such as a headache after drinking a bottle of wine or
25 boredom after opting not to go out, teaches a person that their choices have real consequences.
26 This can increase autonomy and cultivate an ability to become aware of and to manage risks
27 more independently.
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31 Nevertheless, in some situations concerns about safety will overwrite concerns about
32 autonomy. To explore an example from *Figure 1*, Peter cannot ‘go out when he feels like it,
33 where he feels like going’, as he requires road safety assistance. Resource constraints may mean
34 that this is not always available. However, he should be in a position to determine what happens
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3 with the few available resources. This is a principle which underpins the current personalization
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5 agenda, but exploring this further would start an entirely new paper.
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9 To conclude, I would like to apply some of Oliver's (1992, p. 111) advice, originally
10 intended for social researchers, to social work. Considering that empowerment cannot be a gift
11 by the powerful, he asserts that we should not be asking ourselves 'how to empower people but,
12 once people have decided to empower themselves, precisely what [we] can then do to facilitate
13 this process'. Professional allies 'have to learn how to put their knowledge and skills at the
14 disposal of their [service users], for them to use in whatever ways they choose'. However, some
15 of the responsibilities of social workers are in direct conflict with these aims, as they have to be
16 accountable to the state. I would therefore like to end with a question aimed at practitioners:
17 (How) Can these contentions be overcome? More precisely, how can you use your skills to
18 support disabled people when making empowered decisions, even within contemporary resource
19 constraints?
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42 BJSW for their patience, Sarah Wheatley for the inspiring conversations and Ken McLaughlin
43 for some informal insights into his emerging work.
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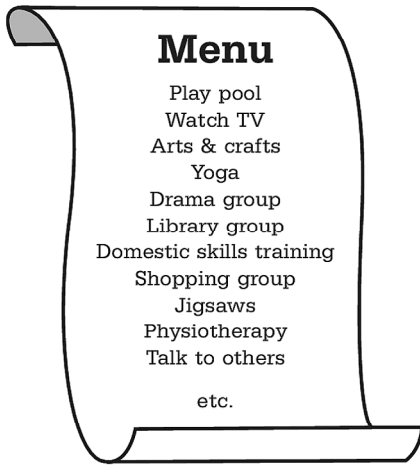
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Not on the menu

Any other leisure activity that is not offered at the day centre.

Paid employment.

Stay in bed all day.

Go out when you feel like it, where you feel like going.

Have sex

Etc.

199x114mm (300 x 300 DPI)

cript for Review