

Realising the right to equal recognition for disabled people

Newbigging, Karen; Ridley, Julie; Sadd, June

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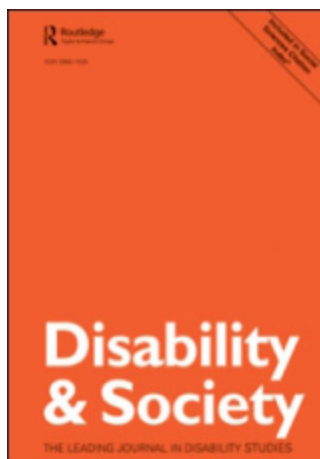
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**Realising the right to equal recognition for disabled people:
Commissioning statutory advocacy in England**

Journal:	<i>Disability & Society</i>
Manuscript ID	CDSO-2019-0173.R3
Manuscript Type:	Original Article
Keywords:	rights, supported decision-making, independent advocacy, United Nations Convention on the Rights of Persons with Disabilities (CRPD), human rights, equalities
Abstract:	Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) asserts the right to equal recognition and non-discrimination before the law. It places an obligation on countries to enable people to access support to exercise this right. This is viewed as a shift from 'substituted decision-making' to 'supported decision-making', with various models emerging. This article considers the right to equal recognition in the context of independent advocacy introduced, by the Care Act 2014 in England, for people requiring social care as one such model. Data from surveys of local authority commissioners and advocacy providers are used to examine early implementation of this statutory duty. The legitimization of advocacy through statute was universally welcomed. Our findings raise questions about its commissioning and implementation as an effective model for supported decision-making and the extent to which it ensures disabled people exercise their right to equal recognition.

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Points of interest

- Advocacy refers to support to enable people to have a voice so they can be fully involved in decisions about their lives.
- Local authorities are required by law to make advocacy available for people requiring social care.
- The way in which local authorities are making advocacy available differs across England. This reflects different understandings of advocacy.
- Cuts in funding by local authorities mean that some forms of advocacy are not being funded.
- Current arrangements for advocacy in England fall short of enabling disabled people to have a voice.
- A review of advocacy and the funding for all forms of advocacy is needed for disabled people to realise their rights.

Realising the right to equal recognition for disabled people: Commissioning statutory advocacy in England

Introduction

Disabled People's Organizations (DPOs) have long campaigned to be treated as active citizens on an equal basis (Campbell and Oliver, 2013). Introduced in 2006, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) outlined a set of standards to promote the rights and dignity of people with cognitive, physical and psychosocial impairments (United Nations, 2007). The UNCRPD is widely viewed as representing a radical paradigm shift to the social model of disability (Richardson, 2012). Its general principles (Article 3) emphasise respect for the dignity, non-discrimination, social inclusion, independence and autonomy of disabled people, including the freedom to make one's own choices. Article 12 states that disabled people have the right to equal recognition everywhere as persons before the law and they have legal capacity on an equal basis with others in all aspects of life. It, therefore, places an obligation on all countries to take appropriate measures to provide access for disabled people to support (if they require it) to exercise their legal capacity, framing disabled people as 'subjects of rights' rather than 'objects of welfare' (Richardson, 2012).

Whilst the interpretation of legal capacity has attracted much debate, Article 12 represents a seismic shift from the paternalism of 'substituted decision-making', as exemplified by guardianship, to that of 'supported decision-making' and the promotion of autonomy, rights and self-determination (Dinerstein, 2011). Supported decision-making takes different forms and, subsequently, a wide range of implementation models have emerged in different countries (Davidson et al, 2016). These have included 'circles of support'; peer support; advance planning, the personal ombudsperson (PO-Skåne) in Sweden, and statutory independent advocacy in the UK and Australia (UN, 2007; Gooding, 2013; Carney 2014). In this article, we consider statutory advocacy (i.e. advocacy required by law) as a model for

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4
5 supported decision-making. In particular, we focus on independent advocacy under the Care
6
7 Act 2014 in England, exploring its early implementation through the commissioning
8
9 arrangements that would enable disabled people's right to equal recognition to be realised.
10

11 12 13 **Background**

14
15 The UNCRPD (2007: 91) states that the disabled person is 'the decision maker; the support
16
17 person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of
18
19 the individual'. It recognises that in some circumstances disabled people will require support
20
21 with decision-making to realise their autonomy and citizenship rights (Dinerstein, 2011;
22
23 Carney, 2014). Thus, supported decision-making is the process whereby a person is enabled to
24
25 make and communicate decisions relating to personal and legal matters. The precise meaning
26
27 of supported decision-making is still evolving as evidence is gathered from implementation
28
29 with disabled people with various impairments (Carney, 2014). Nonetheless it is clear that it
30
31 represents a radical departure from 'does this person have the capacity to make decisions?' to
32
33 'what does this person require to make decisions?' (Gooding, 2013; Davidson et al., 2015). In
34
35 human services the radical shift to a 'support model', first campaigned for by disabled people
36
37 more than 30 years ago, emphasises individual choice and self-determination. It requires
38
39 systems that offer options for choice, support and guidance: facilitation rather than direction
40
41 (Bradley et al. 1994). Person-centred planning, personal futures planning, and user-driven
42
43 services, are, similarly built on partnership between disabled people, their families, and
44
45 professionals, where professionals more readily accept direction from users. It also recognises
46
47 that some people may have unique forms of communication and require additional and
48
49 specialist support in communication (Bach and Kerzner, 2014). Thus, the degree of choice
50
51 exercised by an individual in their daily life will clearly be affected not only by the availability
52
53 of opportunities but also by access to support when required. Carney (2014), however,
54
55 distinguishes between 'support with decision-making, i.e. informal support that all citizens
56
57 enjoy, and 'supported decision-making, which is formalised legal or civil society mandated
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1
2 support, as important for emerging practice.
3
4

5 *Advocacy and supporting decision-making*

6

7
8 Recognising the limits of traditional mechanisms, such as litigation, for rights-enforcement,
9
10 Flynn (2013) argues for statutory advocacy as a ‘crucial component of the support measures
11
12 envisaged by the UNCRPD for the exercise of legal capacity’, arguing that the role of the
13
14 advocate is ‘to support the individual to understand her rights and support her to assert them to
15
16 strengthen her personal autonomy’ (p 499). Thus, advocacy in domestic law in tandem with
17
18 the UNCRPD enables equal recognition, facilitating access to justice for disabled people at
19
20 both individual and systemic levels. Well before the UNCRPD, however, supported decision-
21
22 making and advocacy were promoted through social movements of disabled people to ensure
23
24 their voices were heard, to both protect and realise their civil rights: captured by the saying
25
26 ‘nothing about us without us’ (Charlton, 1998).
27
28

29
30 A wide range of advocacy models have emerged, and their core purpose has been articulated
31
32 as ‘a cluster of liberatory practices whose goal is to (re)enfranchise epistemically
33
34 disadvantaged, marginalized, disenfranchised others’ (Code, 2006: 165). The conception of
35
36 advocacy in a health and social care context recognises the fundamental power disparities
37
38 between individuals and statutory services and professionals on which they rely for support
39
40 (O’Brien, 1987; El Ansari et al., 2007; Centre for Social Justice, 2011; Sharif et al., 2012;
41
42 Lonbay and Brandon, 2017; Newbigging and Ridley, 2018). Such accounts situate advocacy
43
44 in exposing the structural and institutional forces at play in maintaining inequalities and
45
46 presumptions of limited agency. A foundational principle of advocacy is, therefore,
47
48 independence from health and social care service providers. This is underlined by the role of
49
50 advocacy being repeatedly emphasised in relation to abuses of human rights, notably inquiries
51
52 into the neglect, abuse and avoidable death of people as a consequence of the behaviour of
53
54 staff and indifference of services to the views and voices of service users, and their families
55
56 (Department of Health 2012; Francis 2013).
57
58
59
60

1
2 The goal of any form of advocacy is self-advocacy, where people speak up for themselves,
3
4 and this is widely promoted in relation to people with learning difficulties. This is distinct
5
6 from citizen advocacy, where another individual will support the person, speak on their
7
8 behalf, or peer advocacy, where the advocate is someone with similar experience, for example
9
10 lived experience of a mental health problem. These types of advocacy are informal and are
11
12 often unpaid volunteer roles in contrast with statutory advocacy, where the role of the
13
14 advocate is defined in law and support is provided by a paid professional advocate.
15
16

17 18 ***Statutory advocacy*** 19

20
21 Prior to the UK becoming a signatory to the UNCRPD in 2009, a range of advocacy was
22
23 available for disabled people in England but the landscape of provision was rapidly evolving
24
25 with the introduction and development of different forms of statutory advocacy. Statutory
26
27 advocacy, also referred to as ‘state-operated advocacy’ (Flynn, 2013), and as professional
28
29 advocacy in service user contexts, is established by legislation. The legislative framing of
30
31 advocacy can be somewhat ambiguous and whilst there is typically a clear emphasis on
32
33 protection and procedural rights (i.e. negative rights), there is increasingly a nod to promoting
34
35 wider wellbeing (i.e. positive rights). This shift is evident since the introduction of
36
37 Independent Complaints Advocacy (ICAS) to provide redress for people making a complaint
38
39 about the National Health Service (Health and Social Care (Community Health and Standards)
40
41 Act 2003). The Mental Capacity Act 2005 focussing on people deemed to be lacking mental
42
43 capacity and related to decisions about where to live and medical treatment, introduced
44
45 Independent Mental Capacity Act Advocates (IMCAs). The model underpinning the Mental
46
47 Capacity Act 2005 is regarded as one of substituted decision-making with the judgement by
48
49 others about ‘best interests’ of an individual lacking capacity. It is predicated on a binary
50
51 model of capacity, which has been critiqued for its lack of sophistication and potential
52
53 inaccuracy, and for institutionalising discriminatory attitudes towards disabled people
54
55 (Davidson et al, 2015; Clough, 2017). In 2007, after a protracted and contested process, the
56
57 Mental Health Amendment Act 2007 introduced Independent Mental Health Act Advocates
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59
60

1
2 (IMHAs). Aimed at people subject to detention under specific sections of the Mental Health
3 Act 1983, and people in local authority care under guardianship, the purpose of IMHA is to
4 safeguard the rights of detained patients and help those people exercise their rights through
5 supporting participation in decision-making. The introduction of IMHA can be interpreted as
6 edging towards supported decision-making, though the very existence of detention and
7 treatment being coercive is viewed as being in contravention of the UNCRPD (Szmukler et
8 al., 2014).
9

10
11 Building on these earlier developments, the Care Act in England in 2014 placed a new duty on
12 local authorities to offer support from an independent advocate (i.e. statutory independent
13 advocacy), if required, to adults and carers requiring social care (see Figure 1). Under this
14 Act, advocacy is defined as 'supporting a person to understand information, express their
15 needs and wishes, secure their rights, represent their interests and obtain the care and support
16 they need' (Department of Health, 2015). Local authorities are required to make a judgement
17 as to whether an individual has **substantial difficulty** in being involved in decision-making,
18 and secondly, if there is an **appropriate individual** to support them.
19

20
21 *Insert Figure 1 here*
22

23
24 In England, local authorities have been commissioning all types of statutory advocacy from
25 2012, as a consequence of the Health and Social Care Act 2012. Commissioning is the
26 process by which support requirements are identified and resources allocated. To do
27 this effectively, local authorities need to understand the diversity of support
28 requirements within local populations; design services to meet these requirements
29 including for advocacy, identify and contract with suitable organisations to provide
30 appropriate, accessible and effective advocacy services, and evaluate those services to
31 ensure appropriate outcomes are achieved (Social Care Institute for Excellence, 2014).
32
33 Although independence is a foundational principle for advocacy, independent sector
34 providers receive funding from the state and are accountable for the delivery of
35 statutory advocacy. This potentially compromises the independence of advocacy providers
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1 to determine how they operate, including to whom they offer support, and at the very least
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3 places them in the invidious position of juggling the demands of the state with the support
4
5 requirements of individuals. Whilst this might be debated as a form of street level bureaucracy
6
7 (Lipsky, 1980), it has clear implications for advocacy as a liberatory practice. Consequently,
8
9 how and what types of independent advocacy under the Care Act are being commissioned
10
11 provides insight into the extent that effective mechanisms for supported decision-making are
12
13 being offered and, thus, the degree to which legislation, such as the Care Act, can meet
14
15 disabled people's aspirations as encapsulated in Article 12 of the UNCRPD.
16
17
18
19

20 *Early evaluation of advocacy under the Care Act*

21
22 Early studies reported low numbers of people were accessing independent advocacy under the
23
24 Care Act despite the new duty, with evidence of poor commissioning practices by some local
25
26 authorities, including a predominance of spot purchasing and contracts with advocacy
27
28 organisations of less than 12 months (Advocacy Action Alliance, 2015). This has been
29
30 attributed to severe budget cuts facing local authorities affecting the availability of
31
32 independent advocacy as well as the quality of training for frontline social care staff to
33
34 implement this duty (McNicoll, 2015). An analysis of Better Care Funding plans for the
35
36 October 2015 Public Accounts Committee, showed that local authorities were spending
37
38 significantly less on advocacy than predicted to meet expected levels of need in line with the
39
40 Department of Health's 2014 estimates (VoiceAbility, 2015). Furthermore, in 62% of these
41
42 plans there was no evidence that the funding requirements for advocacy under the Care Act
43
44 had been included. Similarly, a review found little evidence of advocacy provision for carers
45
46 (Bennett, 2016). The failure by a local authority to offer advocacy subsequently resulted in
47
48 the first legal challenge in the case of R (SG) v London Borough of Haringey (Schwehr,
49
50 2016). The local authority was judged to have undertaken a flawed assessment of the
51
52 accommodation requirements of a destitute asylum seeker with mental health problems
53
54 because of a lack of advocacy. The argument that demand for advocacy under the Care Act
55
56 had outstripped supply was no defence; reinforcing the requirement for local authorities to
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1
2 have adequate arrangements in place.
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5 **Aims and methodology**

6
7 The prime aim of our study was to identify models of commissioning independent advocacy,
8 introduced under the 2014 Care Act in England and how they could be strengthened. The
9 approach taken was appreciative in that we set out to specifically focus on, and identify what
10 was working well to support development of positive practice and an ethos of learning and
11 development (Hammond, 2013). We, therefore, sought to identify how the duty to offer
12 independent advocacy was being implemented through commissioning practices, and what
13 this tells us about the extent to which principles of supported decision-making were being
14 promoted.
15
16

17
18 The study was undertaken by the authors, one of whom is a disabled person. We deployed
19 multiple methods including two online surveys, using the Bristol On-line Survey tool
20 (<https://www.onlinesurveys.ac.uk/>). The purpose of the surveys was to explore commissioning
21 models and identify positive practice with one aimed at local authority commissioners and one
22 for providers. Similar question areas were asked of both types of respondents whilst being
23 tailored to their different contexts. The general lines of inquiry are summarised in
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38 Figure 2.

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40 *Insert Figure 2 here*

41
42 Data was collected between May and September 2016. From the initial analysis of survey
43 responses, potential examples of positive practice were identified and follow-on interviews
44 were arranged with both commissioners and providers to gather further detail on
45 commissioning practices. This enabled exploration of the factors influencing commissioning
46 and access to advocacy from these two contrasting perspectives. Local evaluation reports and
47 commissioning documents were gathered, and a web-based search was also undertaken to
48 identify public tender documents and published information from other organisations.
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58 **Participants**

1
2 Local authority participants were identified from the Association of Directors of Social
3
4 Services (ADASS) website and invitations sent via the regional commissioning networks.
5
6 Advocacy providers were recruited primarily via the Action Advocacy Alliance, a network of
7
8 300 advocacy providers hosted by the Mental Health Foundation, and the Older People's
9
10 Advocacy Alliance (OPAAL) in the UK. In total, there were 107 survey responses: 58
11
12 responses from local authorities equating to 46% of local authorities in England, as some
13
14 responses were on behalf of a consortium involving more than one local authority. As the
15
16 survey invitation was explicit in terms of understanding and highlighting positive practice, it
17
18 is reasonable to assume that responding local authorities were the ones who considered they
19
20 had a good story to tell. A further 51 responses were received from advocacy providers, which
21
22 represented 64 different services, as several larger providers responded in relation to their
23
24 provision in more than one local authority area. Thirty-five local authority and 36 advocacy
25
26 provider respondents indicated they were willing to participate in a follow-on interview. A
27
28 purposive sample of participants was constructed drawing on both sets of survey responses
29
30 where there was an indication of positive practice, and efforts were made to ensure a broad
31
32 geographical spread. A total of 23 follow-on interviews were undertaken with local authority
33
34 commissioners (n = 12), advocacy providers for the respective local authority (n = 10), and a
35
36 national organisation (n = 1).
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41 *Analysis*

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44 Data analysis was an iterative process of thematically analysing and synthesising the data
45
46 from the different sources, with a combination of open and emergent coding (Saldana, 2015;
47
48 Silverman, 2016). The initial framework for analysis included categories relating to the
49
50 research objectives. Subsequent reading and re-reading of transcripts, survey responses and
51
52 relevant documents yielded new codes, which were then applied to the data. Preliminary
53
54 findings were presented at a roundtable event involving invited stakeholders representing
55
56 commissioners; advocacy providers; disabled people; and representatives from the
57
58 Department of Health and Social Care Institute of Excellence (SCIE). The purpose of this was
59
60

1
2 to deepen our analysis, exploring interpretations that were grounded in different stakeholder
3 experiences, and to develop recommendations for strengthening the future commissioning of
4 Care Act advocacy (Newbigging, Ridley and Sadd, 2017).
5
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7

8 9 ***Ethical approval***

10 Ethical approval for the study was granted by the first author's University Ethics Committee.
11 Key ethical issues that arose from this research were achieving voluntary informed consent,
12 ensuring confidentiality and data protection. Completion of an online survey was taken to
13 imply consent, and those participating in interviews had the right to withdraw from the study.
14 We adhered to the first author's University's Data Protection policy, ensuring that all
15 information was treated with care at all times, and in accordance with accepted codes of
16 conduct.
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28 **Findings**

29 The findings presented here report on how independent advocacy was being commissioned
30 and, therefore, the extent to which it was available to support decision- making and self-
31 determination. This starts with considering how advocacy was being conceptualised and,
32 therefore, the prioritising of supporting decision-making.
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39 ***Understandings of advocacy***

40 Two contrasting conceptualisations of advocacy emerged: advocacy as 'law-based (i.e.
41 following the letter of the law), and advocacy as 'value-based' (i.e. consistent with the
42 foundational principles of advocacy, voice and primacy in decision-making). Law-based
43 conceptions were reflected in a narrow interpretation of the new statutory duty and, in such,
44 instances, commissioners considered that it would apply to relatively small numbers of
45 people. In contrast, commissioners who conceptualised advocacy in terms of its foundational
46 aims recognised the value of the new duty as being broadly supportive to many people
47 accessing social care:
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1
2 *“If they meet the threshold and it’s about their life, they get an advocate. The threshold is that*
3 *there must be a communication difficulty and they are unfriended. I think there is a mix- up*
4 *about advocacy - it’s not just about the law. We call it social care and community advocacy.”*
5
6
7

8 Local authority commissioner (Newbigging, Ridley and Sadd, 2017, p6)
9

10 Explicit links were made by some participants between the Care Act’s focus on promoting
11 wellbeing with other participants stating that advocacy should be ‘*a consistent thread*’ across
12 all contacts with social care and health services. These commissioners were finding ways to
13 make the new duty work to meet local support requirements and, unsurprisingly, were more
14 likely to be cited as examples of positive commissioning practice by advocacy providers:
15
16
17
18

19 *“Prior to the Care Act advocacy, we had a general advocacy contract. We haven’t lost that*
20 *contract: the council said you can keep that finance but you must prioritise statutory*
21 *advocacy. We prioritise all the time, we need to use the funds for the Care Act but we have*
22 *this pot for things like parents with learning disabilities whose children have gone into care*
23 *proceedings. We have specialist advocates in family advocacy that is part of our advocacy*
24 *contract. We have kept that and we use it for people with a severe impairment, for example,*
25 *someone with autism and a learning disability.”*
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35 Advocacy provider
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37 Despite this, we found no mention of a rights based approach and specifically of Article 12 of
38 the UNCRPD, even when commissioners had adopted a broad interpretation of advocacy
39 under the Care Act. Indeed, they tended to emphasise self-determination and support to
40 achieve this as opposed to supporting rights or emphasising using advocacy to achieving
41 equality and anti-discrimination. However, a small number viewed access to advocacy as
42 consistent with the positive Care Act duty on local authorities to promote wellbeing in
43 carrying out its functions.
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52 ***Understanding needs for advocacy*** 53 54 55 56 57 58 59 60

1
2 Commissioning advocacy under the Care Act emerged as an evolving practice and there was
3
4 evidence that many local authorities were initially being cautious in their approach; using the
5
6 first year to better gauge levels of need and demand. Advocacy providers, however, indicated
7
8 that some local authorities expected them to absorb any increased demand for advocacy,
9
10 arising from implementing the Care Act, within existing contracts. There had been some
11
12 consultation with existing advocacy providers: four out of five advocacy providers indicated
13
14 the local authority had consulted them prior to the commissioning process, and this included
15
16 requests for information about need and demand for advocacy. A small number had worked
17
18 with the local authority anticipating the introduction of the Act to pilot new models, building
19
20 on existing good relationships. However, some advocacy providers were more sanguine
21
22 commenting that although they had been asked for their input their opinions had been
23
24 disregarded:
25

26
27 *“We have always been able to provide a quick response for advocacy but currently have 50*
28
29 *people on the waiting list. Our advocates currently have an average caseload of 30 people but*
30
31 *they are very experienced. We have asked for additional hours to respond to the demand but*
32
33 *have had no response from the Local Authority.”*
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Advocacy manager

Almost half (48%) of commissioners reported involving people using social care in the
commissioning process. In general, it was not clear to what extent these were consultation
processes rather than meaningful involvement in developing better advocacy provision
through co-production. Furthermore, some commissioners who reported no involvement
indicated that they planned to do so in the future:

*“Not for the pilot period but (we) will be involving them with the commissioning process of the
service going forward.”*

Local authority commissioner

1
2 The involvement methods described included workshops, surveys and questionnaires and
3
4 some described engaging with different groups of disabled people as well as with older
5
6 people. There were examples of approaches that went beyond consultation and feedback,
7
8 shifting towards coproduction. One local authority area demonstrated exemplary practice,
9
10 potentially providing a template for other organisations to follow:

11
12 *“A series of co-production events from inception of delivery model to writing of the service*
13
14 *specification. Some of the events were facilitated by an independent consultant to ensure the*
15
16 *approach was not led by the local authority, but [disabled people were] involved as an equal*
17
18 *partner.”*

19
20
21 Local Authority commissioner

22
23 In this instance, 100 people attended an initial event and two independent consultants, one
24
25 with learning difficulties, coordinated and facilitated the event. Participatory group methods
26
27 were drawn on, both Open Space (Owen, 2008), where participants set the agenda and identify
28
29 priorities, and ‘World Café, which is more structured but also maximise opportunities for
30
31 participants to interact and discuss specific topics (Fouché, and Light, 2011). A steering group
32
33 of disabled people, service users and carers was formed at the event to continue working with
34
35 the commissioner to write the specification for advocacy services and define the outcomes. A
36
37 description of this process is available from Think Local Act Personal (available at:
38
39 [https://www.thinklocalactpersonal.org.uk/co-production-in-commissioning-tool/stories-and-](https://www.thinklocalactpersonal.org.uk/co-production-in-commissioning-tool/stories-and-resources/Co-producing-a-new-advocacy-service-in-Kent-Getting-started/)
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41 [resources/Co-producing-a-new-advocacy-service-in-Kent-Getting-started/](https://www.thinklocalactpersonal.org.uk/co-production-in-commissioning-tool/stories-and-resources/Co-producing-a-new-advocacy-service-in-Kent-Getting-started/)).

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45 Despite references to service user feedback for monitoring and review gathered on an
46
47 individual basis, the provider responses suggested, that local authorities generally lacked a
48
49 strategic approach to involving service users and carers in monitoring and developing better
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51 advocacy services.
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Patterns of commissioning

The study identified a number of different commissioning models for advocacy with 60% of local authorities adopting a 'single provider model', contracting with a single advocacy provider to provide all types of advocacy required. Another 38% of local authorities had adopted a partnership or consortium approach, which was referred to variously as an 'integrated advocacy service', 'partnership', 'framework', or 'hub' model. In these cases, a lead advocacy provider often acted as a gateway or filter to different forms of advocacy from different providers and those specialising in working with specific groups; for instance, people with learning difficulties. While other studies reported 'spot purchasing' as the prevalent pattern of commissioning, we found this to be less common. It would be fair to say that patterns of commissioning were in flux, with 30% of local authorities having changed the contracted advocacy provider for Care Act advocacy since April 2015. This was explained as being a result of learning together with advocacy providers what was needed and commissioning processes evolving, to become more outcomes focused.

How advocacy was provided

In recognising what one respondent identified as the 'benefits of different forms of advocacy', overall local authorities were commissioning a range of advocacy provision. All reported commissioning IMCA services alongside Care Act advocacy. Providers commented on the advantages of co-location of different forms of advocacy in terms of flexibility and being able to respond to changing needs. In particular, the benefits of aligning advocacy provision under both the Care Act and the Mental Capacity Act were highlighted by commissioners and providers alike:

"We remain committed to continue the close links between Care Act Advocacy and IMCA and would need to be strongly convinced to separate the providers of these two forms of Advocacy and would recommend that other local authorities take a similar approach."

Local authority commissioner

1
2 Other forms of advocacy commissioned were IMHA; advocacy for carers; generic advocacy
3
4 for disabled people; domestic violence advocacy; and advocacy tailored to the requirements of
5
6 particular groups of people - notably deaf service users; older people; those affected by
7
8 dementia; and people with learning difficulties. The value-based conception of advocacy was
9
10 often associated with the commissioning of a 'hub model' of provision, underpinned by the
11
12 idea that access to advocacy needs to be as simple and as flexible as possible. All provider
13
14 respondents were voluntary sector organisations with the types of organisation varying. The
15
16 dominant type of advocacy provider was a professional organisation with Trustees often
17
18 having a professional background outside of advocacy but relevant to the organisation's
19
20 mission. More than half of the provider respondents were small local advocacy services (62%)
21
22 with approximately a fifth being local offices of national or regional advocacy organisations.
23
24 Disabled people's organisations (DPOs) made up 12% of the organisations being
25
26 commissioned to provide advocacy. The staffing and framing of the organisation's mission
27
28 varied, with some emphasising a traditional welfare conception of responding to disadvantage
29
30 and vulnerability whilst for others, empowerment and advancing rights were clear goals, often
31
32 aligned with the social model of disability.
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35 36 *Access to advocacy*

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39 The overwhelming majority of advocacy providers rated the referral arrangements for
40
41 advocacy under the Care Act as 'not working' or 'poor' (71%) which contrasts with local
42
43 authority commissioners who generally thought the current arrangements were 'satisfactory'
44
45 (41%), or 'good' (43%), with 4% judging them to be 'excellent'. Many local authorities could
46
47 not easily provide information on the numbers of people who had been assessed for an
48
49 advocate under the Care Act since April 2015; responding that either this information was 'not
50
51 to hand' or that they did not keep such records. Where information was available, significant
52
53 variation in the number of referrals was evident ranging from fewer than 10 to 4000
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55 assessments since April 2015. This difference could be attributed to variations in
56
57 understandings of advocacy, described earlier, informing the approach as to who required
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1
2 advocacy. For example, the local authority that reported 4000 assessments indicated that
3
4 everyone needing social care was potentially eligible. Consequently, some advocacy providers
5
6 reported a dramatic increase in referrals for advocacy since the implementation of the Care
7
8 Act, while others commented that rates of referral were far lower than expected. Many
9
10 providers attributed this to a lack of effective training for frontline social care staff about the
11
12 duty to refer for advocacy.
13

14 The largest proportion of participants (41%) indicated they only accepted local authority
15
16 referrals, with only a minority accepting referrals from health professionals (2%) or reporting
17
18 that the referral had to be signed off by the local authority to confirm eligibility for the
19
20 advocacy service (2%). This is consistent with the commissioner responses, the majority of
21
22 which identified the touchpoints for accessing social care (eg. local authority customer contact
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24 centres, mental health NHS Trusts for people detained under the Mental Health Act, and
25
26 social care staff) as the route into advocacy. However, over a third (34%) of the advocacy
27
28 providers reported an open referral system, taking referrals from any source including self-
29
30 referral and from family members. A small number reported that they were in the process of
31
32 changing their referral process to open referral systems. It is possible that the pattern we found
33
34 reflects the cautious approach adopted in the face of uncertainty about needs for support with
35
36 decision-making. Only a minority (11%) reported solely taking self-referrals or from carers,
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38 and these responses were mainly from DPOs.
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43 *Factors influencing commissioning and provision*

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45 We identified three key factors that influenced commissioning practice: the provision of
46
47 advocacy services: the legal framework, the economic climate of austerity and severe
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49 Government cuts to local authorities, and different operational challenges.
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51

52 **1. The legal framework**

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54 Both commissioners and advocacy providers welcomed the inclusion of advocacy in the Care
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56 Act. Two main reasons were given: first, it increased the legitimization of advocacy and
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1 reinforced its importance, and second, it created an opportunity to bring different forms of
2 advocacy together to provide a more integrated approach to varying and diverse needs. This
3 integration between the different statutes, however, was challenging for advocacy providers,
4 who were often left to figure out how best to make this work in practice. On the other hand,
5 the introduction of the duty to provide advocacy under the Care Act was also viewed as
6 constraining advocacy practice, particularly by some provider organisations who voiced
7 concerns about the prioritisation of statutory advocacy limiting the funding for other types of
8 advocacy:
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*“It has limited the capacity of the service to meet more general need which is often
preventative. The voice of people who are vulnerable is controlled by a professional who has
to decide whether the individual has substantial difficulty, so there is a concern that others
will not be heard or may not be referred because there is lack of learning disability knowledge
in social work teams. Voices will be lost and unheard.”*

Advocacy provider

2. Economic climate

Both commissioners and providers viewed the financial climate and reductions in local
authority budgets as having an adverse impact on all forms of advocacy. Twenty
percent of commissioners reported stopping or reducing access to non-statutory
advocacy during 2015/16 and reductions in funding for local authorities were cited as
the main reason for this change in commissioning practice. Viewing all advocacy as
covered by the Care Act was identified as one way of protecting wider forms of
advocacy from budget restrictions. One commissioner reported that their contract included
20% for non-statutory advocacy recognising that people on the margins of needing social care
may still benefit from advocacy. However, some commissioners argued that as the demand for
statutory advocacy increased there was likely to be less resource available for these other
forms of advocacy. Local authority austerity measures were identified by some advocacy
providers as adversely affecting their capacity to respond to need. This coupled with a contract

1
2 culture that favoured larger, better-resourced organisations also fuelled concerns about the
3
4 lack of sustainability for local advocacy provision.
5

6 **3. Operational challenges**

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8 Clearly, the major operational challenge was ensuring the sustainability of provision in an
9
10 uncertain funding context. Operationalising the duty to provide advocacy was evidently easier
11
12 where good relationships between local authorities and advocacy providers already existed
13
14 along with a history of ongoing dialogue. Two additional challenges were identified in
15
16 relation to identifying and responding to advocacy needs and, linked to this, the awareness of
17
18 front line social care staff. First, concerns that people requiring advocacy may not be well
19
20 supported because of increasing demands on advocacy services and frontline staff's lack of
21
22 understanding of the duty to provide advocacy under the Care Act, despite many local
23
24 authorities reporting that they had provided training. Second, the complexity of the legal
25
26 landscape for advocacy, wider legislation relating to the Deprivation of Liberty Safeguards
27
28 (DoLS), capacity legislation and case law made keeping up to date challenging for
29
30 practitioners. The value of advocates that were multi-skilled, understood the different
31
32 legislative requirements and who were able to take on various roles, (IMHA, IMCA, DoLS
33
34 'relevant person's representative') was, therefore, identified by advocacy providers as one
35
36 potential solution. Nonetheless, advocacy providers drew attention to the unintended
37
38 consequences of the cumulative statutory requirements for advocacy increasing the
39
40 professionalization of advocacy and thus, the difficulty, of retaining the foundational
41
42 principles of being user-led.
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47 **Discussion**

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49 The UNCRPD represented a breakthrough in consolidating rights and realising equal
50
51 citizenship for disabled people. Article 12 is inextricably linked with the realisation of rights
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53 under other articles in promoting the shift from guardianship and substituted decision-making
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55 to supported decision-making. However, as Dixon et al. (2018) have observed,
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57 implementation will depend on various factors including political will and the resources
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1 available. This study provides insight into an aspect of the enactment of Article 12 in an
2 English legislative context. Statutory advocacy in England as in other countries such as
3
4 Canada and Australia has evolved rapidly in the last 10 years (Browning, et al. 2014; Carney,
5
6 2015). The introduction of advocacy under the Care Act 2014 represented an opportunity to
7
8 provide a mechanism for supported decision-making by reducing fragmentation and by
9
10 offering more comprehensive, universal provision. It could achieve this through
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12 commissioning practice that brings together different forms of statutory advocacy, alongside
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14 non- statutory advocacy.
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19 Paradoxically, although advocacy originated from social movements of disabled people,
20
21 including mental health survivors, we found DPOs to be in the minority of commissioned
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23 advocacy providers. Furthermore, it was evident that a strategic approach to involving
24
25 disabled people in both commissioning and provision was frequently lacking. This means that
26
27 advocacy is at greater risk of becoming decoupled from both its foundational principles and
28
29 the UNCRPD right to equal recognition. This was evident in the different conceptions of
30
31 advocacy as law-based or as value-based, with some commissioners clearly working hard, in
32
33 an arduous financial context, to navigate the complexity of legal provisions to realise the
34
35 foundational principles of advocacy. Nevertheless, hard- pressed local authorities may be
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37 commissioning advocacy that enables them to demonstrate procedural etiquette and
38
39 compliance with legislation without, in reality, enabling disabled people to have greater say in
40
41 decisions about their lives i.e. offering procedural as opposed to substantive justice
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43 (Newbigging, Ridley and Sadd, 2017). Such shallow impact clearly comes nowhere near to
44
45 realising the aspirations of supported decision-making envisaged in the UNCRPD.
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49 Alongside the approach and quality of commissioning, the limited scope for self-referral
50
51 places the local authority, commissioners and front-line staff central to decision-making in
52
53 defining eligibility for access to advocacy. There are three difficulties with such an
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55 arrangement. First, the local authority can restrict access to advocacy, as demonstrated by
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57 those commissioners who framed advocacy under the Care Act narrowly in terms of the
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1
2 legislation. Second, access to social care more broadly is defined by increasingly restrictive
3
4 eligibility criteria (Ellis, 2011) and, although access to advocacy under the Care Act is
5
6 available for people funding their own care, the sheer existence of the eligibility criteria for
7
8 social care may impede access to advocacy for all. Third, our participants emphasised that the
9
10 understanding and attitudes to advocacy of front-line social care staff play a critical role in
11
12 facilitating access. Other studies have identified confusion and ambivalence amongst front-
13
14 line staff about independent advocacy (Carver and Morrison, 2005; Newbigging et al., 2015).
15
16 In particular social workers and nurses often claim advocacy as part of their role (Forbat and
17
18 Atkinson, 2005; McKeown et al., 2014). This positioning of advocacy as inherent in
19
20 professional roles has been interpreted as a reaction to the bureaucratisation of welfare
21
22 services (Forbat and Atkinson, 2005). Thus, the consistent reports that social care front-line
23
24 staff were impeding access to advocacy merits further investigation, as well as training and
25
26 workforce development. The combination of various advocacy functions, particularly
27
28 combining IMCA, and advocacy under the Care Act, has implications for the advocates' role
29
30 in adapting from a model of substituted decision-making to supported decision-making. This
31
32 rests on a developed understanding of when the severity of intellectual and communication
33
34 impairments is profoundly compromising capacity for decision-making and where substituted
35
36 decision-making emerges as the only option. (See Thomas 2004 for a fuller discussion of the
37
38 relationship between impairment and disability.) However, interpretation of the UNCRPD
39
40 right to recognition requires that the starting point is removing the restrictions on
41
42 decision-making that are socially imposed (i.e. assuming the person is unable to
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44 communicate their wishes without appropriate efforts being made) rather than with the
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46 impairment.

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52 Taken together with the definition of access to advocacy being dominated by statutory
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54 authorities, this research shows that current arrangements for advocacy in England fall short of
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56 enabling the right to recognition. For this to be more fully achieved, local authorities need to
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58 be commissioning DPOs to provide advocacy and ensuring that the processes enable disabled
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1 people to directly access advocacy. Furthermore, and perhaps our most significant finding, is
2 the lack of any clear alignment of advocacy with supported decision-making and the rights-
3 based framework of the UNCRPD. Locating advocacy under the Care Act in this rights-based
4 context requires a shift from commissioning short-term, issue-based advocacy that potentially
5 skews the advocacy experience and impact (Brown, Standen and Khilji, 2013). It also
6 requires DPOs to be an integral element of advocacy provision. These organisations take
7 rights as their starting point and are grounded in the values of independence and inclusion
8 (Shaping Our Lives and the National Survivor User Network, 2019). The advocacy model
9 provided by DPOs is typically one of self-advocacy and peer advocacy, building on shared
10 experience such that the distinction between advocates and advocacy partners is blurred.
11 These organisations foreground user knowledge addressing forms of epistemic injustice and
12 are committed to capacity building and self-advocacy (i.e. positive rights as opposed to
13 negative rights) (Newbigging and Ridley, 2018). Therefore, they are potentially better placed
14 to realise the liberatory potential of advocacy. Thus, our findings indicate that the inclusion of
15 statutory advocacy in domestic law, as argued by Flynn (2013) may be a necessary condition
16 but it is not sufficient for realising the right to equal recognition. The enactment of this law in
17 commissioning and providing statutory advocacy is critical to realising the ambitions of
18 Article 12. This study reinforces the need for further research to investigate the practice and
19 outcomes of models of supported decision-making. Examining the extent to which statutory
20 advocacy enables people to self-advocate, have a voice and achieve an equal right to
21 recognition needs to be a priority for future research. Other areas for investigations include
22 how to move from substituted decision-making to supported decision-making; the
23 understanding of the rights of disabled people, and the operationalisation of a rights-based
24 focus in supported decision-making.

25 **Limitations**

26 The study investigated commissioning practices at an early stage of implementation of
27 independent advocacy under the Care Act in England. The picture may prove more positive as
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1
2 commissioners gain understanding of the requirements for, and the outcomes of this type of
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4 statutory advocacy. The major limitation of the study is that the perspectives of disabled
5
6 people as participants was limited to involvement in the roundtable with stakeholders.
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9 **Conclusion**

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11 In 2017, the United Nations report on the UK's performance under the UNCRPD was
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13 published and the UK was found to be in breach of the Convention, with 80 recommendations
14
15 for improvement (UN, 2017). The UN called for the abolition of substituted decision-making
16
17 through the reform of existing laws, and improvements in supported decision-making.
18
19 Independent advocacy has the potential to support disabled people to make their own
20
21 decisions but, as our findings from a study of the commissioning of statutory advocacy
22
23 indicate, this is being implemented in a piecemeal and conceptually confused manner. This is
24
25 compounded when severity of intellectual and communication impairments compromises
26
27 actual or perceived capacity for decision-making. Furthermore, DPOs are not being
28
29 commissioned to provide advocacy and may be squeezed as statutory advocacy occupies
30
31 centre ground leaving forms of self and user-driven advocacy on the margins of provision. A
32
33 fundamental review of and investment in advocacy that accurately locates it within Article 12
34
35 of the UNCRPD as a mechanism for supported decision-making is needed. This would redress
36
37 the omission in current arrangements and properly move towards the right to equal recognition
38
39 for disabled people.
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46
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48
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50
51 Excellence for funding this study.
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3 *Figure 1. The processes for which a local authority is required to provide*
4 *independent advocacy to support decision-making (Source: SCIE, 2014:6).*
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- Adult's needs assessment
 - Carer's assessment
 - Preparation and/or review of an adult's care and support or support plan
 - A child's needs assessment as they transition towards adult care
 - A child's carer's assessment (therefore some people below 16 years of age)
 - A young carer's assessment
 - A safeguarding enquiry or safeguarding adults review
 - An appeal against a Local Authority decision under Part 1 of the Care Act (from April 2016).

Figure 2: Survey questions

- Organisations being commissioned, area and population covered
- Type and length of contact to provide advocacy under the Care Act
- Investment in advocacy
- Types of advocacy being commissioned
- Methods for estimating need and understanding requirements
- Co-production in commissioning and provision of Care Act advocacy
- Access, identification of requirements and uptake of advocacy under the Care Act
- Monitoring and evaluation of advocacy provision
- What is working and not work in commissioning advocacy under the Care Act
- Training of front-line staff
- Assessment of how well the arrangements for access to advocacy for disabled people are working
- Willingness to be involved in a subsequent interview

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For Peer Review Only