

Realising the right to equal recognition for disabled people

Newbigging, Karen; Ridley, Julie; Sadd, June

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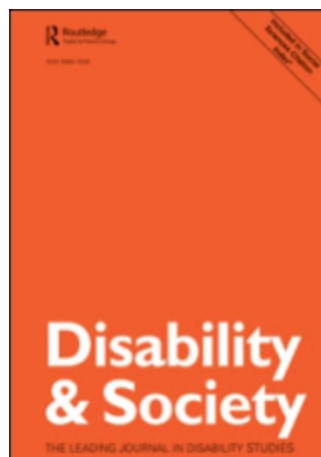
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**Realising the right to equal recognition for disabled people:
Commissioning statutory advocacy in England**

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

Background

The UNCRPD (2007: 91) states that the disabled person is ‘the decision maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual’. It recognises that in some circumstances disabled people will require support with decision-making to realise their autonomy and citizenship rights (Dinerstein, 2011; Carney, 2014). Thus, supported decision-making is the process whereby a person is enabled to make and communicate decisions relating to personal and legal matters. The precise meaning of supported decision-making is still evolving as evidence is gathered from implementation with disabled people with various impairments (Carney, 2014). Nonetheless it is clear that it represents a radical departure from ‘does this person have the capacity to make decisions?’ to ‘what does this person require to make decisions?’ (Gooding, 2013; Davidson et al., 2015). In human services the radical shift to a ‘support model’, first campaigned for by disabled people more than 30 years ago, emphasises individual choice and self-determination. It requires systems that offer options for choice, support and guidance: facilitation rather than direction (Bradley et al. 1994). Person-centred planning, personal futures planning, and user-driven services, are, similarly built on partnership between disabled people, their families, and professionals, where professionals more readily accept direction from users. It also recognises that some people may have unique forms of communication and require additional and specialist support in communication (Bach and Kerzner, 2014). Thus, the degree of choice exercised by an individual in their daily life will clearly be affected not only by the availability of opportunities but also by access to support when required. Carney (2014), however, distinguishes between ‘support with decision-making, i.e. informal support that all citizens enjoy, and ‘supported decision-making, which is formalised legal or civil society mandated

support, as important for emerging practice.

Advocacy and supporting decision-making

Recognising the limits of traditional mechanisms, such as litigation, for rights-enforcement, Flynn (2013) argues for statutory advocacy as a 'crucial component of the support measures envisaged by the UNCRPD for the exercise of legal capacity', arguing that the role of the advocate is 'to support the individual to understand her rights and support her to assert them to strengthen her personal autonomy' (p 499). Thus, advocacy in domestic law in tandem with the UNCRPD enables equal recognition, facilitating access to justice for disabled people at both individual and systemic levels. Well before the UNCRPD, however, supported decision-making and advocacy were promoted through social movements of disabled people to ensure their voices were heard, to both protect and realise their civil rights: captured by the saying 'nothing about us without us' (Charlton, 1998).

A wide range of advocacy models have emerged, and their core purpose has been articulated as 'a cluster of liberatory practices whose goal is to (re)enfranchise epistemically disadvantaged, marginalized, disenfranchised others' (Code, 2006: 165). The conception of advocacy in a health and social care context recognises the fundamental power disparities between individuals and statutory services and professionals on which they rely for support (O'Brien, 1987; El Ansari et al., 2007; Centre for Social Justice, 2011; Sharif et al., 2012; Lonbay and Brandon, 2017; Newbigging and Ridley, 2018). Such accounts situate advocacy in exposing the structural and institutional forces at play in maintaining inequalities and presumptions of limited agency. A foundational principle of advocacy is, therefore, independence from health and social care service providers. This is underlined by the role of advocacy being repeatedly emphasised in relation to abuses of human rights, notably inquiries into the neglect, abuse and avoidable death of people as a consequence of the behaviour of staff and indifference of services to the views and voices of service users, and their families (Department of Health 2012; Francis 2013).

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

Statutory advocacy

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

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

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

Insert Figure 1 here

In England, local authorities have been commissioning all types of statutory advocacy from 2012, as a consequence of the Health and Social Care Act 2012. Commissioning is the process by which support requirements are identified and resources allocated. To do this effectively, local authorities need to understand the diversity of support requirements within local populations; design services to meet these requirements including for advocacy, identify and contract with suitable organisations to provide appropriate, accessible and effective advocacy services, and evaluate those services to ensure appropriate outcomes are achieved (Social Care Institute for Excellence, 2014). Although independence is a foundational principle for advocacy, independent sector providers receive funding from the state and are accountable for the delivery of statutory advocacy. This potentially compromises the independence of advocacy providers

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to determine how they operate, including to whom they offer support, and at the very least places them in the invidious position of juggling the demands of the state with the support requirements of individuals. Whilst this might be debated as a form of street level bureaucracy (Lipsky, 1980), it has clear implications for advocacy as a liberatory practice. Consequently, how and what types of independent advocacy under the Care Act are being commissioned provides insight into the extent that effective mechanisms for supported decision-making are being offered and, thus, the degree to which legislation, such as the Care Act, can meet disabled people’s aspirations as encapsulated in Article 12 of the UNCRPD.

Early evaluation of advocacy under the Care Act

Early studies reported low numbers of people were accessing independent advocacy under the Care Act despite the new duty, with evidence of poor commissioning practices by some local authorities, including a predominance of spot purchasing and contracts with advocacy organisations of less than 12 months (Advocacy Action Alliance, 2015). This has been attributed to severe budget cuts facing local authorities affecting the availability of independent advocacy as well as the quality of training for frontline social care staff to implement this duty (McNicoll, 2015). An analysis of Better Care Funding plans for the October 2015 Public Accounts Committee, showed that local authorities were spending significantly less on advocacy than predicted to meet expected levels of need in line with the Department of Health’s 2014 estimates (VoiceAbility, 2015). Furthermore, in 62% of these plans there was no evidence that the funding requirements for advocacy under the Care Act had been included. Similarly, a review found little evidence of advocacy provision for carers (Bennett, 2016). The failure by a local authority to offer advocacy subsequently resulted in the first legal challenge in the case of R (SG) v London Borough of Haringey (Schwehr, 2016). The local authority was judged to have undertaken a flawed assessment of the accommodation requirements of a destitute asylum seeker with mental health problems because of a lack of advocacy. The argument that demand for advocacy under the Care Act had outstripped supply was no defence; reinforcing the requirement for local authorities to

have adequate arrangements in place.

Aims and methodology

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

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

Figure 2.

Insert Figure 2 here

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

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

Analysis

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

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

Ethical approval

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

Findings

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

Understandings of advocacy

Two contrasting conceptualisations of advocacy emerged: advocacy as 'law-based (i.e. following the letter of the law), and advocacy as 'value-based' (i.e. consistent with the foundational principles of advocacy, voice and primacy in decision-making). Law-based conceptions were reflected in a narrow interpretation of the new statutory duty and, in such, instances, commissioners considered that it would apply to relatively small numbers of people. In contrast, commissioners who conceptualised advocacy in terms of its foundational aims recognised the value of the new duty as being broadly supportive to many people accessing social care:

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“If they meet the threshold and it’s about their life, they get an advocate. The threshold is that there must be a communication difficulty and they are unfriended. I think there is a mix- up about advocacy - it’s not just about the law. We call it social care and community advocacy.”

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

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

“Prior to the Care Act advocacy, we had a general advocacy contract. We haven’t lost that contract: the council said you can keep that finance but you must prioritise statutory advocacy. We prioritise all the time, we need to use the funds for the Care Act but we have this pot for things like parents with learning disabilities whose children have gone into care proceedings. We have specialist advocates in family advocacy that is part of our advocacy contract. We have kept that and we use it for people with a severe impairment, for example, someone with autism and a learning disability.”

Advocacy provider

Despite this, we found no mention of a rights based approach and specifically of Article 12 of the UNCRPD, even when commissioners had adopted a broad interpretation of advocacy under the Care Act. Indeed, they tended to emphasise self-determination and support to achieve this as opposed to supporting rights or emphasising using advocacy to achieving equality and anti-discrimination. However, a small number viewed access to advocacy as consistent with the positive Care Act duty on local authorities to promote wellbeing in carrying out its functions.

Understanding needs for advocacy

Commissioning advocacy under the Care Act emerged as an evolving practice and there was evidence that many local authorities were initially being cautious in their approach; using the first year to better gauge levels of need and demand. Advocacy providers, however, indicated that some local authorities expected them to absorb any increased demand for advocacy, arising from implementing the Care Act, within existing contracts. There had been some consultation with existing advocacy providers: four out of five advocacy providers indicated the local authority had consulted them prior to the commissioning process, and this included requests for information about need and demand for advocacy. A small number had worked with the local authority anticipating the introduction of the Act to pilot new models, building on existing good relationships. However, some advocacy providers were more sanguine commenting that although they had been asked for their input their opinions had been disregarded:

"We have always been able to provide a quick response for advocacy but currently have 50 people on the waiting list. Our advocates currently have an average caseload of 30 people but they are very experienced. We have asked for additional hours to respond to the demand but have had no response from the Local Authority."

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

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

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

Local Authority commissioner

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

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

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

Other forms of advocacy commissioned were IMHA; advocacy for carers; generic advocacy for disabled people; domestic violence advocacy; and advocacy tailored to the requirements of particular groups of people - notably deaf service users; older people; those affected by dementia; and people with learning difficulties. The value-based conception of advocacy was often associated with the commissioning of a 'hub model' of provision, underpinned by the idea that access to advocacy needs to be as simple and as flexible as possible. All provider respondents were voluntary sector organisations with the types of organisation varying. The dominant type of advocacy provider was a professional organisation with Trustees often having a professional background outside of advocacy but relevant to the organisation's mission. More than half of the provider respondents were small local advocacy services (62%) with approximately a fifth being local offices of national or regional advocacy organisations. Disabled people's organisations (DPOs) made up 12% of the organisations being commissioned to provide advocacy. The staffing and framing of the organisation's mission varied, with some emphasising a traditional welfare conception of responding to disadvantage and vulnerability whilst for others, empowerment and advancing rights were clear goals, often aligned with the social model of disability.

Access to advocacy

The overwhelming majority of advocacy providers rated the referral arrangements for advocacy under the Care Act as 'not working' or 'poor' (71%) which contrasts with local authority commissioners who generally thought the current arrangements were 'satisfactory' (41%), or 'good' (43%), with 4% judging them to be 'excellent'. Many local authorities could not easily provide information on the numbers of people who had been assessed for an advocate under the Care Act since April 2015; responding that either this information was 'not to hand' or that they did not keep such records. Where information was available, significant variation in the number of referrals was evident ranging from fewer than 10 to 4000 assessments since April 2015. This difference could be attributed to variations in understandings of advocacy, described earlier, informing the approach as to who required

advocacy. For example, the local authority that reported 4000 assessments indicated that everyone needing social care was potentially eligible. Consequently, some advocacy providers reported a dramatic increase in referrals for advocacy since the implementation of the Care Act, while others commented that rates of referral were far lower than expected. Many providers attributed this to a lack of effective training for frontline social care staff about the duty to refer for advocacy.

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

Factors influencing commissioning and provision

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

1. The legal framework

Both commissioners and advocacy providers welcomed the inclusion of advocacy in the Care Act. Two main reasons were given: first, it increased the legitimization of advocacy and

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reinforced its importance, and second, it created an opportunity to bring different forms of advocacy together to provide a more integrated approach to varying and diverse needs. This integration between the different statutes, however, was challenging for advocacy providers, who were often left to figure out how best to make this work in practice. On the other hand, the introduction of the duty to provide advocacy under the Care Act was also viewed as constraining advocacy practice, particularly by some provider organisations who voiced concerns about the prioritisation of statutory advocacy limiting the funding for other types of advocacy:

“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

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2 culture that favoured larger, better-resourced organisations also fuelled concerns about the
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4 lack of sustainability for local advocacy provision.
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6 7 **3. Operational challenges**

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9 Clearly, the major operational challenge was ensuring the sustainability of provision in an
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11 uncertain funding context. Operationalising the duty to provide advocacy was evidently easier
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13 where good relationships between local authorities and advocacy providers already existed
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15 along with a history of ongoing dialogue. Two additional challenges were identified in
16
17 relation to identifying and responding to advocacy needs and, linked to this, the awareness of
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19 front line social care staff. First, concerns that people requiring advocacy may not be well
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21 supported because of increasing demands on advocacy services and frontline staff's lack of
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23 understanding of the duty to provide advocacy under the Care Act, despite many local
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25 authorities reporting that they had provided training. Second, the complexity of the legal
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27 landscape for advocacy, wider legislation relating to the Deprivation of Liberty Safeguards
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29 (DoLS), capacity legislation and case law made keeping up to date challenging for
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31 practitioners. The value of advocates that were multi-skilled, understood the different
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33 legislative requirements and who were able to take on various roles, (IMHA, IMCA, DoLS
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35 'relevant person's representative') was, therefore, identified by advocacy providers as one
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37 potential solution. Nonetheless, advocacy providers drew attention to the unintended
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39 consequences of the cumulative statutory requirements for advocacy increasing the
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41 professionalization of advocacy and thus, the difficulty, of retaining the foundational
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43 principles of being user-led.
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47 48 **Discussion**

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50 The UNCRPD represented a breakthrough in consolidating rights and realising equal
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52 citizenship for disabled people. Article 12 is inextricably linked with the realisation of rights
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54 under other articles in promoting the shift from guardianship and substituted decision-making
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56 to supported decision-making. However, as Dixon et al. (2018) have observed,
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58 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
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4 Canada and Australia has evolved rapidly in the last 10 years (Browning, et al. 2014; Carney,
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6 2015). The introduction of advocacy under the Care Act 2014 represented an opportunity to
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8 provide a mechanism for supported decision-making by reducing fragmentation and by
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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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18 Paradoxically, although advocacy originated from social movements of disabled people,
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20 including mental health survivors, we found DPOs to be in the minority of commissioned
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22 advocacy providers. Furthermore, it was evident that a strategic approach to involving
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24 disabled people in both commissioning and provision was frequently lacking. This means that
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26 advocacy is at greater risk of becoming decoupled from both its foundational principles and
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28 the UNCRPD right to equal recognition. This was evident in the different conceptions of
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30 advocacy as law-based or as value-based, with some commissioners clearly working hard, in
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32 an arduous financial context, to navigate the complexity of legal provisions to realise the
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34 foundational principles of advocacy. Nevertheless, hard- pressed local authorities may be
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36 commissioning advocacy that enables them to demonstrate procedural etiquette and
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38 compliance with legislation without, in reality, enabling disabled people to have greater say in
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40 decisions about their lives i.e. offering procedural as opposed to substantive justice
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42 (Newbigging, Ridley and Sadd, 2017). Such shallow impact clearly comes nowhere near to
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44 realising the aspirations of supported decision-making envisaged in the UNCRPD.
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47 Alongside the approach and quality of commissioning, the limited scope for self-referral
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49 places the local authority, commissioners and front-line staff central to decision-making in
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51 defining eligibility for access to advocacy. There are three difficulties with such an
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53 arrangement. First, the local authority can restrict access to advocacy, as demonstrated by
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55 those commissioners who framed advocacy under the Care Act narrowly in terms of the
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2 legislation. Second, access to social care more broadly is defined by increasingly restrictive
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4 eligibility criteria (Ellis, 2011) and, although access to advocacy under the Care Act is
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6 available for people funding their own care, the sheer existence of the eligibility criteria for
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8 social care may impede access to advocacy for all. Third, our participants emphasised that the
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10 understanding and attitudes to advocacy of front-line social care staff play a critical role in
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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).
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16 In particular social workers and nurses often claim advocacy as part of their role (Forbat and
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18 Atkinson, 2005; McKeown et al., 2014). This positioning of advocacy as inherent in
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20 professional roles has been interpreted as a reaction to the bureaucratisation of welfare
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22 services (Forbat and Atkinson, 2005). Thus, the consistent reports that social care front-line
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24 staff were impeding access to advocacy merits further investigation, as well as training and
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26 workforce development. The combination of various advocacy functions, particularly
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28 combining IMCA, and advocacy under the Care Act, has implications for the advocates' role
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30 in adapting from a model of substituted decision-making to supported decision-making. This
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32 rests on a developed understanding of when the severity of intellectual and communication
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34 impairments is profoundly compromising capacity for decision-making and where substituted
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36 decision-making emerges as the only option. (See Thomas 2004 for a fuller discussion of the
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38 relationship between impairment and disability.) However, interpretation of the UNCRPD
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40 right to recognition requires that the starting point is removing the restrictions on
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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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people to directly access advocacy. Furthermore, and perhaps our most significant finding, is the lack of any clear alignment of advocacy with supported decision-making and the rights-based framework of the UNCRPD. Locating advocacy under the Care Act in this rights-based context requires a shift from commissioning short-term, issue-based advocacy that potentially skews the advocacy experience and impact (Brown, Standen and Khilji, 2013). It also requires DPOs to be an integral element of advocacy provision. These organisations take rights as their starting point and are grounded in the values of independence and inclusion (Shaping Our Lives and the National Survivor User Network, 2019). The advocacy model provided by DPOs is typically one of self-advocacy and peer advocacy, building on shared experience such that the distinction between advocates and advocacy partners is blurred. These organisations foreground user knowledge addressing forms of epistemic injustice and are committed to capacity building and self-advocacy (i.e. positive rights as opposed to negative rights) (Newbigging and Ridley, 2018). Therefore, they are potentially better placed to realise the liberatory potential of advocacy. Thus, our findings indicate that the inclusion of statutory advocacy in domestic law, as argued by Flynn (2013) may be a necessary condition but it is not sufficient for realising the right to equal recognition. The enactment of this law in commissioning and providing statutory advocacy is critical to realising the ambitions of Article 12. This study reinforces the need for further research to investigate the practice and outcomes of models of supported decision-making. Examining the extent to which statutory advocacy enables people to self-advocate, have a voice and achieve an equal right to recognition needs to be a priority for future research. Other areas for investigations include how to move from substituted decision-making to supported decision-making; the understanding of the rights of disabled people, and the operationalisation of a rights-based focus in supported decision-making.

Limitations

The study investigated commissioning practices at an early stage of implementation of independent advocacy under the Care Act in England. The picture may prove more positive as

commissioners gain understanding of the requirements for, and the outcomes of this type of statutory advocacy. The major limitation of the study is that the perspectives of disabled people as participants was limited to involvement in the roundtable with stakeholders.

Conclusion

In 2017, the United Nations report on the UK's performance under the UNCRPD was published and the UK was found to be in breach of the Convention, with 80 recommendations for improvement (UN, 2017). The UN called for the abolition of substituted decision-making through the reform of existing laws, and improvements in supported decision-making. Independent advocacy has the potential to support disabled people to make their own decisions but, as our findings from a study of the commissioning of statutory advocacy indicate, this is being implemented in a piecemeal and conceptually confused manner. This is compounded when severity of intellectual and communication impairments compromises actual or perceived capacity for decision-making. Furthermore, DPOs are not being commissioned to provide advocacy and may be squeezed as statutory advocacy occupies centre ground leaving forms of self and user-driven advocacy on the margins of provision. A fundamental review of and investment in advocacy that accurately locates it within Article 12 of the UNCRPD as a mechanism for supported decision-making is needed. This would redress the omission in current arrangements and properly move towards the right to equal recognition for disabled people.

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Figure 1. The processes for which a local authority is required to provide independent advocacy to support decision-making (Source: SCIE, 2014:6).

- 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