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Redefining Self-Advocacy: A Practice Theory-Based Approach

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Abstract

The disabled people's movements have successfully influenced public policies and laws. Self-advocates who are autistic or have an intellectual disability have been working alongside other advocates for recent decades. Practice theory has rarely been used in disability research. This study explores "practice theory" through the analysis of interviews with advocates and self-advocates within the autism and intellectual disability advocacy movements. This is a qualitative, empirical study based on interviews and focus groups with 43 participants in two countries. The data were collected in 2016–17. Content analysis was used to identify themes. Data indicate that everyday practices of self-advocates and advocates such as parent advocates and professional advocates largely overlap. There are five major types of practices that are done by nearly all advocates: "informing and being informed," "using media," "supporting each other," "speaking up," and "bureaucratic duties." Contrary to several previous studies on self-advocacy that emphasized "speaking up" as the main activity in advocacy, this study found that most practices of advocates and self-advocates are "para-advocacy" practices that may or may not lead directly to "speaking up." Practices of self-advocates are often embedded in other everyday activities people do. The line between practices that belong to self-advocacy and practices outside self-advocacy may not always be clear even to self-advocates. Findings also indicate that hierarchies in the disability movement influence strongly the position of self-advocates.

Keywords: autism, disability advocacy, disability movement, intellectual disability, practice theory, self-advocacy

Introduction

Disability advocacy, including intellectual disability (self-) advocacy and autism (self-)advocacy have been largely underresearched (Manthorpe, Rapaport, Hussein, Moriarty, & Collins, 2005; Campbell & Oliver, 2013; Petri, Beadle-Brown & Bradshaw, 2017). Studies focusing on intellectual disability (ID) and autistic (self-)advocacy have been dominated by studies in the context of organizations or advocacy groups, often building on individual accounts of members of organizations (Birtha, 2014; Goodley, 2000; McColl & Boyce, 2003; J. McNally, 2005; S. Mcnally, 2003; Tilley, 2006a; Tsuda & Smith, 2004). Authors also emphasize historical differences between social groups within the advocacy movement (Bylov, 2006; Wehmeyer, Bersani, & Gagne, 2000): for example, it is claimed that professionals, parents and disabled people have had different views about what advocacy should achieve (Waltz, 2013). Many studies focused on power struggles within or between organizations and authorities (Balazs & Petri, 2010; Bertilsdotter, Brownlow, & O'Dell, 2015; Callus, 2014; Tilley, 2006b; Tilley, 2013; Waltz, den Bosch, Ebben, & Schippers, 2015). What is common in these studies is that they usually see social structures such as organizations or groups as primary contexts to understanding features of ID or autistic advocacy. The aim of the present article is to depart from the view that sees organizations as the main context of advocacy and use practice theory to appraise contemporary self-advocacy by analyzing practices that members of the disability movement do.

Organizations and groups are of course prevalent forms of disability (self-)advocacy. Such forms include self-advocacy groups or parents' advocacy groups, that work in various organizational forms such as charities, non-governmental organizations (NGOs) or disabled people's organizations (DPOs) (Goodley & Ramcharan, 2010), and even human rights watchdogs that work under the disability "human rights model" (Degener, 2014). These organizational forms of advocacy are descriptive categories that maintain a dominantly *structural view* on the disability advocacy movement, with a strong emphasis on social structures such as organizations, or rules that may influence how organizations work. This emphasis on social structures when explaining social phenomena is commonly associated with *structuralism* or *functionalism* in social theory (Giddens, 1989).

(Self-)advocacy can also be looked at from another viewpoint, from the perspective of individuals navigating between forms of advocacy. Often, individuals' accounts, including the analysis of their life histories, are the main focus of studies where the emphasis is on the *actor* or *individual* who advocates (Atkinson, 1998; Atkinson, Cooper, & Ferris, 2006; Atkinson,

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McCarthy, Walmsley, Cooper, & Ferris, 1999; Dybwad & Bersani, 1996; Goodley, 2000; Hamilton & Atkinson, 2009; Hreinsdóttir, Stefánsdóttir, Lewthwaite, Ledger, & Shufflebotham, 2006; Spedding, Harkness, Townson, Docherty, & Chapman, 2002; Traustadóttir, 2006). Studies centering around the individual illuminate personal backgrounds, properties (such as being a parent, being a disabled person, etc.), experiences, identities, and aspirations that impact the form of advocacy people participate in. Disability studies has long been concerned with personal independence (Barnes, 2012), or the autonomy and agency of the individual—therefore the emphasis on personal accounts and individual agency is characteristic of studies on self-advocacy even in organizational studies. Such strong emphasis on individuals, their choices, actions, and their agency is what social theorists often call—following Max Weber's original German term *methodische Individualismus* (Weber, 1978)—*methodological individualism* (Heath, 2015).

These two approaches represent two different social theory traditions. There have been longstanding debates among social theorists whether *social structures* on the one hand, or *individual agency* on the other have primacy in influencing or defining human behavior (Giddens, 1979).

To offer a new way of looking at (self-)advocacy, and to appraise how previous concepts of disability advocacy are influenced by what (self-)advocates do when they (self-)advocate, a third tradition in social theory, "practice theory" has been proposed (Schatzki, 1996) and was used for the analysis of empirical data on ID and autism (self-)advocacy. Practice theory may be a useful lens through which to view practices of members of the disability movement.

Practice Theory: A Third Way

Practice theory has a long tradition in social theory and social research. Elements of practice theory are already found in works of French theorist Pierre Bourdieu who put forward "praxeology" as a term in his work Outline of a Theory of Practice (1977). Bourdieu, together with English sociologist Anthony Giddens emphasized that practice is as important as structure or agency in understanding the social world. Giddens (1984) stated that "principles of order could both produce and be reproduced at the level of practice itself" (p. 376). Other philosophers also developed or used elements of practice theory in their works, for example Ludwig Wittgenstein described language as "a set of practices embedded in convention" (Couldry, 2012). In addition, Foucault (1977), was concerned with practices such as punishment or incarceration in the West. Recently, feminist philosopher Butler (2011) built on practice theory in her works about performative gender studies.

Others such as Turner (1994) further developed practice theory, elaborating the notion of both "tradition" and "tacit knowledge" and their importance in practices, but also pointing out the fuzziness of the concept of practices. Schatzki (1996) has been influential in theorizing the notion of practice. For Schatzki, practice becomes a central and highly complex theoretical concept which is more than just a descriptive category of the social world. He implies that seemingly mundane practices such as doing leisure activities have particular organizing properties in the social world. In fact, Schatzki (2001) states that the social world is constituted by practices, and "the social is a field of embodied, materially interwoven practices centrally organized around shared understandings" (p. 3).

Indeed, practice theorists see the concept of practices as central to understanding individuals, systems, structures, institutions, or even language. Practice theory is more interested in the "everyday" or "life worlds" (Reckwitz, 2002) than in "structure." Reckwitz (2002) synthesized the work of theorists such as Bourdieu, Schatzki, and Foucault and provided a concise—or as he called it "idealized"—concept of practice that is a "routinized type of behaviour" (p. 249).

Practice theory positions itself between previously mentioned traditions in social theory such as *structuralism* and *methodological individualism*; however, despite efforts by practice theorists like Schatzki, Reckwitz, or Turner, practice theory has not one single agreed-upon coherent concept. In fact, practice theory remains a "body of highly diverse writings by thinkers who adopt a loosely defined 'practice approach'" (Postill, 2011). This diversity within practice-based theories and approaches has become a fertile ground for innovative research in other disciplines such as consumerism studies, cultural studies, anthropology, and in contemporary media studies where theorists and empirical researchers were similarly inspired by a renewed focus on practices.

For example, in media studies, a major "practice turn" was demonstrated in the works of leading theorists of the field (Bräuchler & Postill, 2010; Couldry, 2012). Couldry (2012) argued that a practice-based approach to understanding contemporary media was needed, mostly because of the complexity and speed of current tendencies in both media usage and media production. Other media theorists have further opened the field for practice theory-inspired inquiries in media studies (Bräuchler & Postill, 2010) and used practice theory to analyze empirical data.

Practice theory, despite its impact in other fields of social sciences, has been rather absent in disability theory. One exception is that of Mladenov's (Mladenov, 2016) inquiry into the relationship between disability and critical theory. Mladenov was inspired by practice theory in his study on disability assessments in Bulgaria and showed convincingly that certain practices contribute to *dis/ablism*, a term developed to mark "behaviours that render some people inferior based on their impairments" (Mladenov, 2016 p. 3). Mladenov's concept of practice follows that of Schatzki's—practices are "patterned networks of interrelated activities mediated by humans and nonhuman entities" (Mladenov, 2016 p. 3).

Another, practice theory-inspired approach was offered in a study about learning by support staff in disability services in Britain (Bradshaw & Goldbart, 2013). The analysis used the concept of "Communities of Practice" (CoPs) which is defined as a "group of people who share a concern or passion for something they do and learn how to do it better as they interact regularly" (Wenger-Trayner & Wenger-Trayner, 2011). By applying this concept, it was found that staff of services function as "CoPs" where experiential knowledge, for example, learning through practice was central.

In order to reveal multiple layers of what contemporary self-advocacy means, it is necessary to change the view on advocacy

and see it as something that is carried out through—using Mladenov's (2016) concept—"patterned networks of interrelated activities" or simply put: through everyday practices. In what follows, a practice-based analysis will be proposed to appraise intellectual disability and autistic self-advocacy.

The analysis is part of a broader doctoral study looking at the position of self-advocates within the broader disability movement—one objective of the study was to explore differences and similarities between positions of self-advocates and other advocates such as parents and professionals. To assess the position of self-advocates within the disability movement, two particular issues were explored. Firstly, whether practices done by self-advocates differed from practices done by other advocates including parents and professionals. Secondly, the practices done by both self-advocates and other advocates were analyzed to reveal topical types of practices relevant to specific groups.

In the following section, when referring to different forms of advocacy, terms will be used in their lay meanings, but also respecting participants' own claims. For example, "advocacy groups" will refer to any kind of collectives where people pursue advocacy; "self-advocacy groups" will denote advocacy collectives of disabled people; and "parents' groups" will signify collectives that are composed of parents or relatives of autistic people or people with an intellectual disability.

Methods

The analysis builds on data collected from 43 advocates and self-advocates (M = 18; F = 25) in the UK and Hungary (Table 1). Data collection was carried out as part of a doctoral study looking at the ways self-advocates with ID or autistic self-advocates participate in the broader social movement of disabled people. Participants included advocates and self-advocates working in paid or unpaid positions in learning disability advocacy or autism advocacy, for example, at advocacy groups, NGOs, DPOs, or as members of parents' groups, self-advocacy groups, or as individual self-advocates. This diversity of organizational background resulted in rich data that included experiences stemming in various forms of advocacy such as professional advocacy (e.g., under the Care Act in the UK), individual advocacy and self-advocacy, human rights advocacy (such as work at legal clinics), work in online (self-)advocacy collectives, peer support, parents' advocacy groups, speaking up groups, and so on.

Most participants were between 26 and 45 years of age, with a small minority of interviewees who were over 45. The level of experience in advocacy varied among participants, many of them having 15–20 years of experience (typically professionals and some parents). The vast majority of participants had 3–10 years of experience in advocacy (most self-advocates, some parents and professionals falling under this category). Groups also overlapped, for example, there were two self-advocates with ID who were also autistic, however, both of them participated in organizations operating in intellectual disability. Also, some parents and professionals advocated for both autistic people and for people with ID.

There was another overlap between two groups of participants: nearly all parent advocates also did some form of professional advocacy. For example, they were founders or leaders of local, regional, or national umbrella NGOs, they gave advocacy training, they engaged in policy-making, and so on. Therefore, in this analysis, the category "parent advocates" does not exclude those having experience as professional advocates. (At the time of recruitment none of the self-advocate participants claimed to be a parent advocate for their child.)

Recruitment in both countries was done through DPOs and the researchers' network, also relying on the contacts of University of Kent, Tizard Centre. Snowball sampling was also used in both countries. Data collection started in September 2016 and finished in May 2017.

Participation was anonymous and voluntary. Reasonable accommodation was given to special needs, for instance some interviews took place at venues with low sensory stimuli or were conducted by Skype. Interviews and focus groups were done in the native language of participants, in English or Hungarian. All information sheets, consent forms, and complaint forms were

Table 1 Participants

Participants	UK	Hungary	Total
Self-advocates with a learning disability	4 interviews (incl. one group interview, n = 2)	1 focus group (n = 3) + 1 interviews = 4 participants	8
Autistic self-advocates	5 interviews	1 focus group (n = 4) + 2 interviews = 6 participants	11
Parent advocates	2 interviews	1 focus group (n = 4) + 1 participant in a focus group together with professionals +4 interviews = 9 participants	11
Professional advocates	8 interviews	4 participants in a focus group featuring a parent as well +1 interview = 5 participants	13
Total	Total in the UK: N = 19 participants	Total in Hungary: N = 24 participants	N = 43 participants

available in two languages, and also in easy-read in English and easy-read in Hungarian. Translation of materials was done by the first author. The data collection was approved by the University of Kent, Tizard Centre's Ethics Committee in June 2016.

Data collection was done by employing both interviews and focus groups—this decision was taken because in both countries, geographic distance made it difficult to organize only focus groups. Also, many participants preferred to take part in individual interviews because they felt anxious to join groups or they did not want to share their views with other participants.

For the data analysis, all interview and focus group recordings were transcribed by one of the researchers in NVIVO software. Transcriptions followed a verbatim transcription tradition. This was an exploratory study that used an inductive coding method to allow data to inform the analysis. Transcribing was done in English for participants interviewed in the UK and in Hungarian for participants in Hungary. All transcribing was done by the one of the researchers between June and August 2017. The analysis was done in English—the authors extensively discussed details of the analysis which allowed all of them to reflect on data and shape the final article. The following analysis was based on a single dataset based on data from both countries. As discussing differences and similarities between advocacy practices in the UK and Hungary is not part of this article, the country origin of participant quotations is not included.

Interviews and focus groups covered a variety of topics relevant to the doctoral research. For this analysis, practices of advocacy and self-advocacy were looked at based on mentions of activities and practices ("what advocates do") during interviews and focus groups. In order to conceptualize advocacy and self-advocacy, two questions were proposed in this analysis:

1. Are there differences between the practices self-advocates do and practices other advocates do as part of their everyday advocacy?
2. What are the emerging themes among practices that members of the intellectual disability and autism advocacy movement do?

There are various research methods used in practice theory-based studies. Although ethnographic data collection is popular in practice-based studies (e.g., Bräuchler & Postill, 2010), the flexibility of practice theory allows for diverse methodologies, including the analysis of texts such as interview transcripts. For example, thematic analysis of semi-structured interviews was used in a study to evaluate the online internet activity at Mexican universities (Gonzalez & Cox, 2013).

To answer the two questions, practices mentioned by participants were looked at by using content analysis (Hsieh & Shannon, 2005). Conventional content analysis is a popular method to analyze textual data—such as interview transcripts—and to describe a phenomenon with limited existing theory (Hsieh & Shannon, 2005 p. 1279). Content analysis is also used to describe hierarchical or other types of relationship between different themes in a set of data.

For the analysis, the researcher read all transcripts several times, scanning the texts for mentions of practices. Mentions of activities people do as part of their advocacy were identified and organized into a catalogue of practices. The list includes activities mentioned by participants as something they themselves do, and also activities participants referred to as things that other advocates do, often speaking in terms of "we," for example, in the context of an association or community. The analysis captured practices mentioned by both self-advocates and other advocates. This broad view ensured that any kind of activity that participants saw as part of ID or autism advocacy got recorded and it also allowed for comparisons between what self-advocates and what other advocates do.

There were robust data available in transcripts: 43 participants mentioned practices in over 50 hours of recorded material over 300 times. This provided a large set of data about what people do as part of their advocacy work. In fact, transcripts were so rich in data that the scanning and listing-up of mentions of practices reached saturation after analyzing three focus groups (n = 11) and six interviews. Interviews and focus groups were sampled to give a balanced representation of all participant groups: parent advocates; professional advocates; and autistic self-advocates and self-advocates with ID. One focus group and one interview with members of each of these groups was selected, and in the case of professional advocates—in the absence of a focus group interviewing only professionals—three interviews were sampled. This sampling method ensures that each of the four participant groups have around three to three and a half hours of recorded material representing their views in this analysis.

Mentions of practices were copied verbatim from transcriptions into a list in MS word, only slightly amending or altering the wording, to allow for contextual understanding of the practice without the surrounding text. Every practice mentioned by participants was selected for this analysis, even if the given practice has already been mentioned before by other participants. This decision was taken to ensure that the catalogue of practices allowed the identification of patterns in what different advocates and self-advocates do—for example, how dominant some practices are among other practices. Therefore, if some practices were mentioned by many participants then this practice appears several times in the catalogue. However, if one single participant mentioned the same practice several times throughout an interview—for example, during a monologue about a topic—then only one mention was listed. This decision was taken because of the limitations of the methodology employed: interviews and focus groups covered various issues, therefore some practices were mentioned several times by participants e.g. when they were telling a story related to a given problem.

Another selection criterion was also applied: activities mentioned explicitly as one-time actions were not included, if it was clear from the transcription that participants talked about an irregular activity. For example, a self-advocate mentioned an incident, a conflict at a conference; this conflict was presented as an exceptional one therefore it did not get recorded. This decision was taken because practice theory is concerned with routines or regular activities (Schatzki, 2001) and not ad hoc or accidental actions.

In the first part of the following analysis, practices were categorized per participant group to highlight differences between what advocates and self-advocates do. The grouping of practices into participant categories allowed for clear comparison from a practice-based point of view, by identifying practices that were

done predominantly by one group of advocates but not by others. For example, if some practices were done predominantly by professional or parent advocates but not by self-advocates, then it may explain why non-disabled advocates usually hold more dominant positions in the movement while self-advocates remain often invisible. Then, in the second part emerging themes within practices were identified. For the identification of these themes, thematic analysis (Braun & Clarke, 2006) was used. To demonstrate the myriad of practices (self-)advocates do, the presentation of results will build strongly on quotes from transcripts.

Results: An Analysis of Practices in Advocacy and Self-Advocacy

First, the catalogue of practices (Table 2.) was looked at to identify general patterns or themes and to familiarize the researcher with the practices. The list demonstrated the extremely wide range of different practices ID or autism (self-) advocacy may include. The analysis was done to appraise whether there was difference between practices mentioned by advocates such as professional or parent advocates vis-à-vis self-advocates.

The presentation of data was based on differences between four groups: parents, professionals, and self-advocates (autistic self-advocates separately from self-advocates with an intellectual disability). This separation of parents, professionals, and self-advocates followed a traditional view that these groups have been often separated by tensions and debates about various issues, including the aims and content of advocacy (Bylov, 2006; Petri et al., 2017; Waltz, 2013; Wehmeyer et al., 2000).

Who Does What?

Practices were grouped into four categories, from the point of view of actors, along the previously stated question: Is there difference between the practices self-advocates do and practices other advocates do as part of their everyday advocacy? (see Table 2).

The list of practices in Table 2 demonstrated that advocates and self-advocates engage with a very broad variety of practices as part of their everyday activities. Importantly, only slight differences appeared between what different participant groups did as part of their advocacy—nearly all practices seemed to be common for both advocates and self-advocates. Few differences were present, for example, the gaining of basic skills for some self-advocates with a learning disability ("learning to introduce ourselves in hospitals," "learning how to handle money," "becoming independent," etc.) was specific to their group; or professionalized practices of advocacy ("going to tribunals," "doing National Health Service (NHS) complaints") were probably more specific to those working as "professional advocates" in the UK.

Some practices like "myth-busting about autism" or "supporting their children" first seemed specific to a certain group—autistic self-advocates and parents, respectively. However, both of these practices could also be belonging to other groups: myth-busting about autism is often done not only by self-advocates but by parents or professionals as well; and similarly, supporting children may be a practice not only for parent advocates, but also for professional advocates or even self-advocates who have children.

From this point of view, very few practices in Table 2 can be associated with exclusively one certain group of advocates: for example, "learning about rights," "attending conferences," "pushing for legal changes," "writing letters," "going to authorities," "giving trainings/lectures," or "supporting each other" were mentioned by both parents, professionals and self-advocates as part of their everyday activities. This finding suggests that many advocacy practices, although they may require skills or resources, could be done by any of the historically separated groups of advocates such as parents, professionals or self-advocates.

Common Themes of Practices

The broad diversity of practices does not mean there is a lack of common themes in what advocates and self-advocates do. In fact, there are several practices that connect groups of advocates and self-advocates. Five types of core practices or themes seem to be integral to advocacy across different groups of advocates.

1. One seminal theme across participant groups is "informing and being informed." Numerous practices were mentioned in this context, on the one hand as learning or developing one's skills, and on the other hand as teaching and giving information to others / to the public in different ways.

- Learning is a common practice in advocacy. Information gained or learned enables people to do advocacy. Practices mentioned in this context include "getting to know ourselves," "learning," "learning about human rights and the movement," "reading on autism and other stuff," "learning how to handle conflicts," "developing new skills," "going to workshops to gain skills," "reading the law," or just "reading things on the internet." These are all practices that most advocates and self-advocates regularly do as part of their advocacy work and not only as prerequisites to advocacy: several participants mentioned these activities as "ongoing." Learning is something that most participants regularly do even after years of experience in disability advocacy.
- Passing on information is a salient practice for nearly all advocates and self-advocates. This can take many forms and includes teaching, giving speeches or handing out written materials. Information is regularly and systematically passed on to others and target groups include peers, people in the community or the wider public. Practices mentioned by participants include "exchanging information or experience with peers," "training self-advocates," "giving trainings," "telling people what autism is and what it is not," "speaking at conferences," "telling people about their rights," "raising public awareness," "myth-busting about autism," "teaching about various issues," "educating neurotypical people about autism," and "teaching advocacy skills" to peers.

Table 2 Examples of practices per participant group

Participants	Practices of advocacy	
Self-advocates with an intellectual disability	Learning to introduce ourselves in hospitals, offices, schools, at a party or elsewhere	Passing on information
	Getting to know ourselves and others or our environment	Giving voice to peers
	Learning how to handle money	Getting help to protect ourselves
	(Practicing the) Nothing about us without us (principle)	Putting things on a website, editing a website
	Standing up for our rights every day	Writing things up
	Gaining confidence and be visible in the world	Giving trainings
	Exchanging information/experience with peers	Learning things
	Helping each other	Speaking with others (including peers)
	Going to conferences and meeting others	Developing new skills
	Preparing for conferences	To become independent
	Telling politicians what we want	To be able to protect yourself
	To protect your peers	To read things on the internet
	Writing letters	Writing up articles
		Learning how to handle conflicts
Autistic self-advocates	Fighting for benefits	Administration in organizations
	Telling people what autism is (what it is not)	Myth-busting about autism
	Passing on information to non-autistic people	Reading on autism and other stuff
	Issuing statements (in the policy context)	Helping autistic peers
	Giving interviews in media (press, TV)	Developing websites
	Doing research on therapies, evidence-based interventions	Making films, videos
		Developing new skills, learning
	Defending rights, using the law	Doing graphic design
	Making videos, putting them online	Raising public awareness, e.g. by giving lectures
	Working together as a community (with autistic people)	Sharing experiences with peers
		Blogging, vlogging
	Supporting each other, even just solidarity	Being active on social media
	Educating neurotypical people about autism	Networking, meeting others
	Starting or signing petitions	
Parent advocates	Writing letters to authorities	Establishing an organization
	Reading the law	Speaking in the media
	Protecting rights	Going to conferences
	Speaking for other families	Speaking at conferences
	Organizing meetings (including for other parents)	Trying to change the law, lobbying
	Bringing together parents	Developing skills (law, financial, leadership, negotiation skills, etc.)
	Making sure my kid is OK in the class	
	Representing the interest of their children (incl. other families)	Supporting self-advocates
		Teaching advocacy skills
	Representing the interest of the whole family	Supporting "our" children (incl. in other families)
	Writing a blog	Influencing policies or laws
	Writing books, articles	Giving trainings to professionals
	Being on social media, Twitter, or Facebook	Traveling a lot (e.g., to conferences)
	Getting in touch with other parents on social media	Not accepting refusal by authorities
Professional advocates	Learning about human rights & the movement	Teaching about various issues
	Organizing rallies	Telling people about their rights
	Making and using leaflets, fliers, etc.	Litigating cases
	Pushing for legal changes, lobbying	Doing NHS complaints or helping people putting together care plans
	Participating in drafting laws and policies	
	Organizing conferences and meetings	Making sure information is accessible to people

(Continues)

Table 2
Continued

Participants	Practices of advocacy	
	Going to authorities, social and health services	Structuring information
	Going to ministries and city councils	Going to tribunals
	To train and support self-advocates	Visiting families
	Making Internet accessible for SAs with ID	Supporting clients emotionally
	Writing to politicians	Talking things through with clients
	Going to trainings or workshops to gain skills	Managing an organization
	Paperwork, administration of cases	Entering confrontations or conflicts
	Participating in formal government consultations	Running legal aid services
	Competing with other advocacy organizations	Talking to media

- One type of practice is often phrased by participants in a specific way that implies the development of basic skills, for example "learning how to introduce ourselves in hospitals, offices, at a party or elsewhere," "becoming independent," "learning how to handle money," or "getting to know ourselves"—these may be seen irrelevant for some advocates, while they mean a type of learning that is a core practice for some self-advocates. These practices expose a "skill gap" within the movement: some advocates are more skilled than others and training needs may differ largely between advocates.

2. Another core theme is "using media" that is closely related to the previous theme, getting or giving information. Media is seen as a tool to transmit or receive information necessary for advocacy and nearly all participants mentioned using the media as integral to their advocacy. This theme signals that popular means of communication, such as the internet, mobile applications or social media are key tools for advocates and self-advocates. "Using media" includes both consuming and producing media content, in fact much of the mentioned practices are about producing media content. Notably, this theme strongly overlaps with all the other themes, because people may be using the media as a means to practice "learning," "support" or "speaking up." Indeed, in today's mediatized society (Couldry, 2012), the presence of media is so pervasive in "all the spheres of society and social life" (Mazzoleni, 2008) that "new types of causal complexity" (Couldry, 2012: 134) emerge between practices. For example, using media in advocacy can be both relational (such as when connecting with peers on Facebook or when partaking in an online campaign) or it can be internal (for instance when an advocate goes online to learn something new). Here, "using media" is presented as a separate theme because of its sheer salience for advocates and self-advocates.

- Online media-related practices include "developing websites," "blogging or vlogging," "getting in touch with other parents on social media," "putting things on a website, editing a website," "reading things on the internet," "making videos, putting them online," "writing a blog," "signing [online] petitions" or simply just "being on social media, Twitter or Facebook." This shows that seemingly mundane practices such as being on Facebook or "reading things on the internet" are in fact part of one's advocacy.
- Offline, more traditional types of media contents are also produced by participants. These include "making films"—which can be shown at trainings or conferences as well, but may also be put online—"writing up articles" or "writing articles or books," or "making and using leaflets and fliers."
- Importantly, the production of media content includes specialized or adapted information. In intellectual disability or autism advocacy the design of media content should be accessible to as many people as possible, including those with an intellectual disability or other types of learning difficulties. Several such practices were mentioned, including "making the internet accessible for self-advocates with ID" "structuring information," or "making information accessible to everyone." Notably, these practices were mentioned in relation to all audiences that may need adapted or accessible content, including parents of disabled children and autistic people.

3. A third theme is closely related to solidarity, reiterating Reckwitz's definition on practices that includes "states of emotions" (2002)—this theme can be labeled as "supporting each other" or "being in the community." Supporting each other is a known concept, relating to forms of peer-support that have been appraised in previous research (e.g., Brown, Shepherd, Wituk, & Meissen, 2008; Carter, Moss, Hoffman, Chung, & Sisco, 2011; Van den Bosch et al., 2018). Here, practices articulating forms of support and solidarity were mentioned in various contexts.

- Solidarity is often practiced through giving or accepting help. Help was mentioned as "helping each other," "helping autistic peers," "supporting clients emotionally," "supporting our children,", "supporting self-advocates," "protecting your peers," "getting help to protect ourselves," or "supporting each other, even just solidarity."

- Supporting others or belonging to a community were frequently framed as correspondence or just "being in touch" with others, for example, "networking, meeting others," "speaking with others," "getting in touch with other parents on social media," "bringing together parents," or "going to conferences and meeting others." Being in touch with peers is a practice that enables people to exchange information, but also to give or to get support, "even just solidarity." This theme demonstrates that communication with peers in any possible ways—online or offline—is an integral practice of advocacy that has important emotional properties for parent advocates and self-advocates as well.
- This theme has less salience for professional advocates, however they also mentioned practices outside their strictly understood job descriptions, for example, "visiting families" or "giving emotional support" to their clients. Notably, for professionals, supporting others means not the support of people of the same group (other professional advocates) but of people with disabilities and their families (clients).

4. Not surprisingly, one of the most salient themes among practices was "speaking up," phrased in various different ways. In previous research, "speaking up" is widely used as a blanket term to describe the main, essential element of all disability advocacy practices (e.g., Buchanan & Walmsley, 2006; Chapman et al., 2012; Goodley & Ramcharan, 2010; Malinga & Gumbo, 2016; Walmsley, 2002); however, in this analysis it is only one among several types of practices that advocates do as part of their advocacy. Notably, in participants' accounts, "speaking up" included practices done by nonverbal people, for example, by using alternative communication.

- Practices under "speaking up" were sometimes mentioned as general statements such as "standing up for our rights," "protecting rights," "representing the interest of the whole family," "doing nothing about us without us," "not accepting refusal by authorities," "entering confrontations or conflicts," "going to authorities," or "influencing policies or laws."
- Often, "speaking up" was framed as an actual advocacy action, for example, "telling politicians what we want," "organizing rallies," "doing street actions," "organizing conferences," "going to ministries or city councils," "litigating cases," "going to tribunals," "participating in formal government consultations," or—for some professional advocates in Britain—"doing NHS complaints."

5. Finally, certain practices related to generic *organizational / bureaucratic duties*, present in all organizations regardless of their nature. These practices are assumed to be more relevant in formalized advocacy and self-advocacy than in individual advocacy or in informal group advocacy. Practices under this theme include "managing an organization," "competing with other advocacy organizations," "paperwork and administration of cases," "paperwork at organizations," and "establishing an organization." This theme was less salient for autistic self-advocates where only one practice "administration in organizations" was mentioned. This difference can be explained by the fact that almost all autistic participants worked outside formalized organizations. Self-advocates with a learning disability did not mention organizational duties at all, which suggests that those involved in self-advocacy groups may not be involved in administrative duties.

The analysis found an overlap between practices of different groups of advocates and self-advocates (see Table 3).

This finding suggests that the ID and autism movement may have features similar to "CoP" (Wenger-Trayner & Wenger-Trayner, 2011). CoP is a known phenomenon in educational theory which emphasizes the importance of experiential knowledge and implicit learning. CoPs are usually defined as "group of people who share a concern or passion for something they do and learn how to do it better as they interact regularly" (Wenger-Trayner & Wenger-Trayner, 2011, p. 1). CoPs—such as collectives or organizations where people share information, learn, develop skills, and so on—are also characterized by implicit forms of learning and *tacit knowledge* (Duguid, 2005), which are core concepts acknowledged by practice theorists as well (Collins, 2001; Schatzki, 2001; Turner, 1994). Tacit knowledge may be an important realm of skills or know-how that allows advocates and self-advocates to practice advocacy. Skills and information needed for (self-)advocacy may be learned tacitly, for example, through shared practices, discussions, or just by "being in the community." The know-how of advocacy practices may be profoundly shaped by tacit knowledge and implicit learning, and their importance may match that of formal education. Future research should provide deeper analysis to explore how the diffusion of knowledge happens within advocacy collectives, and how forms of learning—including implicit forms of learning—shape the way advocates or DPOs work.

Conclusions

The analysis demonstrates that (self-)advocates do more than just "speaking up." In fact, (self-)advocacy itself is much more than just "speaking up." Most practices, including those under "using the media," "supporting others," "organizational duties" and the sub-theme "learning" go beyond simply "speaking up" and they are not at all specific to disability advocacy but may be present in many other occupations in the 21st century. These are activities that draw attention to important and less-recognized practices of advocacy and self-advocacy. In fact, they propose an alternative, practice-based definition of advocacy: "advocacy and self-advocacy are a collection of complex, routinely executed actions embedded in everyday practices that may or may not result in speaking up."

Substantial part of everyday activities in advocacy is actually rather generic everyday activities that many people do routinely. Such everyday practices may not be separated from other practices people do, because advocacy and self-advocacy are often woven into other practices. People write, send, and read emails; do "paperwork" or do bureaucratic duties; they spend time on social media to correspond with others; they attend trainings, workshops or conferences; they meet others; they travel to meetings or other events; they read things such as laws, articles or other materials; they organize meetings; they support others, for example they talk things through with them or they just simply give signs of solidarity. The list could be continued almost

Table 3 Examples of overlapping themes per participant group

	Professional advocates	**Parent advocates**	**Autistic self-advocates**	**Self-advocates with intellectual disability**
Informing and being informed	Learning about human rights and the movement Going to trainings/ workshops Teaching about various issues Telling people about their rights Running legal aid services	Reading the law Developing skills (law, financial, leadership, negotiation skills, etc.) Teaching advocacy skills Giving trainings to professionals Being on social media, Twitter, or Facebook	Telling people what autism is (and what it is not) Passing on information to non-autistic people Myth-busting about autism Reading on autism and other stuff Developing new skills, learning	Passing on information Learning to introduce ourselves Getting to know ourselves and others, or our environment Learning how to handle money Giving trainings Learning things
Using media	Making and using leaflets, fliers, etc. Making Internet accessible for SAs with ID Making sure information is accessible to people Talking to media	Writing a blog Writing books, articles Being on social media/ Twitter/Facebook Getting in touch with other parents on social media Speaking in the media	Giving interviews in media Making videos, putting them online Developing websites Blogging, vlogging Being active on social media Doing graphic design	Putting things on a website, editing a website To read things on the internet Writing up articles
Supporting each other/being in the community	Visiting families (of autistic children) Giving emotional support to clients	Speaking for other families Going to conferences Bringing together parents Supporting self-advocates Supporting "our" children (incl. in other families)	Working together as a community (with autistic people) Supporting each other, even just solidarity Helping autistic peers Sharing experiences with peers	Helping each other Giving voice to peers Getting help to protect ourselves Speaking with others (incl. peers) Going to conferences and meeting others
Speaking up	Organizing rallies Pushing for legal changes, lobbying Participating in drafting laws & policies Going to ministries and city councils Litigating cases Going to tribunals	Writing letters to authorities Protecting rights Representing the interest of the whole family Trying to change the law, lobbying Not accepting refusal by authorities Influencing policies and laws	Fighting for benefits Issuing statements (in the policy context) Defending rights, using the law Starting or signing petitions	(Practicing the) Nothing about us without us (principle) Standing up for our rights every day Gaining confidence and be visible in the world Telling politicians what we want
Organizational/ bureaucratic duties	Paperwork, administration of cases Participating in government consultations Managing an organization	Organizing meetings Establishing an organization Traveling a lot (e.g., to conferences)	Administration in organizations	–

infinitely depending on advocates' personal lives and chosen activities. Importantly, people do all these practices in various possible combinations, appropriate to their lives, preferences, choices, skills or resources available to them.

Advocacy and self-advocacy are much more than just practicing "speaking up." These other "para-advocacy" activities include routinely done practices that may take up significant amount of time and resources of advocates and self-advocates. Here, the suggested term "para-advocacy" refers to practices that are indeed integral part of above-analyzed practices of "advocacy" but they are also practices that are not "speaking up," which is a widely used lay-definition of advocacy. Importantly, these activities should not be seen as purely auxiliary to "speaking up." Participants' statements indicate the contrary: "para-advocacy" practices are in fact necessary to "speaking up" or integral parts of being an advocate. For example, in order to go to a conference to "speak up," one advocate needs to prepare for the travel, correspond not only with organizers but peers who may be attendees, plan interventions, discuss various details, and so on. All these practices are done routinely and often beyond strictly understood advocacy activities. Using Reckwitz's statement about agents who "consist in" routinized practices (Reckwitz, 2002, p. 257), it is the assertion of this paper that self-advocates and advocates may also "consist in" practices they do, and the line between advocacy and other practices is often blurred in their lives.

What Are the Emerging Themes among Practices that Members of the Intellectual Disability and Autism Advocacy Movement Do?

Analysis revealed five common themes across practices which included the previously dominant definition of advocacy "speaking up," but also other themes such as "informing and being informed," "using the media," "supporting others or being in the community," and "organizational duties." This suggests that significant parts of what advocates and self-advocates do are in fact "para-advocacy" practices embedded in people's everyday routines. Similarly to Warde's observation on consumption (Warde, 2005), which is "not itself a practice but rather a moment in every practice" (p. 137), it is possible that advocacy practices are not always practices themselves, rather moments or actions embedded in other practices. When a self-advocate or a parent of a child with an intellectual disability goes online to chat with peers, it may be crucial for the advocacy they do, although the activity itself may not be seen as "(self-) advocacy." Also, a one-time action by a (self-)advocate may become a practice over time but as a single event might not be intended or seen as part of advocacy, even by the very actor who does it. Thus, the line is often blurred between what is recognized to be part of advocacy or self-advocacy ("speaking up") and what members of the movement do (various para-advocacy practices). These tacitly but regularly done para-advocacy practices include consuming and producing media content, the use of social media, supporting others, or informing and being informed. The use of media is a salient practice across the disability movement, yet it is rarely researched (Trevisan, 2016). Further research on media-related advocacy practices should explore how advocates and self-advocates use and rely on the media in the fight for social inclusion. Advocacy and self-advocacy may also include significant bureaucratic duties. The importance of para-advocacy practices relating to (self-)advocacy calls for a renewal of previous definitions.

Is There Difference Between the Practices Self-Advocates Do and Practices Other Advocates Do as Part of Their Advocacy?

This question was concerned with historical differences between groups of members of the advocacy movement, such as parents, professionals and self-advocates. Only slight differences appear between what different participant groups do as part of their advocacy. This finding suggests that roles currently occupied dominantly by a specific group of advocates can be occupied by members of another group as well. For example, although common knowledge may suggest that delivering training is something that mostly professional advocates do, in fact training and lectures are already delivered regularly by self-advocates with ID, autistic people and parent advocates as well. This finding may also suggest that historical differences and power imbalances between groups of advocates (such as parents, professionals and self-advocates) are not present purely because a certain group is unable to engage with core practices of advocacy. If the majority of practices integral to advocacy are already done by both disabled and nondisabled members of the movement, then power imbalances within the movement may have explanatory factors outside the presence of the disability one has. It is possible that self-advocates' participation in the disability movement is hindered by other factors—such as skills and necessary resources. This assumption is supported by practice theorists' observation that practices may be in hierarchical relationships with one another. For example, Warde (2005) claimed that different practices may involve different rewards where "contrasting understandings, levels of practical competence, and degrees of involvement generate behavioural variation" (p. 147). Indeed, some differences between advocacy practices may be explained by different "degrees of involvement" in the disability movement.

For example, while skills required for practices like "attending meetings," "being on social media," "meeting peers," "writing things up," or "passing on information" are often available to most (self-)advocates, other practices need solid technical knowledge: "making videos," "litigating cases," "managing an organization," "organizing rallies," and "graphic design." Further research could investigate the complex relationship between self-advocates' roles in the disability movement from the perspective of available skills and trainings that enable self-advocates to occupy roles needing more technical knowledge. It is possible that self-advocates may be excluded from certain roles (including leadership roles) not merely because they do not have the potential skills or even experience to occupy those positions, but because formal trainings, formal qualifications or "learning from practice" are not available to them.

Related to skills, different practices may also demand different resources. One can only do practices that one has the necessary resources for. The spectrum can be quite broad: some practices are done with minimal material, financial, or human

resources, while others are very resource demanding. For example, while "writing letters" requires relatively minimal resources, "going to conferences" or "going to trainings" may involve substantial costs for travel, registration fees or accommodation—which may exclude self-advocates or parent advocates from the possibility of joining those practices. Further research could focus on internal disparities within the ID and autism advocacy movement in terms of available resources. Individuals' income, the availability of paid positions within the movement, and costs of doing advocacy practices (including the costs of "para-advocacy" practices discussed earlier) may influence strongly the level of involvement of self-advocates within the movement. It is possible that many self-advocates, although they have the will and skills to do advocacy, are hindered from doing advocacy practices for financial reasons or because paid positions at organizations are not equally available to them. It is also possible that available resources including paid positions and technical equipment are not equally controlled by advocates and self-advocates, and professional advocates and parents may still control most available resources. This problem is also related to hierarchical relationships between different groups within the disability movement (see, e.g., Aspis, 2002; Meyers & Lockwood, 2014; Petri et al., 2017). It is likely that power imbalances between parents' groups vs. self-advocates, professionals vs. parents, and so on continue to silence people by making certain positions (or practices) unavailable to them. Further research is needed to verify these assumptions.

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