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# **Management, leadership and user control in self-advocacy: an English case study**

## **Abstract**

This paper presents findings from a qualitative research project on an English self-advocacy organization. In light of recent political and economic developments that have threatened the sustainability of a number of self-advocacy groups for people with intellectual disabilities, I seek to explore how one particular organization managed to survive and grow. In particular, the paper explores themes of management, leadership, and user control, linking these to external perceptions about self-advocacy organizations. The organization in my study developed an ‘interdependent’ governance model based on key organizational roles for non-disabled advisors and self-advocates which proved popular with external funders. Despite the organization’s notable achievements, their success raises questions for the wider self-advocacy movement, notably how leadership capacity can be developed amongst self-advocates.

## **Introduction**

Self-advocacy for people with intellectual disabilities has been described as “people coming together to speak up for themselves” (DH, 2009: 96). Self-advocacy has been posited as an activity, a process, and an outcome; a space in which people with intellectual disabilities can develop not only their confidence, skills and leadership capacity (Caldwell, 2010), but also a collective identity, providing an essential foundation for grass roots activism (Goodley, 2005; Bylov, 2006; Siska, 2006; CEPF, 2012). Studies have highlighted the ‘transformative’ potential of self-advocacy in supporting people to challenge normative assumptions about intellectual disability (Goodley, 1997; Beart et al 2004; Tsuda and Smith, 2004) and for providing opportunities for people to expand their social networks and develop long-lasting friendships (CEPF 2010; Changing Our Lives, 2010).

In England, self-advocacy gained momentum with the publication of *Valuing People* in 2001, the first White Paper on intellectual disability for 30 years. Although *Valuing People* had cross-party consensus, its focus on rights, independence, choice, and inclusion mirrored the wider New Labour vision of ‘third way’ politics - a renewal of social democracy which embodied a middle ground between the market individualism of neo-liberalism and the collectivist state-centred approach of past Labour governments (Giddens, 1998; Newman 2001). In the realm of intellectual disability, service users were invited to contribute to decision-making and planning at the national level by linking to the government’s learning disability Taskforce, through the National Forum<sup>1</sup>. Local authorities were required to establish Learning Disability Partnership Boards (LDPBs), with high hopes for their potential to truly involve users and carers in the development of services (Fyson and Simons, 2003). Self-advocacy was seen as vital to support the inclusion of people with intellectual disabilities, and central government funding was made available to develop its capacity (Ramcharan, 2005). In this context, Dearden-Phillips and Fountain (2005) argued that self-advocacy took the ‘leading role in shaping the way people with learning difficulties and statutory providers communicate’ (2005: 200).

As self-advocacy gained political attention, researchers began to reflect on the relationship between self-advocacy and the state (Buchanan and Walmsley 2006). While the focus on advocacy (and the associated ring-fenced funding) in the White Paper clearly signaled the influence and achievement of advocacy champions in England, others highlighted concerns that self-advocacy might inadvertently become a ‘service’ (Aspis, 2002; Chapman, 2005; Buchanan and Walmsley 2006). Goodley wrote about state sponsored advocacy:

It seems so at odds with some of the more radical elements of the movement. Many key players from self-advocacy are pulled into boards, consultation programmes and user consultation

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<sup>1</sup> The National Forum of People with Learning Difficulties has a regional network and membership of the National Learning Disability Programme Board, chaired by the Minister for Care Services

contexts. As they leave, so the political core of self-advocacy is at risk of being ripped out of the movement. Our key activists become key consultants. The resilience of activism is lost with them. (2005: 342)

The contention is that as self-advocacy moves up the political agenda, people with intellectual disabilities run the risk of being co-opted into working for commissioners and service providers, rather than for themselves. This is in spite of the fact that people with intellectual disabilities have made it explicitly clear that they view self-advocacy as an important mechanism to improve aspects of their lives that are **not** directly related to intellectual disability services (Aspis 1997, 2002; Lawton 2007). Funding via projects initiated by government bodies with associated contracts or Service Level Agreements creates uncertainty about what happens when the money runs out. Indeed, a national survey of self-advocacy and advocacy groups in England discovered that many groups were under significant financial pressures despite a rise in demand following cuts to welfare and services (A4A 2011). A survey of groups in one English region showed that only a small number of self-advocacy groups had survived recent funding cuts (CEPF 2012). A Government published report for self-advocacy organizations, encouraged them to take a more strategic approach (National Forum 2011). The report confirmed the suspicions of earlier commentators when it suggested:

Your group may not be able to do exactly what you want to if you still want to get public money. Some self advocacy groups don't want to be "service providers", but may need to think more about this in order to survive. (National Forum 2011: 32)

In a difficult climate for self-advocacy, it is important to consider factors that enable some organizations to survive while others fold. Numerous studies have explored different typologies of advocacy organizations, frequently drawing distinctions between those that are 'service-based' and 'independent'

with an assumption that independent organizations are more 'self-advocate-centred' and thus afford people with intellectual disabilities more power and control (Crawley 1988; McNally 2002; Tsuda and Smith, 2004). The term 'independent' is also used to describe self-advocacy organizations that have people with intellectual disabilities in positions of authority. Many such groups constitute themselves as 'People First' organizations, following in the footsteps of the early pioneers (Buchanan and Walmsley, 2006; National Forum, 2011). People First organizations are generally underpinned by key principles which include being led and controlled by people with intellectual disabilities. This means that self-advocates hold roles such as Chief Executive, Treasurer, or Chair of the Board, and thus have ultimate responsibility (and liability) for organizational issues such as employing support staff; managing funds; and ensuring the organization is legally compliant (Chapman 2005; Chapman and Tilley, 2013).

A small number of researchers have addressed questions about organizational structures, values, tasks and responsibilities, and the nature of support (Goodley, 2000; Clement, 2003; Beart et al, 2004; Chapman, 2005). Clement (2003) recorded that the organizational rhetoric of 'control' did not always mirror his observations of group meetings and management processes, and witnessed internal tensions that often threatened to stall the group's work altogether. Others have drawn attention to power issues at the heart of the support worker role (Goodley, 2000; Chapman, 2005; Chapman and Tilley, 2013) reflecting concerns raised by the earliest self-advocacy 'advisors' (Williams and Schoultz, 1982; Hersov, 1996; Tsuda and Smith, 2004). These studies demonstrate the ways in which self-advocates and non-disabled advisors negotiate the precarious balance between support and control; while official organizational discourses stated firmly that self-advocates were in charge, the empirical data revealed a more complex picture.

Although the independent model of self-advocacy espoused in much of the literature points to the importance of people with intellectual disabilities running their own organization, much of the history of self-advocacy is one of alliances between those with the label of intellectual disability, and those without

(Hersov, 1996; Chapman, 2005; Siska, 2006). While Bylov's (2006) research on the Danish self-advocacy movement points to 'generations' of self-advocacy, ultimately leading to full control by people with intellectual disabilities, Tsuda and Smith (2004), based on their research in Japan, propose an alternative 'interdependent' framework, one in which the mark of a mature self-advocacy movement is evidence of reciprocity and equality between self-advocates and advisors. They argue that while the 'independent' model of self-advocacy that proliferates much of the literature may be aligned with the values of autonomy and freedom of opportunity that are at the heart of many modern societies, it is also important to consider the interpersonal tendencies that people display in group situations. Tsuda and Smith suggest that the danger of promoting an independent model of self-advocacy above other typologies is that:

Such a focus does little or nothing to address the physical and attitudinal barriers presented to people with disabilities by society and, as such, does nothing to confront the ableist ideas and practices that continue to exist (2004: 629)

Indeed, they suggest that for self-advocacy organizations to make an impact on community issues, it may be necessary to harness and support interpersonal tendencies – both between self-advocates, and between self-advocates and advisors, and acknowledge that a successful self-advocacy organization may not necessarily be one in which people with intellectual disabilities hold particular roles, but rather one in which the individual interests and expertise of both advisors and self-advocates are utilized to develop a more effective partnership.

The research I conducted for my PhD project in 2004-2006 aimed to build on these studies, with the specific intention of collecting data from a self-advocacy group that did not identify itself along the 'People First' model, to explore whether the underpinning ethos and approach was different from those

reported in existing studies (both in the UK, and internationally), and to consider the implications for people with intellectual disabilities. The two key research questions that informed the study were: ‘What are the tensions and challenges that arise in the practice of self-advocacy?’ (providing a focus on organizational roles, structures and values), and ‘How do relationships with external stakeholders influence the practice of self-advocacy?’ (providing an opportunity to explore the interface between self-advocacy and the wider social, political and economic context). However, in the period after the research, I became increasingly interested in how and why the organization continued to flourish when others were winding down. As such, I revisited my data alongside the growing body of literature on self-advocacy to explore what factors may have led to the long-term success of the self-advocacy organization at the centre of the study. In this paper I focus on the organization’s leadership and management, the extent of self-advocates’ organizational control, and the implications for the group’s ability to manage the rapidly shifting policy and funding environment, both during the period of data collection, and in the time after.

## **Methods**

The research was conducted in a self-advocacy organization in the South of England. It started life under the umbrella of a wider advocacy organization in the mid 1990s and in 2000 the self-advocates, with their advisor, decided to constitute the group as an independent organization, with one paid (non-disabled) advisor. That advisor was Chief Executive when I conducted the research, and continues to hold this role at the time of writing (2013). At the time the research was conducted there were a further two paid non-disabled advisors (funded through projects) and one paid administrator. The Board of Trustees, including the Chair, comprised local volunteers who were non-disabled, and the Management Committee (with responsibility for operational issues) was made up of self-advocates who were supported by the advisors. The Board and the Management Committee met every few weeks to make key strategic decisions. The organization worked to develop self-advocacy with approximately 200 people with intellectual disabilities in the local area through a network of smaller self-advocacy groups, but a ‘core’ membership of about

fifteen self-advocates were involved in running the organization with the advisors. The organization received funding from a range of sources but was primarily reliant upon funding from the local authority.

Acknowledging Miller's observation that 'different qualitative methods provide researchers with different possibilities for 'knowing' the social settings that they describe and analyse' (1997: 1), I developed a multi-method research design to undertake this research, with an emphasis on semi-structured interviews, alongside observation of the group and documentary analysis of organizational material. My data were collected simultaneously, creating processes in the research that were 'iterative and overlapping' (Turner, 1988: 110). Using a grounded theory approach (Strauss and Corbin 1990), findings that emerged from one method fed into the collection of subsequent data via another method, as I gradually built up a complex picture of organizational life. I approached the research inductively as there was no overarching theoretical framework for the practice of self-advocacy, although the research was informed by previous studies that had uncovered various facets of self-advocacy organizational structures, values and support (Clement 2003; Tsuda and Smith, 2004; Chapman 2005).

In total, I conducted 14 interviews, with self-advocates from the group, advisors, members of the Board of Trustees, and local commissioners and learning disability service managers (see Table 1 below).

Respondents were found through network sampling, in which interviewees were obtained through referrals among people with similar characteristics (Bloch, 2004); and by identifying 'key informants' (Seale, 2004). My commitment to obtaining multiple perspectives about self-advocacy – both within and outside the organization – encouraged me to locate as many participants as possible, until I felt that I was approaching 'saturation' point (Dipex, 2005). I was interested in interviewing individuals who would provide a cross section of views, both at different levels within the group, and also within the local social services. Some interviews were conducted jointly, indicated by a '\*' in the table. Interviews lasted between half an hour and one and a half hours, and were conducted within a range of settings (including offices and day services). An interview guide was developed, with approximately six broad question areas



used as prompts for discussion (such as exploring how someone came to be involved in self-advocacy), rather than a set of specific questions that were repeated across all interviews. All of the interviews were tape recorded with signed consent. I observed nine organizational meetings during the research and spent time ‘hanging around’ the office, getting to know people. In total, I observed the organization for approximately 30 hours. I was also granted access over a two day period to read organizational documents, including publicity material, annual reports, and research projects undertaken by the group.

Table 1:

Respondents from the self-advocacy group (SAG)  (in chronological order of interviews)	Respondents from Local Council (in chronological order of interviews)
<p><b>SAG 1a</b> Chief Executive</p> <p><b>SAG 1b</b> Chief Executive</p> <p><b>SAG2*</b> Self-advocate</p> <p><b>SAG3*</b> Self-advocate</p> <p><b>SAG4</b> Self-advocate</p> <p><b>SAG5</b> Self-advocate</p> <p><b>SAG6</b> Advisor</p> <p><b>SAG 7</b> Advisor</p> <p><b>SAG 8</b> Chair of the Board</p> <p><b>SAG 9</b> Self-Advocate</p>	<p><b>LC1*</b> Valuing People Strategy Manager</p> <p><b>LC2*</b> Executive Manager of the Integrated Learning Disability Services</p> <p><b>LC3</b> Head of Adult Disability and Mental Health Services</p> <p><b>LC4</b> Commissioner for Advocacy</p>

Ethical approval was secured from the Open University's Human Participants and Material Ethics Committee. Ensuring fully informed consent in research with participants with intellectual disability has been raised as a concern (Rolph, 1999), so accessible information and consent sheets were prepared. I viewed consent as an *ongoing process* and revisited this with participants at different points in the research. Ethical dilemmas at the heart of this research, particularly the question of anonymity, have been covered in more depth elsewhere (Tilley and Woodthorpe, 2011).

### ***Data Analysis***

I analyzed the data using a broadly thematic approach. In line with a modified grounded theory methodology, some codes were anticipated (such as advisor concerns about assuming too much power), but many emerged through the course of the data collection and analysis (for example, the use of humour and drama to break down barriers between self-advocates and external partners). I immersed myself in the data both during and after my time in the field. I read, reflected, and re-read the transcripts, documents and field notes until I had become familiar with the data. I examined the ways in which organizational values and rhetoric were espoused through documentary sources (such as annual reports) and compared this to the data that emerged in interviews. The analysis process involved constant comparative work – both within my own data, but also with other research in the literature. I was also alert to ‘deviant’ cases that arose (Locock, 2005). I then began coding the data into broad categories and went on to develop sub-themes that I felt best reflected significant issues arising from the material. In particular, I was exploring the meanings attached to these themes by different participants. For example, I contrasted how respondents narrated their experiences with organizational rhetoric, and discovered a number of tensions between espoused values and practice. By the end of the analysis stage, I had made an initial attempt to develop categories that illuminated my data; ‘saturated’ those categories with many appropriate cases in order to demonstrate their relevance; and developed those categories into more general analytic frameworks with relevance outside the setting (Denzin and Lincoln, 2003; Silverman, 2000: 179).

## **Exploring the data**

The group described itself in official documentation as being ‘user-led’, while frequently highlighting the importance of their ‘team approach’. In practice, members produced a variety of accounts with regard to how their organization was managed and led, suggesting that the language of ‘user control’ and notions of the ‘team’ were ambiguous and may have disguised as well as shed light upon certain organizational processes. However, the findings suggested that the group’s structure and ethos was appealing to external stakeholders. The data is organized around four key issues: the boundaries of user control; the ‘team’ discourse; reluctant leaders: advisors narrating themselves out of their role; and external perceptions: the ‘reasonable face’ of self-advocacy.

### ***The boundaries of user control***

When discussing the organization’s structure, the Chief Executive said:

*You know in our info pack we describe it with the circles, and in the middle are people with learning disabilities, well, that’s how we see ourselves.*

This was illustrated by one self-advocate, who outlined his participation in the Board:

*Self-advocate: And also I’m part of the, also I come to the board meetings.*

*Author: And what do you talk about in those meetings?*

*Self-advocate: We talk about just about anything and everything to do with the organization, don’t we? We talk about funding, money, then the finances come out, and we see how much, see whether we’ve overspent or not spent enough. We talk about new people coming in, and we give our apologies if people aren’t there.*

I observed one Board meeting. My sense was that self-advocates did contribute to this meeting, but at times the pace was too fast for them to be meaningfully involved. Some trustees did not convey information in a way that was particularly accessible (in particular the Treasurer's report), and this seemed to impact upon the level of self-advocate participation. However, it was also clear that the organization had a significant amount of work to get through within the timeframe available. Two hours were scheduled for the meeting (which took place in the evening to ensure that more people could attend), and the group only just managed to deal with all of the items in time. Alternatively, fully explaining all the elements of the organization's finances to self-advocates may not have been a priority issue for the Board member responsible for the organization's budget. This revealed a tension concerning the boundaries around the involvement of self-advocates in the running of the organization and the level of financial detail they were perceived capable of understanding. It also raised questions about the Board's commitment to user involvement, and why the meetings were not structured in a manner that allowed more time for discussion.

In the quotation below, the Chief Executive outlines the historical position of the Management Committee at the organization:

*That group of people were more involved in the organization, the development of where we are, what should we do, what should we take on.*

This suggests that the Management Committee had played an important role in influencing the direction of the organization. I observed two Management Committee meetings. Unlike the Board meeting, these meetings were conducted at a slower pace, permitting more time for self-advocates to discuss agenda items. In contrast to the Board meeting, self-advocates were more vocal in the Management Group meetings, which may suggest they perceived them as being a 'safer' environment in which to raise and

debate issues. Self-advocates were consulted on a range of management decisions, including bidding for new contracts. For example, the group had a lengthy discussion about the challenges involved in tendering for a self-advocacy contract in another locality<sup>2</sup>. The self-advocates argued that despite the difficulties, they believed they should still pursue the contract.

This example, and others I witnessed, indicated that self-advocates were not just consulted on a particular issue, they also had the final decision about which course of action to take. This demonstrated the advisors' belief that self-advocates who are involved in the Management Committee take on a significant amount of responsibility within the organization:

*They're all really professional. You know, there's lots of people and they say 'yeah, I want to be more involved', and we say 'yeah, great, come along'. But then in reality, they want to go to Gateway, or to a disco. Because if you've committed to be involved in the Management Committee, you need to go to those meetings to talk about budgets... the Management Committee isn't a pretend thing... people in the Management Group have responsibility.*

The advisor was keen to emphasize that the Management Committee is 'real', playing a genuine role in the organization's development. This comment reflected consistent messages from advisors in interviews and observations that self-advocates were active (and valued) agents involved in shaping the organization for the benefit of the wider constituency, drawing on their particular areas of expertise. The Chief Executive reiterated this on a number of occasions, for example:

*we got ourselves into a situation where there was a lot of pressure on a small group of people... And so we've now started to split things off a little bit... so we can move away from a situation where people are*

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<sup>2</sup>During the period of research, some local authorities in England began tendering for 'self-advocacy services', rather than issuing funding grants. Self-advocacy organizations thus found themselves in competition for local funding.

*seen, or are expected to be experts at everything. So people will learn as they develop their skills and interests, to focus on something that's particularly interesting for them, or that they feel they're good at.*

This principle of developing people's specific expertise arguably helped the organization to avoid the position described by Clement (2003) as 'absurd', in which self-advocates are expected to undertake all manner of organizational activities in ways that would not be expected of people without learning difficulties working in similar organizations.

### ***The 'team' discourse***

Through observing internal management meetings, I gathered evidence of significant self-advocate participation in decision-making processes. However, many of the items discussed were *initiated* by the advisors. It appeared that they were the people through whom knowledge from the external environment (particularly the local authority) was channeled back to self-advocates. Receiving information in this way may have had implications for the level of control self-advocates had in prioritizing organizational issues and concerns. In addition, the Chief Executive dealt with a number of practical (and necessary) organizational tasks, which she described as 'the things that need to be done so that the group can work properly'. This indicates that boundaries existed with regard to *how* and *where* service users were 'in control', 'leading' or 'participating' in the group's development. This was framed in official rhetoric around the notion of the 'team' in which it was contended that people take on different roles within the group, depending on their particular expertise:

*Teamwork works and we are a team that works.*

(Annual Report, 2005-2006)

However, the language of a 'team' might be viewed as ambiguous. The Chief Executive's frequent use of 'we' when describing how actions were taken and decisions made at the group, was illustrative of such ambiguity. When pursued about this, she said that it was not the first time that she had been asked about it:

*I'd worked with people with learning disabilities for a lot of years, and when I worked in one place, one of the people said 'whenever you talk, you always say "we did this" or "we went there", who do you mean?', and I said 'people with learning disabilities'. And it was just so natural to me...there was nothing I was doing on my own, there was nothing that I could achieve on my own. It's a 'we'!*

She appeared to use language such as 'we' and 'the team' so as not to distinguish her work from that of self-advocates. On the one hand this reflects a political position in which non-disabled people's contributions are not privileged above those of people with intellectual disabilities. Indeed, the advisors all acknowledged that their jobs were dependent upon people with intellectual disabilities being committed to self-advocacy and continuing to require their assistance. However, while the notion of a team was raised in interviews, none of the self-advocates expressed explicit views on it. Without their perspectives, it was difficult to establish the extent to which self-advocates had chosen to cede control of certain organizational processes to the advisors, or whether these decisions had been made on their behalf.

#### ***Reluctant leaders: advisors narrating themselves out of their role***

In contrast to People First self-advocacy organizations, it was the non-disabled (paid) advisors who held formal job titles. This included the role of Chief Executive, which (symbolically at least) denotes a position of leadership. However, the Chief Executive was keen to stress that the advisors rarely use these titles:

*We very rarely use job titles when we go out. As far as we're concerned, we're the (organization name) team, but we have to have job titles for lots of various reasons. So I carry the very grand name of 'Chief*

*Executive’ (laughs), which I use very rarely. And then there’s our administrator and our project coordinators, who work on involvement and inclusion.*

The Chief Executive suggested that while job titles were not an indication of hierarchy within the group, relationships with external stakeholders made the adoption of such titles an organizational necessity. By focusing the narrative away from the titles adopted by the advisors, she seemed to acknowledge the implicit tension between her role as Chief Executive and the organizational ideal of user control.

While the Chief Executive appeared to introduce the idea of the ‘team’ in her narrative to emphasize parity among different organizational members and to highlight self-advocates’ valued social roles (see Chapman and Tilley 2013 for further discussion), the self-advocates frequently offered a different picture – one in which the advisors (and the Chief Executive in particular) were conceptualized as having influential roles within the organization. This suggests that, despite advisors’ attempt to narrate themselves into less prominent positions, self-advocates may still have perceived the advisors as ‘running’ the organization:

*Author: So when did you first get involved with the group?*

*Self-advocate: In 2000. Yeah, and the first three team members I got involved with were ...  
(names three advisors)*

The point was reiterated later in the interview:

*Author: Ok, so how did you get more involved?*

*Self-advocate: Well I was actually asked by (an advisor), one of the founder team leaders, if I’d like to help them out with some of the projects they were doing at the time.*

While the research demonstrated that people with intellectual disabilities played a role in shaping the development of the organization, the advisors continued to hold important positions of influence and the



Chief Executive stood out as being a particularly significant key player. The Chair of the Board commented:

*I think it was, well, a lot of it was down to her, and her huge professionalism. Once she started networking, the proof of the pudding was, you know, what she delivered was of such high standard...my key role is to support her.*

Some self-advocates also highlighted the Chief Executive's important role. One person described her as co-running the organization in the early days with a service user, although she was quick to dismiss this herself. The Chief Executive was regularly spoken about in positive terms by the self-advocates. One person recalled the time when he and another self-advocate approached officers at the local integrated learning disability team for help in organizing an event for her. The gathering was kept secret from the Chief Executive and was intended to thank her for her work with the organization. This story suggested that the self-advocates both acknowledged and appreciated the responsibilities she took on. The Chief Executive described this event as an example of 'self-advocacy in action', because organizing it required initiative, confidence and the ability to utilize connections. The story might also denote self-advocacy in another form. Organizing the event symbolized the self-advocates' valuing of the role taken on by the Chief Executive – a role that they appeared happy to endorse in the belief that she supported the organization to meet members' shared aims.

### ***External perceptions: the 'reasonable' face of self-advocacy***

In interviews with those outside the organization, statutory officials emphasized that the organization had 'won over' stakeholders initially hostile to service user involvement through their use of humor. One person added that this also enabled the groups to raise serious points that challenged services in a manner which avoided confrontation:

*The other strength I see with them is they have a reasonably artistic, dramatic approach, and they are able to convey messages in an entertaining, humorous and non-threatening way. At last week's Partnership Board they had a stint they did jointly with carers on care management. And it took the form of a discussion between a few people who were trying to work out what the care manager is. 'Oh, I think I'd like to have one of those – I wonder what they might do?'. And actually, there was quite a sharp point to it, and it certainly gave me the opportunity at the end to sort of throw my hands up in self-defence and say 'can't argue with that!' (laughs)*

I observed two Annual General Meetings (in 2005 and 2006), in which managers, professionals and carers were in attendance. At both meetings the organization presented their annual reports 'dramatically', using role-play, sketches, and playing pre-prepared 'films' that 'starred' self-advocates. The presentations included a number of jokes and the gentle teasing of professionals, while making serious points such as the need for sustained funding for self-advocacy. Both self-advocates and advisors emphasized in interviews how their particular style of self-advocacy had helped to ensure that relations with the statutory authority had developed in a way which maximised partnership working between service users and officials:

*whereas historically there's always been fear of advocacy, and self-advocacy, because we're around and about, and people see so much more of the way that we work, and what we do, they don't see us as threatening, even though they see us as quite a strength, if that makes sense. (advisor)*

Another advisor contended that the preparation undertaken by self-advocates had been an important element in enabling them to gain credibility in the eyes of others:

*There's lots of time spent supporting people to make sure that they're prepared, to ensure that they understand the situation that they're going into...The senior managers hopefully very much respect the views of the self-advocates that attend Partnership Board meetings. They work hard at listening, and try*

*to be very positive – and I'm sure that a lot of that comes down to the fact that the self-advocates are perceived as knowledgeable, prepared, and well-supported individuals who are able to represent others, which makes the group essentially a powerful force...*

This point was endorsed by the Local Authority Valuing People Strategy Manager, who added that another strength she perceived was the organization's ability to be 'reasonable' and reflective:

*And I think this is one of the real skills that the group offers to people, because they do a lot of preparation work before anything happens, and before they get into a conversation outside of themselves, and then they do a lot of reflection, and one of the things they have learnt is actually to present arguments in a way that people like us have no argument back! (Laughs). And they're always terribly reasonable, and terribly understanding...The group has it (the skills for negotiation) in spades, they're really very good at it. And they're very **reasoned** about it – they'll go back and think about things, things that have challenged.*

This interviewee added that their approach stood in contrast with her experiences of other self-advocacy organizations, some of whom had adopted more confrontational methods. This corresponds with Buchanan and Walmsley's (2006) observation that managers of social services sometimes struggle to accept the demands placed upon them by consultative exercises that embrace the diversity of people with intellectual disabilities:

*And my experience with a lot of advocacy organizations is that they support people to be angry... and there's a place to be angry – but it's the how. You know, I've seen so many people with learning disabilities marginalized because they haven't got the techniques to use to confront things in well-reasoned arguments. And so they get marginalized and dismissed because they're just being a nuisance.*

(Head of Learning Disability and Mental Health Services)

## **Findings and Discussion**

The self-advocacy organization at the centre of this study managed to survive the challenging economic circumstances that have led others to close. Indeed, they expanded their remit in the period following fieldwork, supporting self-advocates in new localities. Drawing on the findings presented here, it can be argued that the organization's management arrangements and presentation to external stakeholders were important factors in their survival. While the official discourse was of an organization that was user-led, in practice this was an organization that relied heavily on the expertise of its paid advisors, in particular its Chief Executive, who assumed responsibility for many of the key organizational tasks and relationships required to sustain the organization through difficult times. The organization's description of being 'user-led' was not borne out in the research, although the notion of a 'team', in which different organizational members contributed particular areas of knowledge, expertise and experiences was more compelling. There was frequent evidence of advisors narrating themselves out of their roles, which at times disguised how dependent the group was upon their work. However, this kind of talk seemed to arise from a desire on the part of advisors to create valued social roles for self-advocates (Wolfensberger, 2002; Johnson and Walmsley 2010) and to adhere to established orthodoxy about how self-advocacy groups should be run (Dowson and Whittaker, 1993; Whittell et al, 1998; Beart et al, 2004; [www.peoplefirstltd.com](http://www.peoplefirstltd.com) 2012).

In terms of its longer term success, the organization I researched developed a wide range of projects across health, social care, education, transport, leisure and employment, alongside an innovative scheme to support people's 'emotional literacy'. The organization achieved a number of political 'wins' in the local area and provided opportunities for self-advocates to socialize, network and make friends. Indeed, a number of the self-advocates interviewed highlighted how important the group had been in terms of meeting people and 'having fun'. It was also an inclusive organization, working alongside people with high support needs and people from Black and Minority Ethnic groups, addressing criticisms leveled at

other self-advocacy organizations that they marginalize those people who are ‘hard to reach’ (Walmsley and Downer, 1997). Management Committee members were motivated and committed, and I did not find examples of internal conflict, in contrast to other studies (Clement 2003). The organization’s work and approach were clearly valued by commissioners and service providers, as evidenced by the research. This was no doubt in part due to their wide-ranging activities, but it was also a cause for concern that groups who present in a more ‘confrontational’ style may have been penalized as a result. The organizations’s approach was one of ‘negotiation’ in its relationships with outside bodies, which was appealing to statutory officials. However, the ongoing challenge for the organization is how such proximity to statutory stakeholders can be straddled alongside its desire to be an influential and independent player. The research raises questions about the extent to which professionals, managers and commissioners are prepared to accept self-advocates in all their diversity, or whether they are stipulating implicitly that people with intellectual disabilities are trained to behave in ‘appropriate’ - and perhaps uncontentious – ways.

While my intention is not to judge the credibility of different models of self-advocacy and what constitutes ‘good’ or ‘bad’ practice (Goodley 2000) I would suggest the organization in my study moved closer towards the ‘interdependent’ model of self-advocacy described earlier (Tsuda and Smith, 2004), even if the advisors were more reluctant to describe it in this way than self-advocates were. However, Gann (1996) has highlighted the dilemmas facing leaders in voluntary organizations whose position requires them to develop structures and processes that enable those who have traditionally been silenced to speak up and become more participative. The challenge for such leaders lies in avoiding the reproduction of embedded power dynamics where ‘the powerless collude in any attempts to exclude them – in simple terms, by learning to “know their place”’ (Gann, 1996: 67). Of greater concern is how the ‘interdependent’ model of self-advocacy advocacy can support the leadership capacity of self-advocates (CEPF 2012). The ageing of many early self-advocacy pioneers has exposed a worrying lack of younger

self-advocates who have the desire or skills to assume leadership positions in the movement (Caldwell, 2010). Advisors are in a powerful position to facilitate or hinder the level of self-determination that can enable self-advocates to adopt greater control in their organizations and thus develop leadership capacity (Nonnemacher and Bambara, 2011).

The research showed that the boundaries between user control and user participation in the governance arrangements of this self-advocacy organization were frequently blurred. In particular, the roles of influential individuals were contested by different organizational members and there were certainly occasions in which non-disabled advisors appeared to be narrating themselves out of their roles. This may be a result of organizational values which emphasized equality and user control. The very notion of 'leaders' – particularly if they do not have intellectual disabilities – may be seen by some to eschew such principles. The advisors stressed the role played by *all* members in the running of the group, and in this way can be seen to adhere to Block's (1993) notion of a collection of 'stewards' guiding and shaping the group's future. However, the accounts by self-advocates and the group's Chair of the Board suggested that advisors – and more specifically the Chief Executive - were perceived as being leading figures within the organization. The risk in this situation is that while these individuals may be responsible for building the organization into a successful entity, they may also be accountable for its collapse should the group neglect to develop effective succession plans. This is likely to be true of self-advocacy organizations that have long-standing experienced or charismatic self-advocates in leadership positions.

In conclusion, this paper has presented qualitative findings about a self-advocacy group that does not operate along a People First model, but which proved remarkably resilient in the context of an economic downturn that was proving challenging for many self-advocacy groups. The study shows that the management and leadership arrangements within this group did not mirror those espoused in much of the literature, but instead moved closer towards the 'interdependent' model of reciprocity between self-advocates and supporters (Tsuda and Smith 2004). The result was an array of projects that supported a

large and diverse group of people with intellectual disabilities to self-advocate. While this may help to account for its success in terms of its organizational achievements and popularity with funders and service providers, it raises troubling questions for the wider self-advocacy movement which has long advocated the importance of self-advocates being involved, included and respected on their own terms and in ways that may not always be palatable to those in positions of power. Somewhat ironically, it seems that despite the values of rights, independence, choice and inclusion at the heart of the Valuing People White Paper - that appears in principle at least to support the 'independent' model of self-advocacy - an unintended consequence of the political and economic context has been to endorse and help sustain a version of self-advocacy that operates in manageable and 'appropriate' ways, while inadvertently destabilizing more diverse elements of the self-advocacy movement.

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