Advocating for Advocacy

Purpose
This viewpoint considers how austerity and managerialism impact advocacy services. It outlines the many roles advocacy encompasses and the benefits advocating contributes to the rebalancing of power.

Design
This commentary is a viewpoint.

Findings
It is suggested advocacy is poorly funded and access is therefore limited at a time when advocating for autism is most needed.

Originality
This viewpoint extends the current debate around advocacy by considering its core function: solidarity with people seeking adequate support.

Keywords
Advocacy, advocating, autism, managerialism, power, austerity

State of the Nation

The paper to which this is a commentary raises questions concerning the legitimacy of the rhetoric about advocacy for autistic people. The author notes the lack of specific provision. This reflects the general state of advocacy: its import is acknowledged in policy whilst its availability speaks otherwise (Cavet and Sloper, 2004). The scarcity formal advocacy services means rhetoric is reduced to a slogan and autistic people are left with few options. This commentary considers how formal advocacy services might fare in the current economic climate, and considers advocacy to be an act of solidarity.

Austerity will – as the sound bite has it - oblige those in control of society's resources to make hard decisions. The choices to impact the poorest and most vulnerable disproportionately come easily, however. It is likely money will be funnelled *away* from providing coherent advocacy services and *toward* 'core services'; but if giving voice to people is not a core function, what is?

At a time when it is most essential, the need for other voices to be heard is being diminished: the power of local authorities and health commissioners to decide who gets which crumb from what table needs examining: power is increasing and more bureaucratic than previously. Advocates might therefore not only represent autistic people but also common sense. It is families, advocates and activists who ask deep questions about values. As authorities strive to balance the books their warrant to deny autistic people the attitudes and services they need grows. In the age of managerialism, advocating for human needs within inhuman systems is hard.

Advocates and self-advocates are those who contribute to the voices of people being heard by convoluted systems: their work is never ending as they seek to challenge oppression: every generation, it seems, face the same battles. Whilst The Care Act requires local authorities to have advocacy provision for those requiring it (SCIE, 2014), there remains limited access to advocacy provision. If the pitiful absence of local authority responses to the Care Act means advocacy services are not available, SCIE suggest care managers or providers might step in. This is naïve and ignores obvious conflicts of interest (Simons, 1992).

Orsini & Smith examine autism advocacy in Canada: the key to challenging the status quo, they suggest, is mobilisation of voice and knowledge from experience (Orsini & Smith, 2010). Advocacy is often political in nature. This is a challenge in the UK when the number of visits allowed to advocates by funders is often limited. There is a fertile ground for others: when the State steps back, space is free for others to step up: people often do what needs to be done.

The Advocate Spectrum

There are many forms of advocating and advocates have many purposes; a support worker might argue for individual preferences on behalf of a person using services; a Care Manager might work toward better options. The work of advocates is determined by their responsiveness to people they serve. Both small improvements and major changes to lifestyle arrangements might involve advocates.

Simply put, advocates can help the voices of the powerless be heard by the powerful. Fundamentally, advocacy is about speaking-up oneself, with others or through others (Atkinson, 1999). (A helpful overview of advocacy can be found in Goodley & Ramcharan, 2010.) For autistic people, simply getting on with their lives is advocating against stereotype-based ignorance.

Autistic people are often very much able to speak for themselves through words, art and behaviour. Sometimes we might *all* benefit from having someone at our side to offer perspective and support. To be unheard is to have our humanity denied. To deny access to advocacy is to comply with old tropes of autism and identity.

Advocates can support people to find their own voice and a sense of having the right to speak; advocates can speak to people the individual with autism themselves may not feel *able* to speak to. SEAP's Code of Practice sets out best practice for advocates when they support or give voice to others; it provides a useful working definition and provides examples of different forms of advocacy (SEAP, 2015) as well as showing how to avoid advocates acquiring 'power over'. Advocates are allies (Bishop, 2002).

Advocates can be parents, friends, citizens; they can be people using services, they can be peers, paid or voluntary; they can be collectives or groups: they can have other roles as well. Paid workers may view advocates who are volunteers with suspicion whereas advocates who are paid may face conflicts between their paid role and advocating for better support. Advocates align themselves with people they seek to serve. Being an advocate requires one to be person-centred.

Advocates can help people they work with resist identities being imposed by those with other agendas. Advocates spend time working alongside people to establish understanding and preferences; advocates can bridge the discrepancy between what is available and what is required. Advocates can work with individuals or groups. Advocates listen well but often are able to demonstrate competencies at selling, telling or (occasionally) yelling on behalf of others.

The Need for Advocates

Institutions did not close themselves. Castlebeck did not announce Winterborne View was offensive due to poor management and monstrous practice. Existing systems primarily respond to their stakeholders: unfortunately these are often *not* autistic people but commissioners and investors. Advocates can challenge practice by being separate and having clear accountabilities. Today as in earlier decades, families, people caught in the web of serviceland, advocates, activists and academics, all contribute to demands for solutions to problems the establishment doesn't recognise it has.

Professionals and commissioners can find themselves time-sampling little moments of people's lives. They gain many impressions but little insight into the narratives important to people. Those data collected are often unreliable and not valid to argue a quality of life; these data are used to justify the status quo. What we count may not matter to people, and what matters to people may not count to professionals. Data may be required for audit purposes not for autistic people to live meaningful lives (Smull & Lakin, 2002). Advocates can help services and commissioners learn to measure the right stuff. It often seems a place at the table is available only to those with sharp elbows and bloody-minded determination. Not investing in advocacy will result in poorer and more arrogant service systems.

Those children diagnosed with communication deficits are often unheard, as are those placed miles from home. Many parents of autistic children know all too well the hard road they follow involves advocating for basic things, things they might expect to be readily available. Every parent is potentially a powerful advocate for their own child and other families. Advocates may not only amplify the voices and opinions of people they serve but be viewed as sources of knowledge that can help grow the quality of provision. Advocates can easily become a movement, and lead change.

Complexity of Advocacy

Advocacy is a nuanced and skilled undertaking. The opportunities for conflicts are many but the opportunities to learn about self and others are uncountable.

Those with communication issues may require additional support to be heard, and additional time allowed for. Often professional's time is of the essence, the voices of families and people have less emphasis (Gosling & Martin, 2012). It might be decision makers lack the skills to listen well to unique voices, else it might be the age-old issue of those with power not needing to bother to hear. Are advocates able to interpret the views of autistic people and represent them honourably? Are they able to hold power to account?

Advocating requires a good deal of self-knowledge and high level of skill; advocates themselves often benefit from support and hearing. The role can be complex and demanding, navigating through disputed spaces can be exhausting. Advocates may find themselves contributing to a service's case for adequate resources one day, the next helping services and families understand the person they support or love has outgrown their situation.

"Some people's ways of communicating leave the important people in their lives unable to hear their views about a life that would make sense," O'Brien writes. "These other people have little choice but to create a story with a valued and central role for the person, whose preferences remain ambiguous. Then, these people make adjustments based on the person's responses to the real settings and experiences that resulted" (O'Brien, 2002, p.412). Advocates might help those in power understand people change and grow, and that packages are for now not forever. Lives do not fit easily into the packages so beloved by managerialism. We may change a hundred times between six-monthly reviews chaired by Care Managers we have never encountered before, who seek to tell us who we are and what we might deserve.

Parallels exist between revealing an autistic self and disclosing other identities. As if living a good life amongst people with little inkling about your unique perceptions and ways of thinking (who have little insight into your gifts) isn't sufficient to produce often overwhelming anxiety, 'coming out' as autistic is itself a matter of import (Davidson & Henderson, 2010). Understanding and responding to being diagnosed (in effect, formally 'outed') can have positive or negative affect on a sense of self and emotional health (Shtayermman, 2009; Huws & Jones, 2009). The very presence of an advocate can have labelling effects. Advocates are privileged when granted access to tacit and highly personal perspectives. Advocates tend to feature strong voices *and* moral compasses, knowing when to speak and remain silent.

Advocates can ask naïve questions about patterns of service delivery, the acceptability of non-person centred assessment and why these still pertain. Many people remain suspended in "nineteenth-century patterns in twenty-first century places" (O'Brien, 2005, p.261). Advocacy asks hard questions of existing provision, and advocates can be critical friends to help improve options.

Advocacy should not limit its objectives to listening and giving volume to voices navigating services; advocacy may contribute to growing legitimate identities. Bagatell reminds us crafting an identity is hard work especially when 'disability' is considered from within the negative tropes society espouses; an autism-positive identity is an act both of self-determination and an opportunity for creative collaboration with those around the person (Bagatell, 2007). (The myth of the non-social autistic says more about a neurotypical person's theory of mind than anything.)

A powerful account of autism has been created by Baggs. This draws parallels between human rights *generally* and how people with autism are thought of *specifically* (Baggs, 2007). Ableist views about which communication methods are acceptable simply mirror ableist views of what behaviour is appropriate. These are social constructions. Advocates and self-advocates bridge the gap between the expectations of conformity and individual expression.

Rosie King talks eloquently about fitting in with the expectations of others whilst living in a society that cherishes 'normality' (King, 2014). The advocate's role might then include a willingness to help the system grow an acceptance of diversity. (There are diminishing returns for staying within standard deviations of normative distributions.)

A research team comprising people labelled with autism and Asperger's examined advocacy in the North of England (Townson *et al.* 2007). The paper presents themes many autistic people might recognise, including a lack of understanding of autism and bad experiences of support that was available (fitting in to pre-existing services risks losing autistic identities). Barriers around communication were experienced and compounded a scarcity of competent advocacy opportunities. Worrying this study suggested a link between inept service responses and crises in emotional well-being.

Autism Speaks considers its goals to include advocacy and has become a significant contributor to policy (Itkonen & Ream, 2013) but can a single organisation speak for all autistic people? Likewise, a self-advocate may not easily speak of the experiences of others, only their own.

State of the Notion

If the state of the nation includes a generation-long austerity, the *notion* of access to decent provision is equally concerning. Managerialism is dominant (Race, 2007). Managerialism refers to the authority of managers as deciders. Managers are accountable and often focus on accounts. The bottom line for managers is the bottom line because services are conceptualised as markets. In markets people are commodities; they are units of economic generation. But as Race notes there is a difference between consumers of products and people who need services to keep well and safe.

Today people making decisions about access to services don't always know what the people they provide for want. This presents new challenges for advocates. Advocates will need to learn the language managerialism comprehends to allow managers to make human decisions. When one encounters standardised assessments and when only generic packages of care are available, where people are squeezed into existing options, there you'll find managerialism.

McCarthy's account on the work of the Children's Society's *All Decisions Project* is worth revisiting. It outlines ways of fostering advocacy. But it makes sobering reading when examining obstacles the project faced: short-term funding reflects short-term planning; funders seek competition for awards, thus obliging projects to spend inordinate time bidding and justifying their existence; finally, the sheer size of organisations can act against dynamic ways of responding to individuals (McCarthy, 2009).

The reality is people remain excluded despite human rights instruments being developed (Bach, 2002). It might be people have intentionally focussed on documents not actions. In law, people cannot be held accountable for 'promises to the future' – it is sufficient to *hope* things will work out, that the *next* Government will enact today's espoused promises. Intentions do not represent doing. And we all know what leads to hell.

A Final Thought

Having an advocate must be a little like carting a boat on your back: at times the boat isn't needed and feels a little heavy. But when a river needs to be crossed a boat is useful. The art of advocacy is to be easily inflatable and most times as light as air to carry.

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